The humanistic perspective of telemedicine care

COPD patients' and nurses' experiences of receiving/providing telemedicine care

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Summary

Background: Chronic obstructive pulmonary disease (COPD) is a serious and progressive disease, entailing chronic, acute and life-threatening illness occurrences with considerable negative impacts on those living with the disease. For patients, nurses and health care systems (HCSs), this disease demands increased care and support in terms of continued, coordinated and routine follow-up. Telemedicine (TM) has shown to have a positive influence on the COPD care; however, there are still contradictions in its use. As TM plays a great role in the global health care delivery, it will be important to develop a strong knowledge base and to further explore how patients with COPD and nurses experience receiving/providing TM care.

Aim: The overall aim of this thesis was to explore and contribute to new knowledge and increase our understanding of the experiences of the patients suffering from COPD and nurses receiving/providing care through TM.

Design and methods: Three papers were conducted using several qualitative research methods. In Paper I, ten in-depth interviews were conducted with COPD patients receiving care through TM. The data were analysed using a descriptive phenomenological research method. Paper II used an ethnographic approach, combining different data collection methods, such as participatory observations, the think-aloud (TA) technique and a focus group interview with TM nurses. The collected data were analysed using qualitative manifest and latent content analysis. Papers I and II were carried out according to the framework of a TM intervention. A meta-ethnographic approach was used in Paper III to collect and synthesise the qualitative papers containing the COPD patients’ experiences of receiving care through TM. Twelve papers, published from 2013 to 2018, were included.

Findings: The patients with COPD experienced a sense of belonging when receiving care through TM, which was grounded in two fundamental conditions: presence and transparency, providing emotional, social and clinical support. The experience of the TM nurses showed that the fundamental development of ‘knowing the patient’, gained through reasoning and decision-making processes, directly impacted the care and guidance of the patients. Hence, the experiences of the patients with COPD and the TM nurses in the receiving/providing care process of TM were based on the relational connection made possible by the TM technology. The TM technology provided a close nurse-patient connection. The human-to-human connection in the TM care was fundamental, whereby the dialogue was necessary to increase the COPD patients' experience of belonging and for the TM nurses to advance their clinical and personal knowledge, with a view to strengthening the nurse-patient relationship. However, the patients with severe and/or unstable/progressive COPD were found to benefit most from the TM care.

Conclusions: The human-to-human connection was identified as an essential element for the patients' experience of belonging in the TM care and for the TM nurses to acquaint themselves with the patients. Hence, this thesis offers three main conclusions. First, high severity of COPD increased the need for connection and belonging in the TM care. This is an important contribution to the existing, albeit contradictory, evidence base, as it contributes to a renewed understanding of who would benefit from TM and why. Second, the TM technology enabled close yet distant TM encounters, where nurses and patients learnt from each other through dialogue, contributing to the well-being and more-being of the COPD patients and increasing the clinical and personal knowledge of the TM nurses. Finally, a humanistic connection of care was obtained by the dialogical act of nursing through the TM care; hence, the dialogue became the caring act of the TM care.

Norsk sammendrag

Bakgrunn: Kronisk obstruktiv lungesykdom (KOLS) er en alvorlig og progressiv sykdom som kan medføre kronisk, akutte og livstruende sykdomshendelser som kan innebære betydelige negative opplevelser for de som til daglig lever med KOLS. Sykdommen fører til et økt behov for omsorg og støtte, samt øker behovet for kontinuerlig, koordinert og rutinemessig oppfølging for både pasienter, sykepleiere og helsevesen. Telemedisin (TM) kan ha en positiv innvirkning for de som lever med KOLS, men forskning på området viser også motstridende funn ved bruk av TM. TM vil i økende grad ha betydning for global helse, og det vil derfor være viktig å utvikle kunnskap som gjenspeiler pasienters og sykepleieres opplevelser ved å motta og gi omsorg ved bruk av TM.

Hensikt: Den overordnede hensikten med doktorgradsavhandlingen var å utforske, samt bidra til ny kunnskap og økt forståelse av erfaringene fra pasienter med KOLS og sykepleiere som mottar og gir omsorg ved bruk av TM.

Design og metoder: Tre studier ble gjennomført med bruk av ulike kvalitative forskningsmetoder. I artikkel I ble det gjennomført ti dybdeintervjuer med pasienter med KOLS. Dataene ble analysert ved bruk av en beskrivende fenomenologisk forskningsmetode. I artikkel II ble det benyttet en etnografisk tilnærming som kombinerte ulike datainnsamlingsmetoder, slik som deltakende observasjoner, en høyt-tenkings teknikk og et fokusgruppeintervju med telemedisinske sykepleiere. De innsamlede dataene ble analysert ved bruk av kvalitativ manifest- og latent innholdsanalyse. Artikkel I og II var del av en telemedisinsk intervensjon. I artikkel III ble en meta-etnografisk tilnærming brukt for å samle og syntetisere kvalitative artikler som inneholdt erfaringer fra pasienter med KOLS som ble fulgt opp ved bruk av TM. Tolv artikler utgitt fra 2013 til 2018 ble inkludert.

Funn: Å motta omsorg og oppfølging ved bruk av TM gav pasienter med KOLS en følelse av tilhørighet. Dette var basert på to fundamentale funn; tilstedeværelse og åpenhet, som førte til emosjonell, sosial og klinisk støtte for pasientene. TM sykepleierne på sin side opplevde å 'bli kjent med pasienten' på et mer personlig plan, støttet opp av refleksjon og faglige vurderinger i TM settingen, hvor dette hadde en direkte innvirkning på utøvelsen av omsorg, samt oppfølgingen av pasientene. Pasient og sykepleiers opplevelser ved å motta og gi omsorg i forbindelse med TM førte til en god relasjon, muliggjort ved bruk av TM teknologien. En god relasjon førte samtidig til en nær kontakt mellom sykepleier og pasient, basert på en gjensidig dialog. Dette viser at den mellommenneskelige kontakten var betydningsfull for pasientenes opplevelse av tilhørighet, og for sykepleiernes mulighet for å øke deres faglige og personlige kunnskap om pasienten – som igjen styrket pasient-sykepleier relasjonen. Pasienter med en alvorlig grad av KOLS og/eller et ustabilt sykdomsforløp opplevde de største fordelene med TM.

Konklusjon: Den mellom-menneskelige forbindelsen i TM ble identifisert som et viktig element for pasientenes opplevelse av tilhørighet, samt for sykepleiere til å gjøre seg kjent med pasientene. Behovet for å ha kontakt med, og opplevelsen av tilhørighet ved bruk av TM oppfølging, var tydeligst hos de pasientene med alvorlig grad av KOLS. Disse funnene er et viktig bidrag til den eksisterende, om enn motstridende forskningen, da de bidrar til en fornyet forståelse av hvem som vil ha fordel av TM og hvorfor. TM oppfølging bidro også til nærhet til tross for avstand, hvor pasient og sykepleier lærte av hverandre gjennom dialog, hvor dette bidro til en bedring i pasienters helse og utvikling (‘well-being’ og ‘more-being’), samt økte sykepleiers kliniske og personlige kunnskap. En mellommenneskelig kontakt ble oppnådd gjennom dialogen, hvor omsorg ble uttrykt i det dialogiske møte mellom pasient og sykepleier, og muliggjort av TM teknologien.

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Tina Lien Barken,
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Paper II

Barken, T. L., Thygesen, E., & Söderhamn, U. (2017). Advancing beyond the system: Telemedicine nurses' clinical reasoning using a computerized decision support system—an ethnographic study. *BMC Medical Informatics and Decision Making, 17*:181. doi:10.1186/s12911-017-0573-7

Paper III

Barken, T. L., Söderhamn, U., & Thygesen, E. A sense of belonging: A meta-ethnography of the experience of patients with chronic obstructive pulmonary disease receiving care through telemedicine (under review).

Abbreviations

CDSS	Computerised Decision Support System
COPD	Chronic Obstructive Pulmonary Disease
EHR	Electronic Health Record
HCP	Health care professionals
HCS	Health care system
HR	Heart rate
ICT	Information and communications technology
TA	Think-Aloud
TM	Telemedicine
TMC	Telemedicine Centre
U4H	United4Health

1 INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a serious and progressive disease (GOLD, 2017; WHO, 2017), with high prevalence, morbidity and mortality (Adeloye et al., 2015; López-Campos, Tan, & Soriano, 2016; Rabe & Watz, 2017). Further, COPD is increasingly becoming common; approximately 150 000 persons suffer from COPD in Norway (FHI, 2018), with 64 million worldwide. WHO estimates that, by 2030, COPD will be the third most common disease globally (WHO, 2017). Living with the illness is accompanied by substantial (Disler et al., 2014) and ever-changing symptoms (Gott et al., 2009; Rosa et al., 2018), which inform an unpredictable disease progression involving chronic, acute and life-threatening illness occurrences (Pooler, 2016). For COPD patients, health care professionals (HCPs) (Gardiner et al., 2010) and health care systems (HCSs) (Adeloye et al., 2015), the uncertain progression of the disease warrants additional care (Gardiner et al., 2010) and support (Gardener, Ewing, Kuhn, & Farquhar, 2018; Kirkpatrick, Wilson, & Wimpenny, 2012) in terms of continued (GOLD, 2017), coordinated (Gott et al., 2009) and routine follow-up (Vogelmeier et al., 2017) to respond to the unpredictable and increasing demands of the illness (Giacomini, DeJean, Simeonov, & Smith, 2012).

Telemedicine (TM) has shown to be clinically effective for patients with COPD (Polisena et al., 2010); it has also shown to be helpful in reducing the use of health care services (Kamei, Yamamoto, Kajii, Nakayama, & Kawakami, 2013; Pedone & Lelli, 2015), increasing the quality of life (Cruz, Brooks, & Marques, 2014) and providing positive influence (McLean et al., 2012), including enhancing the experience of living with the illness (Morton et al., 2017). Although the use of TM has increased significantly in the past years (Wootton, 2012), contradictions (Brunton, Bower, & Sanders, 2015), uncertainty about efficiency (Cruz et al., 2014; Pedone & Lelli, 2015), hospital admissions, mortality (Kamei et al., 2013; McLean et al., 2012) and health-related quality of life (Gregersen et al., 2016) persist.

Several studies have argued that qualitative research is required (Brunton et al., 2015; Lilholt, Witt Udsen, Ehlers, & Hejlesen, 2017; McLean et al., 2012) to address the clinical needs (Kenealy et al., 2015) and help identify the subgroups of patients with COPD, who would benefit from TM (Cruz et al., 2014; Gregersen et al., 2016; Pedone & Lelli, 2015). As TM plays an increasingly greater role in global health care delivery, it is doubly important to develop a strong knowledge base (Dinesen et al., 2016) about the things that matter most to the users of TM technology (Greenhalgh et al., 2015; Greenhalgh et al., 2013). Hence, further research and knowledge development are required to obtain evidence to support the changes in the nursing practice concerning the increased use of TM, including ways to support the patients and nurses receiving/providing care through TM (Nagel, Pomerleau, & Penner, 2013). It is crucial that these changes are understood and addressed (Bartoli, Zanaboni, Masella, & Ursini, 2009) with a renewed focus on development in health care and patients' and HCPs' needs (van den Berg, Schumann, Kraft, & Hoffmann, 2012).

This thesis explores the experiences of patients with COPD and nurses receiving/providing care through TM. It consists of three papers that were conducted using various qualitative research methods, including a meta-ethnography (Paper III). Two of the papers (Papers I and II) were part of a larger European project, 'United4Health', which were carried out in southern Norway; they explored a TM intervention aimed at monitoring patients diagnosed with COPD (European Commission, 2015; Gerdes, Gallefoss, & Fensli, 2017; Smaradottir, Gerdes, Martinez, & Fensli, 2016).

2 AIM OF THE THESIS

The overall aim of this thesis was to explore and contribute to the existing knowledge and increase our understanding of the experiences of the patients with COPD and nurses receiving/providing care through TM. The thesis comprises three papers with the following specific aims:

- To describe the quality of life of a group of patients living with COPD who were included in a TM intervention after hospitalisation for disease exacerbation (Paper I).

- To explore the process of TM nurses' clinical reasoning when using a computerised decision support system (CDSS) for the management of patients with COPD. The factors influencing the clinical reasoning and decision-making processes were investigated (Paper II).

- To synthesise the qualitative research in the literature addressing how patients with COPD experience care received through TM (Paper III).

3 BACKGROUND

3.1 Chronic obstructive pulmonary disease (COPD)

COPD is an umbrella term that describes progressive lung diseases such as chronic bronchitis and emphysema (WHO, 2017), which can be defined as 'a persistent airflow limitation that is usually progressive and associated with an increased chronic inflammatory response in the airways and the lungs to noxious particles or gasses' (Vogelmeier et al., 2017, p. 558), including permanent limitation of airflow (Rabe & Watz, 2017). Dyspnoea, or breathlessness, is found to be the most characteristic symptom (GOLD, 2017; Vogelmeier et al., 2017). Other typical symptoms are cough, sputum production, wheezing and chest tightness. Further symptoms in severe cases can be fatigue and weight loss (Vogelmeier et al., 2017).

COPD is associated with exacerbations, which are severe and complex disease incidences associated with breathlessness and are often caused by airway infections (Seemungal et al., 1998; Vogelmeier et al., 2017; Wedzicha & Seemungal, 2007). Exacerbations negatively impact the health status and illness progression and are a significant cause of morbidity and mortality. Exacerbations can also increase the likelihood of hospitalisation and readmission (Vogelmeier et al., 2017). The classification of airflow limitations ranges from mild (1) to moderate (2), severe (3) and very severe (4) degrees of COPD. There are several factors affecting the severity of COPD (GOLD, 2017), such as symptom burden, risk of exacerbations and severity limitations (Grades 1–4) (Vogelmeier et al., 2017). Moreover, COPD often coexists with other illnesses, such as various heart diseases and/or diabetes. Comorbidities may negatively impact prognosis, severity and progression rate (Rabe & Watz, 2017; Vogelmeier et al., 2017).

3.1.1 Living with COPD: Experience and management

Living with COPD implies a high symptom burden (Gardiner et al., 2010; Simpson & Rocker, 2008), with ever-changing symptoms that have a considerable impact on the quality of life (Ek & Ternestedt, 2008; Fraser, Kee, & Minick, 2006; Simpson & Rocker, 2008). Consequently, living with COPD is related to both physical and emotional limitations, which negatively impact daily life (Barnett, 2005; Marx et al., 2016; Pooler, 2016), entailing a poor physical, emotional and social function (Gysels & Higginson, 2010, 2011). Breathlessness has been found to be particularly difficult to be handled and endured by patients (Blinderman, Homel, Billings, Tennstedt, & Portenoy, 2009; Ek & Ternestedt, 2008) and is often associated with distress, anxiety and panic (Gysels & Higginson, 2011). Consequently, breathlessness brings about the greatest restrictions in daily life (Blinderman et al., 2009; Ek & Ternestedt, 2008), often reducing activities to the essentials. Hence, the high symptom burden of COPD is often followed by a poor control of symptoms (Gardiner et al., 2010).

The care and support needs required by the patients with COPD are complex and comprehensive (Gardener et al., 2018; Gott et al., 2009), mainly because of the unpredictable nature of the disease, which includes periods of stability and acute episodes of ever-changing symptoms (Gott et al., 2009; Rosa et al., 2018), involving both physical, psychological and social aspects (Gardener et al., 2018). Patients with COPD often experience several unmet needs (Schroedl et al., 2014) and are found to have a poor understanding of their condition (Disler et al., 2014). However, managing the illness is a challenge for both patients, HCPs and HCSs (Hanlon et al., 2017; WHO, 2017) and requires comprehensive coordination of the health care (Gott et al., 2009). For HCPs and patients, this involves both continuity and flexibility to respond to the unpredictable and increasing demands of the illness over time (Giacomini et al., 2012).

To meet the requirements for care and support for patients with COPD, some of the strategies suggested are person-centred approaches (Gardener et al., 2018), consistent support (GOLD, 2017; Kirkpatrick et al., 2012), routine follow-up (Vogelmeier et al., 2017) and good communication practices (Gysels & Higginson, 2010). Patients with COPD greatly need care and support (Pooler, 2016). Hence, there is a need for interventions to improve the quality of life of the patients suffering from this disabling condition (Wedzicha & Seemungal, 2007). TM has been promoted as a solution to meet these requirements for care (Vitacca, Montini, & Comini, 2018) and has shown promising results (McLean et al., 2012).

3.2 Telemedicine (TM)

Information and communications technology (ICT) offers new possibilities for delivering remotely specialised and advanced health care (Vitacca et al., 2018). TM is part of the ICT that provides communication infrastructure and a variety of care options (Rheuban & Shipman, 2018). However, there is hardly a single definitive definition of TM (WHO, 2010). TM is often seen in parallel with similar concepts such as telecare, telemonitoring or telehealth (Solli, Bjørk, Hvalvik, & Hellesø, 2012). However, in this thesis, the concept of TM was chosen to be used, with the following comprehensive definition:

> Information, communication, and monitoring technologies which allow healthcare providers to remotely evaluate health status, give educational intervention, or deliver health and social care to patients in their homes (Solli et al., 2012, p. 2831).

TM entails complex interventions which include on the one hand an electronic transmission of patient information to the HCS and the follow-up response by the HCP (Vitacca et al., 2018) and on the other a growing and wide variety of technologies (Rheuban & Shipman, 2018; Vitacca et al., 2018). These technologies can include real-time videoconferencing, which involves a meeting that connects two individuals at a distance, allowing the participants to see and hear one another (Rheuban & Shipman, 2018). In addition, TM often includes the Internet platforms, store-and-forward technologies, mobile and wireless communication tools (Rheuban & Shipman, 2018; Vitacca et al., 2018) and the collection and transmission of clinical patient data for assessment and follow-up (for example heart rate (HR) and saturations using a pulse oxymetri device) from one site to another (WHO, 2010), through which clinical care is provided (Rheuban & Shipman, 2018).

3.2.1 TM to patients with COPD

TM has significant potential to address many of the challenges facing health care today (Bashshur et al., 2016; Vitacca et al., 2018; WHO, 2010), which include access to health care services, quality of care and cost-effectiveness (WHO, 2010). Providing TM to the patients who suffer from COPD offers continuous monitoring aimed at the right care, at the right time and from any location and distance (Tucker, 2018) to assist individuals in remaining independent at home and improving their quality of life (Horton, 2008). In addition, TM can provide timely treatment of exacerbations that can predict worsening scenarios and prevent further deterioration to reduce hospital admissions (Pinnock & McKinstry, 2018; WHO, 2010). Furthermore, TM has been well documented in the management of COPD with a growing evidence base (Nesbitt & Katz-Bell, 2018; Wootton, 2012). In Norway, TM is widely adopted (Zanaboni, Knarvik, & Wootton, 2014) and has gained growing popularity in the past years and is now used in almost all health regions (Zanaboni & Wootton, 2016). Given that TM has an increasing role in global health care delivery (Dinesen et al., 2016; Nesbitt & Katz-Bell, 2018; Wootton, 2012) and can address the growing burden of COPD on the HCS, it will be increasingly important to develop a strong knowledge base (Dinesen et al., 2016).

Research result shows that TM has several benefits for the patients with COPD, such as patient satisfaction (Kruse et al., 2017) with increased engagement with health care services, patient knowledge and health literacy (Kenealy et al., 2015) and patients and relatives taking an active role in self-management (Hanlon et al., 2017; Kenealy et al., 2015). Furthermore, patients with COPD experience closer contact with their HCPs, have greater self-awareness of their condition (Morton et al., 2017) and symptoms (Lilholt, Hæsum, & Hejlesen, 2015) and experience to be better cared for than the traditional health care services (Morton et al., 2017). In addition, TM care for patients with COPD has shown to be clinically effective (Polisena et al., 2010); it decreases the use of the health care services (Kamei et al., 2013) and reduces hospital admissions and emergency department visits (Cruz et al., 2014; McLean et al., 2012; Pedone & Lelli, 2015), thereby improving the patients' quality of life (Cruz et al., 2014).

According to Kenealy et al. (2015) patients' and HCPs' experiences of TM both complement and contrast evidence obtained through quantitative research. Although several positive aspects have been associated with the managing of COPD through the TM care, the evidence base is still contradictory (Brunton et al., 2015), with a lack of clear and clinical evidence (Cruz et al., 2014; Gregersen et al., 2016; Pedone & Lelli, 2015). Pinnock and McKinstry (2018) suggest that these contradictions may be influenced by the complexity and the large symptom burden of COPD, indicating that it is problematic to measure the clear predictors of exacerbations. To date, evidence shows that TM for patients with COPD delivers similar rather than better results compared with those of the traditional care (Lilholt et al., 2017). However, when TM includes regular follow-up, aged and severely ill patients are found to benefit the most (Vitacca et al., 2018).

3.2.2 TM and nursing practice

TM includes the provision of advanced nursing care in a new clinical environment where care is provided at a distance from where the patient is located (Oudshoorn, 2016; Pols, 2006); this has resulted in a reconfiguration of the traditional practices (Bartoli et al., 2009; Rouleau et al., 2017) and, in turn, has changed the nursing practice (Peck, 2005). This change has developed new nursing roles (Carnwell & Daly, 2003; Carrington & Tiase, 2013; Jenkins & White, 2001) in the expanding field of TM (Nagel et al., 2013; Wootton, 2012).

These developments in health care affect anyone that is involved in the provision of care (Vitacca et al., 2018) and change how nurses interact with patients (Bartoli et al., 2009; Nesbitt & Katz-Bell, 2018; Resneck, Trujillo, & Schleiter, 2018); they also influence how nurses plan, deliver, document, communicate and review clinical care (Pols, 2006). Hence, further research is required to obtain evidence to support changes in the nursing practice using TM (Bartoli et al., 2009; Nagel et al., 2013; van den Berg et al., 2012).

Nursing knowledge, clinical reasoning and decision-making in the TM care

Nursing skills and knowledge are complex and diverse and require theoretical knowledge, creativity, moral decisions and nursing experience to care for patients (Carper, 1978). Competence in clinical reasoning and decision-making is developed progressively through a process which includes experience, reflection (Banning, 2008; Benner, Tanner, & Chesla, 2009; Nibbelink & Brewer, 2018) and a combination of theoretical, ethical and practical nursing knowledge (Carper, 1978; Karoliussen, 2011). Furthermore, to guide clinical decision-making and reasoning, it is important to integrate multiple forms of thinking patterns (Carper, 1978). Clinical reasoning requires that nurses gather information, analyse data and make decisions about a patient (Simmons, Lanuza, Fonteyn, Hicks, & Holm, 2003) and is the sum of critical thinking and decision-making processes associated with clinical practice (Higgs & Jones, 2008). Hence, clinical reasoning is an essential component of nursing practice (Simmons, 2010; Simmons et al., 2003) and can be defined thus:

> The cognitive processes and strategies that nurses use to understand the significance of patient data, to identify and diagnose actual or potential patient problems, to make clinical decisions to assist in problem resolution, and to achieve positive patient outcome (Fonteyn & Ritter, 2008, p. 236).

Reasoning is based on nurses’ careful thoughts in different clinical settings (Alfaro-LeFevre, 2013). Hence, because of the distance, the use of technology in health care requires complex decisions (Simmons et al., 2003). Nursing in a TM context involves advanced nursing practice, which is knowledge intensive and entails complex patient care (Holmstrom & Hoglund, 2007; van Houwelingen, Moerman, Ettema, Kort, & ten Cate, 2016); this requires nurses with the appropriate skills and knowledge to ensure that quality care is maintained

(Rheuban & Shipman, 2018). In a TM context, nurses should be able to process large quantities of data from a system (e.g. vital signs and symptoms) and perform individual clinical decision-making (Oudshoorn, 2016). Complex clinical practice requires that nurses use appropriate clinical reasoning skills (Lee, Lee, Bae, & Seo, 2016). Consequently, it is essential that, within TM, nurses' clinical reasoning and decision-making be supported.

Computerised decision support system

A computerised decision support system (CDSS) is an automated system and is accessible from various devices (e.g. computers); the CDSS is meant to facilitate, support and assist HCPs' decision-making processes (Mair et al, 2009) in clinical practice (Anderson & Willson, 2008; Randell, Mitchell, Dowding, Cullum, & Thompson, 2007). The CDSS uses algorithms to produce patient-specific assessments (Kawamoto, Houlihan, Balas, & Lobach, 2005) and decision-making recommendations to support nurses' reasoning (Greenes, 2007; Grimmer & Loftus, 2008), generate better clinical decisions (Fonteyn & Ritter, 2008) and improve patient care (Kawamoto et al., 2005).

The use of CDSS to aid nurses' decision-making is new (Anderson & Willson, 2008) and has increased in recent years (Greenes, 2007). Because of the technological advances, this field of nursing practice is rapidly evolving, with great benefits that the computerisation of the health care environment can offer (Garg et al., 2005). However, various factors can influence the decision-making process (Dowding et al., 2009; Oudshoorn, 2016), such as familiarity with the patient (Cappelletti, Engel, & Prentice, 2014; Dowding et al., 2009; Edwards, 1994; Tanner, 2006), the patient's health condition and the CDSS technology used (Dowding et al., 2009; Oudshoorn, 2016).

The CDSS has been used in hospitals (Bucknall, 2003; Ganley & Gloster, 2011; Lee et al., 2016), primary care (Dowding et al., 2009), phone-based counselling (Holmstrom & Hoglund, 2007; O'Cathain, Sampson, Munro, Thomas, & Nicholl, 2004; Randell et al., 2007) and chronic care settings (Roshanov et al., 2011; Velickovski et al., 2014). The CDSS use for long-term management involves complex decision-making (Greenes, 2007), which requires advanced training, especially when used in a TM setting (Peck, 2005). However, research findings are far from certain about the use of CDSS in TM for patients with COPD (Mudura, Frosini, & Iadanza, 2018) besides concerns over its adoption, implementation (Greenes, 2007; Miller et al., 2015) and accuracy (Sanchez-Morillo, Fernandez-

Granero, & Leon-Jimenez, 2016). However, CDSSs may improve HCPs' performance. Both the CDSS and the nurse are essential to the clinical decision-making (O'Cathain et al., 2004), and CDSS use can improve nurses' decision-making processes (Thompson, Aitken, Doran, & Dowding, 2013).

4 THEORETICAL FRAMEWORK

To emphasise the meaning of human experience, this thesis seeks to create a deeper understanding of the perspectives of patients with COPD and TM nurses and their unique view through which they experience the world in the light of Paterson and Zderad's (1976) humanistic nursing theory.

4.1 Humanistic nursing theory

The humanistic nursing theory, developed by Josephine Paterson and Loretta Zderad (1976), has been influenced by existentialism, humanistic psychology and phenomenology (Praeger & Hogart, 1990). The theory is a result of Paterson and Zderad's (1976) practice, teaching and lived experiences as nurses. It incorporates multiple ways of knowing one's self and that of another human being to conceptualise nursing. Paterson and Zderad (1976) pioneered the nursing theory, portraying descriptions of nursing experiences to emphasise the quality of patient care and outcome in the nursing literature (Munhall, 2012), whereby the nurse-patient and human-to-human—as an intersubjective transaction—constitute the core of nursing:

> Humanism in nursing is an authentic presence of a 'knowing' nurse who dwells in the existence of another with an evident or anticipated health need in order to ameliorate or improve that person's human condition or help him/her face death (Kleiman, 2005, p. 14).

Humanistic nursing is a moving process that occurs in the living context of human beings who interact with others and things in the world (Kleiman, 1993) and values the need for human interaction and the lived experiences between human beings (O'Connor, 1993). Three concepts provide the foundation of the humanistic nursing theory: (a) the lived dialogue, (b) community and (c) phenomenological nursology. This thesis emphasises the lived dialogue and will further elaborate the essential elements that occur within this concept (e.g. *meeting, call and response, relating* and *presence*) (Paterson & Zderad, 1976). In addition, *knowing, doing* and *being* are essential parts of humanistic nursing (O'Connor, 1993) and will be presented too.

4.1.1 Nursing as a lived dialogue

Nursing takes place when two (or more) human beings are connected in a shared situation; it involves nurturing, being nurtured and the development of a relation—'the between' through which the nurturance occurs (Paterson & Zderad, 1976). The *meeting* and interaction that occur between the nurse and the patient during a nursing encounter are significant in humanistic nursing (Kleiman, 2009; Praeger & Hogart, 1990); it is in this interaction that the lived dialogue occurs (Paterson & Zderad, 1976). Paterson and Zderad (1976) use the terms receiver and caller to explain how the lived dialogue is achieved through call and response. *Call and response* can be referred to as the relationship between the patient and nurse in the context of the patient need for care (Kleiman, 2009): 'human centred nursing is a lived dialogue, a call-and-response event, that occurs between a nurse and a person who come together in a nursing occasion' (Kleiman, 2009, p. 5). The purpose of this dialogue, as an intersubjective *relating*, is to nurture the well-being (being just so) and more-being (becoming through choices) of patients in need of help (Paterson & Zderad, 1976). Hence, what happens during this dialogue, the between as an intersubjective relating, is nursing. Subsequently, the call and response process is the essence of the theory (Kleiman, 1993) and is a 'transactive' process which means that the nursing process goes both ways between the nurse and the nursed (Paterson & Zderad, 1976).

Figure 1 illustrates an explanation of the humanistic nursing theory and the process of the call and response through dialogue to nurture the well-being and more-being through an intersubjective relating. 'Gestalt' and 'incarnate in time and space' indicate the patients' and nurses' all-at-once.

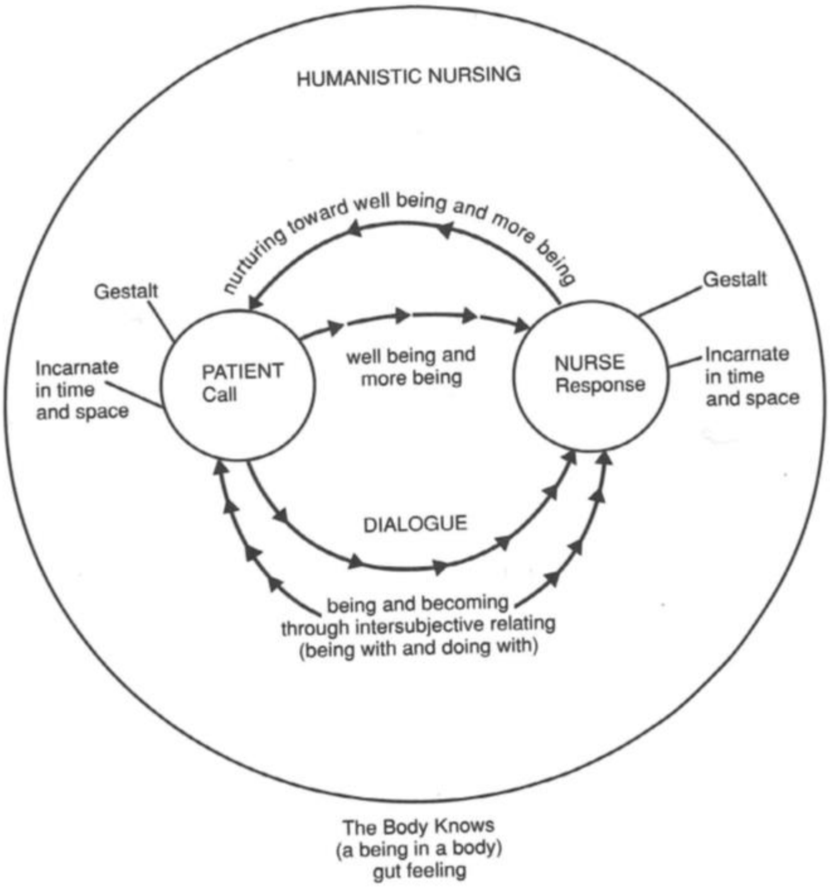


Figure 1. A presentation of the humanistic nursing theory developed by Kleiman (1993) by courtesy and permission of the National League for Nursing Press (Appendix 1).

The ‘lived dialogue’, as far as it concerns nursing (Paterson & Zderad, 1976), is based on the existential philosophy grounded on the work of Martin Buber (Buber, 1958). Buber explains that authentic connections between humans occur as encounters experienced as I-It or I-Thou (Thomas & Pollio, 2002), presenting different perspectives in a relationship; ‘I-Thou’ as a combining perspective and the ‘I-It’ as a separating perspective (Buber, 1958). These two modes of relating are present in the nursing situation, explained by the dual nature of ‘I-Thou’ and ‘I-It’ (O'Connor, 1993, p. 31). A reformulation of Buber’s ‘I-Thou’ relationship, as proposed by Paterson and Zderad (1976), is the ‘I-Thou, I-It, all-at-once’, which explains the unique and complex aspects of relating in the nursing encounter (O'Connor, 1993). The ‘all-at-once’ indicates that these perspectives occur simultaneously, perspectives such as emotions, desires and values. The lived nursing act then is the nurse’s and patient’s experiences ‘all-at-once’ (O'Connor, 1993). Lastly, the humanistic nursing theory combines the views of Buber in the nursing process with subject (I-Thou), object (I-It) and intersubjectivity (the between) to support well-being and more-being for the purpose of comfort (Paterson & Zderad, 1976).

