DISCURSIVE PAPER



Partnership-based nursing practice framework for patients with advanced chronic obstructive pulmonary disease and their families—A discursive paper

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Abstract

Aim: The increase in the number of people with chronic obstructive pulmonary disease (COPD) and the disease burden, has prompted concerted efforts to improve healthcare, particularly outpatient services. In line with these attempts the Partnership-Based Nursing Practice Theoretical Framework for People with COPD was developed to guide outpatient nursing care. The principal approach of the framework is a 'Dialogue' with the patients, which has four components: 'Establishing family involvement', 'Assisting living with symptoms' and 'Facilitating access to healthcare', with the primary goal being 'Enhancement of the health experience'. With new knowledge, research on the framework, and extensive experience in using it, a need arose to modify the framework to maximize its clinical utility.

Design: Discursive paper.

Methods: A narrative review and critical reflection was conducted to revise the nursing practice framework via selected literature search from 2012 to 2022, research on the framework, and the authors' reflections on the clinical experience of using the framework.

Results: The nursing practice framework highlights capacities and possibilities that lie in the nurse-patient relationship. The overarching dialogue in the revised framework includes both patients and families. The action-related component 'Assisting living with the disease' was added to the framework to underscore the significance of attempting to understand what may lie ahead for patients and families. The other action-related components are as follows: 'Assisting living with symptoms' and 'Facilitating access to healthcare'. The primary goal remains unchanged: enhancing the 'Health experience'.

Conclusion: Using the revised nursing practice framework in outpatient care may help to enhance the lives of people with COPD and their families, particularly at advanced stages of the disease. It may have transferability to other groups of people living with progressive diseases dealing with complicated health problems, and to reduce the usage of costly healthcare resources such as hospital care.

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Implications for the Profession and/or Patient Care: The partnership-based nursing practice framework assumes an extension of conventional specialized respiratory service and embraces a comprehensive account for that which may influence the patient's health problems. This guidance, which holistically attends to patient-family needs of living with complicated and progressive health predicaments, is fundamental. It contributes to strengthening the disciplinary focus of nursing, interdisciplinary collaboration, person-family-centred quality nursing care and inspires research initiatives. Critical reflections and updates on nursing practice frameworks, such as this revision, are essential to advance nursing and healthcare.

Patient or Public Contribution: There is no direct patient- or public contribution.

KEYWORDS

advanced nursing practice, chronic disease, chronic obstructive pulmonary disease, family nursing, hospital outpatient clinic, medical-surgical nursing, nursing care, palliative care, patient-centred care, self-management

1 | INTRODUCTION

The increase in the number of people with chronic obstructive pulmonary disease (COPD) and the burden that the disease causes, has prompted concerted efforts to expand healthcare for these people. Such care aims to prevent and minimize the number and severity of exacerbations and to preserve and enhance the quality of life, concomitant with costs-containment, particularly by avoiding the need for acute hospital admissions and emergency room visits (Effing et al., 2016; López-Campos et al., 2016; Wedzicha et al., 2017). People with COPD appreciate effective treatment of exacerbations. especially the prevention of hospitalizations (Zhang et al., 2018). Healthcare for people with COPD has primarily been medically oriented and limited to the person having the disease. In the chronic phase of the disease, this approach is especially limited. There has been a concerted call for expanding the healthcare of people with COPD to embark on a collaborative/partnership-based approach, not only with patients but with families as well, but practice frameworks are scarce (Delaney et al., 2022; Jonsdottir, 2013). One of a few such frameworks is the Partnership-based nursing practice for people with COPD and their families, which has guided nursing care in an outpatient university hospital clinic for a couple of decades with notable effectiveness (Ingadottir & Jonsdottir, 2010; Jonsdottir & Ingadottir, 2011). Since the initiation of using this framework in practice (Jonsdottir, Halldorsdottir, & Gunnarsdottir, 2004), research on it, new knowledge on characteristics of patients with COPD and their families and knowledge on healthcare for people with COPD, along with reflections by the nurses using the framework in clinical practice, indicated that there was a need to reconsider its focus. The need was especially related to living with the nature of this progressive disease and to the families as recipients of care. This paper aims to revise the Partnership-based nursing practice for people with COPD and their families to highlight its focus on the progression of the disease and the families as the healthcare clients.

2 | BACKGROUND

Growing recognition of the comprehensive and deep-seated health problems that people with COPD face has led to calls to escalate research and healthcare improvement, not only to halter the progression of the disease, but to maximize treatment (GOLD, 2023) and ease the widespread influences that its existence has on the lives of those involved—patients and families (Giacomini et al., 2012).