Additionally, the subject-object (I-It) relating entails a scientific and objective approach with the possibility of gaining knowledge about a person. In the subject-subject (I-Thou) relating, Paterson and Zderad (1976) believe that it is possible to know a person as a unique individual. According to the humanistic nursing theory, both subject-subject and subject-object relationships are significant in the process of clinical nursing; in other words, nursing is more than the doing of nursing, which can be scientifically and objectively observed to include the being of nursing, which occurs in the intersubjective nurse-patient experience. Consequently, it is through the relationships with other humans as well as the ability to develop one's human potential and become a unique individual rest. During a nurse-patient encounter, it is 'the between', as a mutual presence of the nurse-nursed (O'Connor, 1993), which makes the nursing situation unique as an intersubjective transaction when combining the perspectives of the patient and the nurse (Paterson & Zderad, 1976). In addition, patients have the capacity to choose to respond, including how to respond (O'Connor, 1993). Hence, in this existential meeting, choices and intersubjectivity are determined by the patient and the nurse (Kleiman, 1993).

4.1.2 Nursing as knowing, doing and being

Nursing is a way of *knowing, doing* and *being,* where knowing in nursing is expressed in the dialogical process through the nursing act, entailing a combination of 'being with' and 'doing with' the patients in a nursing situation (O'Connor, 1993). Nursing as an intersubjective experience involves both a being and doing. The doing entails nurses' observable procedures in nursing care. Further, in the human experience of nursing, the being of nursing entails a 'being with' or a 'being there', a *presence* in the realm of both a personal and professional connection (O'Connor, 1993). Hence, presence is a central term in the humanistic nursing theory, involving both the being and doing of nursing (Paterson & Zderad, 1976) and including availability (in a supportive way), openness (to a person with needs) and reciprocity (seeing both nurse and patient as persons who have different modes of being in the shared nursing situation) (O'Connor, 1993).

Nursing encounters are based upon a purpose related to health-illness with a response to a certain need, were nurses experience patients' diverse life occurrences (Paterson & Zderad, 1976). Subsequently, patients and nurses bring all that they are, ‘all-at-once’, as they engage in a dialogue. The ‘all-at-once’ includes the patient’s and the nurse’s unique and individual lifeworld. Hence, all who they are enters the nursing interaction. This includes the patient’s previous experiences, patterns of coping, gender, illness and so on. In addition, nurses’ earlier nursing experiences, professional role, ethics and knowledge provide the foundation of the nursing response (Kleiman, 1993). In conclusion, nurses’ skills and knowledge require them to balance the doing, being and ‘all-at-once’ (O'Connor, 1993). Subsequently, nursing is the quality of being expressed in the doing (Paterson & Zderad, 1976). In these experiences and encounters, it is important that nurses be present, available, open and reciprocal. Consequently, this is how nurses come to know ‘the meaning of nursing as a living human act is in the act itself’ (Paterson & Zderad, 1976, p. 11).

4.2 The humanistic perspective in nursing practice

The humanistic nursing theory has influenced nursing scholars and clinicians (Wolf & Bailey, 2013) and has been the basis for several studies in clinical nursing practice (Praeger & Hogart, 1990; Toole, 2014). The studies have mainly been family centred (Stubblefield & Murray, 1999), spiritual (Davis, 2005; Vassallo, 2001), palliative and has involved hospice care (Wu & Volker, 2012) and have similarly been applied to nursing education (Doane, 2002; Hanson & Stenvig, 2008). Over time, the theory has endured in practice settings and in the changing patterns of nursing (Kleiman, 1993) and has continued to evolve since its origins in the 1970s with relevance to contemporary nursing practice (Boykin & Schoenhofer, 2001; Kleiman, 2005; McCamant, 2006).

The humanistic nursing theory is a meta-theory, which has been critiqued for its limited use in guiding specific interventions or patient care strategies (Praeger & Hogart, 1990; Wolf & Bailey, 2013). However, the theory illustrates the importance of the nurse-patient relationship and the different and unique lifeworld of patients and nurses; it emphasises the relational encounter in nursing care (Wolf & Bailey, 2013). The philosophy of this theory can be used in every nursing practice that involves an interaction between a patient and a nurse, where a receiving/providing process of care emerges. This thesis incorporates the humanistic perspective in the context of TM care.

5 METHODS

5.1 Philosophical foundations

The philosophical foundation of this thesis originates in the interpretative (naturalistic) paradigm (Polit & Beck, 2010). As opposed to a positivist worldview (Delanty & Strydom, 2003), the interpretative paradigm is characterised by the ontological viewpoint of multiple realities whose meaning is grounded in experience (Monti & Tingen, 2006) and strives to ‘understand’ rather than ‘explain’ (Delanty & Strydom, 2003).

Various ways of knowing emphasises knowledge that is rooted in human experience whose reality is complex, holistic (Lincon & Guba, 1985) and subjective. Additionally, the context in which the experience emerges and evolves is significant (Munhall, 2012). Subsequently, wholes cannot be understood in isolation from their contexts, nor can they be separated into parts (Lincon & Guba, 1985, p. 39).

The ontological and epistemological assumptions of a paradigm guide its methodologies (Kuhn, 2012; Monti & Tingen, 2006). Hence, in the interpretative paradigm, the use of qualitative methods searches for meaning within the experience of individuals to understand what it means to be in this world and to provide a voice to their unique experiencing. The qualitative research methods emphasise a phenomenon or experience and the individuals who are involved in that phenomenon (Munhall, 2012; Polit & Beck, 2010). Interpretative methods include several qualitative research methods, such as phenomenology, hermeneutics and ethnography (Monti & Tingen, 2006; Polit & Beck, 2010). These methods are congruent with nursing paradigms and worldviews (Munhall, 2012) and seek to answer the questions of the nursing discipline (Polit & Beck, 2010), aimed at describing and interpreting reality through the medium of language (naturalistic inquiry) (Lincon & Guba, 1985). Hence, the ontological and epistemological assumptions of the interpretative paradigm guide the methodologies chosen in this thesis.

5.2 Design

This thesis consists of three papers that were conducted using various qualitative research methods. Two of them (Papers I and II) were carried out within the framework of a TM intervention as part of the U4H project implemented in southern Norway (European Commission, 2015; Gerdes et al., 2017; Smaradottir et al., 2016). Various qualitative research approaches such as the descriptive phenomenological approach (Giorgi, 2009) (Paper I) and the ethnographic approach (Hammersley & Atkinson, 2007) (Paper II) were used in accordance with the aim of each paper. Paper III was a meta-ethnography (Britten et al., 2002; Noblit & Hare, 1988), which synthesised the experiences of the patients with COPD receiving care through TM. Table 1 presents the design, participants, data collection methods and analyses of Papers I, II and III.

Table 1. Design, participants, data collection methods and analyses

Paper No	Design	Participants	Data collection methods	Methods of analyses
I	Descriptive phenomenology	10 COPD patients	In-depth interviews	Descriptive phenomenological research method
II	Ethnography	3 TM nurses	Participatory observations, the TA technique and focus group interview	Qualitative manifest and latent content analysis
III	Meta-ethnography	163 COPD patients	Qualitative systematic review	Meta-ethnography synthesis

5.2.1 Descriptive phenomenology

The descriptive phenomenological approach was used in Paper I to narrate the lived experiences of the quality of life of a group of patients living with COPD and receiving care through TM. Phenomenology is the study of structures in a phenomenon, as they appear in our consciousness (Giorgi, 2009, 2012). Edmund Husserl founded the philosophical thinking of modern phenomenology and believed that a phenomenon can only exist in people’s mind and can only be explained based on the perspective of those who experienced it (Giorgi, 2009). Hence, the main concern of phenomenology is with the nature and meaning of human experience. Furthermore, experience is viewed as a necessary part for understanding the nature of knowledge (Moran, 2000).

5.2.2 Ethnography

The ethnographic approach (Hammersley & Atkinson, 2007), involving participatory observations, the TA technique (Lundgren-Laine & Salantera, 2010) and a focus group interview (Krueger & Casey, 2015), was used in Paper II to investigate the reasoning and decision-making processes of the TM nurses. Fieldwork generates knowledge of participants' subjective world in their natural setting (Madden, 2010; Mays & Pope, 1995) and can be used to reach parts of a research field that other methods fall short of it. In addition, this method can provide a more nuanced picture of the field investigated (Mays & Pope, 1995; Savage, 2000) and increase our understanding of the subjective world of health professionals in their natural setting (Savage, 2000). Additionally, the triangulation of multiple data collection methods can provide a comprehensive picture of the phenomenon investigated (Polit & Beck, 2010).

5.2.3 Meta-ethnography

A meta-ethnography developed by Noblit and Hare (1988) and further adapted for health research (Britten et al., 2002) was conducted in Paper III to collect and synthesise the qualitative papers of how patients with COPD experience receiving care through TM. The meta-ethnographic method (Noblit & Hare, 1988) is a seven-step process. Step 1 is defining the object of interest and developing a conceptual question (the aim of the synthesis). Step 2 constitutes the search methods, search outcomes and the quality appraisal process (data collection method). Steps 3–6 comprise the reporting of the analytic and synthesising processes. Step 7 involves articulating the synthesis.

Furthermore, meta-ethnography is an inductive method within an interpretative paradigm. The synthesis aims to interpret rather than describe, with the context as a fundamental condition for understanding (Noblit & Hare, 1988); it also allows a body of qualitative research to be drawn together in a systematic way (Campbell et al., 2011). To enhance quality and trustworthiness, the ENTREQ (Tong, Flemming, McInnes, Oliver, & Craig, 2012) and eMERGe (France et al., 2019) guidelines were followed.

5.3 Setting

Papers I and II were part of the U4H project whose setting is described thus. A telemedicine centre (TMC) was established in southern Norway as part of the U4H project (European Commission, 2015; Gerdes et al., 2017; Smaradottir et al., 2016). The TMC was located in a municipal subacute ward that provided medical services to acutely ill patients. The centre was open from 8 a.m. to 3 p.m., Monday to Saturday, and had seven registered nurses who managed the COPD patients from several municipalities. The TMC was operated and managed by a single nurse at any given time who could manage up to 12 patients daily.

5.3.1 The TM intervention

The U4H project consisted of a TM intervention that lasted for three months and consisted of a technical solution, monitoring and follow-up by nurses working in the TMC. When patients with COPD were discharged from the hospital after illness exacerbation, the patients received TM equipment for usage at home if they accepted to participate in the intervention. A specialist lung nurse provided each patient with the user instructions of the TM equipment, and a technical assistant installed the equipment at the patient's home. The technical equipment consisted of a tablet with a video camera and a pulse oximetry device for daily measuring of the HR and oxygen saturation. The data were transmitted by the patient wirelessly from the tablet application to the TMC. The tablet software also included a questionnaire to measure the patient's subjective symptoms and self-evaluation, such as well-being, breathlessness, sputum characteristics and medication use.

For the first two weeks after discharge from the hospital, the intervention consisted of daily contact between the patient and a trained TM nurse. This included the evaluation of the transmitted health data (HR, oxygen saturation and subjective symptoms) and follow-up with video communication. After two weeks and in collaboration with each patient, the daily video contact was reduced to two or three times a week. However, the patient would be contacted by a TM nurse if his or her health data fell outside the normal range or if the health data were not received by a set time every day. The TM nurses assessed the transmitted health data over a period of approximately 30 days. After this point, the follow-up was completed, and the patient returned the TM equipment to the local hospital. In addition, for the next two months, the patient had the opportunity to contact a TM nurse at the TMC by telephone for advice.

5.3.2 CDSS

To monitor and assess the COPD patients' transmitted clinical data, a CDSS was used. The CDSS is a triage-based model that was developed by medical and technical experts employed at the local hospital and university and is used to support the TM nurses' reasoning and decision-making processes. The model was developed to ensure that patients with time-critical needs for assistance would be prioritised; it also sought to ensure that the correct resource and appropriate treatment were given to the patients at the right time. The TM nurses evaluated the patients' information, including the current health status and progress by daily clinical measurements. A daily questionnaire was used to evaluate the subjective data by the following questions:

1. How do you feel today? (Patient's response options: as usual, worse, much worse)
2. How is your breathing today? (Patient's response options: as usual, worse, much worse)
3. How is your amount of sputum today? (Patient's response options: as usual, worse, much worse)
4. What is the colour of your sputum today? (Patient's response options: No or clear/white/yellow/green/brown)
5. Are you using rescue medication/nebuliser or oxygen today? (Patient's response options: no, as usual, more than usual, much more than usual)
6. Have you begun taking additional antibiotics after your last discharge? (Patient's response options: no, yes)
7. Have you begun taking new Prednisolon after your last discharge? (Patient's response options: no, yes)

In addition, the CDSS displayed colour codes (green, yellow, red) as warning alerts for patients' health status. The thresholds for clinical measurements were predefined for each patient based on their normal values. The algorithms for the CDSS were as follows (Gerdes et al., 2017):

- **Green colour code:** Stable patient; self-reported health symptoms unchanged or improved. Oxygen saturation and HR within the acceptable range compared to individual reference values.
- **Yellow colour code:** Unstable patient indicating change that needs follow-up: oxygen saturation and/or HR indicate deterioration since previous day or hospital discharge, a yellow alert is triggered. Change indicating increase in HR more than 10 beats/min, reduction in saturation of approximately 5%, an answer to questions 1, 2, 3 or 4 defined as 'worse' or question 5 answered with 'more than usual'.

- **Red colour code:** Unstable patient indicating severe change or critical condition; oxygen saturation and/or HR or self-reported health symptoms indicating significant deterioration since previous day or hospital discharge, a red alert is triggered. Change indicating increase in HR more than 15 beats/min, reduction in saturation lower than 6% or daily questionnaire (questions 1–5) answered with ‘much more than usual’.

If the clinical measurements fell outside the normal range or if the patients answered ‘worse’ for subjective data, the colour code would be yellow or red according to the severity of health change. Appropriate actions to secure positive patient outcome would be taken corresponding to the extent of the illness severity.

5.4 Participants

The inclusion criteria for Paper I required that the participants be COPD patients who had been followed up between one and three months during the TM intervention and, at the point of the interview, had returned the TM equipment to the local hospital. All the patients who fulfilled these criteria were asked by a TM nurse at the TMC if they would participate in the study. The TM nurse was asked to choose patients from both genders and a diverse range of ages and degrees of COPD severity. The nurse gave the initial information about the study and emphasised that participation was voluntary. Ten of the 12 invited participants agreed to take part in the research (two participants withdrew due to acute illness) and were then contacted by phone by the author of this thesis. The participants included three women and seven men, aged 61–80. In addition, the severity of COPD ranged from moderate to very severe. The characteristics of the participants are displayed in Table 2.

Table 2. Participants' characteristics in Paper I

Participant	Gender	Age	COPD severity*	Included in intervention (weeks)
A	Male	74	Moderate	4
B	Female	74	Severe	6
C	Male	61	Very severe	8
D	Male	75	Severe	4
E	Male	63	Very severe	5
F	Male	80	Moderate	4
G	Male	75	Very severe	4
H	Female	77	Severe	6
I	Female	73	Severe	6
J	Male	70	Moderate	6

*Moderate: mild or moderate airflow limitation with a low risk of exacerbation; severe: severe airflow limitation with a high risk of exacerbation; very severe: very severe airflow limitation with a high risk of exacerbation (Vogelmeier et al., 2017)

The inclusion criteria for Paper II required that the participants be registered nurses who were employed at the TMC as part of the TM intervention. The participants were contacted by the head of the department at the TMC with a request for voluntary participation. Three of the seven nurses working at the TMC agreed to participate. The four nurses who did not wish to participate were employed part-time with once-a-month weekend shifts. All the participants were female and aged between 27 and 46, with 6 to 23 years of experience as a nurse and from 4 months to 2 years of experience as a TM nurse. Their workload at the TMC ranged from 45% to 80%. Two of the nurses had advanced education; one nurse had a master's degree in health and social informatics and the other had majored in geriatrics.

Paper III was a meta-ethnography which included 12 papers focusing on the patients with COPD and their experiences of receiving care through TM, which were published between 2013 and 2018. In total, there were 163 participants, aged between 44 and 85, who suffered from mild, moderate, severe and very severe degrees of COPD. The descriptive data were extracted from each study according to year, country, aim, description of the TM intervention and participants (including patient group, gender, age and degree of COPD) and data collection (a comprehensive table is presented in Paper III, which provides information on data collection (e.g. time point of data collection), method of analysis and a short summary of the findings). The descriptions of the included papers and participants are given in Table 3.

Table 3. Characteristics of 12 eligible papers in Paper III

Reference/ country	Aims	Interventions	Participants
Barken et al. (2018) Norway	To describe the lived experiences of the quality of life of a group of patients living with COPD who were included in a TM intervention after hospitalisation for disease exacerbations	A technological solution and follow-up through a telemedical centre; the technological solution consisted of a tablet with a video camera and pulse oximetry for daily monitoring of pulse and oxygen saturation; the software consisted of a questionnaire regarding self-evaluation. Regular real-time follow-up was carried out by video communication with a trained nurse at the telemedical centre Duration: 1-3 months	10 patients: 7 men/3 women Age: 61–80 Moderate to very severe COPD
Fairbrother et al. (2012) Scotland	To explore the views of patients and professionals on telemonitoring; the perceived impact of telemonitoring on the continuity of care was investigated as part of the research	The telemonitoring service enabled the patients to assess their symptoms using an online touch-screen questionnaire. A linked pulse oximeter, peak flow meter and electronic weighing scales transmitted physiological measurements to the device. The patients completed the questionnaire and measured oxygen saturation daily and used the peak flow device and scales on a weekly basis. The HCPs contacted patients to address health changes Duration: 1 year	38 patients: 18 men/20 women Age: 44–85 Moderate to very severe COPD
Fairbrother et al. (2013) Scotland	To explore the views of patients and HCPs who were using telemonitoring as part of the TELESCOT COPD trial of the impact of telemonitoring on self-management in COPD	See Fairbrother et al. (2012)	See Fairbrother et al. (2012)
Fitzsimmons et al. (2016) United Kingdom	To qualitatively explore the experiences of patients with COPD who had received either a telehealth-supported or a specialist nursing	Telehealth system provided both monitoring and self-management support. The patients answered questions about their health status using a small hand-held device. Blood pressure was monitored, and an oximeter was used to measure the blood oxygen levels each day. The	9 patients: 5 patients receiving TM: 3 men/2 women Mean age 67.22

	intervention following their discharge from hospital after an admission for an exacerbation of COPD	system generated an alert when the reported signs and symptoms fell outside the normal range or when the patient failed to undertake monitoring activity. Telephone contact after a system-generated alert was also made Duration: Follow-up eight weeks after the exacerbation of COPD	4 female patients receiving standard service Early-stage COPD
Gale and Sultan (2013) United Kingdom	To document the experience of people with COPD and their interaction with technology to understand how they negotiated incorporating telehealth technologies into their everyday life and home space and to understand why they valued it	The pilot intervention consisted of recording oxygen saturation, blood pressure, weight and temperature every weekday morning. The readings were sent to the community respiratory service team. Only the red alert demanded action from the community respiratory service. No face-to-face contact but self-referral mechanism Duration: 9 months	7 patients: 5 men/2 women Age: 57–85 Mild to very severe COPD
Gorst et al. (2016) United Kingdom	To explore the beliefs and perceptions of the patients with COPD who are currently using home telehealth and are not enrolled in a trial	Six patients used small-sized telehealth equipment, with the ability to send the readings of their vital signs. Two patients used larger equipment with the same information but with the possibility of viewing the charts. Five patients used TM every weekday morning and three patients every morning, with monitoring follow-up shortly after. Vital signs: blood pressure, oxygen level, pulse rate, temperature and weight (only large equipment) Duration: 6 months to 3 years	8 patients: 3 men/ 5 women Age: 58–84 Length of years with COPD: from 4 to 18 years Severity unknown
Huniche et al. (2013) Denmark	To explore how the COPD patients make use of readings during 16 weeks of self-monitoring in the Telekat project	The telehealth monitor box collected data on the patients' blood pressure, pulse, weight, oxygen level and lung function. HCPs monitored the readings and contacted the patients by telephone to discuss health development and provide advice. Duration: 16 weeks	22 patients: 8 men/14 women Age: 45–81 Severe and very severe COPD
Mathar et al. (2015) Denmark	The experiences and preferences of COPD patients in relation to discharge from hospital with	The intervention compromised eight 30-min televideo consultations over a 2-week period, conducted by especially trained community nurses and physiotherapists. A pulse oximeter was used to measure saturation and	6 patients: 3 men/3 women Age: 67–83

	televideo consultations	pulse. Vital observations, dyspnoea, chest pain, expectoration, cough, oedema and well-being were also monitored Duration: 2 weeks	Severe and very severe COPD
Nissen and Lindhart (2017) Denmark	To illuminate the experiences of patients with stable COPD participating in a 6-month TM intervention substituting for visits to the outpatient clinic	The NET-COPD intervention consisted of a tablet computer with a web camera and measurement equipment; it submitted the readings of saturation, pulse, weight and changes in dyspnoea, cough and sputum three times a week in the first month and then once a week, including video follow-ups. One red alert or two yellow ones were used; a respiratory nurse would contact the patients Duration: 6 months	14 patients: 6 men/8 women Age: 55–83 Severe and very severe COPD
Ure et al. (2012) Scotland	To explore the perceptions of patients and professionals about the pilot implementation of a COPD tele-monitoring service	TM service incorporating a touch-screen computer for the daily recording of symptoms and weekly oximetry and spirometry measurements; the data were transmitted via a broadband link to a call centre where trained support staff would contact the patient according to an algorithm or if no data were submitted Duration: 2 months	20 patients: 13 men/7 women Mean age: 68.9 Moderate to severe COPD
Vatnøy et al. (2017) Norway	To investigate how patients experienced the follow-ups using a TM intervention and the extent to which it supported and improved coping with the resources and independence	See Barken et al. (2018)	10 patients: 7 men/3 women 55–83 Minimal to major self-reported impact of COPD on daily life
Williams et al. (2014) United Kingdom	To explore the patients' expectations and experience of using an mHealth telehealth application to determine how such a system may impact their perceived well-being	An mHealth intervention was used, involving a tablet computer. The patients completed pulse rate, oxygen level and symptom diary every day. The data were reviewed at regular intervals by the nurse (not daily) Duration: 6 months	19 patients: 11 men/8 women 50–85 Moderate to very severe COPD

	and ability to manage their COPD	

5.5 Data collection

To understand the experience of patients with COPD and nurses receiving/providing care through TM, data were gathered through several qualitative data collection methods (Table 1). The methods chosen for data collection consisted of in-depth interviews (Paper I), fieldwork and a focus group interview (Paper II) and a qualitative review method (meta-ethnography) (Paper III).

5.5.1 In-depth interviews

The in-depth interviews of the patients with COPD were used in Paper I. Interviewing in a phenomenological way seeks to achieve as complete a description as possible of the experiences that the participants have lived through (Giorgi, 2009). By using a descriptive phenomenological research method (Giorgi, 2009), the participants were encouraged to narrate their experiences of the phenomenon of living with COPD and receiving care through TM. The methodological ideal of phenomenology underlines allowing the participants to share their experiences openly and freely (Giorgi, 2009). The interviews consisted of two open questions: (a) ‘Please tell me about a situation when you could improve your quality of life as a result of being included in the TM intervention.’ and (b) ‘Please tell me about a situation when you could not improve your quality of life as a result of being included in the TM intervention.’ To explore deeper and guide the conversation, further probing questions were asked (e.g. ‘Can you tell me more about that and can you describe this further?’) (Appendix 2). The interviews were audiotaped and transcribed verbatim and lasted from 30–50 minutes, with an average of 38 minutes.

5.5.2 Fieldwork, the TA technique and a focus group interview

A triangulation of the qualitative data collection methods was used in Paper II. The fieldwork enabled gaining insights through participatory observations of the TM nurses when performing clinical reasoning, decision-making and video consultations with the patients. This form of research is well suited to studying organisations (Mays & Pope, 1995) and how people in organisations perform their functions. Through participatory observations, one obtains insights into the participants' world and can capture the actions that participants themselves may not be aware of (Hammersley & Atkinson, 2007).

To register and organise the data (Hammersley & Atkinson, 2007), field notes were written. Field notes consisted of observations, actual incidents, reflections and interpretations, and were undertaken during and after the day's observations (Hammersley & Atkinson, 2007; Hellesø, Melby, & Hauge, 2015; Madden, 2010). Approximately 60 patient consultations were observed during 60 hours of fieldwork; Nurse 1 was followed for 30 hours, and Nurses 2 and 3 were followed for 15 hours each.

The TA technique (Lundgren-Laine & Salantera, 2010) facilitated access to the participants' inner verbalisations, clinical information processing and performance of different tasks. Each nurse was asked to express their thoughts aloud, explaining each step in their reasoning process. Probing questions such as 'Could you please elaborate your reasoning?' or 'Could you please continue to think aloud?' were asked to gather information and seek clarifications during each patient assessment.

After the fieldwork completion, a focus group interview (Krueger & Casey, 2015) was conducted to gain insights into the participants' reasoning and decision-making processes when using the CDSS. A semi-structured interview approach was used (Kvale & Brinkmann, 2009); open-ended questions focused on the use of the system and the nurses' reasoning and decision-making processes. Examples of some of the questions included were thus: 'What is your experience of the computerised decision support system in supporting and improving the decision-making process when assessing patients?' or 'Could you give some examples of how you used your expertise to make decisions about the patient?' (Appendix 3). A moderator was present during the 90-minute interview, and the collected data were subsequently transcribed verbatim.

5.5.3 Search methods and search outcomes

The search method in the meta-ethnography (Paper III) sought to identify papers that had explored the patients with COPD and their experiences of receiving care through TM. Databases such as Medline, Embase and PsycInfo via OvidSP (database host) and Cinahl (Ebscho Host) were used for the searches and chosen to incorporate the different disciplines within the research topic (e.g. nursing, health care and technology). These databases were chosen because they had a good coverage of qualitative studies on illness and health (Booth, Sutton, &

Papaioannou, 2016). Further, a non-systematic search for grey literature was performed in Google Scholar, ProQuest, Web of Science and the Cochrane Library; however, these search engines did not retrieve any relevant articles. The reference lists of the included studies were also sifted for relevant and new articles to no avail, though.

The search was based on an adjusted PICO-method, focusing on population and intervention. The adjusted method was used to avoid overlooking the relevant studies. A manual sifting of papers was therefore considered a more thorough approach. The search was guided by search terms as Medical Subject Headings and abstract keywords for the two concepts of COPD and TM. The search strategy was developed iteratively to ensure balance between sensitivity and specificity (Booth et al., 2016). The search terms were slightly different in the various databases, mainly because of different index systems. The following search terms were combined as follows:

1. (chronic airflow obstruction* or chronic airway obstruction* or chronic bronchitis or chronic lung disease* or chronic obstructive airway disease* or chronic obstructive bronchitis or chronic obstructive bronchopulmonary disease* or chronic obstructive lung or chronic obstructive pulmonary or chronic obstructive respiratory or chronic respiratory disease or coad or copd or pulmonary emphysema or obstructive lung disease or obstructive respiratory disease or obstructive respiratory tract disease*).ti,ab,kf.
2. exp Pulmonary Disease, Chronic Obstructive/
3. exp Telemedicine/
4. (telemedicin* or mhealth or ehealth or Telemedical* or telenurs* or tele nurs* or telerehabiliation* or telemonitor* or telehealth* or technology or technologies or ((mobile or digital) adj3 (app* or communication*)) or teleconsulation* or telehomecare or (tele adj2 home) or (remote adj2 monitor*)).ti,ab,kf.
5. (telecare* or ((tele* or home) adj2 monitor) or smart phone* or smartphone* or ((mobile* or digital*) adj2 health*) or ((video* or tele*) adj2 (admission* or consult*))).ti,ab,kf.
6. 1 or 2
7. 3 or 4 or 5
8. 6 and 7

The abbreviations ‘ti, ab, kf’ indicate that the searches are linked to the title, abstract and keywords in the different papers. The symbol * indicates a truncation which retrieves words containing different endings (for example nurs*: nurses, nursing). ADJ (2 and 3) was used to combine different concepts by for example linking video* and tele* with admission* or consult* to avoid the inclusion of words concerning different concepts other than admission* or consult*; N or Near was used in Cinahl, illustrating that the results which contained the combinations of these search terms were written with N2 for example, which indicated that the combinations of words should be the same or less than two words in between.

A total of 4051 papers were identified through database searching. The titles and abstracts were screened in relation to the inclusion and exclusion criteria. The inclusion criteria were papers published in the English or Nordic language, primary studies/original research, qualitative studies (reporting detailed and in-depth descriptions of findings), patients with COPD and TM as defined by Solli et al. (2012). Papers that did not meet the inclusion criteria or TM as defined (e.g. tele-rehabilitation, usability, tele-yoga, education (not-treatment), virtual admission, personal visits) were excluded, so were papers whose results did not distinguish the patient groups and/or users of TM.

Furthermore, full-text papers were retrieved for further inspection when the titles and abstracts met the inclusion criteria. After this process, 66 full-text papers describing TM and COPD with a qualitative method were reviewed in relation to the eligibility criteria. Twelve papers were included in the review. The process is displayed in a Prisma flow chart (presented in Paper III). In addition, each of the included papers was assessed for quality using the CASP tool (Critical Appraisal Skills Programme, 2018). The papers included in the review were of moderate to high quality.

5.6 Analyses

5.6.1 Descriptive phenomenology

The collected data in Paper I were analysed using Giorgi’s (2009) descriptive phenomenological research method and were based on the narratives of the lived experiences of the quality of life of the patients living with COPD receiving care through TM. The analysis consisted of four steps: (a) the text was read to gain a sense of the whole, maintaining a holistic approach; (b) the text was read repeatedly and the meaning units were established; (c) the meaning units were transformed from the participants' everyday language into a health science perspective, emphasising the phenomenon being investigated and using free imaginative variations relevant to the perspective through a reflective process; (d) the transformed meaning units were then synthesised into a consistent statement (situated structure) of the phenomenon for each interview, producing 10 specific situated structures, each representing an interview. These steps formed the general structure of the lived experiences of the patients living with COPD and receiving care through TM. The general structure is the identification of the constituents that are essential for the phenomenon to manifest itself, and it illustrates how these constituents relate to each other.

5.6.2 Qualitative manifest and latent content analysis

The collected data in Paper II, consisting of both observational data and data from a focus group interview, were analysed using the manifest and latent content analysis (Graneheim, Lindgren, & Lundman, 2017; Graneheim & Lundman, 2004). The analysis followed five steps. First, the interview text was repeatedly read to gain a deeper understanding of the whole. Second, it was divided into the meaning units. Third, the meaning units were condensed to reflect the participants' statements from the interview (focus group) and the data from the observations. Fourth, the condensed meaning units were abstracted and grouped together into codes with common denominators to achieve an outline of the data. Finally, the codes were organised into categories and sub-categories. These steps in the analysis represent the manifest analysis, where the analysed text is still close to the original statement. The material was sorted using NVivo 10 (QSR International, 2012). In the final phase, the latent analysis involved an interpretation of the underlying meaning of the text; it also involved a process of studying the non-verbal language of the participants and the TM setting, all of which led to an overall theme.

5.6.3 Meta-ethnography

The synthesis in Paper III was guided by the meta-ethnographic approach according to Noblit and Hare (1988) and Britten et al. (2002). This approach entails a seven-step method; however, the reporting of the analytic approach and the synthesising process contain steps 3 to 6.

In Step 3, the included papers were read repeatedly while the details of the primary studies were extracted (a detailed table of the characteristics of the included papers are presented in Paper III). Further, the empirical materials (the findings section) were located and then sorted into a conceptual map where relevant themes and metaphors from each primary study were listed in vertical columns arranged with first-order constructs (participants' quotes) and second-order constructs (authors' interpretations in the included papers) (Britten et al., 2002).

Step 4 in the meta-ethnographic approach was to determine how the studies were related. According to Noblit and Hare (1988), the approach can either (a) be directly comparable in a reciprocal translation (comparing across studies), (b) be in opposition to each other (refutational), where the differences of studies are evident or (c) present a 'line of argument' to tie the studies to one another. In the process of the fourth step, an identification of re-occurring and refutational themes were found, from which a 'line of argument' analysis could be performed.

To translate the studies into one another, a process in Step 5, the papers were vertically arranged starting with an index paper. The included paper of Gorst, Coates and Armitage (2016) was chosen based on the papers' conceptual richness and quality (the paper was granted a score of 9 of 10 according to the CASP assessment tool). Following the index paper, the papers were arranged according to quality, rigor and thick descriptions. Further, the key themes from the index study were compared with the second paper and the synthesis of these two papers were compared with the third paper and so on. Key concepts were identified and translated across all the papers. Subsequently, metaphors and key concepts were determined using a constant comparison method (Britten et al., 2002). During the process of constant comparison, similar metaphors and concepts were placed in close proximity, a process of re-ordering, re-linking and re-assembling (clustering) metaphors until identifying a common metaphor (Campbell et al., 2011).

Lastly, in Step 6, the metaphors were further analysed and abstracted to form a third-order conceptual framework. This framework involved both the first-order and second-order constructs (Britten et al., 2002). The findings of Paper III were systematically linked to establish new relationships between the concepts. The process of re-conceptualising indicates the reading of the concepts and interpretation 'of the grid' (Britten et al., 2002, p. 211). Hence, a third order-interpretation based on the third-order constructs was performed involving repeated comparisons between the papers. Hence, the third-order interpretation was developed through a line-of-argument synthesis. The interpretation placed all the similarities and differences into a new perspective to help in discovering the whole from the components (Noblit & Hare, 1988).

The synthesising process was a non-linear approach and thus entailed going back and forth within the steps of the method. This process enhanced the familiarity with the metaphors and concept of each paper, while considering the context and details. The final interpretation aimed to develop a model to explain the overall concepts of receiving care through TM by the patients suffering from COPD.

5.7 Ethical considerations

Papers I and II were designed and performed in accordance with the Declaration of Helsinki (Declaration of Helsinki, 2013) and common principles used in clinical research (Beauchamp & Childress, 2013). For both papers, the ethical approval was obtained from the NSD (Norwegian Centre for Research Data; project number Paper I: 41146, project number Paper II: 42445) (Appendix 4 and 5). In addition, the manager at the TMC gave verbal approval for conducting the field research in Paper II. Furthermore, the oral and written informed consent was obtained from each participant. They were informed about the aim of the study and that participation was voluntary, anonymity was guaranteed and the right of withdrawal from the research at any time for any reason was honoured (Appendix 6 and 7).

During the fieldwork and observations in Paper II, the researcher was present in the room when the TM nurses performed their video consultations with the patients. To ensure that the patients agreed to a researcher being present in the room, oral consent was obtained prior to conducting the videoconference. However, to minimise influence, the researcher seated herself in a place where the patients could neither see or hear the researcher during the consultations. The researcher could hear the nurses speak; however, the TM nurses were wearing headphones to ensure that the researcher would not hear the patients' statements.

It was also important to adhere to an ethical research practice in the meetings between the researcher and the participants. In Paper I, the interviews were conducted with the participants who were severely ill. An important aspect was the participants' dyspnoea, breathlessness and cough. The length of each interview was informed by the participants' health status at the time of the interview. Suffering from a chronic illness is challenging and participating in a TM intervention and contributing to research was difficult for a few participants. One participant needed a break from the interview when she began to experience breathlessness and serious coughs, and another needed a break to catch his breath when speaking during the interview. However, all the participants in Paper I felt that it was important for them to express their thoughts, feelings and experiences about the TM intervention. Despite some pauses, the interviews were conducted as planned.

6 FINDINGS

This thesis aims to study the patients with COPD and TM nurses receiving/providing care through TM. The findings of Papers I and III reveal the COPD patients' experiences of receiving care through TM. Paper II emphasises the TM nurses' experiences of providing TM care and how they reason and reach decisions in a TM setting. The interrelationships between Papers I, II and III will be elaborated at the end of the findings section.

6.1 COPD patients' experiences of receiving care through TM

In Papers I and III, the COPD patients' experiences of receiving care through TM were explored and the findings in these two papers will be presented accordingly.

6.1.1 Unlocking the limitations of COPD

The participants in Paper I observed that living with COPD limited their lives, both mentally and physically. However, TM was perceived to unlock these limitations and provide an enhanced quality of life. Hence, Paper I presents a general structure in line with the descriptive phenomenological research method (Giorgi, 2009). An overview of the themes and sub-themes of Paper I are presented in Table 4.

Table 4. Themes and sub-themes (Paper I)

Themes	**Living with COPD: Physical and mental limitations**	**Receiving care through TM**	**The dual chore of receiving care through TM**
Sub-themes	Limitations of the diseased body Limitations of the growing identity as patient	Accessibility Support Clinical insight Mutual clinical language	

The participants in Paper I remarked that they found themselves limited by the increasing symptom burden of living with COPD, creating physical and mental limitations for the diseased body, which reduced mobility and scope of activities while increasing dependence on others. In addition, the instability of the disease created anxiety and inhibited social participation. Furthermore, past and present health care experiences influenced their current lifestyle and was a constant reminder of the advancing illness with growing worries for the future. This increased the participants' identity as a patient and led to a reduced quality of life:

> […] when I experience breathlessness, I lose control, and then my anxiety kicks in. I have to learn to live with the anxiety at one level, then the next stage comes, and it gets worse… So, it [the disease] is constantly deteriorating! It is absolutely terrible… I spend a lot of time sitting inside, it is not nice at all, but it has just to be like that. (Participant C in Paper I)

Closely related to the stories of the increasing limitations of body, mind and identity were stories of how receiving care through TM could increase accessibility to health care services and support from the TM nurses. Accessibility was found to provide a sense of security and peace of mind; video consultations were considered important to this end. In addition, the participants experienced support when the TM nurses provided feedback and advice on their health status, which assured a personal connection with the TM nurses. Subsequently, this provided a feeling of being known because the TM nurses had competence in both illness and personal health.

When using a pulse oximeter, the self-measurement of the health data increased the participants' clinical insights; these improved coping with the recurring fear of disease exacerbations and breathlessness by providing an overview of disease development and enhanced self-reliance. In addition, a mutual clinical language was created in consultation with the TM nurses, which increased the understandings of the individual health developments. Regular dialogue fostered collaborative decision-making, which led to an improved quality of life:

> I think that [connection with nurses] is very nice, because they understood what I was talking about … everything! If I said, 'Oh! Today I experience breathlessness!' 'Yes, what have you done?', then the TM nurses would accept you, right, and then they asked, 'How do you feel?' and that kind of thing. It is a completely different way to connect and I get positive effects to talk to someone like that. (Participant B in Paper I)

The findings of Paper I revealed that there were nuances related to disease severity. There was a clear dissociation between severity of COPD and the experience of receiving care through TM. The patients with moderate COPD sometimes experienced TM as an obstruction in life, because their need for follow-up and support was reduced when they were in good health. In contrast, the participants with severe or very severe COPD did not experience the TM intervention as an impediment and rather felt they received additional support with regular follow-up. Hence, receiving care through TM was also experienced as a dual chore: 'I have to plan more, knowing that I have TM. I am not sure that this could replace the security… I felt "locked" to a certain time'. (Participant J in Paper I)

6.1.2 A sense of belonging

The meta-ethnographic synthesis (Noblit & Hare, 1988) in Paper III generated a line-of-argument: that patients with COPD experienced a sense of belonging when receiving care through TM. The line-of-argument was developed based on three (third-order) constructs: (a) presence (accessibility and digital proximity), (b) transparency (clinical awareness and reciprocal dialogue) and (c) ambivalence (independent yet close, and restricted yet detached). A presentation of the line-of-argument is provided in Table 5.

Table 5. A line-of-argument from the second-order and third-order constructs (Paper III)

No	Second-order construct	Third-order construct	Line-of-argument
1	Accessibility Digital proximity	Presence	Patients with COPD experienced a sense of belonging when receiving care through TM
2	Clinical awareness Reciprocal dialogue	Transparency	
3	Independent yet close Restricted yet detached	Ambivalence	

The experience of belonging was rooted in two fundamental conditions for the TM care: presence and transparency. First, presence was perceived to provide emotional and social support, which was based on accessibility to health care services and availability of HCP in addition to digital proximity. The predictability and legitimised contact with the HCPs, offered by the TM care, provided stability and regularity. This was found to strengthen the nurse-patient relationships and the human aspect of TM, supporting the burden of living with the illness:

> […] It's sort of a lifeline; you know that it's going somewhere else... Knowing somebody is at the end of the line, that's important... I think I would have been in hospital without it [telehealth], because it's gone so bad. (Participant Collette in (Gorst et al., 2016) in Paper III)

Second, transparency provided openness, linked to clinical awareness, and a reciprocal dialogue with the HCPs. This enhanced sharing, discussing and reflecting on the clinical data with the HCP, promoted greater understanding of a new clinical language and equipped the patients with an active voice. In addition, transparency advanced the patients understanding of the progression/symptoms of each individual's COPD illness and provided the patients with the ability to differentiate the normal readings from the abnormal ones, and how this was connected to their illness/symptoms. Subsequently, the patients felt that they were part of the health care process and connected with the HCP through the TM technology and that transparency was found to increase their clinical competence and personal growth:

> I think I keep a better track of my illness than I did before. Before, I just felt my way forward. Now I can tell what every little thing is about. I couldn't before. (Female patient in (Huniche et al., 2013) in Paper III)

The synthesis showed that the severity of COPD directly influenced patients' sense of belonging and that receiving care through TM was experienced as ambivalent. The patients with unstable COPD felt more independent yet desired closeness when the illness emerged with increased symptom burden, unstable periods and uncertainty:

> It gives me a lot more independence. I am not dependent on making the judgement myself. You're using measurements which normally wouldn't be available to me as a patient… that's good. (Male, 71 in (Fairbrother et al., 2013) in Paper III)

However, the patients with a low symptom burden or in a stable and early phase of the illness experienced the TM care as an unnecessary intervention in their lives and felt restricted, although they wished to be detached:

> I'm more conscious of it of course […] because those questions also set their mark on me […] think about how you are in fact, and how you've been coughing a lot […] so it influences me in the direction that I'm more aware of my disease […] I'd rather forget it, wouldn't I? (Participant 9 in (Nissen & Lindhardt, 2017) in Paper III)

Consequently, the experience of belonging was perceived to provide a need for closeness or detachment (see Figure 2) as a level of connectedness in TM care. The synthesis illustrates that the level of connectedness and the requirement to belong to the TM care increase with the progression of illness burden and severity. The following conceptual model illustrates the interrelationship between the conditions of the TM care, the severity of COPD and the need for connectedness (Figure 2).

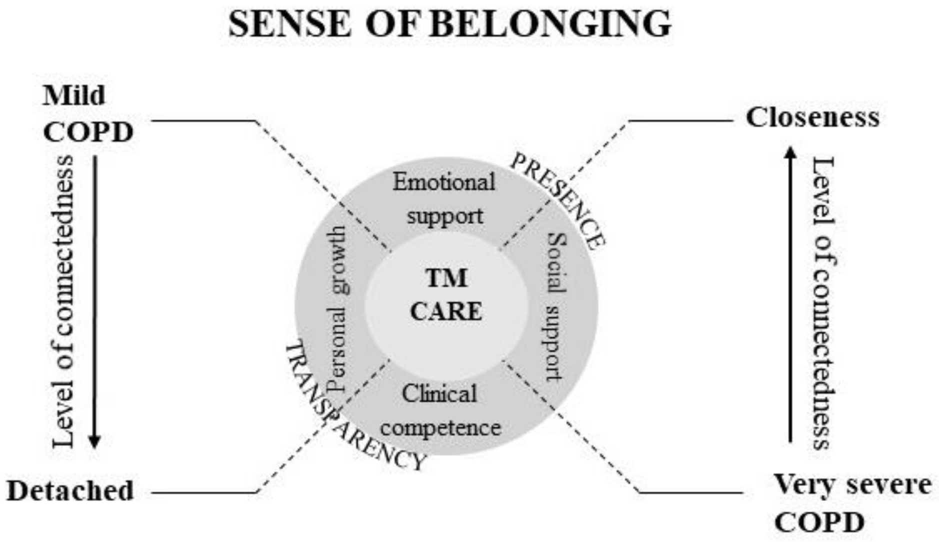


Figure 2. The interrelationships between the conditions of TM care, the severity of COPD and the level of connectedness (Paper III)

6.2 TM nurses’ experience of providing TM care

In Paper II, the process of TM nurses’ clinical reasoning using a CDSS in a TM setting was explored, including what factors influenced the reasoning process using manifest and latent analysis (Graneheim & Lundman, 2004). Two categories emerged from the analysis: (a) the process of TM nurses’ reasoning to assess health change and (b) the influence of the TM setting on nurses’ reasoning and decision-making processes. In addition, the overarching theme, advancing beyond the system, was identified, indicating that TM nurses advanced beyond the system in their reasoning and decision-making processes.

6.2.1 The reasoning and decision-making processes

The process of TM nurses’ reasoning to assess health change in the TM setting was circular and dynamic and consisted of five stages: (a) assessing the CDSS recommendation, (b) mapping data, (c) combining data, (d) data interpretation to form a pre-decision and (e) a final decision in collaboration with the patient (the reasoning and decision-making processes are presented in Figure 2):

> The nurses formed a mental image of the patient and then gathered diverse information from earlier nursing documentation and made mental notes. They then reviewed the system recommendation and detailed information to form the whole picture. The processes involved observing, analysing, reflecting and recognising a pattern. (Fieldwork observation in Paper II)

The TM setting, which consisted of a technologically advanced environment, played a significant role in the nurses’ reasoning and decision-making processes; for example, it allowed the nurses to over-ride the system recommendation, hosted poorly integrated information systems, had frequent technical failures and allowed clinical reasoning to be performed alone and at a distance from the patient:

> I would like us to share information and collaborate more because we manage the TMC alone. There is no one else to talk to except for the written reports […]. (Nurse 3 in Paper II)

6.2.2 Advancing beyond the system

The environmental and technological aspects defined and structured the nurses’ work, which both enabled and constrained nurses’ reasoning and decision-making processes. However, the findings of Paper II illustrate that, although these aspects provided challenges, they also provided time and support, influencing the nurses' reasoning processes, such as daily clinical and subjective data, regular patient contact and continuous follow-up. This provided the nurses with detailed patient- and illness-specific knowledge, strengthening a close relationship with the patient:

> You get a different relationship with patients [using TM and video-conferencing] … somewhat closer, and it is much more personal. (Nurse 2 in Paper II)
>
> A TM nurse gains insight into more than just the health status of each patient. One gets to learn so much more about the patient's life, which is important for the clinical reasoning and decision-making processes in TM work. (Fieldwork observation in Paper II)

However, while the CDSS was intended to support the reasoning and decision-making processes, nurses regularly needed to advance beyond the system recommendations. The overarching theme in Paper II shows that the TM nurses rarely used the recommendations from the CDSS in isolation. They combined and compared the digitally clinical and subjective patient data to identify the conflicts, if any; they then compared the outcomes using their long-term acquired patient knowledge:

> I need to combine the [system] information with something. I cannot look at the CDSS recommendation alone. I need to see the whole picture, the [patient's] history, everything. (Nurse 1 in Paper II)

An in-depth knowledge of each patient enabled the nurses to see past the system recommendation, termed 'advancing beyond the system'. Advancing beyond the system was a significant component of the reasoning process. Furthermore, knowledge of the patient ensured competence in detecting CDSS biases and enabled the gathering of patient-specific information to detect individual changes in the health status, leading to a more accurate and nuanced decision. Figure 3 presents the circular and dynamic process of reasoning and decision-making in the TM setting. Knowing the patient was central, forming a foundation for reasoning across all five stages of the process.

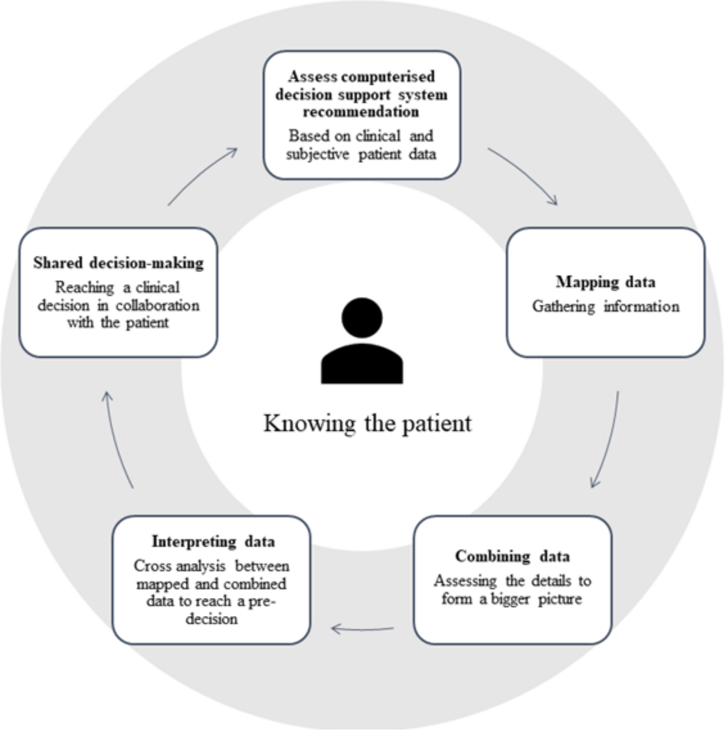


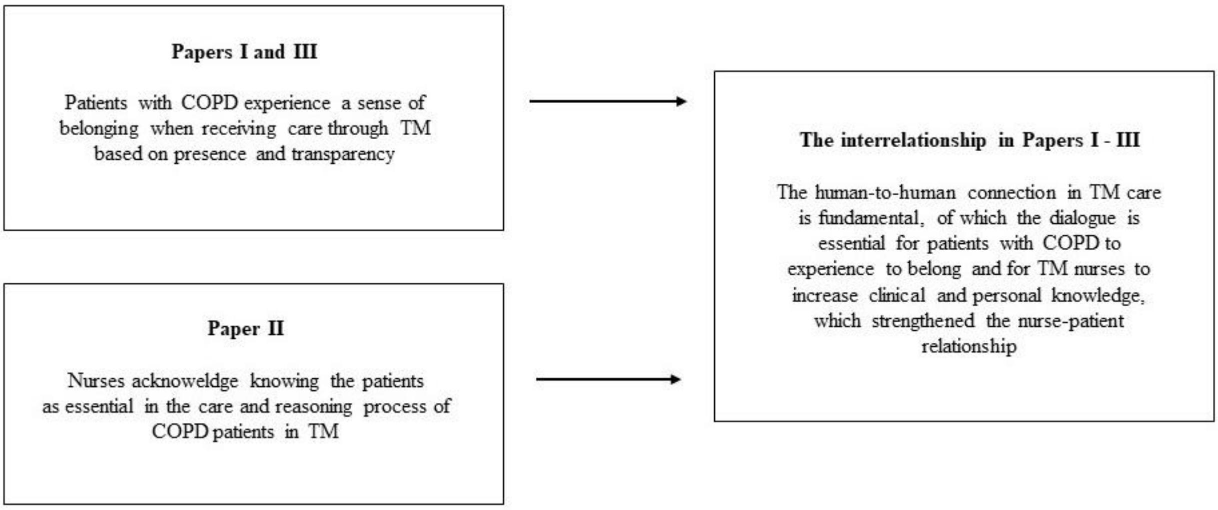
Figure 3. The reasoning and decision-making processes in the TM setting (Paper II)

6.3 The interrelationship between the findings in Papers I–III

This thesis emphasises combining the perspectives of both patients and nurses in the receiving/providing care process through TM. In this process, a coherent concept within the empirical material from Papers I–III emerged, which illustrates that the humanistic connection between the nurse and the patient through TM is a central component for strengthening the nurse-patient relationship, considering that the *dialogue* is key to achieving it. Figure 4 displays the interrelationships of Papers I–III. Based on the aims of this thesis and its empirical materials and analyses, three main findings emerged:

- Patients with COPD experienced a sense of belonging when receiving care through TM, which was grounded in two fundamental conditions in the TM care: presence and transparency. Presence and transparency were perceived to provide emotional, social and clinical support, received mainly because of the relational connection with a TM nurse, enabled by the TM technology (Papers I and III).

- A fundamental aspect of the reasoning and decision-making processes was the crucial development of ‘knowing the patient’, which directly impacted the care and guidance of the patients and represented the connection between the nurses and patients in the relational encounters in TM (Paper II).
- The human-to-human connection in the TM care is fundamental, in which it is essential that the patients with COPD engage in dialogue to experience belonging and for the TM nurses to increase their clinical and personal knowledge, aimed at strengthening the nurse-patient relationship (Papers I-III).



Papers I and III

Patients with COPD experience a sense of belonging when receiving care through TM based on presence and transparency

Paper II

Nurses acknoweldge knowing the patients as essential in the care and reasoning process of COPD patients in TM

The interrelationship in Papers I - III

The human-to-human connection in TM care is fundamental, of which the dialogue is essential for patients with COPD to experience to belong and for TM nurses to increase clinical and personal knowledge, which strengthened the nurse-patient relationship

Figure 4. The overview of the interrelationships in Papers I–III and the presentation of the main findings of the thesis

7 DISCUSSION

The overall aim of this thesis was to explore and contribute to the existing knowledge and increase our understanding of the experiences of the patients with COPD and nurses receiving/providing care through TM. By gathering the perspectives of patients and nurses through a variety of qualitative methods, this thesis was able to gain rich insights into the experiences of the patients and nurses in a TM care setting. This thesis illustrates the significant role of the relational encounter in the patients' experiences of belonging, knowing in nursing, and the development of the nurse-patient relationship.

7.1 The humanistic perspective of the TM care

In the light of Paterson and Zderad's (1976) humanistic nursing theory, this thesis argues for a humanistic perspective of the TM care. The humanistic nursing theory highlights the relational encounter in nursing, directing the value and influence of the patient-nurse interactions to patients' and nurses' lifeworld (Wolf & Bailey, 2013).

However, the humanistic and relational aspects of nursing have been the focus for several nursing theorists in the nursing literature (Benner & Wrubel, 1989; Martinsen, 2003; Parse, 1998; Peplau, 1952; Travelbee, 1971). Thus, utilising the humanistic nursing theory (Paterson & Zderad, 1976) offers one unique way of applying the humanistic perspective in the domain of the TM care.

Humanistic nursing is concerned with the phenomenon of nursing wherever it occurs, regardless of its clinical context and nursing situation (Paterson & Zderad, 1976). In the domain of nursing and technology, the humanistic perspective can assist with the improvement of health care, clinical practice and patient care (Barnard, 2002), despite the fact that care is provided at a distance from the patient. Hence, technology plays an important part in nursing, society and health care, and nursing is significantly shaped by the rapid growth of technology (Barnard, 2007). The relationship between technology and care has been the subject of much debate in the nursing literature for decades (Barnard & Locsin, 2007; Benner & Wrubel, 1989; Sandelowski, 1998). According to Barnard and Sandelowski (2001), technology and care are complicated and comprehensive besides being user, receiver and context dependent.

However, rather than thinking of TM as a disruptive technology (Carroll, 2018), under the guidance of the nursing theory, the TM nursing can be considered an opportunity to transform the art of care (Carroll, 2018; Locsin & Barnard, 2007; Macdonald, 2008). To find meaning in the care technology, it is important to explore the social and professional influence of the technological change to predict the future developments in the nursing care (Bardy, 2019; Barnard, 2007). In this thesis, a coherent concept emerged across all the three papers, suggesting that the relational encounter between the patient and nurse and the human-to-human connection is achievable using the TM technology and care. Therefore, the overall findings will be discussed from the perspective of the humanistic nursing theory in the TM care, which emphasise *belonging in the TM care, knowing in nursing, and the doing, being and all-at-once*, integrating the perspectives of nurses and patients and highlighting the relational encounters and the dialogic acts of TM nursing.

7.1.1 Belonging

Papers I and III concentrate on the patients with COPD and their experiences of receiving care through TM. Paper I is part of the meta-ethnography approach (Paper III), and the findings in Paper I correspond with the findings of Paper III. Therefore, the findings of Paper III will be discussed first. Hence, in Paper III, a sense of belonging was found to be pivotal to the experiences of patients with COPD receiving care through TM. Accordingly, this experience was rooted in two fundamental conditions for the TM care: presence and transparency.

Presence was experienced to provide emotional and social support based on accessibility to health care services and the availability of HCPs besides digital proximity. Presence can be defined as ‘a reciprocal and healing relationship between the nurse and patient through a compassionate exchange of the human experience’ (Hessel, 2009, p. 281), which also includes trust, listening and attentive focus (Hessel, 2009). Presence in an existential sense has been said to be the ‘guardian against distance and detachment’ (Doona, Haggerty, & Chase, 1997, p. 14) and is an essential part of the humanistic nursing approach (Paterson & Zderad, 1976). According to this approach, presence is explained as a humanistic connection involving being-there-for and being-there-with, seeing and being seen, and is grounded in the realm of the patient’s call and the nurse’s response (Kleiman, 2009; O'Connor, 1993).

In the traditional health care services, nursing is primarily a relationship-centred collaboration between the nurse and patient (Doona, Chase, & Haggerty, 1999; Finfgeld-Connett, 2006, 2008), while the core of TM is care provided through consultation, follow-up and communication between the patient and the TM nurse at a distance and through technology (Barrett, 2017; Oudshoorn, 2016; Pols, 2006). Yet, this thesis found that, in the TM care, it was not the ‘being-there-with’ that was found essential but rather the ‘being-there-for’—seeing and being seen—indicating that it was the relation encounter that was key to achieving presence. Hence, the core structure of the TM care involves setting the stage for these meetings and encounters. The latter implies that the TM technology aids a digital relational encounter through availability, accessibility and proximity to the TM nurse. Availability (Hessel, 2009; Shattell, 2004), accountability (Mohammadipour, Atashzadeh-Shoorideh, Parvizy, & Hosseini, 2017) and being attuned (Lasater et al., 2014) are found to be the essential aspects of achieving presence, regardless of closeness or distance in these encounters. Nevertheless, although the TM technology provides presence, Paterson and Zderad (1976) believe this is not synonymous with the presence obtained as an emotional, attentive or reciprocal response if the TM nurse is not receptive in the nursing situation. Thus, social connectedness with an HCP is an essential component of the TM care for experiencing presence, contributing to a sense of belonging through the emotional and social support. Presence then, is ‘the being’ of the TM care.

Transparency was found to be another core condition of the TM care, which increased the COPD patients’ clinical competence and awareness by performing regular clinical readings. This awareness of readings enabled the patients to distinguish between normal and abnormal clinical levels (measuring HR and saturation). However, this awareness was equally based on a reciprocal dialogue that involved sharing, discussing and reflecting on the clinical data with the HCP. Hence, regular clinical communication through TM consultation with the HCP increased the patients’ personal growth. As a result, the importance of developing a clinical language was discovered in Papers I and III, indicating that learning the clinical language of one’s own illness can augment a medical dialogue, integrating the individual illness narratives and experiences with those of the individual clinical understandings. These findings support the notion that medical language is not always dehumanising (Walton & Madjar, 1999).

Transparency is a rather new concept in the nursing literature and involves a sharing of information based on trust (Horne, 2012). This thesis provides a further understanding of the concept of transparency in a TM care setting; it strengthens the ability of the patients with COPD to understand and adapt to the detailed and complex clinical language of their illness, thus obtaining increased health literacy. In contrast, the patients with COPD have been found to have a poor understanding of their disease (Gardiner et al., 2010) and low health literacy, acting as a language barrier (Giacomini et al., 2012) to which limited compliance and poor health outcomes can be added (Puente-Maestu et al., 2016; Roberts, Ghiassi, & Partridge, 2008). Hence, transparency in a TM context strengthens the patients' ability to cope with the burden of living with the illness. TM then provides a horizontal, interactive opportunity for communication rather than a vertical one, which is common in regular health care services (Mort, Roberts, Pols, Domenech, & Moser, 2015). The openness in the TM HCS also supports a humanistic mindset, allowing the patients to enter the nurses' world, enabling receptivity to the patient from the nurse (Kleiman, 2009). More important, the openness in the TM care contributed to the patients' feeling that they were a part of the health care process and connected with the HCP through the TM technology (Paper III)—a key part in the sense of belonging in the TM care. Transparency in short is the 'doing' in the TM care, which increases involvement and engagement when receiving care by TM, contributing to a sense of belonging through a shared care and understanding.

Furthermore, the findings in Paper III show that the patients experienced belonging and connection with the nurses through the TM encounters. The sense of belonging was experienced as connectedness to the TM nurse achievable by the context and condition of the TM care (i.e. presence and transparency). A sense of belonging can be defined as 'the experience of personal involvement in a system or environment so that persons feel themselves to be an integral part of that system or environment' (Hagerty, Lynch-Sauer, Patusky, Bouwsema, & Collier, 1992, p. 172). Hence, people's need for belonging is a fundamental human need (Maslow, 1943). A sense of belonging has been found to be clinically relevant, giving support to patients to develop capacity and skills (Hagerty, Williams, Coyne, & Early, 1996) and enhance their social support (Halding, Wahl, & Heggdal, 2010). There are several associations between the need for belonging and the cognitive processes, emotional patterns, behavioural responses and health and well-being (Baumeister & Leary, 1995), and several of these factors mirror the findings of Paper III. Individual knowledge development, emotional and social support suggest that the TM care provides belongingness to the patients with COPD. This has been found as an essential care need (Gardiner et al., 2010), enhancing the

COPD patients' well-being and more-being (Paterson & Zderad, 1976) through the 'being' and 'doing' of TM nursing based on connectedness.

Furthermore, Paper III (also Paper I) showed that the severity of COPD directly influenced the sense of belonging and that receiving care through TM was experienced as ambivalent. The patients with severe and very severe COPD felt more dependent yet desired closeness when the illness emerged with increased symptom burden, unstable periods and uncertainty. On the other hand, patients with a low symptom burden or in a stable and early phase of the illness experienced the TM care as an unnecessary intervention in their lives and felt restricted yet wished to be detached. The patients with good health sought detachment when the TM care became a reminder of illness, also found by Brunton et al., (2015) and Pols (2006). Consequently, the experience of belonging was perceived to provide a need for closeness or detachment, illustrated in Figure 2 as the level of connectedness in the TM care. This indicates that the need for connectedness and belonging increases with the progression of the illness burden and severity. This is a significant contribution to the existing literature albeit with contradictory results (Brunton et al., 2015; Cruz et al., 2014; Gregersen et al., 2016; Pedone & Lelli, 2015), complicating the understanding as which COPD patient benefits from TM and what their preferences are (Vitacca et al., 2018). However, this thesis extends this research, as it shows that the TM care can broadly support several of the challenges facing people with COPD, such as physical, psychological, and social support, which are introduced as the main support needs for the patients with COPD (Gardener et al., 2018) and can thus aid patients' living with this unpredictable and progressive illness (Giacomini et al., 2012; Pooler, 2016).

7.1.2 Knowing the patient

Paper II explored the process of the TM nurses' clinical reasoning when using CDSS for the management and care of the patients with COPD, including the factors influencing this process. Hence, the TM care was based on several enabling factors, made possible by technology, such as the clinical and subjective data received daily and regular patient contact and continuous follow-up, which provided the nurses with detailed patient- and illness-specific knowledge. In contrast to the traditional nursing practice, reasoning and decision-making in TM imply a different approach to patients, involving advanced care performed remotely and supported by the ICT (Oudshoorn, 2016; Pols, 2006). This has altered how nurses come to know the patients, including how to obtain information and communicate with patients (Macdonald, 2008). In making clinical decisions, nurses consider different sources of knowledge (Stein-Parbury, 2009), which are related to rationality, intuition, experience and involvement in the clinical situation (Benner et al., 2009); these are complex, cognitive processes that require multiple ways of coming to know a situation. Thus, knowing the patient is one approach (Benner et al., 2009; Stein-Parbury, 2009).

Knowing the patient was fundamental to the reasoning and decision-making processes in the TM care setting. In Paper II, the personal patient knowledge was an essential factor in understanding a patient's health care needs, although this has been found to be the most difficult to learn and understand (Carper, 1978; Walton & Madjar, 1999). Furthermore, knowing the patient is an essential part of a humanistic nursing approach (Kleiman, 2009; Locsin & Barnard, 2007; Paterson & Zderad, 1976) and can be used to come to know the patients as persons (Locsin & Barnard, 2007). Several other studies have found that knowing the patient can influence the reasoning and decision-making processes (Cappelletti et al., 2014; Dowding et al., 2009; Edwards, 1994; Tanner, 2006). Hence, knowing the patient is essential for quality (Benner et al., 2009; Macdonald, 2008; Nagel et al., 2013) in the nursing care (Benner et al., 2009; Swanson, 1993; Tanner, Benner, Chesla, & Gordon, 1993). Personal and in-depth patient knowledge as well as the knowledge of the patient's disease can provide valuable information on pattern recognition and responses (Cappelletti et al., 2014; Oudshoorn, 2016; Tanner, 2006). Accordingly, this thesis suggests that personal and in-depth knowledge of each patient provided the TM nurses with the ability to 'advance beyond the system' and provide suggestions that did not reflect the patient's health status, as provided by the CDSS. In line with Edwards (1994), personal and in-depth knowledge enabled the TM nurses to detect the CDSS biases and enabled the gathering of patient-specific information, which helped in detecting individual changes in the health status and reaching a more accurate and nuanced decision.