In developing healthcare for people with COPD self-management interventions and palliative care are common concepts with person-centred care and continuity of care emerging. Selfmanagement interventions for people with COPD predominantly have a focus on education and counselling to facilitate 'goals of motivating, engaging and supporting the patients to positively adapt their health behaviour(s) and develop skills to better manage their disease' (Effing et al., 2016, p. 50). Palliative care, which is generally family-centred, aimed at early identification and treatment of symptoms, preserving the quality of life and relieving suffering (WHO, 2017), is increasingly promoted for people with COPD (GOLD, 2023; Vermylen et al., 2015). Despite the pressing need, timely palliative care is yet to be adequately accessible to people with COPD (Beernaert et al., 2013; Iyer et al., 2019). Although differently articulated self-management interventions and palliative care have common aims, particularly the confinement of symptoms and preservation and enhancement of health-related quality of life. Person-centred care is yet another approach to healthcare for people with chronic conditions. Brighton et al. (2019) reviewed studies on healthcare for breathlessness in people with advanced diseases, including COPD, and found that patients valued the person-centred care provided by clinical experts. The significance of continuity of care for patients with COPD is emerging (Giacomini et al., 2012). In a meta-analysis of self-management interventions, the duration of the interventions was the only factor that consistently showed a positive outcome (Jonkman et al., 2016). A systematic review of the

effectiveness of nurse-led services for people with chronic diseases demonstrated positive outcomes of continuity of care on hospitalizations, readmissions and patient satisfaction (Davis et al., 2021).

Families require healthcare regarding their own health and well-being as well as their 'enabling needs' concerning taking care of the sick person (Farguhar, 2018). Family members experience profound influences on all areas of life; physical, leisure, social, relational, financial and employment, with growing intensity as the disease progresses (Cruz et al., 2017; Mi et al., 2017; Miravitlles et al., 2015). The prevalence of anxiety and depression in caregivers is high and associated with that of their patient counterparts when COPD is at an advanced stage (46% and 23% respectively) (Mi et al., 2017). There is an increased realization that coming to terms with COPD may be a major challenge for families (Atlantis et al., 2013; Bragadottir et al., 2018; Gardener et al., 2018), as well as living with (Jonsdottir, 2007) and acknowledging its progression (Giacomini et al., 2012; Pinnock et al., 2011). Living in parallel worlds' expresses the experience of patients with COPD in its early stages and their spouses indicating that family members are unaware of the many levels on which the disease afflicts them (Bragadottir et al., 2018). 'Binding vigilance' refers to the constant need of the family to meticulously monitor the physical and emotional condition of patients with advanced stages of the disease (Gullick & Stainton, 2012, p. 33).

A synthesis of approaches is needed to maximize proper symptom management and to account for the complex and deep-seated existential, psychological and social issues that people with COPD and their families face (Iyer et al., 2019; Ora et al., 2023). Vermylen et al. (2015) suggested a model, *Proactive palliative care in COPD*, that highlights ongoing communication with patients, incorporating advanced care planning, 'meaning-centred care' and collaboration as appropriate. Healthcare professionals were to focus on what is in the patients' best interests and approach them in a joint effort to support their self-determination and live a life worth living.

The practice framework, *Partnership-based nursing practice for people with COPD and their families*, incorporates the abovementioned service approaches. The framework consists of an overarching *dialogue*, within which three action-related components that nurses ground their interaction with the patients: *Establishing family*

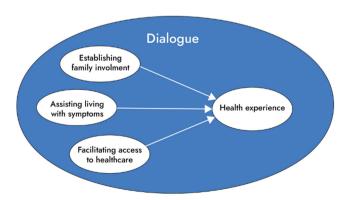
involvement, assisting living with symptoms and facilitating access to healthcare, along with the outcome component, enhancement of the health experience (Ingadottir & Jonsdottir, 2010) (see Figure 1). Research on the effectiveness of using the framework in an outpatient clinic for patients with advanced stages of the disease showed a stark reduction in the number of admissions to the emergency unit and the hospital and the number of hospital days (Ingadottir & Jonsdottir, 2010). In addition, there was a significant improvement in other outcome measures—health-related quality of life, symptoms of dyspnoea, anxiety and depression, body mass index and profi-

of dyspnoea, anxiety and depression, body mass index and proficiency in inhalers— (ibid.). With qualitative findings, the patient-family experience of receiving the nursing care was articulated in the statements 'surfacing and contextualizing health problems', 'responsiveness of services', 'security-stability-self-direction' and 'unified family efforts-transformation' (Jonsdottir & Ingadottir, 2011). In another study, the patient-spouse experience was conveyed with the statements 'living life fully and taking things as they come' and 'efficient use of health care' and the partnership process as 'finding

coherence in life with symptoms and treatment regimens', which referred to how the couple gradually developed new understanding about their life with the disease; something to which they had been

unaccustomed (Jonsdottir, 2007).