To provide an in-depth knowledge of the individual COPD patients, nurses in Paper II were concerned with the illness narratives (e.g. the stories of the patients' lives), and how they experienced living with the illness and symptom burden. Consistent with the findings of Paper II, Benner et al. (2009) also found that nurses' understanding of the patients' situation was made possible by listening to their experience of the illness. The role of narratives is a central aspect of the nursing care (Fredriksson, 1999) and has also been found to involve learning and developing clinical expertise, including understanding both the biological and human world of patients (Benner et al., 2009) and influencing patient outcomes (Benner & Wrubel, 1989). In line with Walton and Madjar (1999), the TM nurses (Paper II) listened to the patients' stories of living with the illness, presented in short segments, and connected these short illness narratives to form a picture of the patients and their illness progress and experiences. Forming a mental image or building a picture was an essential part of knowing the patient and is found equally important in the other TM settings (Edwards, 1994; Nagel et al., 2017). This thesis found that the TM reasoning and care were situated at an intersection of interpreting individual clinical data and integrating them with personal illness narratives (see Benner & Wrubel, (1989)); this brings about an understanding of the differences and relationships among health, illness and disease. In this way, the TM nurses gained both personal and individual clinical knowledge of each patient—an essential part of knowing the patient.

As shown in Paper II, the TM nurses would perform shared decision-making to move from a pre-decision to a final decision in collaboration with the patient. The regular dialogues (TM consultations) between the TM nurse and patient were essential to validate and elaborate the reasoning process. In this course of decision-making, nurses valued the patients' situations seriously and considered the patients' illness narratives as equally important to clinical data from the CDSS. Consistent with the findings of Paper II, Elwyn et al. (2000), Elwyn et al. (2012) and Zoffman et al. (2008) also found that collaboration with the patient supported the patient's values and preferences. This view could be seen in line with Paterson and Zderad's (1976) humanistic nursing valuing of patients' choices to achieve well-being and more-being. However, shared decision-making requires that nurses have appropriate communication skills (Friesen-Storms, Bours, van der Weijden, & Beurskens, 2015). In a TM setting, this requires that the TM nurses have the knowledge and skills needed to use the technology as intended, so that the potential barriers such as communication and the nurse-patient connections are not affected rather than situating the patient in the centre of the care provided (Barry & Edgman-Levitan, 2012; Rheuban & Shipman, 2018). This is supported by Van Houwelingen et al. (2016) and Henry et al. (2017) who found that the competence needed for nurses in a TM setting includes clinical knowledge and communicative skills, with a renewed focus on interpersonal need and care. Consequently, nursing practice and research need to account for the patients' participation in the decision-making processes (Edwards & Sines, 2008).

Paper II found that close patient contact enabled the TM nurses to gain a detailed understanding of the challenges associated with the individual nature of COPD. Nurses are present in some of the most vulnerable occasions in human life (Madjar & Walton, 1999), and chronic illnesses demand some of the most complete, expert and total nursing care (Paterson & Zderad, 1976). Hence, patients require continuous knowing (Locsin & Barnard, 2007), especially those suffering from COPD, who are facing ever-changing symptoms and often an unpredictable disease progression (Pooler, 2016). Paterson and Zderad (1976) note that it is essential that the human potential be valued. Kleiman (2009), Benner and Wrubel (1989) and Toombs (1993) argue that patients need to be acknowledged as subjective beings rather than objects of disease; this is fundamental to the humanistic perspective. When nurses demonstrate understanding of the personal and unique experiences of patients, they are therapeutically connecting on an interpersonal level (Paterson & Zderad, 1976). In this thesis, fostering a close relationship with the patient was an important factor in the care provided to the COPD patients through the TM care, reasoning and decision-making. This illustrates that, besides strengthening the nurse-patient relationship, an increased understanding of the knowing aspects of the TM care can provide new insights into how and why the TM nurses are able to provide personal and clinical knowledge of the individual COPD patients.

7.1.3 The doing, being and all-at-once

In the receiving/providing care process of TM, the human-to-human connection was found to be a recurrent finding across all the three Papers (I, II and III). The human-to-human connection was found as an essential part of the patients' experience of belonging in the TM care and that of the TM nurses of coming to know the patients. Consequently, the doing, being and all-at-once (Paterson & Zderad, 1976) in the TM care begins with a human connection, enabled by the TM technology. Accordingly, along with technical competence, the ability to establish human connection is essential for clinical knowledge in the nursing practice (Stein-Parbury, 2009). Hence, TM utilises a technology that connects nurses and patients who receive health care (Carroll, 2018) and can be a humanising factor as it is socially (Barnard & Sandelowski, 2001) and collaboratively constructed (Bardy, 2019). However, Paterson and Zderad (1976) questioned the dialogic act of nursing, considering the factors associated with the results of the technological advances in the nursing care. They were concerned whether technology was a bridge or a barrier in 'the between' (the dialogue) to human interaction or, as Kleiman (1993) enquired, whether technology was humanising or de-humanising?

In response to this, the TM care is found to entail both 'temporal and relational aspects' (Bardy, 2019, p. 228). In line with Bardy (2019), this thesis found that, in the relational encounter in the TM care, the digital communication (e.g. the lived dialogue (Paterson & Zderad, 1976)) connects the nurse to the patient—the receiver to the provider—which strengthens the nurse-patient relationship. For example, the clinical measurements were transmitted from the patient and verbalised between the patient and the nurse through the TM technology, entailing shared decision-making (Paper II) and a reciprocal dialogue (Paper III). Hence, communication in the TM care is vital (Henry et al., 2017; van Houwelingen et al., 2016) and requires that the TM nurses be able to engage in dialogue with the patients to grasp the 'patient-as-subject' about the 'body-as-organism' part of the clinical knowledge (Bardy, 2019, p. 26). Therefore, nursing care is performed in a physical space and, at the same time, in a personal space (Nerheim, 1995), both of which are important in the realm of the TM care, as shown in this thesis. Being-there-for (Paterson & Zderad, 1976) and actively listening to patients' narratives of their individual illness, as shown in Paper II, are important processes in the care of patients with COPD. Listening to the COPD patients and how they are affected by their symptoms can improve the patients' experiences of living with COPD, which was also found by Barnett (2005).

The dialogue involves every feature of human communication and is characterised as the core of the nursing act (Kleiman, 2009) and a unique encounter between the nurse and patient (Paterson & Zderad, 1976). The interpersonal relationships between the patient and nurse humanise health care because nurses are responsive to their patients' subjective experiences. The relationship combines the nurses' knowledge with the patients' experience of the health events (Stein-Parbury, 2009). Nurses' personal involvement and knowledge become essential to everything nurses do and are (Pajnkihar, 2008). In the light of Paterson and Zderad's (1976) humanistic nursing theory, this thesis found that the 'doing' of TM care entails the patients' belonging through transparency and nurses' reasoning process grounded in clinical knowledge. The 'being' of the TM care calls for the patients' belonging through presence and nurses' genuine listening to patients' illness narratives (shared decision-making). Hence, the all-at-once is the combined product of these elements in the dialogic act of the TM care, bringing all that they are (emotional, social, personal and clinical) in this dialogical meeting, fostering a strong nurse-patient relationship.

Hence, the TM care advocates a paradigm change (Schermer, 2009) and, within nursing, science and technology, a ‘paradigm of relation’ (Hawthorne & Yurkovich, 1995, p. 1090), focusing on relationships with others and the world and creating an understanding of what it is to care (Hawthorne & Yurkovich, 1995). Thus, a human connection in the form of a nurse-patient relationship is vital to nursing (Stein-Parbury, 2009). In summary, the TM care is changing the social space of the nurse-patient interaction (O'Keefe-McCarthy, 2009) and involves a shift from the technological concern to focus on the nurse-patient relationship (LeRouge, Garfield, & Collins, 2012). The art of nursing is embodied in this very interaction between the nurses and patients and involves both the patients’ and nurses’ subjective and objective lifeworld (Paterson & Zderad, 1976). Hence, exploring the lived experiences of patients and nurses deepens our understanding of the phenomenon of the art of nursing (Appleton, 1993).

7.2 Methodological considerations

This thesis adds valuable evidence to the existing body of knowledge about patients’ and nurses’ experiences of receiving/providing the TM care. The qualitative research method helps in describing or interpreting a phenomenon and understanding the lifeworld of the participants (Denzin & Lincoln, 2005). This thesis explored the experiences of both patients and nurses as users of TM technology (Papers I and II) and a meta-ethnography synthesising COPD patients’ experiences with TM (Paper III), including (a) a description of the patients with COPD and their experiences of receiving care through TM (Papers I and III) and (b) exploring the TM nurses’ clinical reasoning using a CDSS in a TM setting providing the TM care. The following section discusses the methodological strengths and limitations as well as the papers’ trustworthiness.

7.2.1 Multiple qualitative methods

The overall aim of this thesis was answered using multiple qualitative methods, utilising the combination of multiple methodological practices, empirical materials and perspectives. The use of combined methods secures an in-depth understanding of the phenomenon in question (Denzin & Lincoln, 2005; Patton, 2002; Polit & Beck, 2010) and can add rigour, breadth, complexity, richness and depth (Denzin

& Lincoln, 2005). Combining different methods can also reveal various aspects of the empirical reality (Patton, 2002). In this thesis, the combination of the different qualitative methods and analyses provided a more comprehensive picture when presenting both the patients' and nurses' receiving/providing experiences of the TM care, representing distinct perspectives within the same phenomenon. Hence, by integrating the perspectives of both nurses and patients, using multiple qualitative methods, the human connection and relational encounter emerged as a recurrent finding within the empirical materials from all the included papers.

However, questions have been raised that the process of combining qualitative methods can result in different directions, where different methods capture various kinds of aspects, making it difficult to reach a coherent result (Erlandson, Harris, Skipper, & Allen, 1993; Patton, 2002). Nevertheless, the combinations of qualitative methods strengthened this thesis by integrating the methods, perspectives and empirical materials, which according to Patton (2002), can increase the accuracy and credibility of the findings, and provide richer and more diverse empirical materials. Hence, this resulted in deeper insights into the phenomenon being studied and generated new knowledge and a deeper understanding of the experiences of the patients with COPD and nurses receiving/providing the TM care. Thus, the methods chosen were one of several possible ways of considering the phenomenon in question.

7.2.2 Study samples

Obtaining an in-depth knowledge of the patients' and nurses' experiences of the receiving/providing care through TM was the focus of this thesis; hence, the selected sample sizes were intended to meet the different aims of the papers.

The sample in Paper I consisted of 10 patients with COPD, receiving care through a TM intervention. Purposive sampling (Malterud, 2013) was used to obtain concrete descriptions of the experiences from the participants who had COPD and had taken part in the TM intervention. The variations in gender, age and various degrees of COPD illness benefited the paper, as they provided different perspectives on the phenomenon in question. The participants' various degrees of illness, from moderate to very severe, were particularly important to enrich the participants' different illness narratives, which provided rich and varied empirical data. It could be argued that the sample of 10 participants was too small. However, in phenomenological studies, large samples are not required, mainly because such researches attempt to enhance the in-depth knowledge of the participants' lives (Giorgi, 2009).

Sample selection in qualitative research can influence the outcome of the empirical materials (Malterud, 2013). A possible limitation in Paper I can be associated with the recruitment of the participants. The participants were recruited by an expert TM nurse who was responsible for managing the TMC and contacting and following up the participants. Although the selection criteria were adhered to, it is difficult to say much about the other choices for recruitment regarding, for example, what possible positive and/or negative opinions the participants could have expressed about the topic to the TM nurse during consultations. One can only argue that the choices were made based on neutrality and objectivity, although this is difficult to verify.

In Paper II, the sample size of three nurses was small. However, in ethnographic studies, Savage (2000) argues that ethnography could be used as a method for every scale, small or large, where social research is performed in a natural, everyday setting. The range of the collected data in qualitative research is equally important as sample size (Denzin & Lincoln, 2005; Sandelowski, 1995). Thus, based on the richness of the data, three TM nurses were considered to be enough to provide in-depth insights. In addition, the three nurses represented a cross section of the TMC, as the four nurses who refused to participate were employed only once a month and had minimal responsibilities for patient follow-ups and for the reasoning and decision-making processes. However, in the ideal would, a larger number of participants would have been more desirable besides an extended research at other locations with similar work settings. In addition, the field observations could have been extended, but had to be ended in cooperation with the participants as they did not wish to continue further.

The recruitment strategy in Paper II was challenging. Taking part in fieldwork can create a feeling of being observed and disturbed in the natural setting, which can hinder the participants from participating in such a form of research. Therefore, it was important to locate the 'gatekeeper'—the person that can give access to the field (Hammersley & Atkinson, 2007). In this case, the 'gatekeeper' was the TM nurse with the widest experience and greatest responsibility at the TMC. The TM nurse invited the potential participants who were employed at the TMC to participate. However, the 'gatekeeper' was also one of the participants, indicating that the 'gatekeeper' had dual roles. Consequently, the other participants could feel that they were obligated to participate as colleagues who managed the same TMC. There is a possibility that the latter could have influenced the recruitment and the data, the extent of which is very difficult to be stated.

Twelve papers were included in Paper III. Although the eligibility criteria were developed carefully to identify the most relevant papers to be included in the meta-ethnography, the included papers displayed variations in terms of the TM intervention and equipment, duration of the TM follow-up (10 days to three years), type and duration of contact (video/non-video), degree of COPD (ranging from mild to very severe), timing of the interviews and types of analysis. Hence, heterogeneity, that is identifying the differences between studies (Booth et al., 2016), is important to be acknowledged, mainly because such variations can influence the synthesis. Thus, regardless of the differences between the studies in Paper III, both the similarities and differences contributed to the findings, indicating variances (refutational findings) in COPD severity. In addition, differences were also found among the TM interventions, as they varied greatly, for example, between the papers that did not include video consultations and those that contributed to the digital proximity construct.

7.2.3 Methodological approach

Interview

Descriptive phenomenology was used to inquire about the participants' experiences of the quality of life when living with COPD and receiving care through TM. In-depth interviewing made it possible to gain insights into and knowledge of the participants' varied experiences. Hence, phenomenology has the ability to make things stand out in a new way. However, this approach has both shortcomings and benefits (Madjar & Walton, 1999).

An important aspect of descriptive phenomenology requires that researchers avoid collecting data on specific details or content but rather encourage the participants to genuinely express their experiences of the phenomenon (Giorgi, 2009, 2012). Hence, to ask open questions forces the interviewer to shift between 'the subject-subject relation and the subject-phenomenon relation' (Englander, 2012, p. 34). This was acknowledged by not introducing new themes in the interview setting but rather guiding the participants to talk about the phenomenon or asking probing questions relating to the narratives they had already mentioned to not elicit specific experiences from the participants. In the interview setting, the participants narrated stories of illness experiences of living with COPD, however this was not part of the open interview questions. Accordingly, in respect for the participants and in light of phenomenological inquiry, I allowed them to narrate these stories to the fullest as I considered that their experiences were significant to them. However, it was during the analyses process I first found that the illness narratives were an entwined and important part of their experience of receiving care through TM; living with the illness were closely related to the experiences of TM follow-up. Subsequently, performing phenomenological interviewing could present a more complete picture of the phenomenon in question, based on letting the participant narrate their experiences open and freely.

Additionally, Giorgi (2009) explains that every participant is different, which can pose challenges in the interview situation. Subsequently, this was especially challenging in Paper I as some participants were reflective and could easily verbalise their experiences; others on the other hand were quieter and more careful. Participants that were quiet and careful demanded more of me in the interview setting, however, was recognised by using more time with these participants, by carefully listening to the participants experiences, and mentally remembering their verbalisation of the experience, to further ask probing questions follow-up on the participants previous verbalisations.

The focus group interview performed in Paper II was complementary to the fieldwork, strengthening the study through methodological triangulation. Performing a focus group interview would help the participants hear each other's responses and allow them to comment beyond their own responses. The interactions between the participants also enhance the data quality (Krueger & Casey, 2015; Patton, 2002). The rationale for performing the focus group interview, as opposed to individual interviews, emanated from the fact that the TM nurses were managing the TMC alone and with limited opportunities for collaboration. The focus group interview created a venue for meeting and encouraged discussion among the nurses, which facilitated a broader sharing of the experiences of the TM context and the use of the CDSS and thereby strengthening the study.

Fieldwork

To explore the TM nurses' reasoning and decision-making in the TM care setting (Paper II), participatory observations and the TA technique were used. In addition, it was important to elicit opinions that provided the most relevant knowledge to answer the specific aim (Malterud, 2013) of Paper II.

When gaining access to the TMC, the author was able to observe the participants in their natural context, thus creating an understanding of behaviour and action within the TM setting (Savage, 2000). However, the TMC were managed through several computers, rather than direct patient work indicating that all reasoning and TM nurse activities were performed on a screen, and that the reasoning and decision-making processes were reached without being verbalised by the nurses (tacit knowledge). Hence, this made it difficult to observe at a distance and indicated that I needed to gain access to data that were not visible to me merely as an observer; I needed to participate in the nurses' work, to be seated closely and to hear their reasoning process. Therefore, the choice of performing participating observations and to use the TA technique was made. Hence, performing observations in the TMC setting was especially challenging, as it was only one participant and me that were present during the observations as the participants were engaged in managing the TMC alone, which caused my presence to be more profound. In this situation, I made the choice to be seated next to, rather than facing the participants, to minimise influencing the participants and the data. Although efforts were taken, when conducting observations, participants' behaviours and actions can be influenced by the presence of the researcher (Hammersley & Atkinson, 2007; Malterud, 2013; Mays & Pope, 1995).

Ethnography pertains to personal involvement, flexibility and the opportunity for close contact with participants (Alvesson & Sköldberg, 2009). However, even though I gained access to the TMC, there was little assurance that data would readily be available (Hammersley & Atkinson, 2007). The knowledge developed by an ethnographic approach to a research field is strongly influenced by the relationship between the participant and researcher (Savage, 2000). In the TM setting, it was important that I achieved mutual trust and drew on discretion and responsibility when the TM nurses were willing to share insights with me about their everyday lives in the TM setting. To achieve this, I needed to constantly balance between the desire for data and the attention of the participants (Malterud, 2013). Hence, fieldnotes were written while the nurses were performing consultations with the patients and during nursing documentations. This was a conscious act, in that, during the observations, I noticed that writing field notes in close proximity to the participants was disturbing their work. Consequently, it was decided that the field notes to be written when the nurses were occupied with writing and/or consulting the patients to minimize any disturbances. In addition, the interpretation of the field notes was undertaken during and after the day's observations (Hammersley & Atkinson, 2007; Hellesø et al., 2015; Madden, 2010). Furthermore, the details of setting, context and human behaviour were documented to provide complete and representative data of the field investigated (Hammersley & Atkinson, 2007). In addition, notes were taken of how the TM nurses would reason and make decision about a patient, how they used the CDSS, how and what information they sought, and how they connected and communicated with the patients using video or phone counselling.

Moreover, the researcher's field objectivity can affect the participants and the collection and interpretation of the data (Polit & Beck, 2010). As a field researcher, one is influenced by the languages, social conditions and various aspirations. However, Madden (2010) questions the researcher's field objectivity or the desire for it and argues how subjectivity can affect both the research and the written text. According to Borbasi, Jackson and Wilkes (2005), many of the skills that a nurse has acquired resemble those held by an ethnographer, such features include listening, interviewing, observing, reflecting and interpreting on multiple levels at the same time and with a conscious presence of oneself. Therefore, as a nurse with professional knowledge and experience I may have offered security in the TM setting, thus experiencing successful interaction.

Qualitative systematic review

Synthesising qualitative research can provide distinct, unique and multiple views of reality based on different qualitative research methods. However, the synthesis of qualitative research can also generate different views on the matter based on epistemological and ontological concerns, assuming that the gathering of research findings by reviews leads to a single 'truth' (Pope, Mays, & Popay, 2007, p. 74). Nevertheless, qualitative systematic reviews create the possibility of extending the knowledge base of qualitative research (Pope et al., 2007) and generating new knowledge (e.g. theory development) (Noblit & Hare, 1988).

Paper III followed Noblit and Hare's (1988) seven-step method of performing a meta-ethnography. The search methods and search outcomes have been thoroughly presented in the methods section to enhance transparency. Hence, performing a qualitative review requires a close collaboration between the first author and the co-authors (the review team) to perform the steps of the method. The review team independently screened the studies using the inclusion and exclusion criteria, appraised the quality of the included papers and reached an agreement. The quality of the included paper by Vatnøy, Thygesen and Dale (2017) was appraised by two of the review team members, excluding Thygesen since she was involved in the original paper. In addition, the included paper (i.e. Barken, Söderhamn and Thygesen (2018)) was appraised for quality by two independent professors with extensive experience in qualitative research for an impartial evaluation.

7.2.4 Analyses

This thesis used several different analysing approaches, such as descriptive phenomenology (Paper I) (Giorgi, 2009), manifest and latent content analysis (Paper II) (Graneheim & Lundman, 2004) and a meta-ethnography synthesis (Paper III) (Noblit & Hare, 1988). While ontological and epistemological assumptions guide the qualitative methodologies, the methodologies used in the present thesis have diverse characteristics influencing qualitative research purposes, data collection methods and analysis approaches (Polit & Beck, 2010).

In Paper I, the analysis process was conducted in the light of the descriptive phenomenological research method (Giorgi, 2009) and was further adapted to the phenomena of the health science. A phenomenological reduction attitude was assumed, indicating ‘a position that exists whatever object of affairs that is present in the consciousness, and refrains from bringing non-given past knowledge to whatever is present’ (Giorgi, 2012, p. 4). Hence, all pre-understanding should be bracketed (Giorgi, 2009). However, to bracket one’s understanding can be challenging. During the interviews and analyses, I had consulted minimal researches on the subject in an attempt to bracket my pre-understanding with a view to reaching as much an unprejudiced description as possible.

Transforming data using free imaginative variations (Step 3 of the analysis method in Paper I) is acknowledged as an integral part of the method (Giorgi, 2012). However, it is important to appreciate whether it is possible to transform at this stage of the analysis without permitting one’s pre-understanding to influence the findings. Dahlberg and Dahlberg (2004, p. 273) believe that it is possible to describe the meaning and essence of the participants’ lifeworld, although one needs to be ‘careful not to make definite that which is indefinite’. To make sure that the data were transformed using free imaginative variations and not interpreted, several rounds to find the best words were performed. This stage entailed going back and forth between the raw data and the transformed descriptions to maintain the meanings behind the experiences of the participants, as Giorgi (2012, p. 8) states: ‘examining various possible expressions that fits the intentional act is to fulfil the expression precisely at it is described’.

The analysis process in Paper II included a manifest and latent content analysis. The manifest stage of the analysis was close to the interview text. However, the latent analysis included an interpretation that was distant from the text, albeit still close to the participant’s lived experiences. The various stages of the analysis were clearly described and showed a clear statement between the various voices of the researcher and the participants (Graneheim et al., 2017). This was acknowledged by following the analysis steps carefully, including discussing the various categories with the co-authors and presenting the various levels of abstraction in the manifest analysis and in the interpretation of the overall theme in the latent analysis.

In Paper III, each step of the synthesis process was discussed thoroughly between the members of the review team to enhance the trustworthiness of the synthesis process. A line-of-argument synthesis could be performed based on both reciprocal and refutational findings. Hence, the synthesis was based on a constant comparison method (Britten et al., 2002) and it is important to describe the arrangement of the included papers in the synthesis (France et al., 2019). Initially, the included papers were arranged based on conceptual richness and quality. Given the variable contexts and interventions, several possible ways were available for arranging the papers, such as by intervention type (e.g. video/non-video) or chronologically. Hence, arranging the papers chronologically would indicate that Paper I (the review team’s own paper) would be the index paper against which all the other papers would be compared. Consequently, the choice of arranging papers by quality could have impacted the findings and may have influenced Paper III in terms of how the synthesis and interpretation were performed. However, to deal with subjectivity, the order of the papers in the synthesis process was discussed thoroughly by the review team. In short, given the interpretative nature of meta-ethnographies, aiming at providing explanatory models (Booth et al., 2016), grouping papers together by conceptual richness was justified.

7.2.5 Pre-understanding, reflexivity and trustworthiness

The author’s role and pre-understanding are important in the qualitative research process, and one may find that the same reality of a phenomenon may be interpreted differently. Therefore, the researcher’s academic perspective, personal experience and understanding will be of importance concerning what kind of knowledge is derived (Malterud, 2013). In this thesis, the author’s pre-understanding as a nurse created many experiences in care situations with patients suffering from chronic diseases and COPD; it also created an understanding of how a disease affects patients. However, the author had no prior experience with TM. Consequently, the acquired knowledge, skills and attitudes as a nurse may have methodological, practical and ethical implications (Borbasi et al., 2005). Hence, the author’s pre-understanding was acknowledged when performing and planning Papers I–III during data collection, analysis and write-up stages while embracing a reflexive position.

Reflexivity is an active role; it implies the ability to question one’s own approach, suggesting an open mind with room for doubt, reflection and unexpected conclusions. Reflexivity advocates that the researcher, through the research process, questions the methods and conclusions within the role of the researcher (Alvesson & Sköldberg, 2009; Malterud, 2013). A systematic reflection on methods and the relevance of knowledge and validity is the means to achieve reflexivity (Malterud, 2013). In addition, the researcher’s role, reflexivity and pre-conceptions can also affect my attempt to obtain an objective attitude towards the field of inquiry (Papers I–III). Reflexivity is a requirement for scientific knowledge, where a systematic reflection on the research process as well as on the validity and relevance of knowledge constitute the core of reflexive thinking (Alvesson & Sköldberg, 2009; Malterud, 2013). Hence, reflexivity must be acknowledged in the light of trustworthiness when conducting the qualitative research (Lincon & Guba, 1985).

Trustworthiness is an overarching concept that describes the aspects of credibility, dependability and transferability in the qualitative research (Graneheim et al., 2017; Lincon & Guba, 1985); there are parallel terms to validity and reliability in the quantitative research (Polit & Beck, 2010). To establish trustworthiness and accuracy, it is important to rigorously elaborate the research process to understand how and why the research was undertaken (Erlandson et al., 1993; Graneheim et al., 2017; Lincon & Guba, 1985).

To achieve trustworthiness in the phenomenological research, it is important to closely adhere to the principles of phenomenology (Söderhamn, 2001). In Paper I, full descriptions were obtained about each participant and how data were collected. In addition, questions were as open as possible to ensure that the participants could narrate their perceptions freely. The analysis process was conducted in the light of the descriptive phenomenological research method (Giorgi, 2009). To establish credibility, which refers to the confidence of the truth of the data (Lincon & Guba, 1985; Polit & Beck, 2010), the author closely adhered to the phenomenological reduction attitude (bracketing). In addition, the analysis was shared and discussed with the co-authors for transparency. Furthermore, the credibility of the findings in Paper I was confirmed by carefully following the analysis steps when searching for the essence in the interview texts.

Moreover, the observations that were performed in Paper II take into account various disturbances and difficulties that could directly impact the production of credible and dependable data. Madden (2010) illustrates the importance of credibility in the research method and researcher's own influence on the research process, including reflection on the role of the researcher through all the stages of the research process and that reflective elements must become part of the research method. To achieve trustworthiness when using qualitative content analysis (Paper II), it is important that the entire research process provide a 'red thread' from the introduction to the method, findings and discussion (Graneheim et al., 2017). In addition, because Paper II triangulated the data collection methods to strengthen the study, credibility was increased, as it provided a more complete and nuanced picture of the phenomenon in question (Erlandson et al., 1993; Polit & Beck, 2010).

Meta-ethnography is a complex synthesis method (Atkins et al., 2008; Britten et al., 2002; France et al., 2019), involving a rigorous methodology and carefully following Noblit and Hare's seven-step approach (Noblit & Hare, 1988). Hence, this approach was applied to achieve credibility and trustworthiness in Paper III (France et al., 2019). To further enhance quality and transparency, Paper III followed the ENTREQ (Tong et al., 2012) and eMERGEe guidelines (France et al., 2019). In addition, being cognisant of the professional background of the authors as nurses and having previous experience of TM and/or COPD as well as being the primary authors of two of the included papers made the review team members' alert to the possibility of influence in Paper III and encouraged them to discuss it through all the stages of the review. Every step in Paper III was thoroughly explained, which included defining the object of interest, search methods and search outcomes, the synthesis process and writing the synthesis.

Furthermore, for the findings of Papers I–III, dependability—the extent to which research findings are consistent and repeatable—was confirmed through the same meanings that unfolded in the interview texts (Papers I and II) and in the findings section of the included papers (Paper III) (Polit & Beck, 2010; Söderhamn, 2001). In addition, quotations were provided in the findings section to further strengthen the credibility of Papers I–III.

Transferability is concerned with the extent to which the findings of a study can be applied to other settings or groups (Polit & Beck, 2010). Variation, sample size and context are important parameters to consider, as they can influence research transferability (Malterud, 2013). The findings of a qualitative study are difficult to generalise; however, the findings could be transferred to similar settings (Graneheim & Lundman, 2004) or patient groups (Erlandson et al., 1993). Hence, the findings of this thesis can be transferrable to other patient groups living with chronic illnesses besides nurses who work in similar health care settings. It is important to note that the data of Papers I and II were collected in Norway, whereas the materials for Paper III were gleaned from Norway, Denmark and the United Kingdom. Hence, the relevance and applicability of the findings to other countries and health care settings should be considered with caution.

8 CONCLUSIONS

The human-to-human connection was identified as an essential component for the patients' experience of belonging in the TM care and for the TM nurses' acquainting themselves with the patients. Hence, three main conclusions can be drawn in this thesis:

- High severity of COPD increased the need for connection and belonging in the TM care. This is an important contribution to the existing, albeit contradictory, evidence base, as it adds and addresses renewed understandings of who would benefit from TM and why.
- In the receiving/providing care process of TM, the TM technology enabled close, albeit distant, TM encounters, where nurses and patients learnt from each other in the all-at-once dialogue, contributing to the well-being and more-being of the COPD patients and increased clinical and personal knowledge for the TM nurses.
- The dialogue became the caring act of the TM care, supported by the humanistic perspective of Paterson & Zderad (1976) in their view of the importance of the lived dialogue in nursing; hence, nursing *is* dialogue. Thus, there is a humanistic connection of care effected by the dialogical act of nursing through the TM care.

8.1 Implications for clinical practice and future research

By drawing on the humanistic perspective in the TM care, this thesis increased our understanding and in-depth knowledge of what nursing is like in the TM care, contributing to the existing empirical evidence base. Therefore, the nursing theory can provide deeper insights into the evolving nursing practice, involving increasing complexity and development (McCamant, 2006). Further, considering the conclusions of this thesis, the following implications for clinical practice and future research are offered:

- The findings of this thesis illustrate how important it is to understand the experiences of those who struggle daily with COPD and receive the TM care; it is also important to gain insights into the experiences of the TM nurses who are responsible for providing care to these patients. Hence, in a TM care setting, it is vital to understand and acknowledge patients' and nurses' experiences when designing, implementing and utilising TM as a permanent solution to COPD patients.

- The patients and nurses in this thesis both referred to the relational encounter, enabled by the TM care technology, as necessary to experience the positive aspects of the TM care (e.g. emotional, social and clinical support), increase clinical and personal knowledge and foster a strong nurse-patient relationship. Hence, these findings indicate that the current and future TM care should maintain regular nurse-patient encounters. Video consultations should be the preferred method for the further strengthening of the relationship.
- The patients with unstable, progressing or severe COPD are the ones who benefit most when receiving the TM care. To further support these patients, the conditions of the TM care should be maintained (i.e. presence and transparency) and continuously supported to increase the sense of belonging. In addition, the patients with severe COPD should be offered a more permanent TM follow-up.
- To support the TM nurses' caring for the patients with COPD at a distance, the reasoning and decision-making processes should acknowledge the nurses' 'knowing the patient' as essential in the reasoning process. Hence, future TM services are recommended to be organised in a way that maintain the continuous flow of the clinical data, involve regular video-mediated contact and promote shared decision-making to support nurses' reasoning. In addition, future research is needed to develop more accurate algorithms, increase system maturity and improve the integration of digital information with clinical experience.
- Lastly, there are several aspects in the TM care that this thesis did not address, such as the impact of comorbidity on the findings, the effect of the housing arrangement (e.g. living alone or with a spouse), the cost of close follow-up and the role and motivation of the patients who declined to participate in the TM intervention. These aspects and their potential impact should be acknowledged in future research.

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Appendices

Paper I-III

1. Permission to include Figure 1 – A presentation of the humanistic nursing theory by courtesy of the National League for Nursing Press
2. Interview guide used in Paper I
3. Interview guide used in Paper II
4. Approval of Paper I from the Norwegian Centre for Research Data (NSD)
5. Approval of Paper II from the Norwegian Centre for Research Data (NSD)
6. Information about the study and informed consent form for participants in Paper I
7. Information about the study and informed consent form for participants in Paper II

Paper I

Unlocking the limitations: Living with chronic obstructive pulmonary disease and receiving care through telemedicine—A phenomenological study

Abstract

Aims and objectives: The aim of this study was to describe the lived experiences of quality of life among a group of patients living with chronic obstructive pulmonary disease (COPD) who were included in a telemedical intervention after hospitalization for disease exacerbation.

Background: Patients with COPD have high symptom burden, poor control of symptoms, and a need for greater requirements in care. Telemedicine (TM) can provide benefits for patients with COPD by improving self-management.

Design: Descriptive phenomenological approach.

Methods: Ten in-depth interviews were conducted with COPD patients participating in a telemedical intervention. The collected data were analysed using a descriptive phenomenological research method.

Results: Living with COPD was experienced as creating physical and mental limitations of the diseased body and an increasing identity as a patient, which led to impaired quality of life. Being included in the TM intervention increased accessibility to health care services and support from TM nurses. Self-measurement of health data increased participants' clinical insight and created a mutual clinical language in dialog with TM nurses, which led to increased quality of life. However, receiving care through TM was also experienced as a dual chore.

Conclusions: TM can reduce the perceived limitations imposed by COPD through four key elements: 1) improving accessibility to health care services, 2) increasing support from health professionals, 3) strengthening clinical insight, and 4) developing a mutual clinical language; thus, increasing quality of life. The transparency facilitated through TM in this health care context encourages open decision-making, where the participants can increase their knowledge and improve acknowledgement of and collaboration with TM nurses.

Relevance to clinical practice: TM can be beneficial when rethinking care for COPD by providing knowledge on how living with COPD can affect the experience of receiving care through TM and further determine for whom TM is useful.

Keywords: chronic obstructive pulmonary disease, nursing, patient experience, phenomenology, quality of life, self-management, telemedicine

Summary box

What does this paper contribute to the wider global clinical community?

- Increased in-depth understanding of care needs for patients with COPD by performing descriptive phenomenological research
- Insight into how living with COPD can affect the experience of receiving care through TM and to further determine for whom TM is useful
- Telemedicine promotes transparency in health care services enabling open decision-making that can improve acknowledgement of and collaboration with health care professionals

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a serious and progressive disease representing a significant burden on both patients and health care systems (Vestbo *et al*. 2013, WHO 2016). Living with COPD is related to both physical and emotional limitations. Having a severe degree of COPD implies a high symptom burden (Simpson & Rocker 2008, Gardiner *et al*. 2009), entailing continuous changes that have a considerable impact on a person's quality of life (Frasier *et al*. 2006, Ek & Ternestedt 2008, Simpson & Rocker 2008, WHO 2016). The breathlessness is particularly difficult to endure and contributes to the greatest restrictions in daily life (Ek & Ternestedt 2008, Blinderman *et al*. 2009); therefore, the high symptom burden of COPD is often followed by poor control of symptoms (Gardiner *et al*. 2009).

COPD is increasingly common, and according to the World Health Organization, COPD will rise from the sixth to the third most common disease worldwide by 2030 (WHO 2016). Due to this increasing prevalence, there is a need for more focus on prevention and treatment (Simpson & Rocker 2008) and requirements for care (Gardiner *et al*. 2009). Following up patients using telemedicine (TM) has shown promising results for patients suffering from COPD (Gale & Sultan 2013, Williams *et al.* 2014, Gorst *et al*. 2016, Vatnøy *et al*. 2016). TM can be defined as 'information, communication, and monitoring technologies which allow healthcare providers to remotely evaluate health status, give educational intervention, or deliver health and social care to patients in their homes' (Solli *et al*. 2012, p. 2813).

BACKGROUND

The use of TM in health care services has increased significantly the last 20 years (Wotton 2012). Although follow-up of patients with COPD using TM has shown promising results, there is still ambiguity with regard to efficiency (Wotton 2012, Cruz *et al*. 2014, Pedone & Lelli 2015). The uncertainty pertains particularly to the effects of hospital admissions and mortality (Kamei *et al*. 2012, McLean *et al*. 2012) and to the effect on quality of life (McLean *et al*. 2012, Gregersen *et al*. 2016). However, as TM is expected to play a greater role in future global health care delivery, it will be increasingly important to develop a strong and diverse evidence base (Dinesen *et al*. 2016).

Living with COPD represents a significant challenge, and to manage the condition and high symptom burden, there is a need for continuity of care, regular follow-up, and support from health care professionals (Pols 2006, Gardiner *et al.* 2009), with a focus on achieving self-management (Lawn *et al*. 2013, Vatnøy *et al*. 2016) to further increase quality of life. Qualitative research has shown that TM has the potential to increase quality of life by giving increased access to health care services, which facilitates collaboration with health care professionals (Mair & Whitten 2000) and access to information (Williams *et al*. 2014). In addition, TM strengthens self-management through self-monitoring (Horton 2008, Vatnøy *et al*. 2016), by contributing to a better understanding of the condition (Gorst *et al*. 2016).

The use of TM represents an intervention in the patient’s daily life and changes the way the patient relates to health care services. Therefore, more studies are needed to gain precise knowledge about the patient’s lived experience related to the use of TM equipment (Ure *et al*. 2012, Emme *et al*. 2013, Greenhalg *et al*. 2013) and to learn about what matters to the user of TM technology (Greenhalg *et al*. 2013, Greenhalg *et al*. 2015). Because people with COPD live with symptoms that present a significant burden in daily life, it is particularly important to have knowledge of how TM affects their life situation. Based on phenomenological philosophy, the present study obtained knowledge on the individuals’ lived experiences of living with COPD when receiving care through TM.

METHODS

The aim of this study was to describe the lived experiences of quality of life among a group of patients living with COPD who were included in a telemedical intervention after hospitalization for disease exacerbation.

Design

The present study consists of a descriptive phenomenological research approach and is based on the narratives of lived experiences of quality of life among patients living with COPD that have been included in a telemedical intervention. Phenomenology is the study of structures in a phenomenon, as they appear in our consciousness. The philosophy of phenomenology goes back to the early twentieth century. Edmund Husserl founded the philosophical thinking of modern phenomenology, stating that a phenomenon exists in people's mind and thus can only be explained on the basis of the perspective of those who have experienced it. Based on this notion, researchers have to set their own pre-understanding in brackets in order to reach an unprejudiced description of the person's experience of the phenomenon (Giorgi, 2009).

Intervention

The study was part of a larger European project 'United4Health', carried out in southern Norway that explored a TM intervention monitoring patients diagnosed with COPD (European Commission 2015, Smaradottir *et al*. 2015). When discharged from the hospital, the patients received TM equipment for usage at home. The technical equipment consisted of a tablet with video camera and a pulse oximetry device for daily measuring of heart rate and oxygen saturation transmitted wirelessly from the tablet application to the TMC. The software also included a questionnaire to measure patients' subjective symptoms and self-evaluation.

The full TM intervention consisted of the technical solution, monitoring, and follow-up by nurses working in a telemedical centre (TMC).

In total, the intervention lasted for three months. For the first two weeks after discharge from the hospital, the intervention consisted of daily contact between patient and a trained TM nurse. This included evaluation of transmitted health data and follow-up with video-communication. After two weeks, and in collaboration with each patient, the daily video contact was reduced to two to three times a week. However, the TM nurse still assessed the transmitted health data daily. At this point, the TM nurse would contact the patient if his or her health data fell outside the normal range. If health data were not received by a set time every day, the TM nurse would contact the patient. After approximately 30 days, the follow-up was completed, and the patients returned the TM equipment to the local hospital. For the next two months, the patients had the opportunity to get in contact by telephone with a TM nurse at the TMC for advice.

Participants

The inclusion criteria were that the patients followed up between one and three months during the TM intervention and returned the TM equipment to the local hospital. All patients who fulfilled these criteria were asked by a trained TM nurse at the TMC if they would participate in the study. The nurse gave initial information about the study and that participating was voluntary. Those patients who were interested were phoned by the first author and had the opportunity to ask questions and give oral consent or to withdraw from participating in the study. Two of twelve contacted patients wished to withdraw. Ten participants were included in the study; three women and seven men ranging in age from 61 to 80 years, with a mean of 72 years (see Table 1). In addition, the severity of COPD ranged from moderate to very severe (Vestbo *et al*. 2013). See Table 1 for demographic characteristics of the participants.

Insert Table 1 here.

Data collection

Data were collected by in-depth interviews over an eight-month period in 2015 from January to August. Nine of the 10 interviews were conducted at the participants' home and one took place at the local university. The participants were encouraged to narrate their own lived experiences. The interviews consisted of two open questions: 'Please, tell me about a situation when you could improve your quality of life as a result of being included in the TM intervention' and 'Please, tell me about a situation when you could not improve your quality of life as a result of being included in the TM intervention'. To go into more detail and guide the conversation, further probing questions were asked, such as, 'Can you tell me more about that and can you describe this further?' Using a descriptive phenomenological research method, it was important to focus on the lived experiences of the participants, and this methodological ideal underlines letting the participants tell their experiences openly and freely (Giorgi 2009). The interviews were audiotaped and transcribed verbatim and lasted from 30 to 50 minutes, with an average of 38 minutes (see Table 1).

Data analysis

The data were analysed using a descriptive phenomenological research method with the following four steps (Giorgi 2009):

1) The text was read in order to get a sense of the whole.
2) The text was read repeatedly, and meaning units were established.

3) Meaning units were transformed from the participants' everyday language into a health science perspective emphasizing the phenomenon being investigated and using free imaginative variations relevant to the perspective.
4) All meaning units were synthesized into a consistent statement (situated structure) of the structure of the phenomenon for each interview. The situated structures formed the general structure of the lived experience of living with COPD and receiving care through TM.

An example of the analysis is illustrated in Table 2.

Insert Table 2 here.

Ethical consideration

The research was designed and performed in accordance to the Declaration of Helsinki (Declaration of Helsinki 2013) and common principles used in clinical research (Beauchamp & Childress 2013). The study was approved by the NSD – Norwegian Centre for Research Data (project number: 41146). Before conducting the interviews, the participants were informed about the study, and their written consent to participate was obtained. In addition, they were notified that they could withdraw from the project at any point and that their confidentiality would be assured. Since the interviews were conducted with participants who were severely ill, an important aspect was the participants' dyspnoea. Thus, the length of each interview was based on the participants' health status at the time of the interview. Despite some pauses, the interviews were conducted as planned.

RESULTS

General structure

Living with COPD was experienced as creating physical and mental limitations of the diseased body and an increasing identity as a patient, which led to impaired quality of life. Being included in the TM intervention increased accessibility to health care services and support from TM nurses. Self-measurement of health data increased participants' clinical insight and created a mutual clinical language in dialog with TM nurses, which led to increased quality of life. However, receiving care through TM was also experienced as a dual chore (see Table 3).

Insert Table 3 here.

Living with COPD: physical and mental limitations

The participants were mostly concerned about their own health status and shared past and present disease experiences and experiences related to the health care system. The stories told were descriptions of the lived experience of COPD, stories of physical and mental limitations related to the diseased body, and the identity as a patient, which all reduced the participants' quality of life.

Limitations of the diseased body

The participants narrated the experience of living with COPD; and how the condition affected both body and mind-set, as a perceived limitation in their everyday life. Several participants experienced increasing difficulties with everyday activities, for example, shovelling snow, going to the store or doing housework. These activities often had to be transferred to their spouse or next of kin:

I cannot do the things I could normally do because I cannot breathe. Like shovelling snow… my wife has to do it for me now (Participant D).

As a result, becoming dependent on medicine, equipment, or other persons led to a sense of loss, with significant impacts towards feeling connected to losing control over their lives. As the body became weaker and dyspnoea worsened, emotions connected to fear, stress, and anxiety increased. One participant narrated how he felt he was in captivity; his diseased body controlled him, and he was afraid of experiencing breathlessness and anxiety. As a consequence, he felt forced to live a passive and isolated life:

[…] when I experience breathlessness, I lose control, and then my anxiety kicks in. I have to learn to live with the anxiety at one level, then the next stage comes, and it gets worse… So, it [the disease] is constantly deteriorating! It is absolutely terrible… I spend a lot of time sitting inside, it is not nice at all, but it has just to be like that (Participant C).

The limitations of the diseased body were perceived differently between the participants. One participant explained that she needed to modify her social life when she could no longer control her breathlessness and anxiety. Her body became a confinement to her, enhancing the feeling of loneliness, and being with friends and family was perceived unmanageable:

[…] so overall my life style has deteriorated very much. I cannot cope with many things, I cannot be the person as I used to be... Before, I was able to do more social activities. Last Saturday, for example, I tried to go out with my friends to a concert, but there was so little air at the venue, so when I had been there for 20-30 minutes, then it was over. I just had to find my way out… and take a taxi home to recover (Participant H).

Another participant had to give up hunting, which was his passion. The diseased body was experienced as reducing mobility, while the instability of the disease created anxiety, and both prevented social participation.

Limitations of the increasing identity as patient

When the participants described what it was like to live with the disease, they described how several past and present health care experiences had influenced their current life. Experiences of disease exacerbation were a reminder of how the illness had evolved, with increasing worries regarding the future. Past experiences related to COPD thereby gave focus to a constant fear of experiencing new disease episodes:

> I usually get two serious infections a year after I developed COPD ... that is when I get really sick! There were infections with so much mucus, and it was like glue! And I could not get the mucus out! And I got a sensation of cramped breathing […], and eventually I ended up gagging to try to get the mucus out. There are many things at once affecting my quality of life. Also, there is the ... the fear! I am afraid I will start to suffer like that again (Participant H).

> The last time I had it [experienced exacerbation], I ended up in hospital, then I was sure that I would not come out again. So, […] as it [the disease] deteriorates … I know I am going to get some 'down' periods (Participant A).

The evolving disease increased the need for health care services and thus fostered the participants' identity as a patient.

Several participants had experienced negative episodes with health care services, which often involved not being taken seriously when trying to seek help for dyspnoea and disease exacerbation:

> I have had negative experiences with the Emergency Department (ED), sometimes I have been sent home with pain killers and other things […] it is experienced differently in the ED, dependent on who is at work (Participant D).

This experience was an apparent frustration when having dyspnoea was experienced as a struggle in itself. They also found it a struggle to get medical attention for their health problems. Consequently, several participants had developed an increasing uncertainty towards health care professionals and the health care system. Some participants narrated how these experiences had led to hospitalizations when the exacerbation was not treated in time due to the reluctance towards seeking timely treatment. Such experiences led to an increasing identity as patient.

Receiving care through TM: accessibility, support, clinical insight, and mutual clinical language

Closely related to the stories about physical and mental limitations, were the stories about how TM was perceived as improving accessibility to health care services and support by TM nurses and providing clinical insight and a mutual clinical language, which in turn increased quality of life.

Accessibility

Having daily contact with the TM nurse through the TM equipment was perceived as improving accessibility to health care services, especially when in need of help. This improved participants' sense of security and peace of mind; knowing that they were monitored every day. The improved accessibility also increased peace of mind of family members and relatives. The participants narrated how their family members knew that competent health professionals, thus improving predictability, were monitoring them:

> It has been a big improvement for me that my children know that I have been followed up, they do not call and make a fuss about it with me ... and THAT is, it made my life situation a lot better! To be self-reliant and ... and to experience everyday security ... I think it has helped me to breathe, to be safer (Participant H).

Furthermore, the care received through TM was experienced as near despite the geographical distance between the participant and TM nurse. Several participants narrated that the real-time video contact gave them the feeling of 'being in the same room' with the TM nurse:

> That was nice [using videoconference]. It is okay using phones and that sort of thing, but it is ... it is a lot better! It is just like, yeah that ... like as we sit now, it is much more contact than it would have been by using phone and other things (Participant F).

This impression increased the sense of accessibility, with the real-time video contact representing an important aspect for achieving it. When in conversation with the TM nurse through video, several participants experienced that the TM nurse focused all the attention towards them, and that this provided individual attentive care despite the distance. The opportunity to see the TM nurse on the screen was considered crucial and compensated for not being in the same room.

Support

Through the TM equipment, the participants experienced improved support from the TM nurse. This support and regular follow-up resulted in an increased awareness towards the diseased body regarding symptoms, ability, and emotions. The support was important to get information on health status, feedback, and advice that was qualified and trustworthy. Thus, the given support was felt as reassuring; one participant described how she often felt unsafe at night, experiencing breathlessness, fear, and anxiety. When she woke up, the first thing she wanted to do was to consult with the TM nurse. The prompt response to her regular clinical readings, whether normal or abnormal, followed by advice and guidance, provided her with reassurance. This information from the TM nurse was very important to her, especially on the days she was not feeling well:

> It was difficult at night, thinking; I am not feeling well. I wanted to talk to the TM nurses in the morning… they could say; you can wait and see, if this worsen you can start with medication if you feel that you need it… It was reassuring (Participant B).

The participants acknowledged the personal connection with the TM nurse, which gave them a feeling of being known. However, it was perceived as similarly important that the TM nurse had adequate competence in both illness and personal health history of each participant to cover both medical and emotional needs. The participants described that the TM nurses understood how their individual limitations were connected to the diseased body:

I think that is [connection with nurse] very nice, because they understood what I was talking about … on everything! If I said that: oh! Today I experience breathlessness! Yes, what have you done? Then the TM nurses accept you, right, and then they ask, how do you feel? and that kind of thing. It is a completely different way to connect and I get positive effects to talk to someone like that (Participant B).

Clinical insight

When participating in the TM intervention, the informants performed daily self-measurements of clinical parameters including oxygen level and heart rate. The daily measuring was perceived to increase clinical insight. Two key elements were apparent: First, daily clinical insight improved coping with the recurrent fear of disease exacerbation and breathlessness by giving an overview of disease development. This provided participants with knowledge on their own health status and progress. Additionally, it was important that the daily measurement was provided promptly, as the quick response helped participants to cope with the fear of breathlessness:

It is all about safety and the contact of course, because I knew… if I had abnormal readings, they would be there right away! Call me up, and ask me what I had done (Participant E).

Second, clinical insight strengthened the participants' self-reliance. Access to clinical information was experienced to improve self-management; thus, increasing engagement and involvement to learn more about the own health condition:

Well, to get an answer yourself, to feel safer, and try to think back; what have I done now since the heart rate is so high? Also, that when it started to go down to normal ... that was very reassuring, in that respect (Participant E).

I thought somehow; what have I done now? To get my heart rate to rise so much! So, then I had to somehow work out ... oh well, I took the garbage outside or something like that... (Participant I).

This insight into clinical measurements increased the ability to compare daily measurements with the experienced symptoms related to COPD. The clinical measurements ameliorated the uncertainty regarding symptoms and contributed to separate anxiety from exacerbations, which had been difficult before. In addition, the increased self-reliance provided participants with confidence to be more involved in their own health.

Mutual clinical language

The participants described how the daily clinical measurements, which were sent to the TM nurses on a daily basis, provided a mutual clinical language. This was perceived to increase the knowledge about the significance of each value and what it represented. Especially measuring oxygen levels provided a visual numeric message, which increased the participants' knowledge and awareness on clinical readings so that they could understand both normal and abnormal values:

If I had a bad day, I could measure it [saturation] you know, if I felt bad you know ... then I could insert my finger in the machine there, too, I could see that it was 94 or 91 [saturation], but if it was under 90, then I knew it was bad (Participant G).

This led to increased understanding of individual health development, both for the participants and for the TM nurse, improving collaboration and dialog, and thus strengthening the relationship with the nurse. This relationship between participant and TM nurse was experienced as collaboration. TM contributed to an increased level of active participation in the own treatment:

When my oxygen [saturation] were low the nurses would contact me … we made a plan, together. It was good to make a plan (Participant C).

The daily follow-up on clinical measurements helped to discover health problems related to COPD in time. Similarly, the participants felt acknowledged when their experiences connected to health status could be verified with the use of the numeric and mutual clinical language. As a result, they experienced to be taken seriously by the TM nurse. One informant reported that when his clinical measurements where abnormal, the TM nurse would contact him, and he would get answer and confirmation, otherwise he would continue to worry:

> I could even see my measurements! When the measurements were abnormal the TM nurse would contact me […] and I got answers and confirmation, otherwise I would worry (Participant G).

Increased knowledge and the mutual clinical language contributed to the participants' experience of being heard and taken seriously by health care professionals.

The dual chore of receiving care through TM

The technology used in the TM intervention was perceived as easy to use and manage. Several participants acknowledged that they felt safer in the transition from hospital to home because of the follow-up through TM. However, when the TM technology failed, the real-time video-dialog was replaced by conversations through mobile phone. This reduced the accessibility and support. As a consequence, many of the positive aspects that the TM equipment initially provided were removed:

> It was very nice to talk with the nurses if I felt something was wrong, but the quality on the tablet was so poor […] many times it did not work! […] only a few times I was able to talk face to face. I missed that type of contact a bit (Participant B).

Although all the participants perceived the TM intervention as positive, there were nuances related to disease severity. A clear dissociation between severity of COPD and the experience of receiving care through TM was found. Receiving care through TM was sometimes perceived as an impediment for the participants with moderate COPD severity:

I have to plan more, know that I have TM. I am not sure that this could replace the security… I felt 'locked' to a certain time (Participant J).

They believed that the TM equipment constrained them in time and place compared to before the intervention, because their need for support and accessibility was reduced when they were in good health. First, the intervention consisted of scheduled contacts with the TMC, and the participants had to plan their day in relation to the TMC program. When family routines conflicted with the TM service, the technology was abandoned or resulted in delayed measurements and dialog. Second, TM occasionally increased the focus towards the condition and related symptoms when in good health. This led to an unwanted and increased focus towards the illness.

In contrast, the participants with severe or very severe COPD did not experience the TM intervention as an obstacle. The condition for these participants was characterized by increased limitations associated with disease severity, making it difficult to participate in other activities due to constant dyspnoea. These participants wanted daily follow-ups and over a longer period. They also desired to continue with TM even when the intervention ended.

I am going to miss it… there is no doubt about that. The peace of mind, and the contact [support] (Participant E).

In addition, some participants also reported becoming increasingly addicted to the oximetry device, experiencing a negative impact on quality of life.

DISCUSSION

The aim of the present study was to describe the lived experiences of quality of life among a group of patients living with COPD who were included in a telemedical intervention after hospitalization for disease exacerbation. In contrast to previous research on this topic, the approach used in the present study was a descriptive phenomenological research method, allowing for more detailed and in-depth descriptions of the participants' life. The obtained data revealed a complex image. The participants described their experiences of living with COPD as limitations caused by the increasing symptom burden. In contrast, receiving care through TM contributed to reducing these limitations. However, there was a clear distinction related to the severity of COPD and the experience of receiving care through TM. The findings will be discussed in detail below.

Unlocking the limitations of COPD through telemedicine

All of the participants experienced how the diseased body led to loss of function and control, and as a consequence, decreased their abilities in daily life. Many patients with chronic conditions, and especially those with COPD, experience a high degree of unpredictability due to ever-changing symptoms (Simpson & Rocker 2008, Gardiner *et al*. 2009, Ek & Ternestedt 2008). These patients often report great benefits of TM in managing COPD compared to usual care (Pols 2006, Brunton *et al*. 2015). Similarly, the TM intervention in the present study was perceived to be of great benefit by increasing accessibility to health care services. An important aspect of accessibility was the tentative focus and responsiveness to individual needs by TM nurses, as previously supported by Fairbrother *et al*. (2012), Gale and Sultan (2013), and Gorst *et al*. (2016), which improved security and peace of mind.

Several studies have expressed concerns that TM would replace hands-on-care and human contact (Gale & Sultan 2013, Mort *et al*. 2013) and could not perform sufficient care on its own (Greenhalg *et al*. 2013), and as a consequence, would contribute to poorer care and less interaction between patients and health care professionals. However, our findings demonstrated that the regular follow-ups from TM nurses through TM and video-consultation were experienced as the opposite and similar to near care despite the geographical distance between participant and TM nurse. The video-consultation was a key contributor to strengthen the patient-nurse interaction due to the possibility to see the TM nurse. Therefore, the TM equipment functioned as a facilitator for closer contact. The significance of the nurses' presence and care through TM compensated for not being in the same space. In addition, the focused attention from TM nurses facilitated by the video consultation could increase the closeness to health professionals and amplify the focus on the patient, unlike regular care where patient contact comprises a list of practical tasks. Similarly, Pols (2006) found that TM technology did not put care at a distance but rather in close proximity. Furthermore, Vatnøy *et al*. (2016) found that face-to-face contact by means of TM and video-consultation was meaningful for individuals with COPD.

The TM nurses were of great importance in providing support, and the findings highlighted the difference between traditional care and TM services, that is, the TM nurses could respond promptly when the participants were in need. In addition, the regular support and encounters with the TM nurses provided better follow-up on the unpredictable changes and limitations of the diseased body. The participants in the present study experienced the daily follow-up as reassuring, compared to seeking contact only when health was deteriorating, as in regular care. This meant that both the medical and social challenges of the illness were addressed, and emphasizes that giving medical information and advice via video can also be seen as a way of caring. TM can function as a new form for communication with health care professionals (Pols 2006) and increase accessibility and support. According to the participants, this reduced the limitations of the diseased body and increased quality of life.

One of the symptoms the participants described as the most difficult to handle and endure was breathing difficulty. The high symptom burden of COPD is often combined with poor symptom control (Gardiner *et al*. 2009), and increased dependence on others affects the person's identity and self-esteem in a negative way (Ek & Ternestedt 2008). Fear and anxiety are also closely connected to breathlessness. To cope with fear, TM can contribute to a reduction in symptoms, such as breathlessness (Pols 2006), through self-measurement, which was apparent in the present study. Poor symptom control creates greater requirements for care (Gardiner *et al.* 2009) where the patients are in the centre of the care effort (Simpson *et al.* 2008).

The findings showed that the participants became more involved and engaged in their illness when performing daily self-measurements. This led to increased clinical insight and overview over the evolving disease. In turn, this provided a better understanding for both present and future health development and contributed to putting the participants in the centre of care with increased control, independence, and confidence in their life. Furthermore, self-management is highlighted as an important aspect for individuals living with COPD to become more active and involved in their illness (Simpson & Rocker 2008). Further, several studies (Williams *et al*. 2014, Gorst *et al*. 2016, Vatnøy *et al*. 2016) have emphasized that TM can promote self-management.

Moreover, the current findings showed that clinical insight led to the development of a mutual clinical language. Mort *et al*. (2013) advocated TM system designs to facilitate horizontal and interactive communication rather than vertical communication, which is common in regular health care services today. Consistent with our findings, Williams *et al*. (2014) found that the monitoring through TM care increased patients' awareness, developing an understanding for normal levels of clinical readings. However, the present findings extend this research, as self-measuring not only increased understanding but also contributed to horizontal communication and strengthened the participants' acknowledgement, collaboration, and dialog with the TM nurses. As a result, this enhanced a more open communication approach to health care professionals, providing a more equal and common understanding while allowing the participants to engage with their individual health challenges. This in turn reduced the limitations of the identity as a patient and further increased quality of life.

However, there are still contradictions when caring through TM (Brunton *et al*. 2015). The present study found that COPD severity, varying from moderate to very severe, influenced how receiving care through TM was perceived. Although participants with moderate COPD severity experienced the TM intervention as positive, they also found it to be a burden. The low symptom burden in moderate COPD enhanced the ability to be more active and independent. In these cases, TM made the participants feel more restricted in time and place and unnecessarily increased their focus on the illness, bringing care too close, which made the illness more dominant in their lives. Similarly, Pols (2006) and Brunton *et al*. (2015) found that care can be harmful when it increases the focus towards the illness rather than reducing it. This shows that the benefits of TM are perceived differently based on disease severity.

Although this phenomenological study contributes to new knowledge regarding the experience of living with COPD and being followed up through TM, it is important to acknowledge some limitations concerning the research method. It is important to be true to the principles of phenomenology to reach trustworthiness in phenomenological research (Söderhamn, 2001). The present study included ten participants, and it could be argued that this sample was too small. However, in phenomenological studies, large samples are not required, because such research enhances the in-depth knowledge of the participants' life. To achieve such knowledge, all pre-understanding has to be bracketed (Giorgi, 2009), including the authors' pre-understanding as nurses. Nevertheless, to bracket one's pre-understanding can be challenging. However, to prevent swaying the findings, most of the previous studies were consulted after having performed the analysis.

The analysis was shared and discussed with co-authors. In addition, an example of the analysis (Table 2) shows how the raw data, the different meaning units, the free imaginative variations and general structure were elaborated. This verifies the findings, and further contributes to trustworthiness. The subjectivity of the data can lead to difficulties in establishing reliability and validity of the methodological approach, and the information it provides. In the present study, the validity of the findings was confirmed by carefully following the analysis steps when searching for the essence in the interview texts. Further, the reliability of the findings was confirmed through the same meaning occurred in the interview texts (Söderhamn, 2001).

CONCLUSION

The increasing care burden on patients with COPD exemplifies the need to reconsider how care is provided. TM can fulfil several unmet needs for patients suffering from COPD, which traditional care has not been able to provide. The findings in the present study show that TM can reduce the perceived limitations of living with COPD through four key elements that reshape the models of care; 1) improving accessibility to health care services, 2) increasing support from health professionals, 3) strengthening clinical insight, and 4) developing a mutual clinical language, which all contribute to increasing quality of life. The transparency facilitated through TM in this health care context encourages open decision-making, where the participants can increase their knowledge, improve acknowledgement of and collaboration with TM nurses, and as a result, experience that they are taken seriously in terms of their health problems.

RELEVANCE TO CLINICAL PRACTICE

The findings in the present study promote new implications for practice and rethinking of care and provide important information on how living with COPD can affect the experience of receiving care through TM. In addition, the present study highlights that patients with severe and very severe COPD are the ones that find TM the most useful when managing their illness. This knowledge can further determine for whom TM is useful and contribute to clinical practice by providing care to those patients who would benefit the most. However, future research, both qualitative and quantitative, is needed to obtain further knowledge on the patients' experiences of receiving care through TM. In addition, TM interventions should be extended over a longer period to fully understand the challenges of living with COPD and further explore for whom TM is most useful.

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Contributions

TLB, ET and US designed the study. TLB performed the data collection. TLB analysed the data and discussed the analysis with EB and US. TLB wrote the manuscript and ET and US reviewed it. All authors approved the final version.

Conflict of interest

The authors declare that they have no conflicts of interest.

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Table 1 Participants' characteristics

Participant	Gender	Age	COPD severity*	Living arrangements	Length of interview (minutes)	Included in intervention (weeks)
A	Male	74	Moderate	With spouse	48	4
B	Female	74	Severe	With spouse	37	6
C	Male	61	Very severe	Alone	40	8
D	Male	75	Severe	With spouse	32	4
E	Male	63	Very severe	Alone	35	5
F	Male	80	Moderate	With spouse	30	4
G	Male	75	Very severe	With spouse	31	4
H	Female	77	Severe	Alone	50	6
I	Female	73	Severe	Alone	29	6
J	Male	70	Moderate	With spouse	48	6

*Moderate: mild or moderate airflow limitation with low risk of exacerbation. Severe: severe airflow limitation with high risk of exacerbation. Very severe: very severe airflow limitation with high risk of exacerbation (Vestbo *et al*. 2013).

Table 2 The participants' experiences of living with COPD and receiving care through TM – illustration of the analytic procedure

Meaning unit	**Transformation – free imaginative variations relevant to health science**	**Themes**
D: I can't do the things I normally could do because I can't breathe. Like shovelling snow… My wife has to do it for me now.	Limitations caused by the disease lead to loss of function.	**Living with COPD: physical and emotional limitations**
H: I experienced that I had a nurse I could talk to every day (…) I felt safer.	Daily follow-up provides safety.	**Receiving care through TM: accessibility, support, clinical insight, mutual clinical language**
G: I could even see my measurements! When the measurements were abnormal the TM nurse would contact me, and I got answers and confirmation. Otherwise, I would worry.	Clinical measuring provides information and confirmation on a daily basis.	
J: I have to plan more, know that I have TM. I am not sure that this could replace the security (…) I felt 'locked' to a certain time.	TM causes the participant to be bound in time and place.	**The dual chore of receiving care through TM**

Table 3 The results presented as themes and subthemes

Themes	**Living with COPD: physical and mental limitations**	**Receiving care through TM: accessibility, support, clinical insight and mutual clinical language**	**The dual chore of receiving care through TM**
Subthemes	Limitations of the diseased body Limitations of the increasing identity as patient	Accessibility Support Clinical insight Mutual clinical language	

Paper II

Advancing beyond the system: telemedicine nurses’ clinical reasoning using a computerised decision support system for patients with COPD – an ethnographic study

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RESEARCH ARTICLE

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Advancing beyond the system: telemedicine nurses' clinical reasoning using a computerised decision support system for patients with COPD – an ethnographic study

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Abstract

Background: Telemedicine is changing traditional nursing care, and entails nurses performing advanced and complex care within a new clinical environment, and monitoring patients at a distance. Telemedicine practice requires complex disease management, advocating that the nurses' reasoning and decision-making processes are supported. Computerised decision support systems are being used increasingly to assist reasoning and decision-making in different situations. However, little research has focused on the clinical reasoning of nurses using a computerised decision support system in a telemedicine setting. Therefore, the objective of the study is to explore the process of telemedicine nurses' clinical reasoning when using a computerised decision support system for the management of patients with chronic obstructive pulmonary disease. The factors influencing the reasoning and decision-making processes were investigated.