A randomized controlled trial was conducted to study the usefulness of the theoretical framework in the primary care context, focusing on patients at the beginning stages of COPD and incorporating the families. The treatment protocol consisted of four nurse-treatment sessions, a smoking cessation programme and one educational group meeting (Jonsdottir et al., 2015). The participants were recruited from primary healthcare settings and private lung physicians' clinics. Unlike previous studies, no improvements were found in the outcome variables, except for illness intrusiveness. Family participation was arbitrary (Jonsdottir & Ingadottir, 2018). The findings were ascribed to the fact that the majority of the participants had the disease at the beginning stages, and one-quarter did not know that they had COPD at the outset of the trial (Jonsdottir et al., 2015). The participants revealed that the process of coming to terms with the disease was long and deluding and that it was not until they had been hit hard with repeated exacerbations that they were able to come to



Original theoretical framework



Revised theoretical framework

FIGURE 1 The practice frameworks of partnership-based nursing practice for people with COPD and their families.

terms with it (Bragadottir et al., 2018). In a qualitative Norwegian study, the significance of receiving nursing care based on the partnership framework for patients recently discharged from the hospital was articulated as 'feeling safe and comforted' and 'motivation to achieve better health' (Leine et al., 2017).

2.1 | Characteristics of the partnership-based nursing practice

Nursing care based on the theoretical framework has been provided in an outpatient university hospital clinic for almost two decades. Clinical criteria for referral include moderate to advanced stage of the lung disease, living alone, recurring hospitalizations within the previous year and rapid worsening of the health condition. Healthcare professionals make referrals to the practice. Patients and family members also make appointments on their initiative. Patients are served by scheduled appointments in the clinic, home visits, telephone conversations and consultations in acute hospital units (Ingadottir & Jonsdottir, 2010). The nursing care is available during daytime working hours. The frequency of contact with each patientfamily may vary from more than one per week, to one per month and even one every few years. As the frequency of appointments differs so does their length. After the patients have been introduced to the practice, they are entitled to receive care for the rest of their lives unless receiving treatment elsewhere, for example, in a nursing home.

The nursing care has been provided to a continually growing group of patients. An increase of 27% is predicted in all patients' contacts between 2018 and 2026, with the highest increase in the age range from 70 to 79 years or 41%. This increase parallels with the increasing national prevalence of COPD (Nielsen et al., 2009). Concurrent with the increasing number of patients, the number of nurses has grown from one to seven, serving 5.3 full positions in 2023. The group consists of two clinical nurse specialists, one master's educated nurse, three specialized registered nurses and one master's student in nursing. The nurses also serve other patients with advanced lung diseases, such as, cystic fibrosis, and idiopathic pulmonary fibrosis, and neurological and trauma patients needing home mechanical ventilation. A professor of nursing who holds a joint position between a university and the hospital collaborates with the nurses.

The nursing care is nested in close interdisciplinary collaboration. There are weekly interdisciplinary team meetings, where lung physicians and residents join the nurses to consult on patient cases to initiate, revise and coordinate treatment plans, not the least by using an evidence-based treatment protocol to select prescriptions (Wedzicha et al., 2017). Other healthcare professionals such as nutritionists, physiotherapists and psychologists, are consulted on demand. Beyond formal meetings, there is frequent contact, even daily, between the interdisciplinary team's members on various treatment and service issues. Care coordination—in fact, the integration of multiple and complex service components—rests on the nurses'

shoulders, where seamless evidence-based healthcare is the goal. A structure for collaboration with community home care and the hospital's palliative care team is in place. The nurses are consulted, particularly in the acute lung wards and other hospital wards, about the patients whom they serve, and the provision of nursing care for lung patients more generally. Referrals to and collaboration with social care and rehabilitation services, as well as nursing homes, occur.

3 | AIMS

The practice framework of *Partnership-based nursing practice for people with COPD and their families* has been in use for almost two decades. With the accumulation of new evidence within the field, research on the framework and extensive clinical experience, a modification of the theoretical framework was requested. There was a particular need to increase the emphasis on assisting living with the progressive nature of the disease and making the focus more prominent on incorporating the families into the care. The purpose of this discursive paper was to present a revision of the nursing practice framework, *Partnership-based nursing practice for people with COPD and their families*.