Methods: In this ethnographic study, a combination of data collection methods, including participatory observations, the think-aloud technique, and a focus group interview was employed. Collected data were analysed using qualitative content analysis.

Results: When telemedicine nurses used a computerised decision support system for the management of patients with complex, unstable chronic obstructive pulmonary disease, two categories emerged: "the process of telemedicine nurses' reasoning to assess health change" and "the influence of the telemedicine setting on nurses' reasoning and decision-making processes". An overall theme, termed "advancing beyond the system", represented the connection between the reasoning processes and the telemedicine work and setting, where being familiar with the patient functioned as a foundation for the nurses' clinical reasoning process.

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Conclusion: In the telemedicine setting, when supported by a computerised decision support system, nurses' reasoning was enabled by the continuous flow of digital clinical data, regular video-mediated contact and shared decision-making with the patient. These factors fostered an in-depth knowledge of the patients and acted as a foundation for the nurses' reasoning process. Nurses' reasoning frequently advanced beyond the computerised decision support system recommendations. Future studies are warranted to develop more accurate algorithms, increase system maturity, and improve the integration of the digital clinical information with clinical experiences, to support telemedicine nurses' reasoning process.

Keywords: Computerised decision support system, Chronic obstructive pulmonary disease, Decision-making, Ethnography, Nursing, Reasoning, Telemedicine, Qualitative

Background

Traditional nursing practice is incorporated in the future of healthcare technology [1, 2] to develop new roles responsive to changing needs [3, 4]. Telemedicine (TM), which can be defined as 'information, communication, and monitoring technologies which allow healthcare providers to remotely evaluate health status, give educational intervention, or deliver health and social care to patients in their homes' ([5] p. 2813), has demonstrated potential for advanced nursing practice regarding efficiency [6] and quality of care [7–9]. However, TM involves the provision of advanced nursing care in a new clinical environment [10], which enables remote care [10, 11] for patients with chronic diseases, such as chronic obstructive pulmonary disease (COPD) [12]. COPD is a serious and progressive chronic disease [12] representing a high symptom burden [13]. Chronic diseases often involve subtle [10] and unpredictable disease developments [9, 14] that require complex disease management strategies [2].

Complex clinical practice entails that nurses use appropriate clinical reasoning skills [15]. Nurses' clinical reasoning can be defined as: "…the cognitive processes and strategies that nurses use to understand the significance of patient data, to identify and diagnose actual or potential patient problems, to make clinical decisions to assist in problem resolution, and to achieve positive patient outcome" ([16] p. 236). Hence, clinical reasoning is the sum of critical thinking and decision-making processes associated with clinical practice [17], where critical thinking is based on nurses' careful, deliberate thoughts in different clinical settings [18]. Consequently, it is essential that within TM, clinical reasoning and decision-making are supported.

Computerised decision support systems (CDSS) use algorithms to produce patient-specific assessments [19] and decision-making recommendations to support reasoning [20, 21], helping nurses to make better clinical decisions [16] and improving patient care [19]. CDSS use has increased in recent years [21], but ambiguity regarding its adoption, implementation [21, 22] and accuracy [23] remains. Various factors, such as familiarity with the patient [24–27], the patient's condition, and the CDSS technology used, can affect the decision-making process [10, 27]. Moreover, CDSS use for long-term management involves complex decision-making [21], which requires advanced training especially when used in a TM setting [1].

CDSSs have been used in hospitals [15, 28, 29], primary [27] and chronic care setting [30, 31], and for phone-based counselling [32–34]. However, few studies have evaluated TM nurses' reasoning using these systems to manage patients with COPD in the primary care setting. Additionally, these systems are developed and implemented based on a limited understanding of clinical work and decision-making [22]. Therefore, the context in which CDSSs are used must be evaluated [32, 35], for example, for nurses' reasoning [16, 36] and decision-making processes [37–39] during the provision of care. The present study combined different qualitative data collection methods consisting of participatory observations, the think-aloud technique, and a focus group interview, to gain a better understanding of TM nurses' clinical reasoning using a CDSS when managing patients with COPD.

Methods

Aim

The purpose of the study was to explore the process of TM nurses' clinical reasoning when using a CDSS for the management of patients with COPD. The factors influencing the clinical reasoning and decision-making processes were investigated.

Design

An ethnographic approach [40] was chosen to investigate the reasoning and decision-making processes of TM nurses, in order to gain insight into their subjective world in their natural settings [41, 42], and to provide a nuanced picture of the field [42, 43]. Participatory observations [40], the think-aloud technique [44] and one focus group interview [45] was employed.

Setting and participants

This study was conducted at a telemedicine centre (TMC) in a municipality in southern Norway, between October

2015 and February 2016. The TMC was established as part of a larger European project; 'United4Health' (U4H). The U4H project explored a TM intervention for patients with COPD, who had been hospitalised for exacerbation and discharged to their home [46, 47].

The present study focused on the TM nurses employed at the TMC, in order to monitor and assess COPD patients. The TMC employed seven registered nurses that managed COPD patients from several municipalities, and was open from 8 am to 3 pm, Monday to Saturday. The TMC was operated and managed by a single nurse at any given time, and could manage up to 12 patients daily. Registered nurses who were employed at the TMC were included in our study sample, and asked to participate. Three of seven nurses agreed to participate. The four nurses who did not wish to participate were employed part-time with weekend shifts once a month. All participants were female and aged between 27 and 46. Table 1 shows the participant characteristics.

Technical equipment and computerised decision support system

The technical equipment used in the intervention consisted of a pulse oximetry device for daily measuring of oxygen saturation and heart rate. In addition, a tablet application which included an electronic questionnaire to gather patients' daily subjective symptoms was used. The questions concerned issues such as well-being, breathlessness, sputum characteristics and medication use (Table 2). Patient measurements and reported subjective symptoms were uploaded by the tablet application and transmitted securely and wirelessly to a data server at the TMC. TM nurses at the TMC monitored and assessed the transmitted data using a CDSS. In addition, TM nurses followed up patients using real-time video-conference supported by the tablet application.

The CDSS was developed by medical and technical experts employed at the local hospital and the university. It provided the TM nurses with a daily overview over patients' health status and condition, and was used to support their reasoning and decision-making processes. The reported patient measurements and subjective symptoms (see Table 2) transmitted from the tablet application, were the basis for an automatic calculation with a specific algorithm that resulted in display of colour codes [47, 48]. The colour codes were either green, yellow, or red, indicating warning alerts on patients' health status and disease development (see Table 3). The thresholds for clinical measurements, such as oxygen saturation and heart rate, were predefined for each patient based on their reference values at hospital

Table 1 Participant characteristics

Participant	Nurse 1	Nurse 2	Nurse 3
Nursing experience	6 years	8 years	23 years
Telemedicine experience	2 years	1.5 years	4 months
Employed at the centre	80%	60%	45%
Continuing education	Master's degree in health and social informatics	–	Geriatrics

Table 2 Daily questionnaire performed by COPD patients, and evaluated by TM nurses [48]

Question	Response
1 How do you feel today?	As usual Worse Much worse
2 How is your breathing today?	As usual Worse Much worse
3 How is your amount of sputum today?	As usual Worse Much worse
4 What is the colour of your sputum today?	No sputum/Clear/White/Yellow/Green/Brown
5 Are you using rescue medication/nebuliser[a] or oxygen today?	No As usual More than usual Much more than usual
6 Have you started up with additional antibiotics after last discharge?	No Yes
7 Have you started up with new Prednisolone[b] after last discharge?	No Yes

[a] Rescue medication/nebuliser; inhalation medicine for breathing treatment

[b] Prednisolone; a steroid, used to treat various conditions including breathing disorders

Table 3 Algorithm for CDSS [48]

Colour displayed at CDSS	Indication of health symptoms
Green	Stable patient: Self-reported health symptoms unchanged or improved. Oxygen saturation and heart rate within acceptable range, compared to individual reference values.
Yellow	Unstable patient indicating change that need follow-up: oxygen saturation and/or heart rate indicate deterioration from previous day or from hospital discharge. Yellow alert is triggered. Change indicating: increase in heart rate more than 10 beats/min, reduction in saturation of approximately 5%, an answer to question 1, 2, 3 or 4 defined as "worse", or question 5 answered with "more than usual" (Table 2).
Red	Unstable patient indicating severe change or critical condition: oxygen saturation and/or heart rate or self-reported health symptoms (Table 2) indicating significant deterioration from previous day or from hospital discharge. Red alert is triggered. Change indicating: increase in heart rate more than 15 beats/min, reduction in saturation lower than 6%, or daily questionnaire (1–5) answered with "much more than usual" (Table 2).

CDSS computerised decision support system discharge, and these were used for the following day-to-day monitoring. To increase the sensitivity of the system, a cut-off value for "yellow" status was added to indicate early warning indicator for health deterioration. The cut off values for "red" alert was developed and based on existing empirical clinical measurements and algorithms used in the UK [48]. If the clinical measurements fell out of the normal (i.e., individual) reference range, or if the patients answered "worse" for subjective symptoms (see Table 2), the colour code became yellow or red depending on severity of the health change (see Table 3). In addition, if health data was not provided on a given day, the nurse would contact the patient.

Data collection

Data were collected through using participatory observations [40] (major data source), the think-aloud technique [44], and a focus group interview [45]. The fieldwork enabled observations of the nurses when performing clinical reasoning, decision-making and video consultations with the patients. Approximately 60 patient consultations were observed during 60 fieldwork hours; Nurse 1 was followed for 30 h, and Nurses 2 and 3 were followed for 15 h each. The fieldwork was then completed according to the wishes of the participants. Observations were conducted between 8.30 and 11.30 am, on weekdays.

The think-aloud technique [44] facilitated insight into participant verbalisations, clinical information processing, and performance of different tasks. Each nurse expressed their thoughts aloud, explaining each step in their reasoning process. Probing questions such as "please, could you elaborate your reasoning" or "please, could you continue to think aloud" were asked to gather information and clarifications during each patient assessment.

Field notes consisting of observations, actual incidences, reflections, and interpretations were made during and after the day's observations [41, 49]. Details of setting and human behaviour were recorded to provide a complete and representative record of the field investigated [40]. Approximately 134 A4 pages were written during the fieldwork.

After fieldwork completion, a focus group interview [45] was conducted to gain insight into the participants' reasoning and decision-making processes experiences when using the CDSS. A semi-structured interview approach was utilised [50]. Open-ended questions focused on the use of the CDSS and the nurses' reasoning and decision-making processes. Example questions included "What is your experience of the CDSS in supporting and improving the decision-making process when assessing patients?" and "Could you give examples of how you used your expertise to make decisions relating to the patient?". A moderator was present during the one hour and thirty-minute discussion, and the collected data was transcribed verbatim.

Data analysis

Data were analysed using qualitative manifest and latent content analysis [51], as follows: in the manifest analysis 1) the text was repeatedly read to gain understanding of the whole, 2) and was divided into meaning units, 3) meaning units were condensed to reflect participants' statements and observational data, 4) condensed meaning units were abstracted and grouped into codes with common denominators to give an outline of the data, and 5) codes were organized into categories and subcategories. The latent analysis involved an interpretation of the underlying meaning of the text, leading to an overall theme [51]. The material was sorted using NVivo 10 [52]. An example of the analytical process is presented in Table 4.

Results

Two categories emerged from the analysis: "the process of TM nurses' reasoning to assess health change" and "the influence of the TM setting on nurses' reasoning and decision-making processes". The overall theme, "advancing beyond the system", represented the connection between the nurses' reasoning process and the TM setting and work (Table 5).

The process of TM nurses' reasoning to assess health change

The process of TM nurses' reasoning to assess health change was circular and dynamic and consisted of five stages: 1) assessing the CDSS recommendation, 2) mapping data, 3) combining data, 4) data interpretation to form a pre-decision, and 5) a final decision in collaboration with the patient (Table 5 and Fig. 1).

Assessing the CDSS recommendation

Nurses observed the CDSS recommendation and began the process of detecting symptom changes based on the patients' normal health status. If the CDSS displayed a green colour-code, less time was spent assessing the patient. If the CDSS displayed a yellow or red colour-code, more time would be spent determining the type and extent of the health change. The nurses experienced that the CDSS often displayed inaccurate alerts. Therefore, they would frequently look beyond the colour-codes to assess the clinical data (saturation and heart rate), subjective symptoms (self-evaluated symptoms based on the questionnaire), and other patient information, regardless of the CDSS recommendations:

> "I cannot look at that alone [the CDSS recommendation]. What colour is it [the system alert]? I need to look at what other diseases the patient has, his or her background, and how the patient has been recently [disease development]." (Nurse 1).

Table 4 Example of the analytical process

Meaning unit	Condensed meaning unit	Code	Sub-category	Category
I cannot look at that alone [the CDSS recommendation] … What colour is it [the system alert]? I need to look at the patient's background, comorbidities, and recent health status [disease development].	The nurse overrides the recommendation by gathering extended clinical data to assess health change	Gathering and searching for extended clinical data to assess the recommendation	Assessing the recommendation	The process of TM nurses' reasoning to assess health change

CDSS computerised decision support system, *TM nurses* telemedicine nurses

As part of the reasoning process, the nurses found recommendations from the software useful for initiating clinical reasoning (identifying health problems) and decision-making (prioritising follow-up needs). The system was used to clarify clinical information relating to each patient's health to ascertain the meaning of any health changes. However, the CDSS did not adequately structure or provide sufficient clinical information regarding each patient's health status. Consequently, system decisions were frequently overridden, and additional clinical information was sought.

Mapping, combining and interpreting data to reach a pre-decision

The data collected, including nursing documentation, which was based on medical records, medical histories, and the system recommendations, were diverse and multifaceted. Mapping of cues and combining clinical data contributed to a clinical overview, assisting interpretation of pattern changes specific to individual patient's symptoms and disease development. These activities aided clarification of the patient's current health status:

> "…the picture, which was presented using the CDSS, was not clear enough for the nurses to evaluate, or to explicitly show the nurses the true picture of the patient's health status. The nurses needed to search for more information by evaluating the available computerised information and analysing the data flow." (Fieldwork observation).

The process of combining clinical data after mapping was complex and time-consuming involving assessing details to produce a complete overview or "bigger picture":

> "I need to combine the [system] information with something. I cannot look at the CDSS recommendation alone. I need to see the whole picture, the [patient's] history, everything." (Nurse 1).

Reflection characterised the combining data process, and a cross analysis of related clinical data between mapping, combining and interpreting. This cross analysis facilitated clarification of relevant information for each patient. During this process, the data gathered were combined and compared to eliminate bias in the system and to link the nurse's in-depth knowledge of the patient with the clinical data. Using this process, the nurses could visualise an image of the patient and their current health status:

> "The nurses formed a mental image of the patient and then gathered diverse information from earlier nursing documentation, and made mental notes. They then reviewed the system recommendation and detailed information to form the whole picture. The processes involved observing, analysing, reflecting, and recognising a pattern." (Fieldwork observation).

The process of mapping, combining and interpreting data also helped to form possible future nursing scenarios including health developments, such as potential disease exacerbations. The nurses' knowledge of each patient was constantly evolving, adding to the sum knowledge regarding the patients' disease development. In addition, the patients' experiences were considered

Table 5 Presentation of the overall theme, categories and sub-categories of the nurses' reasoning and decision-making processes

Overall theme	Advancing beyond the system	
Categories	The process of TM nurses' reasoning to assess health change	The influence of the TM setting on nurses' reasoning and decision-making processes
Sub-categories	Assessing the CDSS recommendations	Environment
	Mapping, combining and interpreting data to reach a pre-decision	Technology
	From pre-decision to shared decision-making	

CDSS computerised decision support system, *TM* telemedicine

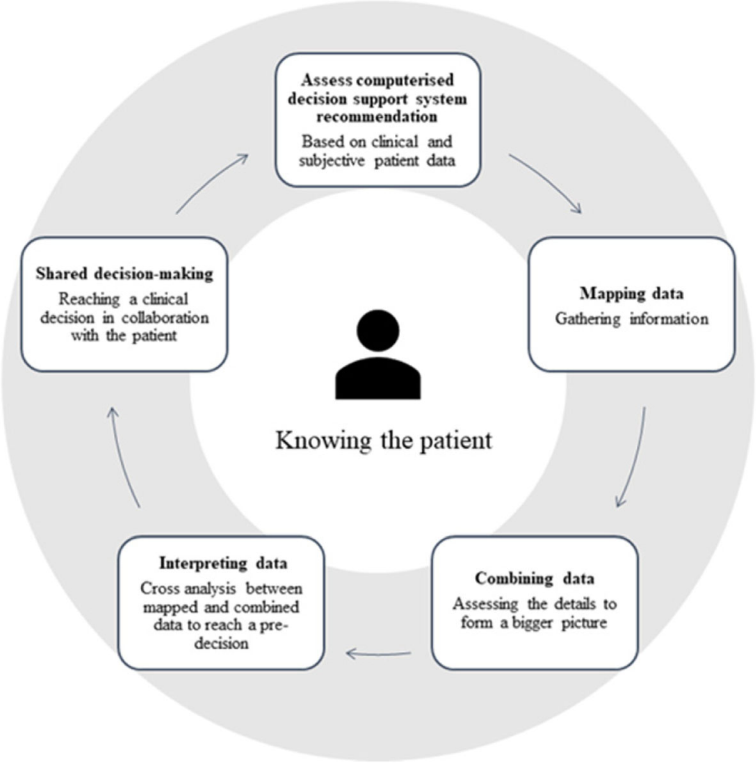

Fig. 1 The five stages of telemedicine nurses' circular reasoning and decision-making compared with that provided by the system alone

highly-valued information. The more complex and unstable the patients' health changes were, the more time was spent on clinical reasoning to reach a pre-decision.

From pre-decision to shared decision-making

Reasoning led to the formulation of a pre-decision regarding the patients' health changes. If the pre-decision was based on deteriorating health, the nurse performed a video consultation to guide and advise the patient and produce a positive patient outcome. During each consultation, probing questions were asked to expand existing knowledge. Increasing the available knowledge led to clarification or adjustment of the pre-decision:

> "If the CDSS indicated changes, or if the patient had indicated that their health had deteriorated, then the TM nurse needed to question the patient regarding the changes. For example, if the patient mentioned increased mucus, the nurse would ask by how much, what colour, and so on." (Fieldwork observation).

Video consultation was important in aiding patient visualisation and was a significant additional component to the system recommendation when nurses were making decisions. Patient conversations became a part of the decision-making process, with the essential information provided increasing confidence in the clinical decision.

The influence of the TM setting on nurses' reasoning and decision-making processes

The TM environmental and technological aspects defined and structured the nurses' work. Hence, the TM setting played an influential role in the nurses' reasoning and decision-making processes.

Environment

Environmental aspects, such as the function and organisation of TM work, influenced the reasoning and decision-making processes. The nurses' abilities to interact with the environment were based on their TM experiences. The nurse employed for the shortest time found the work more challenging:

> "I must be honest. I am the one that has worked here for the shortest time, and I think that it has been difficult to get into this way of working." (Nurse 3).

However, the TM intervention formed part of a newly developed project, and the recurring changes in the project development and management of new work tasks was a challenge for all the nurses:

> "The project is evolving all the time. If you work on a ward, it is work [nursing] you have conducted for many years, and it is familiar and known, but here [at

> the TMC] it is a new way of working […] It is constantly changing. One live in such concentration because you experience things that are new. It is just how it is. It is not easy." (Nurse 1).

Moreover, the nurses managed the TMC alone, which restricted collaboration between the nurses, physicians, and other healthcare professionals when making decisions:

> "When I am alone at work I have to decide (concerning a patient) what I should or should not do… one feels very alone." (Nurse 2).

Consequently, a lack of collaboration led to an absence of individual and shared goals for each patient. Therefore, the care plan and guidance provided to patients by the nurses was divergent. One nurse described how she was missing a more united and goal-setting collaboration:

> "I would like us to share information, and collaborate more because we manage the TMC alone. There is no one else to talk to, except for the written reports […] And what it is we are supposed to achieve… the goal, what is the goal? A common goal, a goal for the individual patient, and intermediate goals..." (Nurse 3).

However, while the nurses found some of the aspects of TM work challenging, they also found it interesting, and the environment of working alone provided time and space to manage the patients regarding care planning, information gathering and consultations. In addition, time could be devoted to thoroughly conducting the reasoning process without distractions. Similarly, the TM setting enabled the development of strong nurse-patient relationships beyond the patient's health, such as their personalities and life histories:

> "You get a different relationship with patients [using TM and video conferencing] … somewhat closer, and it is much more personal." (Nurse 2).

> "A TM nurse gains insight into more than just the health status of each patient. One gets to learn so much more about the patient's life, which is important for the clinical reasoning and decision-making processes in telemedicine work." (Fieldwork observation).

Technology

The TM technology enabled the collection of daily clinical and subjective patient information, facilitated frequent distant monitoring of patients, and assisted in managing continuous follow-up. The TM nurses operated and managed three different screens representing different IT systems; one for assessing system recommendations (i.e. the CDSS), another for nursing documentation and electronic health record (EHR), and a third for performing real-time video consultations with the patients.

The patient information provided by the technology and being able to perform regular video-consultations supported the nurses' reasoning and decision-making processes. However, at times the technology constrained the nurses' work. The computer housing the CDSS and the EHR system were poorly integrated leading to increased time spent searching for relevant clinical information:

> "The nurses are constantly handling two different software systems on two different computers. They spend much time searching for clinical information, leading to double entries. It seems ineffective and unnecessary, but such is the system." (Fieldwork observation).

In addition, technical problems often interrupted the follow-up before addressing clinical problems. Consequently, the focus on medical urgency was displaced by the focus on technical difficulties. Fieldwork observations revealed that almost half of the daily conversations with the patients involved attempts to find a solution to technical problems. Once technical difficulties were resolved, patients were often tired and needed rest. Technical difficulties were mostly related to tablet malfunctions including the application or 3G/4G coverage, which wasted time and interrupted the nurses' reasoning and decision-making processes:

> "Technical failures occurred often. These were perceived as a burden on both the patient and nurse and the technical factor became the urgent problem. Technical problems overshadowed the patients' health problems, and the reasoning and decision-making processes were disturbed. The TM nurses were tiring and sometimes postponed fixing the problem. It became a dilemma of time and resources." (Fieldwork observation).

Consequently, video consultation follow-up was often replaced by telephone calls, meaning that the relevant visual information used for the reasoning and decision-making processes were difficult to implement. Furthermore, the recurring technical problems affected the nurses' view towards their work and led to increasing frustration. The focus group interview revealed these frustrations with one nurse commenting:

> "It is frustrating when you go all in. Telemedicine should be fast and simple, and almost all we do is sit fiddling with technical problems". (Nurse 3).

Therefore, in some cases, the technology became a burden rather than support for reasoning and decision-making processes.

Advancing beyond the system

The TM nurses' reasoning and decision-making processes were influenced by the TM work and setting, which consisted of a highly technological environment, nurses over-riding the system recommendations, poorly integrated information systems, and clinical reasoning performed alone and at a distance from the patient. The TM setting, including the environmental and technological characteristics, both enabled and constrained nurses' reasoning and decision-making processes. Although the setting, work and system provided challenges, it also provided time and support, influencing the nurses' reasoning process. Daily clinical and subjective data, regular patient contact and continuous follow-up provided the nurses with detailed patient- and illness-specific knowledge cementing a close relationship with the patient. However, while the CDSS was intended to support the reasoning and decision-making processes, nurses regularly needed to advance beyond the system recommendations.

The TM nurses rarely used the recommendations from the CDSS in isolation, they combined and compared digital clinical and subjective patient data to identify any conflicts, then compared the outcomes using their long-term acquired patient knowledge. An acquired in-depth knowledge of each patient enabled the nurses to see past the system recommendation, termed "advancing beyond the system" (Fig. 1). Advancing beyond the system was a significant component of the reasoning process. Knowledge of the patient ensured competence in detecting CDSS biases and enabled the gathering of patient-specific information to detect individual changes in health status, producing a more accurate and nuanced decision. Figure 1 illustrates the circular and dynamic processes of reasoning and decision-making in the telemedicine setting (grey colouring shows settings). Knowing the patient is central, forming a foundation for reasoning at all five stages of the process.

Discussion

The present study explored the process of TM nurses' clinical reasoning when using a CDSS for the management of patients with COPD. The factors influencing the clinical reasoning and decision-making processes were also investigated. The study found that the TM nurses frequently advanced beyond the CDSS recommendations, and that the system both enabled and constrained the nurses' reasoning process. Therefore, this discussion aims to provide a nuanced picture of the association between the reasoning and decision-making processes and various enablers and constraints of the TM setting.

In the present study, the CDSS enabled access to digital patient data and was helpful in initiating the reasoning process if the patient's health status was unchanged. However, adverse changes in the patient's health status produced inaccurate alerts, highlighting a limitation of the system. Consequently, reasoning and decision-making processes could not be based on the system recommendations alone. In addition, repeated technical errors and poorly integrated systems further constrained the nurses' reasoning process as considerable time was spent gathering patient-related information. Therefore, the nurses would frequently override the system recommendation, which is also notable in previous studies [27, 33]. Furthermore, Oudshoorn [10] found that TM nurses often developed workarounds to provide care according to their standards and acquired patient knowledge. Cappelletti et al. [26] suggests that the methods of information gathering and sharing can influence the type and depth of the reasoning process. Consequently, it is important that the CDSS facilitates efficient access to information [53], and provide accurate recommendations [23], especially for remote care.

The present study revealed that in the remote care, the TM nurses were dependent of patient information made available by technology. Reasoning in a TM setting implies a different approach to patients than in traditional nursing care, entailing advanced care performed remotely and supported by information and communication technology [10, 11]. Studies have shown that systems generating alerts are effective for improving clinical practice [19], patient care [19, 31] and chronic disease management (28,29). By contrast, Miller et al. [22] suggests that CDSSs is an emerging technology, with poor system uptake and use. Therefore, and to further support nurses' reasoning using CDSS, system development should be both theoretical [54] and evidence-based [39, 55], including knowledge reflecting nursing expertise [56].

The TM nurses in the present study were alone in making decisions concerning patients, and, although frequently overriding the CDSS, were simultaneously dependent on the information the CDSS provided. Several studies show that absence of the patient and of visual cues in the TM setting reduces the reliable information sources [10, 32–34]. The present study shows that video-mediated contact is a key in enhancing the reasoning and decision-making processes facilitating individualised follow-up, patient involvement, and forming close nurse-patient relationships. Regular patient contact provided an opportunity to ask patients probing questions and to gather extensive clinical and subjective information, beyond what provided by the CDSS. This indicates that performing regular video consultations in a TM setting provides additional and valuable patient information and strengthens the nurse-patient relationship. By contrast, technical problems, resulting in telephone-mediated consultations constrained the reasoning process in the TM setting.

Personal patient knowledge was an essential factor in understanding a patient's healthcare needs in a remote care setting. Knowing the patient has been proven to influence the reasoning process [24–27]. An adequate knowledge of the patients, as well as knowledge of their disease, can provide valuable information on pattern recognition and responses [10, 25, 26]. In line with these studies, the present study demonstrated that in-depth knowledge of each patient provided the nurses with the ability to "advance beyond the system" and detect health changes beyond the recommendations provided by the CDSS. These findings are supported by Edwards [24], who showed that knowing the patient provides the nurse with a standard set of clinical data, enabling the variation elimination and providing more accurate and controlled information.

The reasoning process in the present study promoted patient involvement through shared decision-making. Nurse-patient conversations were necessary to verify and elaborate on the initial reasoning process. Patients' experiences of illness and symptoms could help to verify or adjust the pre-decision, indicating that the patients' illness narratives and subjective symptoms often played an equally significant role as the clinical measurements displayed by the CDSS. Patient involvement and shared decision-making were also reported in studies that focused on the patients' experience when receiving TM [9, 57]. However, several aspects can influence the patients' preference for shared decision-making, such as the experience of and involvement with illness and the nurse-patient relationship [58]. Consequently, nursing practice and research need to account for the patients' participation in the decision-making process [59] when using CDSS.

The present study found that the continuous flow of digital data provided by the CDSS, might facilitate a detailed understanding of the individual COPD patient's health and provide a better overview of chronic disease development unique to an individual. However; long-term management of patients with COPD often involve different illness progression rates, comorbidities, and patient anxieties. Also, patients' symptoms for chronic illness are often subtle [10] and the physical and mental limitations of patients with COPD are often unpredictable [9, 14], leading to diverse [60, 61] and complex decision-making [21]. Gerdes et al. [48] found limitations in the long-term monitoring for patients with COPD when using CDSS in relation to day-to-day interpretation of the patients' health status. This indicates that nurses are essential for understanding and interpreting the complex, subtle and unpredictable health changes in long-term management of COPD. TM monitoring transforms care into a continuous process [10, 62], which facilitates the notion of a continuum of care [63], supporting the role of TM nurses in the reasoning and decision-making processes when using CDSS.

Strengths and limitations

The present study has limitations. First, the sample size of three nurses was small. The ideal would have been to include more participants as well as to perform extended observations. However, even though the nurses did not want to participate further, a rich data material was collected. Savage [43] indicates that ethnography could be used as a method for every scale, small or large, where social research is performed in a natural, everyday setting.

Secondly, fieldwork might affect the participants' behaviours and actions [42], and the researchers objectivity to the field can both affect the researcher, data collection and interpretation [64]. During the observations, the first author used a reflective approach, acknowledging bias, preferences, and preconceptions. Further, the first author is a registered nurse, and many of the skills that a nurse has acquired is similar to what an ethnographer holds, for example features such as listening, interviewing, observing, reflecting and interpreting on multiple levels at the same time, and with a conscious use of oneself. This illustrates that a nurse with professional knowledge and experience can offer security in the TM setting, thus experiencing successful interaction [65]. In addition, with the use of the think-aloud technique, the author was positioned next to, rather than facing, the participants to minimise influence on the participants.

The present study used a combination of different data collection methods to strengthen the study as it provides a more nuanced and complete picture of the phenomenon investigated [64]. Also, the focus group interview promoted a meeting point and discussion between the nurses, which facilitated a broader experience regarding the TM context, and of the use of the CDSS. The findings of a qualitative study are difficult to generalise, however the findings can be transferred to similar settings [51].

Conclusions

In the TM setting, nurses' reasoning supported by a CDSS was enabled by the continuous flow of computerised clinical data, regular video-mediated contact with the patients and shared decision-making, all of which strengthened in-depth knowledge of the patients, acting as a foundation for nurses' reasoning and decision-making processes. Regular patient contact via TM promoted a continuum of care, supporting the role of TM nurses' in the long-term management of COPD. Nevertheless, nurses frequently advanced beyond the system recommendations, which indicates that future research is needed to develop more accurate algorithms, increase system maturity and improve the integration of digital clinical information with clinical experiences. Future TM services should be organised in a way that maintains the continuous flow of clinical data, involve regular video-mediated contact and promote shared decision-making to support nurses' reasoning.

Abbreviations

CDSS: Computerised decision support system; COPD: Chronic obstructive pulmonary disease; EHR: Electronic health record; TM nurses: Telemedicine nurses; TM: Telemedicine; TMC: Telemedicine centre; U4H: United4Health

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Availability of data and materials

The interview data will not be shared since the participants are guaranteed full anonymity.

Authors' contributions

TLB, ET and US designed the study. TLB performed the data collection. TLB analysed the data and discussed the analysis with ET and US. TLB wrote the manuscript and ET and US reviewed it. All authors approved the final version.

Competing interest

The authors declare that they have no competing interest.

Ethics approval and consent to participate

This study was designed and performed in accordance with the Declaration of Helsinki [66] and common principles used in clinical research [67]. Ethical approval was obtained from the NSD – Norwegian Centre for Research Data (project number: 42,445). Oral and written informed consent was obtained from all participants before study commencement. Participants were informed that participation was voluntary and that they could withdraw at any time for any reason. All of them were guaranteed anonymity.

The nurse asked the patients if they would consent to the first author being present but unable to see or hear the patient during video consultations. All patients provided oral consent before performing a consultation.

Consent for publication

Not applicable.

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Paper III

A sense of belonging: A meta-ethnography of the experience of patients with chronic obstructive pulmonary disease receiving care through telemedicine

A sense of belonging: A meta-ethnography of the experience of patients with chronic obstructive pulmonary disease receiving care through telemedicine

Abstract

Aim: To synthesise the qualitative research in the literature addressing how patients with COPD experience care received by telemedicine.

Design: Meta-ethnography.

Data Sources: Twelve studies, published from 2013 to 2018, were identified by a search of relevant systematic databases in June 2017, including updated searches performed to June 2018.

Review Methods: The studies were reviewed and critically appraised independently by three researchers. The review followed the seven steps of meta-ethnography developed by Noblit and Hare, including a line-of-argument synthesis.

Results: The synthesis revealed three second-order constructs: presence, transparency, and ambivalence. Using a line-of-argument synthesis, a model was developed that showed patients' experience of a sense of belonging when receiving care by telemedicine.

Conclusion: This meta-ethnography contributes to the existing and contradictory evidence base of telemedicine to COPD patients. It addresses and adds renewed understanding of who would benefit from TM, and why, by illustrating the interrelationship between the conditions of telemedicine care, the severity of COPD and the need for connectedness, and emphasises that the need to belong in telemedicine care increases with the progression of illness burden and severity.

Impact: The present study endorses the view that the patients with a severe illness burden are likely to benefit the most when receiving care by telemedicine. However, the benefits rely on the fact that the telemedicine interventions involve emotional, social, and clinical support, including regular contact with health care professionals, to meet the requirements to belong.

Keywords: chronic obstructive pulmonary disease, experience, meta-ethnography, nurse-patient relationship, nursing, systematic review, telemedicine

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is increasing in prevalence, morbidity, and mortality (López-Campos, Tan, & Soriano, 2016), and is expected to be the third leading cause of death by 2030 (WHO, 2017). COPD is a serious and progressive disease characterised by persistent respiratory symptoms and airflow limitation (Vogelmeier et al., 2017, p. 558). Chronic and progressive dyspnoea is the characteristic symptom of COPD (Vogelmeier et al., 2017), which causes breathlessness, anxiety, and depression. Living with COPD imposes increasing limitations and dependence on others for care (Ek & Ternestedt, 2008; Giacomini, DeJean, Simeonov, & Smith, 2012).

The care required by patients with COPD is complex because of the unpredictable nature of the disease, which includes periods of stability and acute episodes of ever-changing symptoms (Gott et al., 2009; Rosa et al., 2018). Managing the illness is a challenge for patients, health care professionals (HCPs), and health care systems (Hanlon et al., 2017; WHO, 2017), and requires continuous, flexible (Giacomini et al., 2012) and comprehensive coordination of health care (Gott et al., 2009) to respond to the unpredictable and increasing demands of the illness over time (Giacomini et al., 2012). Routine follow-up is essential for patients with COPD (Vogelmeier et al., 2017), and telemedicine (TM) has shown promising results (McLean et al., 2012), in that patients with COPD experience closer contact with their HCPs, are better cared for, and have increased self-awareness of their condition (Morton et al., 2017).

Background

TM can be defined as “the information, communication, and monitoring technologies which allow healthcare providers to remotely evaluate health status, give educational intervention, or deliver health and social care to patients in their homes” (Solli, Bjørk, Hvalvik, & Hellesø, 2012, p. 2813). TM care for patients with COPD has been shown to be clinically effective (Polisena et al., 2010) by decreasing the use of health care services (Kamei, Yamamoto, Kajii, Nakayama, & Kawakami, 2013) and reducing hospital admissions and emergency department visits (Cruz, Brooks, & Marques, 2014; McLean et al., 2012; Pedone & Lelli, 2015), thereby improving quality of life for patients (Cruz et al., 2014). Nevertheless, these reviews have focused mostly on efficiency (Cruz et al., 2014; Pedone & Lelli, 2015), mortality and hospital admission rates (Kamei et al., 2013; McLean et al., 2012), or health-related quality of life (Gregersen et al., 2016), with uncertain conclusions and a lack of clear clinical evidence (Cruz et al., 2014; Gregersen et al., 2016; Pedone & Lelli, 2015), and overlooked how patients with COPD experience care via TM.

Given that TM has an increasing role in global health care delivery and can address the growing burden of COPD on health care systems, it will be increasingly important to develop a strong knowledge base (Dinesen et al., 2016). Several studies have mentioned that qualitative research is required (Brunton, Bower, & Sanders, 2015; Lilholt, Witt Udsen, Ehlers, & Hejlesen, 2017; McLean et al., 2012) to identify subgroups of patients with COPD who would benefit from TM (Cruz et al., 2014; Gregersen et al., 2016; Lilholt et al., 2017; Pedone & Lelli, 2015) and those who would not (Gorst, Armitage, Brownsell, & Hawley, 2014).

Although meta-ethnographies have been performed in patients with COPD and in the use of TM technology, they have investigated either the user perspective involving both nurses and patients (Brunton et al., 2015) or self-management of several chronic conditions (Morton et al., 2017). To our knowledge, this meta-ethnography is the first to investigate how patients with COPD experience care delivered by TM, and was performed to ensure that the views and experiences of patients with COPD are fully represented in the evidence base and to complement the quantitative systematic reviews (Campbell et al., 2011).

THE REVIEW

Aim

The aim of this meta-ethnography was to synthesise the qualitative research in the literature addressing how patients with COPD experience care received by TM.

Design

A meta-ethnography, as developed by Noblit and Hare (1988) and further adapted for health research by Britten et al. (2002), was conducted to collect and synthesise qualitative papers on how patients with COPD experience receiving care by TM. Meta-ethnography is an inductive method within an interpretative paradigm. The synthesis aims to interpret rather than describe a condition within a context for understanding (Noblit & Hare, 1988) and allows a body of qualitative research to be collected in a systematic way (Campbell et al., 2011). Following Noblit and Hare (1988), the meta-ethnographic method included seven steps. Step 1 was defining the object of interest (aim), followed by the search methods, outcomes, and quality appraisal (step 2), then synthesis (steps 3–6), and writing of the results (step 7). To enhance transparency and quality of the paper, the study followed the ENTREQ (Tong, Flemming, McInnes, Oliver, & Craig, 2012) and eMERGe guidelines (France et al., 2019).

Search methods

Following step 2 in Noblit and Hare's (1988) approach, we sought to identify qualitative papers investigating patients with COPD and their experience of care by TM. Systematic literature searches were conducted until 19 June 2017 and updated on 8 June 2018. The Medline, Embase and PsycInfo via OvidSP (database host), and Cinahl via Ebscho Host databases were searched. These databases were chosen to include the various relevant disciplines (e.g., nursing, health care, technology) and because these databases have the best coverage of qualitative studies on illness and health (Booth, Sutton, & Papaioannou, 2016). A non-systematic search for grey literature were performed in Google Scholar, ProQuest, Web of Science, and The Cochrane Library, but did not retrieve any relevant articles. The reference lists of the included studies were also hand-searched for further articles, but none were identified.

The search was guided by search terms as Medical Subject Headings and abstract key words for two concepts, i.e., "chronic obstructive pulmonary disease" and "telemedicine" (see supplementary information Table 1). The search was based on an adjusted PICO-method that focused on population and intervention (Booth et al., 2016). The search terms were slightly different between the databases because of their different index systems. The search strategy was devised in collaboration with a specialist librarian and was developed iteratively to ensure a balance between sensitivity and specificity (Booth et al., 2016).

Search outcomes

The database search yielded 4,051 studies, with 2,429 remaining after removal of duplicates. The three authors independently screened the titles and abstracts in relation to the inclusion and exclusion criteria (Table 2) using Covidence (Covidence systematic review software, 2018). Full-text articles were retrieved for further inspection when the title and abstract met the inclusion criteria. The eligibility criteria are shown in Table 2.

Insert Table 2 about here.

Sixty-six full-text papers describing TM and COPD and having a qualitative methodology were reviewed for eligibility. Fifty-four studies were excluded for the following reasons: non-English language (*n* = 3); not being original research (*n* = 8); inappropriate study design, i.e., non-qualitative data (*n* = 7), an inappropriate patient population, i.e., without COPD (*n* = 2), not TM as defined (*n* = 22: including tele-rehabilitation [n = 10], usability studies [n = 7], tele-yoga [n = 1], education/conversation, i.e., no treatment [n = 2], virtual admission [1], and personal visits [n = 1]), wrong outcomes, i.e., not about experience of patients with COPD (*n* = 3), and results not separating patient group/users of TM (*n* = 9). Twelve papers (representing 10 studies) were included in the review. The selection process is shown in a PRISMA flow chart (Figure 1).

Insert Figure 1 about here.

Quality appraisal

The 12 included papers were assessed for quality by the review team independently using the CASP tool (Critical Appraisal Skills Programme, 2018). After independently assessing each paper, consensus was reached by discussion (see supplementary information Table 3). The studies were of moderate to high quality. Two of the studies (Fitzsimmons, Thompson, Bentley, & Mountain, 2016; Mathar, Fastholm, & Sandholm, 2015) were appraised as low-quality because of insufficient analytic rigor; however, their findings were similar to those of the studies of strong quality, so were included in the review. During the quality appraisal, we found limited reporting of ethics and descriptions of the analysis process in several studies, but most had a clear statement of findings. The study by Barken, Thygesen, and Söderhamn (2018) was assessed for quality by two independent professors with extensive experience in qualitative research to provide an impartial evaluation. The study by Vatnøy, Thygesen, and Dale (2017) was assessed for quality by TLB and US in view of the fact that ET was part of the original study.

Data abstraction and synthesis

Steps 3–6 in Noblit and Hare's (1988) approach are the reporting of the analytic and synthesizing process. Steps 3–6 were not a linear process and entailed going back and forth within the steps of the method. The process enhanced the authors' familiarity with the metaphors and concept of each study. The synthesis was performed by the first author; however, each step was thoroughly discussed with the co-authors.

Step 3: The 12 included papers were read repeatedly, and the details of the primary studies were extracted (see Table 4 and supplementary information Table 5). The studies contained 163 patients aged from 44 to 85 years and suffering from mild to very severe COPD. The studies were performed in the UK, Norway, and Denmark. Further, the empirical materials (the findings sections) were located and then sorted in a conceptual map where relevant themes and metaphors from each primary study were listed in vertical columns and arranged with first-order constructs (participants' quotes) and second-order constructs (authors' interpretations) (Britten et al., 2002). To determine how the studies were related (step 4), the relationship between the studies were found to be both reciprocal and refutational, from which a line-of-argument analysis could be performed.

Step 5: To translate the studies into each other, the papers were vertically arranged starting with an index study by Gorst, Coates, and Armitage (2016). The index study was chosen on the basis of its conceptual richness and high-quality appraisal. Following the index study, the studies were arranged according to high-quality appraisal, analytical rigor, and thick descriptions. The key themes from the index study were compared with those of the second study, and the synthesis of these two studies was compared with the third study, and so on. Key concepts were translated across all studies. Thereafter, using a constant comparison method (Britten et al., 2002), metaphors and key concepts were determined. During the comparison, similar metaphors and concepts were placed in close proximity, going back and forth, re-ordering, re-linking, and reassembling (clustering) the metaphors until a common metaphor was identified (Campbell et al., 2011).

Step 6: The metaphors were further analysed and abstracted to form a third-order conceptual framework involving both the first-order and second-order constructs (Britten et al., 2002). In the process of re-conceptualising, the findings of the studies were systematically related to establish new relationships between the concepts. This indicated reading the concepts and interpretation “of the grid” (Britten et al., 2002, p. 211), and involved repeated comparison between studies of which a third-order interpretation was developed through a line-of-argument synthesis. The interpretation placed any similarities and differences into a new interpretation, to discover the whole from a set of parts (Noblit & Hare, 1988). An example of the synthesis process is presented in Table 6.

Insert Table 4 about here.

RESULTS

The synthesis revealed three third-order and six second-order constructs during the translation of concepts in the papers, i.e., presence (accessibility and digital proximity), transparency (clinical awareness and reciprocal dialogue), and ambivalence (independent yet close, and restricted yet detached) (Table 7). Further, a line-of-argument was developed which indicates that patients with COPD experience a sense of belonging when receiving care through TM. The line-of-argument builds on the three third-order constructs, through which a conceptual model has been developed that illustrates the interrelationship between the conditions of TM care, the severity of COPD and the need for connectedness (Figure 2).

Insert Table 6 about here.

Insert Table 7 about here.

Presence

The synthesis represented an overview of how patients with COPD experience presence as increased accessibility/availability to health care services and/or proximity as a fundamental condition for care through TM. Presence was established on a predictable daily basis through legitimised contact with HCPs offering stability and regularity. The regularity also strengthened the nurse-patient relationship and the human aspect of TM care, providing both emotional support and social contact, i.e., supporting the burden of living with the illness.

Accessibility

Patients in 10 studies (Table 7) experienced care by TM as increased accessibility to health care services, which had two significant aspects. Firstly, TM care legitimised contact with an HCP when help was needed (Fairbrother et al., 2013; Gale & Sultan, 2013; Nissen & Lindhardt, 2017; Vatnøy et al., 2017). Secondly, it allowed patients regular contact with health care services (Huniche, Dinesen, Nielsen, Grann, & Toft, 2013; Vatnøy et al., 2017; Williams, Price, Hardinge, Tarassenko, & Farmer, 2014), providing them with peace of mind (Barken et al., 2018; Gale & Sultan, 2013) and increasing trust (Fairbrother et al., 2012; Vatnøy et al., 2017) and control (Mathar et al., 2015; Nissen & Lindhardt, 2017).

Availability of an HCP mediated by TM technology provided the patients with a more predictable daily life (Barken et al., 2018). Follow-up by TM also led to a reduction in health care needs (Gorst et al., 2016), was more personal (Barken et al., 2018; Fairbrother et al., 2012), and was experienced as an improvement over standard care (Fairbrother et al., 2012; Gorst et al., 2016).

Digital proximity

TM enabled patients with COPD to be followed up and monitored by an HCP at a distance. Despite the distance, patients in ten studies experienced digital proximity (Table 7). The experience of digital proximity was described as a feeling of being watched over (Fairbrother et al., 2012; Ure et al., 2012; Williams et al., 2014) that provided safety (Fitzsimmons et al., 2016) and reassurance (Fairbrother et al., 2013; Williams et al., 2014) and reduced worry, and was explained as “sort of a lifeline” (Gorst et al., 2016). Digital proximity was further strengthened when performing video consultations as part of the TM intervention (Barken et al., 2018; Mathar et al., 2015; Nissen & Lindhardt, 2017; Vatnøy et al., 2017). Several patients experienced video consultation as being the centre of attention, which allowed closer contact with nurses (Nissen & Lindhardt, 2017) and compensated for not being in the same room (Barken et al., 2018; Vatnøy et al., 2017).

Moreover, accessibility and digital proximity reduced worry and brought peace of mind for family members (Barken et al., 2018; Gale & Sultan, 2013; Gorst et al., 2016; Huniche et al., 2013; Nissen & Lindhardt, 2017). When concerns are legitimised and function as a common point of reference, family members become more involved in managing the illness (Huniche et al., 2013). However, two studies have reported that some participants missed contact in-person (Gorst et al., 2014; Nissen & Lindhardt, 2017).

Transparency

Transparency functioned as a fundamental condition for TM care, and represented a clinical openness based on increased clinical awareness and a reciprocal dialogue with the HCP. Transparency advanced an understanding of the progression of the patient’s illness/symptoms, allowing the patient to distinguish normal from abnormal readings and what they mean in relation to their illness/symptoms. Sharing, discussing, and reflecting on the clinical data with the HCP represented active engagement and participation, fostering the ability to adapt to a new clinical language and provide patients with an active voice.

Clinical awareness

Patients in nine of the studies (Table 7) found that assessing clinical measurements provided them with an insight into their health, which in turn increased their awareness of their individual data. Furthermore, regular measurements increased their clinical understanding of their illness (Gale & Sultan, 2013; Gorst et al., 2016) and encouraged them to become more involved and engaged (Barken et al., 2018), thereby promoting a more structured approach to their health (Huniche et al., 2013; Williams et al., 2014).

Furthermore, clinical measurements enabled patients to contrast readings to determine if they were normal or not (Barken et al., 2018; Huniche et al., 2013), which in turn, increased awareness of changes in their symptoms and clinical data (Barken et al., 2018; Gale & Sultan, 2013; Gorst et al., 2016; Nissen & Lindhardt, 2017) so that patients could understand why they felt unwell (Fairbrother et al., 2013; Huniche et al., 2013; Nissen & Lindhardt, 2017; Ure et al., 2012; Vatnøy et al., 2017; Williams et al., 2014).

Reciprocal dialogue

An important aspect of the patients' understanding of their illness was the sharing of their self-measured data with the HCP, promoting a shared concern (Huniche et al., 2013) and receiving support through advice and guidance (Barken et al., 2018; Nissen & Lindhardt, 2017; Vatnøy et al., 2017). Sharing their clinical data endorsed a mutual and horizontal clinical language (Barken et al., 2018; Williams et al., 2014) that improved collaboration and dialogue with the HCP (Barken et al., 2018) and encouraged active participation in the management of their illness (Gorst et al., 2016; Vatnøy et al., 2017; Williams et al., 2014). Similarly, increased understanding was used to validate their own health status, assist their judgement regarding when to contact the HCP (Gale & Sultan, 2013; Huniche et al., 2013), and establish a nurse-patient relationship based on trust and close personal contact (Barken et al., 2018; Nissen & Lindhardt, 2017).

Ambivalence

The synthesis indicated that receiving care by TM was experienced as ambivalent. This ambivalence was associated with a feeling of being independent yet close and/or restricted yet detached. Patients with unstable COPD felt more independent in their everyday life when receiving TM, whereas patients with stable COPD and in otherwise good health often felt restricted. For patients with good health, TM became a burden rather than supporting the struggles caused by the illness and focused attention on the disease in periods of good health.

Independent yet close

Patients in 11 studies (Table 7) found that TM technology was easy to manage (Barken et al., 2018; Fairbrother et al., 2013; Fitzsimmons et al., 2016; Nissen & Lindhardt, 2017; Ure et al., 2012; Vatnøy et al., 2017; Williams et al., 2014) and provided meaning (Vatnøy et al., 2017), independence in daily life (Gale & Sultan, 2013; Gorst et al., 2016; Mathar et al., 2015), control (Mathar et al., 2015; Nissen & Lindhardt, 2017) and dignity (Vatnøy et al., 2017) because of the integrated, personalised, and timely follow-up (Fitzsimmons et al., 2016). In particular, patients with unstable COPD and/or severe/very severe disease (Barken et al., 2018; Huniche et al., 2013; Vatnøy et al., 2017) felt safer and more independent, indicating the need for closeness in TM care. The sense of independence was increased further when patients were able to make judgements about their own health (Huniche et al., 2013).

Restricted yet detached

In eight studies, the TM technology was experienced by some patients as restricting their everyday life (Table 7). For example, patients in a state of good health considered that TM should be offered to patients who were far more ill (Barken et al., 2018; Mathar et al., 2015). Most patients who felt restricted by TM had mild or stable COPD (Barken et al., 2018; Huniche et al., 2013; Nissen & Lindhardt, 2017; Vatnøy et al., 2017) and felt that TM directed attention to their COPD when they were in good health, and consequently became a reminder of illness (Nissen & Lindhardt, 2017; Vatnøy et al., 2017) and of being bound to certain times of the day (Fitzsimmons et al., 2016; Mathar et al., 2015), indicating that these patients wanted to feel more detached. Two studies found that TM was similarly not worthwhile in patients suffering from comorbidities (Huniche et al., 2013; Williams et al., 2014).

Failure of technology was another restriction (Barken et al., 2018; Fitzsimmons et al., 2016; Ure et al., 2012). Furthermore, some participants commented on removal of TM equipment (Fitzsimmons et al., 2016) when they were dependent on the technology as well as a need to “rewire the panic button again” (Gale & Sultan, 2013).

Patients with COPD and their experience of belonging through TM care

The final section of the synthesis includes the line-of-argument that patients with COPD experience a sense of belonging when receiving care through TM (Figure 2). The experience of belonging was rooted in two fundamental conditions for TM care; TM was experienced to provide emotional and social support (presence) and increased clinical knowledge and individual growth (transparency). Patients felt that they were a part of the health care process and connected with the HCP through the TM technology.

The severity of COPD directly influenced on the sense of belonging (ambivalence), and to what extent the experience of belonging was perceived to provide a need for closeness or detachment (level of connectedness) in TM care. With an increased symptom burden, unstable periods, and uncertainty, an increased need for closeness in TM care emerged. However, patients with a low symptom burden, or in a stable and early phase of the illness, experienced TM care as an unnecessary intervention in their lives. The disease was perceived to come too close, with a need to be detached. Consequently, there is a connection between experienced illness burden and the need to belong in TM care. The level of connectedness and the requirement to belong increases with the progression of illness burden and severity.

Insert figure 2 about here.

DISCUSSION

A line of argument was developed that indicates patients with COPD experience a sense of belonging when receiving care through TM. A sense of belonging can been defined as “the experience of personal involvement in a system or environment so that persons feel themselves to be an integral part of that system or environment” (Hagerty, Lynch-Sauer, Patusky, Bouwsema, & Collier, 1992, p. 172), a concept that is clinically relevant and can support patients to develop capacity and skills (Hagerty, Williams, Coyne, & Early, 1996). This meta-ethnography shows two fundamental conditions of TM care: presence and transparency, which influenced the sense of belonging.

Presence, defined as “a reciprocal and healing relationship between the nurse and patient through a compassionate exchange of the human experience” (Hessel, 2009, p. 281), is one of the care conditions in TM care. It incorporates emotional and social support to patients with COPD through accessibility of care, availability of HCP, and digital proximity. Emotional and social support have been found to be important for patients with COPD (Gardener, Ewing, Kuhn, & Farquhar, 2018; Gardiner et al., 2010), as they often experience social isolation, loneliness and anxiety (Gysels & Higginson, 2011). The chronic, acute, and life-threating course of the disease (Pooler, 2016) promote the need for continuous emotional and social support, which was found in this meta-ethnography to be dependent on the regular, personal connection forged between the nurse and patient during TM consultations.

TM care comprises of a complex relationship between nurse, patient, and technology (Nagel, Pomerleau, & Penner, 2013), where technology can be a humanising factor because it is socially constructed (Barnard & Sandelowski, 2001) and creates a connection between nurses and patients (Carroll, 2018). As a consequence, TM care has altered the typical pattern of nurse-patient proximity (Currell, Urquhart, Wainwright, & Lewis, 2000; Grumme, Barry, Gordon, & Ray, 2016; Savage, 1997; Tuxbury, 2013). A review on nurse-patient interaction show that the relationship between nurses and patients is more important than other aspects of care (Shattell, 2004). Social connections have been found to have strong influences on health (Benzo, 2017; Holt-Lunstad, 2018). However, little attention has been paid to the social interactions between nurses and patients (Mohammadipour, Atashzadeh-Shoorideh, Parvizy, & Hosseini, 2017). This meta-ethnography found that video-contact and consultations are important to achieve digital proximity. Other studies have also found that video consultations are important in meeting the patient’s need for care (Kruse et al., 2017; Pols, 2006). Non-video interventions (Gale & Sultan, 2013; Huniche et al., 2013) in our study did not contribute to the digital proximity construct, but patients in these studies experienced increased clinical competence. There is a possibility that differences between TM interventions would impact on the findings. However, both in studies with video and non-video interventions we found that social connectedness with an HCP is an essential part of TM care to experience support and presence, contributing to a sense of belonging through emotional and social support.

Transparency, defined as “the opening-closing of a system by sharing-keeping information as change arises with mutual trust” (Horne, 2012, p. 330), was equally important for the sense of belonging, promoting increased clinical competence and personal growth through clinical awareness and reciprocal dialogue. The care conditions of transparency in TM increase openness because individual clinical data are available, shared, and discussed with HCPs. A recent systematic review showed that patients need both knowledge and power to participate in shared decision-making to manage their disease (Joseph-Williams, Elwyn, & Edwards, 2014), redefining the patient role in health care (Joseph-Williams et al., 2014; Oudshoorn, 2016).

Patients with COPD have been found to have a poor understanding of their disease and its implications (Gardiner et al., 2010), in particular those with low health literacy and language barriers, which can cause them to cope with the disease negatively (Giacomini et al., 2012). This meta-ethnography provides a further understanding of the concept of transparency in health care in a TM context, i.e., that transparency strengthens the ability of patients with COPD to understand and adapt to the detailed and complex clinical language of their illness, thereby strengthening their health literacy. This exemplifies how transparency provides an active voice for patients with COPD, which increases involvement and engagement when receiving care by TM, contributing to a sense of belonging through shared care and understanding.

However, the experience of belonging was ambivalent. The findings indicate that when COPD was unstable, progressing, or severe, patients experienced independence yet wanted closeness to TM care. Patients with good health sought detachment when TM care became a reminder of illness, which is supported by Brunton et al. (2015) and Pols (2006), thus indicating that there is a connection between illness burden and the experienced need to belong. Consequently, the need for connectedness and the requirement to belong increases with the progression of illness burden and severity. This is an important contribution to the existing evidence base that shows contradictory results (Brunton et al., 2015; Cruz et al., 2014; Gregersen et al., 2016; Pedone & Lelli, 2015) and a lack of understanding of who would benefit the most from TM, including their preferences (Vitacca, Montini, & Comini, 2018). Pinnock and McKinstry (2018) suggest that these contradictions may be influenced by the complexity and the large symptom burden of the disease. This meta-ethnography shows that TM care can broadly support several of the challenges facing people with COPD, such as physical, psychological, and social support, which is promoted as the main support needs for patients with COPD (Gardener et al., 2018), and can accommodate the unpredictable nature of COPD (Giacomini et al., 2012).

Implications for practice

A model has been developed that can help HCPs, researchers, educators, and students to understand patients with COPD and their experience of receiving care through TM. Future research and developments of TM interventions should acknowledge the patients' experience when implementing TM in practice. In light of the findings that patients with severe COPD benefit the most from TM care, it would appear that these patients should be offered a more permanent TM follow-up. Such a follow-up may guarantee that the conditions of TM care are maintained, including regular contact to HCPs for continuous support of the unpredictable disease progression to increase the sense of belonging.

Strengths and limitations

A rigorous methodological approach was applied by following the seven steps of Noblit and Hare (1988) to achieve credibility and trustworthiness. The review team (TLB, US, and ET) independently screened studies using the eligibility criteria, appraised the quality of the studies, and reached consensus by discussion. Moreover, our background understanding as nurses, our previous experience with TM and COPD, and as the primary authors of two of the included studies, the review team have been aware their possible influence and have discussed it through all stages of the review.

The included papers were arranged based on studies that had conceptual richness and high-quality appraisal. Given the variable contexts and interventions, arranging them by type of intervention (e.g., video/non-video) or chronologically, could also be a possible way to group papers. However, given the interpretative nature of meta-ethnographies aiming at providing explanatory models (Booth et al., 2016), we found that grouping papers by conceptual richness was justified to achieving this. However, the choice of arranging papers by quality appraisal could have had an impact on the findings and may have influenced the study.

While the eligibility criteria were developed cautiously to identify the most relevant studies, the included studies varied in terms of TM interventions and equipment, duration of follow-up (10 days to 3 years), type and duration of contact (video/non-video), degree of COPD (ranging from mild to very severe), timing of interviews, and type of analysis. Such variations can be a weakness and influence a synthesis (Booth et al., 2016). However, despite the differences between the studies, this meta-ethnography found both similarities and differences contributing to the refutational findings (e.g., severity of COPD). Finally, the included studies were performed in the UK, Norway, and Denmark, so the relevance of their findings to other countries and health care settings should be assessed with caution.

CONCLUSION

This meta-ethnography reconceptualises and provides a new understanding of the experience of patients with COPD receiving care by TM. A model is presented that illustrates the interrelationship between the conditions of TM care, the severity of COPD, and the need for connectedness, and emphasises that the level of connectedness and the requirement for having a sense of belonging increases with the progression of illness burden and severity. The findings are an important contribution to the existing and contradictory evidence base, as it addresses and adds renewed understanding of who would benefit from TM, and why. Additionally, the findings of this meta-ethnography reflect how important it is to understand the experience of those who struggle daily with COPD.

Conflicts of interest

The authors declare no conflict of interest.

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Table 1. Example of search terms/search strategy in Cinahl via EbscoHost

Search terms	
COPD	TM
MH Pulmonary disease, Chronic obstructive	MH "Telecommunications+"
COPD	telemedicin*
"chronic airflow obstruction*"	mHealth
"chronic airway obstruction*"	eHealth
"chronic bronchitis*"	telemedical
"chronic lung disease*"	telenurs*
"chronic obstructive airway disease*"	"tele nurs*"
"chronic obstructive bronchitis*"	telerehabilitation*
"chronic obstructive bronchopulmonary disease*"	telemonitor*
"chronic obstructive lung*"	telehealth*
"chronic obstructive pulmonary*"	"tele health*"
"chronic obstructive respiratory*"	technology
"chronic respiratory disease*"	technologies
coad	teleconsultation*
"pulmonary emphysema"	telehomecare*
"obstructive lung disease*"	telecare*
"obstructive respiratory disease*"	smartphone*
"obstructive respiratory tract disease*"	"smart phone*"
	teleconferenc*
	(mobile n2 (app* or communication*))
	(tele* n1 home)
	(remote n1 monitor*)
	(remote n3 consultation*)
	((mobile* or digital) n1 health*)
	((tele* or home) n1 monitor*)
	((video* or tele*) n2 (admission* or consult* or conferenc*))

MH, Medical Subject Heading; +, explode term; *, truncation ", search term as Boolean operator. COPD, chronic obstructive pulmonary disease; TM, telemedicine

Table 2. Eligibility criteria

Inclusion criteria	Exclusion criteria
Studies published in English or Nordic language	Non-English or non-Nordic language
Primary studies/original research	Non-primary studies/non-original research
Qualitative studies (reporting detailed and in-depth description of findings)	Non-qualitative data or non-in-depth description of findings/wrong study design
Patients with COPD	Non-COPD/wrong patient population
TM defined by Sollie et al. (2012)	Studies that did not correspond with the definition of TM as defined (e.g., tele-rehabilitation, usability, tele-yoga, education (not treatment), virtual admission, personal visits.
Experience of patients with COPD receiving care by TM	Not about experience of patients with COPD receiving care through TM/wrong outcome
Results separating patient groups (e.g., different diagnosis) or users of TM	Results not separating patient groups and/or users of TM (e.g., health care professionals, physiotherapists, general practitioner)

COPD, chronic obstructive pulmonary disease; TM, telemedicine

Table 3. Critical appraisal of included studies

Study number												
Critical appraisal question	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
1. Clear statement of the aims?	X	X	X	X	X	X	X	X	X	X	X	X
2. Qualitative methodology appropriate?	X	X	X	X	X	X	X	X	X	X	X	X
3. Methodology appropriate for study design?	X	X	X	X	X	X	X	X	X	X	X	X
4. Recruitment strategy appropriate to aims?	X	X	X		X	X	X		X	X	X	
5. Data collection style address research issue?	X	X	X	X	X	X	X	X	X	X	X	X
6. Researcher and participant relationship considered?	N											X
7. Ethical issues taken into consideration?	X	X	X	X	X	X	X	X	X	X	X	X
8. Data analysis sufficient rigorous?	X		N	N	N	X	N	N	X	X	X	X
9. Clear statement of findings?	X	X	X	X	X	X	X	N	X	X	X	X
10. Is the research valuable?	X	X	X	X	X	X	X	N	X	X	X	X

X = yes, N = No, blank = cannot tell based on the CASP quality appraisal tool. The studies are listed alphabetically, from 1 to 12.

Table 4. Characteristics of 12 eligible qualitative studies among COPD patients who were included in a TM intervention

Author (year)	**Aims**	**TM intervention**	**Participants**	**Design/analysis**
Barken et al. (2018)	To describe experiences of QoL of COPD patients included in a TM intervention	Reading heart rate and saturation and regular real-time follow-up by video communication	10 – Moderate to very severe	Descriptive phenomenology
Fairbrother et al. (2012)	To explore the views of patients and professionals on TM	Online questionnaire and pulse oximeter used daily. HCPs contacted patients to address health changes	38 – Moderate to very severe	Framework approach
Fairbrother et al. (2013)	To explore the views of patients and HCPs who were using TM	See Fairbrother et al., 2012	See Fairbrother et al., 2012	See Fairbrother et al., 2012
Fitzsimmons et al. (2016)	To explore the experiences of COPD patients included in a TM intervention	Monitoring self-answered health questions, blood pressure and oximeter. Telephone contact after system alert	9 – Early-stage	Framework analysis
Gale & Sultan (2013)	To document the experience of COPD patients who interact with technology	Recording oxygen saturation, blood pressure, weight and temperature. Red alert activated action from the CRC	7 – Mild to very severe	Framework analysis
Gorst et al. (2016)	To explore beliefs/perceptions of COPD patients using home telehealth	Reading blood pressure, oxygen level, pulse rate, temperature and weight. Regular follow up after readings	8 – Severity unknown	Interpretative phenomenology
Huniche et al. (2013)	To explore how COPD patients making use of readings during self-monitoring	Collecting blood pressure, pulse, weight, oxygen level, and lung function. HCPs contacted patients by telephone	22 – Severe to very severe	Thematic analysis
Mathar et al. (2014)	Experiences of COPD patients who received tele-video consultations	Monitoring vital signs, dyspnoea, chest pain, expectoration, cough, oedema and well-being. Video-consultations by HCPs	6 – Severe and very severe	Systematic text condensation
Nissen & Lindhart (2017)	To illuminate experience of stable COPD patients included in a TM intervention	Reading pulse, weight, dyspnoea, cough, sputum. Regular video follow-up. Nurses contacted when health deteriorated	14 – Severe and very severe	Manifest and latent content analysis
Ure et al. (2012)	To explore perceptions of COPD patients and professionals about TM service	Daily recording of symptoms, weekly oximetry, spirometry. Support staff contacted patients when health deteriorated	20 – Moderate to severe	Thematic analysis
Vatnøy et al. (2017)	To investigate how patients experienced follow-up using a TM intervention	See Barken et al. (2018)	10 – Minimal to major COPD	Qualitative content analysis
Williams et al. (2014)	To explore patients' experience of using an MHealth telehealth application	Monitoring pulse rate, oxygen level and symptom diary daily. Data reviewed at regular intervals by nurse	19 – Moderate to very severe	Grounded theory approach

COPD, chronic obstructive pulmonary disease; CRC, community respiratory service; HCPs, Health Care Professionals; QoL, quality of life; TM, telemedicine

Table 5. Additional information of characteristics of the 12 eligible studies

Reference	Country	Aims	Intervention	Participants	Data collection	Analysis	Main findings
Barken et al. (2018)	Norway	To describe the lived experiences of quality of life among a group of patients living with COPD who were included in a telemedical intervention after hospitalisation for disease exacerbations.	A technological solution and follow-up through a telemedical centre. The technological solution consisted of a tablet with video camera and pulse oximetry for daily monitoring of pulse and oxygen saturation, and software consisted of a questionnaire regarding self-evaluation. Regular real-time follow-up by video communication with a trained nurse at the telemedical centre. Duration: 3 months	10 patients: 7 men/3 women Age: 61–80 years People with moderate to very severe COPD	In-depth interviews 4–8 weeks into the intervention	Descriptive phenomenology	Living with COPD led to impaired QoL. Being included in a TM intervention increased accessibility to health care services, support from health care professionals and clinical insight, and developed a mutual clinical language, increasing QoL. However, TM was also experienced as a dual chore.
Fairbrother et al. (2012)	Scotland	To explore the views of patients and professionals on telemonitoring. The perceived impact of telemonitoring on continuity of care was investigated as part of the research.	The telemonitoring service enabled patients to assess their symptoms using an online touch-screen questionnaire. A linked pulse oximeter, peak flow meter, and electronic weighing scales transmitted physiological measurements to the device. Patients completed the questionnaire and measured oxygen saturation daily and used the peak flow device and scales on a weekly basis. Heath care professionals contact patients to address health changes. Duration: 1 year	38 patients: 18 men/20 women, Age: 44–85 years People with moderate to very severe COPD (according to the MRC dyspnoea scale)	Semi-structured interviews 6 months into the trial	Framework approach	Patients considered relationship-based continuity of care important in TM care due to increased accessibility, trust, and reassurance.
Fairbrother et al. (2013)	Scotland	To explore the views of patients and health care professionals who were using telemonitoring as	See Fairbrother et al., 2012	See Fairbrother et al., 2012	See Fairbrother et al., 2012	See Fairbrother et al., 2012	TM empowered self-management by enhancing understanding of COPD and provided justification

		part of the TELESCOT COPD trial of the impact of telemonitoring on self-management in COPD.					to seek professional advice. Patients embraced greater responsibility for their health.
Fitzsimmons et al. (2016)	UK	To qualitatively explore the experiences of patients with COPD who had received either a Telehealth-supported or a specialist nursing intervention following their discharge from hospital after an admission for an exacerbation of COPD	Telehealth system provided both monitoring and self-management support. Patients answered questions about their health status using a small hand-held device. Blood pressure was monitored and an oximeter was used to measure blood oxygen levels each day. The system generated an alert if reported signs and symptoms fell outside the normal range, or if the patient failed to undertake monitoring activity. Telephone contact after a system-generated alert. Duration: Follow-up 8 weeks after exacerbation of COPD	9 patients: 5 patients receiving TM: 3 men/2 women (mean age 67,22) 4 patients receiving standard service Early-stage COPD	Semi-structured interviews	Framework analysis	Recipients of telehealth-supported service reported feelings of safety and enthusiasm delivered of an integrated, community-based service.
Gale & Sultan (2013)	UK	To document the experience of people with COPD and their interaction with technology, in order to understand how they negotiated incorporating telehealth technologies into their everyday life and home space, and to understand why they valued it	Pilot intervention consisted of recording oxygen saturation, blood pressure, weight and temperature every weekday morning. Readings were sent to community respiratory service team. Only red alert activated action from the community respiratory service. No face-to-face contact, but self-referral mechanism. Duration: 9 months	7 patients: 5 men/ 2 women Age: 57–85 years People with mild to very severe COPD	In-depth interview of patients (relatives present), including observation of home setting Interviews conducted during telehealth use	Framework analysis	Telehealth brought peace of mind by legitimising contact with health professionals and increased patient confidence in managing their condition.

Gorst et al. (2016)	UK	Explore the beliefs and perceptions of patients with COPD currently using home telehealth and who are not enrolled in a trial	Six patients used small-sized telehealth equipment, with ability to send readings of vital signs. Two patients were using larger equipment with the same information, but with the possibility to view charts. Five patients used TM every weekday morning and three patients every morning, with monitoring follow-up shortly after. Vital signs: blood pressure, oxygen level, pulse rate, temperature and weight (only large equipment). Duration: 6 months to 3 years	8 patients: 3 men/ 5 women. Age: 58–84 years Length of years with COPD: from 4 to 18 years. Severity unknown	Semi-structured interview Difference in use of TM equipment, from 6 months to 3 years when interview was undertaken	Interpretative phenomenological approach	Patients experienced “being watched over” as providing peace of mind, learning about the condition and the impact on self-management, active engagement and better access to health care, important with in-person care; however, still valued face-to-face contact.
Huniche et al. (2013)	Denmark	To explore how chronic obstructive pulmonary disease patients’, make use of readings during 16 weeks of self-monitoring in the Telekat project.	The telehealth monitor box collected data on the patient’s blood pressure, pulse, weight, oxygen level, and lung function. Health care professionals monitored readings and contacted the patient by telephone to discuss health development and provide advice. Duration: 16 weeks	22 patients: 8 men/14 women Age: 45–81 years Severe and very severe COPD	Semi-structured interviews Interviewed three times; beginning, halfway and after TM equipment was collected	Thematic analysis	Self-monitoring can produce a sense of security because readings can explain symptoms and increase possibilities for acting. Readings was encouraging and reassuring, but also depressing, worrisome, and disturbing. Not making use of self-monitoring include good health or was experience as not relevant for patients.
Mathar et al. (2014)	Denmark	The experiences and preferences of COPD patients in relation to discharge from hospital with televideo consultations	The intervention compromised eight 30-min televideo consultations over a 2-week period, conducted by specially trained community nurses and physiotherapists. A pulse oximeter was used to measure saturation and pulse. Vital observations, dyspnoea, chest pain,	6 patients: 3 men/3 women Age: 67–83 years Severe and very severe	Semi structured interview Interviewed after trial end	Systematic text condensation method	Patients experienced control/loss of control and security/obligations as being part in a TM intervention.

			expectoration, cough, oedema and well-being were also monitored. Duration: 2 weeks				
Nissen & Lindhart (2017)	Denmark	To illuminate the experience of patients with stable COPD participating in a 6-month telemedicine intervention substituting for visits to the outpatient clinic.	The NET-COPD intervention consisted of a tablet computer with a web camera and measurement equipment. Submitted readings of saturation, pulse, weight, and changes in dyspnoea, cough, and sputum. Three times a week in the first month, then once a week, including video follow-up. One red alert or two yellow, a respiratory nurse would contact the patient. Duration: 6 months	14 patients: 6 men/8 women Age: 55–83 years Severe and very severe	Semi-structured interviews via video link during intervention (12) or in their homes (2) after the intervention	Manifest and latent content analysis	Participants experienced increased sense of security, and more understanding and competence in self-management in relation to the disease.
Ure et al. (2012)	Scotland	To explore the perceptions of patients and professionals about the pilot implementation of a COPD tele-monitoring service.	TM service incorporating a touch-screen computer for daily recording of symptoms and weekly oximetry and spirometry measurements. Data were transmitted via a broadband link to a call centre where trained support staff would contact the patient according to an algorithm, or if no data were submitted. Duration: 2 months	20 patients: 13 men/7 women Age: mean age 68.9 years Moderate to severe COPD	Semi-structured interviews, observation 18 patients' pre-installation, 2 patients' post-installation (two months' experience)	Thematic analysis	Patients were positive about the technology, which enabled earlier recognition of exacerbations and facilitated access to clinical advice.
Vatnøy et al. (2017)	Norway	To investigate how patients experienced follow-up using a TM intervention, and the extent to which it supported and	See Barken et al. (2018)	10 patients: 7 men/3 women, 55–83 years	Semi-structured interview	Qualitative content analysis	The patients had positive experiences because the TM intervention was comprehensible and manageable, providing meaning in daily life. TM

		improved coping resources and independence		Minimal to major self-reported impact of COPD on daily life	10 days into the intervention		also provided trust and confidence on independence and self-management, contributing to stress reduction and facilitating living as normally as possible.
Williams et al. (2014)	UK	Explore patients' expectations and experience of using an MHealth telehealth application to determine how such a system may impact their perceived well-being and ability to manage their COPD	A mHealth intervention was used, involving a tablet computer. Patients completed pulse rate, oxygen level and symptom diary daily. Data reviewed at regular intervals by nurse (not daily). Duration: 6 months	19 patients: 11 men/8 women, 50–85 years People with moderate to very severe COPD	Semi-structured interviews, before telehealth use and after 6 months use	Grounded theory approach	Patients experienced using the mHealth application as increasing awareness of the variability of their symptoms (exacerbations and recovery time), and reassurance through monitoring (continuity of care).

COPD, chronic obstructive pulmonary disease; QoL, quality of life; TM, telemedicine

Table 6: An example of the synthesis process – from first order construct to a line-of-argument

First order construct	Second order construct	Third order construct	Line-of-argument
(…) It means that I'm not anxious … as much as I have been before … because I can control how I am … I couldn't before. I can get in contact with you very quickly; of course, I could before, but it was in a different way. (…) this gives a feeling of security, and when you feel secure, you don't hyperventilate, and then you don't get breathless so much, and that descending spiral is turned the other way around, (…) so you feel much better in general. And you are happier and more energetic (Participant 10 in Nissen & Lindhardt, 2017).	Accessibility	Presence	Patients with COPD experience a sense of belonging when receiving care through telemedicine
'It's nice to know that you've got it ... you're being monitored you know, and it gives a sense, you know, this is all getting back to some central computer and it's all being monitored. So, somebody's actually looking at how you are, without me actually going to the doctors, so you get that feeling that you're being looked after (Participant HA014 in Williams et al, 2014).			
(…) It's sort of a lifeline; you know that it's going somewhere else... Knowing somebody is at the end of the line, that's important... I think I would have been in hospital without it [telehealth] because it's gone so bad (Participant Collette in Gorst et al, 2016).	Digital proximity		
That was nice [using videoconference]. It is okay using phones and that sort of thing, but it is... it is a lot better! It is just like, yeah that...like as we sit now, it is much more contact than it would have been by using phone and other things. (Participant F in (Barken et al, 2018)			

Table 7. Presentation of the second and third-order constructs

	Third-order constructs	Presence		Transparency		Ambivalence	
	Second-order constructs	Accessibility	Digital proximity	Clinical awareness	Reciprocal dialogue	Independent yet close	Restricted yet detached
	Study						
1	Barken *et al.* (2018)	X	X	X	X	X	X
2	Fairbrother *et al.* (2012)	X	X				
3	Fairbrother *et al.* (2013)	X	X	X		X	
4	Fitzsimmons *et al.* (2016)		X			X	X
5	Gale & Sultan (2013)	X		X	X	X	X
6	Gorst *et al*. (2016)	X	X	X	X	X	
7	Huniche *et al.* (2013)	X		X	X	X	X
8	Mathar *et al.* (2014)	X	X			X	X
9	Nissen & Lindhart (2017)	X	X	X	X	X	X
10	Ure *et al.* (2012)		X	X		X	
11	Vatnøy *et al.* (2017)	X	X	X	X	X	X
12	Williams *et al.* (2014)	X	X	X	X	X	X

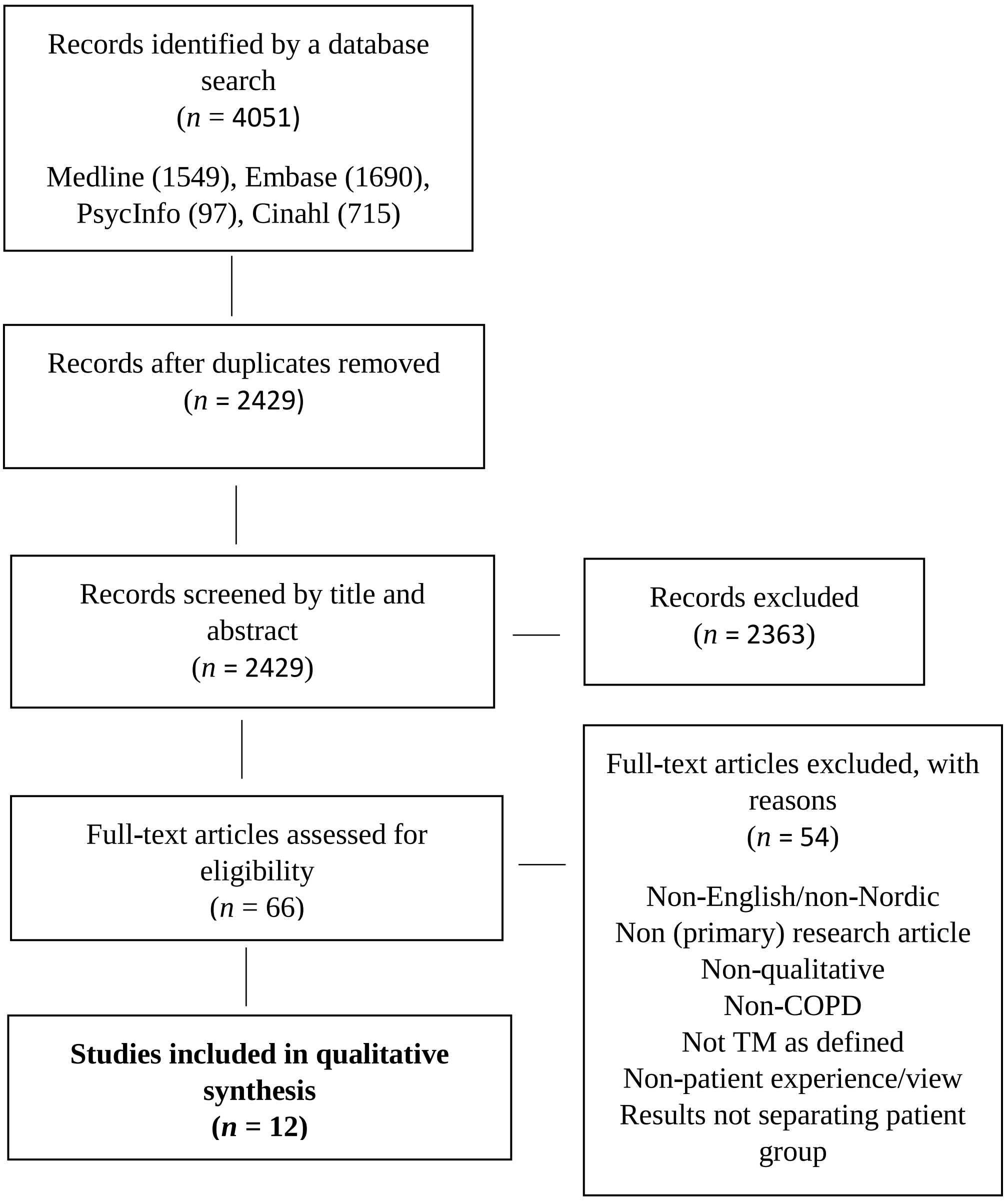

Fig. 1 The inclusion of studies by systematic literature research

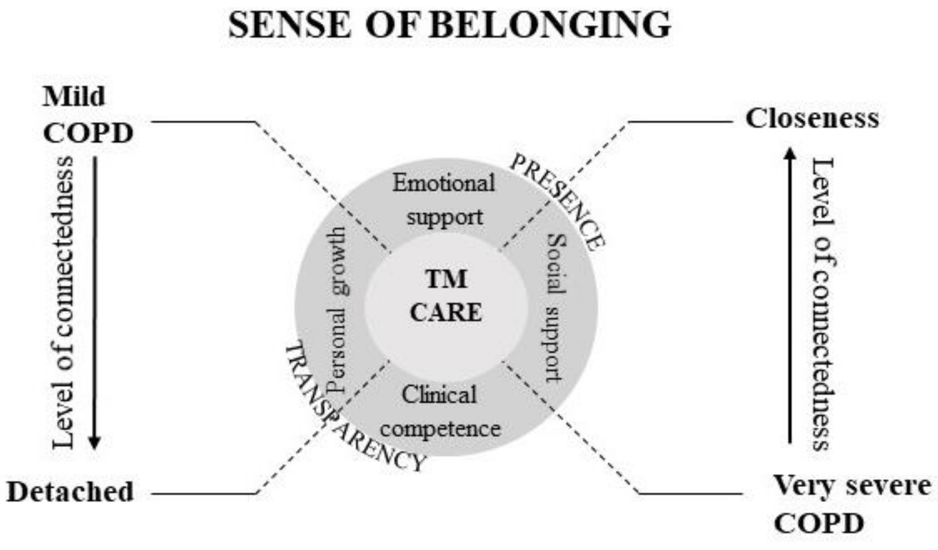

Figure 2. Patients with COPD and their experience of belonging through TM care

Appendix 1

Permission to include Figure 1 – A presentation of the humanistic nursing theory by courtesy of the National League for Nursing Press

NLN
National League
for Nursing

February 22, 2018

Tina Lien Barken
Research fellow
University of Agder, Norway
tina.l.barken@uia.no

Dear Ms. Barken:

I am writing in response to your email, dated February 19, 2018, in which you requested permission to include a figure from an NLN Press book in your doctoral dissertation. You requested permission for the following.

> The figure, "*World of Others and Things (Figure 3.1)*" which appears on page 22 of the book noted below, may be included within your doctoral dissertation.
>
> > Parker, M.E.. (Ed.). (1993). **Patterns of nursing theories in practice**. New York: National League for Nursing Press.

In granting permission to include the figure noted above, it is understood that the following assumptions operate and caveats will be respected.

- The figure will only be used for the purpose outlined above.
- The figure will be included in its entirely and **<u>not modified in any way</u>**
- The dissertation will acknowledge that the figure has been included with the permission of the National League for Nursing, Washington DC
- The National League for Nursing owns these rights being granted
- No fees are being charged for permission to include the figure

We are pleased that material published by the NLN Press is seen as valuable and that we are able to grant permission for its use. Thank you.

Respectfully,

Janice G. Brewington

Janice Brewington, PhD, RN, FAAN
Chief Program Officer

Appendix 2

Interview guide used in Paper I

Intervjuguide – telemedisinsk oppfølging av KOLS pasienter, en fenomenologisk tilnærming

Innledende samtale

1. Presentere meg selv og prosjektet
2. Demografisk kartlegging
    - Navn
    - Kjønn
    - Fødselsdato/alder
    - Yrke
    - Utdanning
    - Boforhold
    - Sivilstatus
3. Hvor lenge har du vært inkludert i telemedisinsk intervensjon (prosjekt?)?

Spørsmål 1

Nå har du vært inkludert i en telemedisinsk intervensjon i … måneder. I den forbindelse, kan du fortelle om en situasjon hvor du har kunnet forbedre din livskvalitet?

Eksempler på oppfølgingsspørsmål:

- Kan du utdype?
- Hvordan opplevde du …?
- Kan du forklare nærmere?
- Kan du si noe mer om det?
- Kan du gi en mer detaljert beskrivelse?
- Har du flere eksempler?

Spørsmål 2

I forbindelse med telemedisinsk intervensjon, kan du fortelle om en situasjon hvor du ikke har kunnet forbedre din livskvalitet?

Eksempler på oppfølgingsspørsmål:

- Kan du utdype?
- Hvordan opplevde du …?
- Kan du forklare nærmere?
- Kan du si noe mer om det?
- Kan du gi en mer detaljert beskrivelse?
- Har du flere eksempler?

Appendix 3

Interview guide used in Paper II

Intervjuguide studie 2 – fokusgruppeintervju

MÅL: Hensikten med studien er å undersøke hvordan sykepleier tar beslutninger ved hjelp av en triage-basert modell i en telemedisinsk sentral i forbindelse med monitorering av pasienter med KOLS, og hvordan erfaring og kliniske kunnskap vil være avgjørende i beslutningstakingsprosessen.

Innledende spørsmål

1. Presentasjon av meg selv og forskningsprosjektet
2. Demografiske spørsmål (samles inn på skjema før igangsetting av intervju)

Triage-basert modell

1. Hvordan er det å arbeide som sykepleier på telemedisinsk sentral?
   - Alene med beslutninger?
   - Erstatter triage en kollega?
   - Omsorg og teknologi?
   - Endring av den kroppslige praksis?
2. Kan dere fortelle litt om de forskjellige nivåene knyttet til triage-basert modell brukt på telemedisinsk sentral?
   - Hvordan gjennomføre en triage?
3. Kan dere fortelle litt om deres forståelse og opplevelse ved bruken av triage modellen?
   - Teknisk?
   - Brukervennlig?
   - Oppfølging og behandling av pasienter?
   - Kjente pasienter?
   - Kronisk sykdom VS akutt?
   - Triagering og oppfølging over en lengre periode?
   - Utvikling i sykdomsforløp?
4. Opplever dere at bruken av denne modellen fungerer som en støtte i deres beslutninger?
5. Kan dere gi et eksempel på når bruken av modellen fungerte på en god måte?
6. Kan dere gi et eksempel på når bruken av modellen ikke fungerte på en god måte?
7. Hvilke erfaringer har dere av å bruke triage ved (tydelig) forverring hos pasient?

Kunnskap og erfaring

8. Har dere fått noen form for opplæring knyttet til bruken av triage-modellen på telemedisinsk sentral? Eventuelt, hva slags?
9. Kan dere gi eksempler på hvordan dere bruker deres kompetanse ved avgjørelser knyttet til pasienten?
    - Erfaring
    - Klinisk kunnskap
    - Holdning
10. Hvilke tanker har du om din egen kompetanse knyttet til beslutninger som tas ved bruk av triage?
11. Hva tenker du om kvaliteten på triage-basert modell?

Avsluttende spørsmål

- Hvilke endringsmuligheter eller forbedringsmuligheter finnes i temaet som er tatt opp i dag?
- Hva kan dere selv bidra med?
- Hvilke betingelser må til?
- Er det noe mer dere vil fortelle om?

Takk for intervjuet!

Appendix 4

Approval of Paper I from the Norwegian Centre for Research Data (NSD)

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Tina Lien Barken
Institutt for helse- og sykepleievitenskap Universitetet i Agder
Postboks 422
4604 KRISTIANSAND S

Vår dato: 22.12.2014	Vår ref: 41146 / 3 / LT	Deres dato:	Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 11.12.2014. Meldingen gjelder prosjektet:

41146	*Living with COPD and being followed up through telemedicin*
Behandlingsansvarlig	*Universitetet i Agder, ved institusjonens øverste leder*
Daglig ansvarlig	*Tina Lien Barken*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 25.11.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Lis Tenold

Kontaktperson: Lis Tenold tlf: 55 58 33 77
Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 41146

Formålet med prosjektet er å beskrive opplevelse av helserelatert livskvalitet hos en gruppe KOLS-pasienter (65+ år) som har vært inkludert i en telemedisinsk intervensjon.

Utvalget informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er godt utformet.

Det behandles sensitive personopplysninger om helseforhold, jf. personopplysningsloven § 2 punkt 8 c).

Personvernombudet legger til grunn at forsker etterfølger Universitetet i Agder sine interne rutiner for datasikkerhet. Dersom personopplysninger skal lagres på mobile enheter, bør opplysningene krypteres tilstrekkelig.

Forventet prosjektslutt er 25.11.2017. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:
- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- slette lydopptak

Prosjektet gjennomføres i samarbeid med Sørlandet sykehus helseforetak (SSHF), kommunene i Agder og Universitetet i Agder. Universitetet i Agder er behandlingsansvarlig institusjon. Personvernombudet forutsetter at ansvaret for behandlingen av personopplysninger er avklart mellom institusjonene. Vi anbefaler at det inngås en avtale som omfatter ansvarsfordeling, ansvarsstruktur, hvem som initierer prosjektet, bruk av data og eventuelt eierskap.

Appendix 5

Approval of Paper II from the Norwegian Centre for Research Data (NSD)

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Tina Lien Barken
Institutt for helse- og sykepleievitenskap Universitetet i Agder
Postboks 422
4604 KRISTIANSAND S

Vår dato: 13.04.2015　Vår ref: 42445 / 3 / LMR　Deres dato:　Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 24.02.2015. Meldingen gjelder prosjektet:

42445	*Living with COPD and being followed up through telemedicine*
Behandlingsansvarlig	*Universitetet i Agder, ved institusjonens øverste leder*
Daglig ansvarlig	*Tina Lien Barken*

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 25.11.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Linn-Merethe Rød

Kontaktperson: Linn-Merethe Rød tlf: 55 58 89 11
Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 42445

Utvalget består av sykepleiere, som informeres skriftlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er godt utformet.

I tillegg inngår observasjon av sykepleiernes samtaler med pasienter, samt at sykepleiertiltak vedrørende pasientene samles inn. Pasientene informeres muntlig og samtykker muntlig til deltakelse. Frivillighetsaspektet synes godt ivaretatt, jf. telefonsamtale med prosjektleder av 09.04.15. Det samles ikke inn eller nedtegnes personidentifiserende opplysninger om pasientene.

Personvernombudet legger til grunn at forsker etterfølger Universitetet i Agder sine interne rutiner for datasikkerhet. Dersom personopplysninger skal lagres på mobile enheter, bør opplysningene krypteres tilstrekkelig.

Forventet prosjektslutt er 25.11.2017. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:
- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)

Appendix 6

Information about the study and informed consent form for participants in Paper I

Forespørsel om deltakelse i forskningsprosjektet
Telemedisinsk oppfølging av KOLS pasienter

Bakgrunn og formål
Dette er et spørsmål til deg om å delta i en forskningsstudie ved Senter for eHelse og omsorgsteknologi og Senter for omsorgsforskning-Sør ved Universitetet i Agder, i samarbeid med Sørlandet sykehus og kommunene i Agder. Studien inngår som en av tre studier i et doktorgradsprosjekt, som er tilknyttet EU-prosjektet United4Health. Hensikten med studien er å beskrive opplevelser om hvordan deltakelse i en telemedisinsk intervensjon kan påvirke livskvalitet.

Studien retter seg mot eldre personer som har vært inkludert i en telemedisinsk intervensjon. Rekruttering av deltakere vil skje gjennom sykepleiere på telemedisinsk sentral, som gir ut informasjonsskriv og forespørsel om å delta i studien. Forskningsansvarlig vil kontakte deg per telefon, dersom du har gitt muntlig tillatelse til å bli kontaktet.

Hva innebærer deltakelse i studien?
Hvis du samtykker til deltakelse, vil forskningsansvarlig gjøre avtale med deg for å foreta en samtale/intervju som kan vare inntil en time. Samtalen vil foregå i ditt eget hjem, eller annet sted etter ditt ønske. I denne samtalen er hensikten å høre dine opplevelser om hvordan deltakelse i en telemedisinsk intervensjon kan påvirke livskvalitet. Dette innebærer både positive og negative opplevelser. Å huske din fortelling er viktig for studiens kvalitet, og derfor vil digital lydopptaker benyttes.

Fordeler og ulemper
Deltakelse i studien vil ikke medføre noen ulemper for deg utover tidsbruk under intervjuet. Din deltakelse i denne studien er et viktig bidrag for forskningen, og kan bidra til et fremtidig bedre helsetilbud i din kommune. Dersom du opplever at intervjuet blir for anstrengende, avslutter vi intervjuet etter ditt ønske.
Hva skjer med informasjonen om deg?

Alle personopplysninger vil bli behandlet konfidensielt. Informasjonen som registreres skal kun brukes slik som beskrevet i hensikten med studien. Lydopptaket av samtalen vil bli oppbevart på passord beskyttet PC. Navnelisten lagres i et låst arkivskap, og det er kun forskere knyttet til prosjektet som har tilgang til disse opplysningene. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Prosjektet skal etter planene avsluttes 25. november 2017. Liste over navn, samt lydopptak vil da slettes.

Frivillig deltakelse
Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert. Dette vil ikke ha noen innvirkning på ditt samarbeid med telemedisinsk sentral.

Dersom du har spørsmål til studien, ta kontakt med doktorgradsstipendiat Tina Lien Barken,

TLF: 37 23 34 68, professor Ulrika Söderhamn, TLF: 37 23 37 89, eller Elin Thygesen, førsteamanuensis, TLF: 38 14 18 52, Fakultet for helse – og idrettsvitenskap, Universitetet i Agder.

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta

(Signert av prosjektdeltaker, dato)

Appendix 7

Information about the study and informed consent form for participants in Paper II

Forespørsel om deltakelse i forskningsprosjektet

Telemedisinsk oppfølging av KOLS pasienter

Bakgrunn og formål

Dette er et spørsmål til deg om å delta i en forskningsstudie ved Senter for eHelse og omsorgsteknologi og Senter for omsorgsforskning-Sør ved Universitetet i Agder, i samarbeid med Sørlandet sykehus og kommunene i Agder. Studien inngår som en av tre studier i et doktorgradsprosjekt som er tilknyttet EU-prosjektet United4Health. Studien retter seg mot sykepleiere som arbeider på en telemedisinsk sentral, og som har fulgt opp pasienter gjennom telemedisinsk utstyr.

Hensikten med studien er å undersøke hvordan du som sykepleier tar beslutninger ved hjelp av en triage-basert modell i en telemedisinsk sentral i forbindelse med monitorering av pasienter med KOLS, og hvordan din erfaring og kliniske kunnskap kan være avgjørende i beslutningstakingsprosessen.

Rekruttering av deltakere vil skje gjennom ansvarlig leder, som gir ut informasjonsskriv og forespørsel om å delta i studien. Forskningsansvarlig vil kontakte deg per telefon, dersom du har gitt muntlig tillatelse til å bli kontaktet.

Hva innebærer deltakelse i studien?

Hvis du samtykker til deltakelse, vil forskningsansvarlig gjøre avtale med deg for å gjennomføre felt-forskning på din arbeidsplass, samt delta i et gruppeintervju i etterkant av gjennomført felt-forskning.

Felt-forskningen innebærer at forsker er sammen med deg i noen timer 2-3 arbeidsdager. Forsker vil observere og ta notater og kan komme med spørsmål for oppklaring, men vil ikke forstyrre deg i ditt arbeid. Gruppeintervjuet vil foregå i et møterom på din arbeidsplass, og det vil være rundt 4 sykepleiere tilstede, i tillegg til to forskere. Spørsmålene vil dreie seg om opplevelser ved bruken av en triage-basert modell i en telemedisinsk sentral, ved oppfølging av KOLS pasienter. Det vil bli brukt åpne spørsmål med mulighet for diskusjon. Å huske din fortelling er viktig for studiens kvalitet, og derfor vil digital lydopptaker benyttes. Intervjuet vil ta omtrent en og en halv time, og en blir sammen enige om et tidspunkt.

Fordeler og ulemper

Deltakelse i studien vil ikke medføre noen ulemper for deg utover tidsbruk for gruppeintervjuet. Din deltakelse i denne studien er et viktig bidrag for et forbedret helsetilbud i din kommune.

Hva skjer med informasjonen om deg?

Alle personopplysninger vil bli behandlet konfidensielt. Informasjonen som registreres skal kun brukes slik som beskrevet i hensikten med studien. Notater og lydopptaket av samtalen vil bli oppbevart på passord-beskyttet PC. Navnelisten lagres i et låst arkivskap, og det er kun forskere knyttet til prosjektet som har tilgang til disse opplysningene. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Prosjektet skal etter planene avsluttes 25. november 2017. Liste over navn, samt lydopptak vil da slettes.

Frivillig deltakelse
Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert. Dette vil ikke ha noen innvirkning på ditt arbeid i telemedisinsk sentral. Dersom du har spørsmål til studien, ta kontakt med doktorgradsstipendiat Tina Lien Barken, TLF: 37 23 34 68, professor Ulrika Söderhamn, TLF: 37 23 37 89, eller Elin Thygesen, førsteamanuensis, TLF: 38 14 18 52, Fakultet for helse – og idrettsvitenskap, Universitetet i Agder.

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Samtykke til deltakelse i studien

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(Signert av prosjektdeltaker, dato)