4 | DESIGN

In this discursive paper, we undertook a critical reflection substantiated by a narrative review of the theoretical framework of *Partnership-based nursing practice for people with COPD and their families*. We searched and selected the state-of-the-art literature on self-management, palliative care, symptoms of and the experience of living with COPD both as regards patients and families from the year 2012 through the year 2022. We systematically reflected on the nursing care in the clinic. We identified challenging issues that may gain unique significance in the nurse-patient-family partnership dialogue, composed some examples of those issues, and considered the issues in the context of the literature for outlining possible nursing actions for which we present an evidence-based rationale.

5 | RESULTS

We present the main premises of the revised theoretical framework of *Partnership-based nursing practice for people with COPD and their families*, elaborating on modifications in the overarching dialogue and its action-related components, followed by the scientific rationale of each of them.

The assumptions of the modified theoretical framework remain the same as the original framework, that is, partnership as practice (Jonsdottir, Litchfield, & Pharris, 2004; Litchfield, 1999; Litchfield & Jonsdottir, 2008). The participatory paradigm (Reason & Bradbury, 2001) informs the framework and phenomenology, particularly the notion of the body as central to possibilities for perception

JAN — WILEY 5

and action (Carel, 2016). The creation of meaning occurs in the dialogue (Bohm, 1994; Jonsdottir, Litchfield, & Pharris, 2004) between the nurse and the patient-family. They try to develop a new understanding of the patient's health situation and the family's world; the nurse 'goes into the problems with the patients' (T.S. Ingadottir, pers. comm., 12 December 2012). That may become the key to the health experience, such as accommodating previously inconceivable treatment modalities into a hectic life situation (Jonsdottir & Ingadottir, 2011).

Diverse knowledge sources are incorporated into the theoretical framework, including knowledge of the medical treatment of COPD (GOLD, 2023), and premises of case management (CCMC, 2019). Some key components of the Chronic Care Model, particularly person- and family-centred care, interdisciplinary teamwork, and the inter-institutional and societal components (Wagner, 1998) inform the framework. Presumptions of palliative care (WHO, 2017) and components of self-management interventions, particularly the teaching of disease management (Effing et al., 2016), are important, as well as the view of the disease trajectory as 'long-term limitations with intermittent serious episodes' (Murray et al., 2005) coexisting with the unpredictability of each person's path, needs and preferences. The nurse addresses the needs of the patient-family as the unit of care to maximize cooperation about the patient's health problem and to preserve and enhance the family's health.

The need to include families in care for people with COPD due to the profound influences of the disease on family members has become apparent (Atlantis et al., 2013; Farguhar, 2018; Gardener et al., 2018; Miravitlles et al., 2015). Our study on the experience of the patients-families receiving the partnership-based nursing care showed what could be achieved when families worked together on containing the disease (Jonsdottir & Ingadottir, 2011). Along with our clinical experience, these findings shaped the conceptualization of the family within the overarching dialogue—dialogue with patient and family—rather than as one of the action-related components. The other findings were of the difficulties patients have in realizing the progressive nature of the disease and the need to come to terms with the disease and what is to come (Bragadottir et al., 2018; Giacomini et al., 2012; Pinnock et al., 2011) for which we added the component: Assisting living with the disease. The other two action-related components of the framework, assisting living with symptoms and facilitating access to healthcare, are unchanged. The outcome component, health experience, remains unchanged. See Figure 1 for conceptualizations of the framework.

5.1 | Dialogue with patient and family

The dialogue is characterized by a caring presence that attempts to relate to people, and to reveal trust and respect for each patient's and family's values and ways of being. The nurse–patient-family creatively 'think together' to find words to express experience, feel, perceive, raise questions and summarize (Bohm, 1994, p. 26 emphasis in original). The dialogue is visualized as 'a stream of meaning flowing

among and through us and between us' (ibid. p. 6 emphasis in original). The nurse encourages exploration of what is most significant to the patient-family regarding living with the disease and helps them to put emotions, feelings, actions and events into perspective with the expectation that in collaboration, they will gradually realize new ways of being and doing. Central in this exploration is what is of *concern* as regards the health of the person with the lung disease, focusing on the complexity and uniqueness of the patient-family health circumstance. Table 1 shows examples of challenges that may gain unique significance in the nurse-patient-family dialogue.

5.1.1 | Assisting living with symptoms

Action

The effort of reading the body-realizing what is going on, sensing when changes in symptoms and function occur, and knowing what to do, how and when-is an unremitting and taxing chore for the patients and their families. Through the nurse-patient-family encounters, assessment, evaluation, teaching, counselling, support and not the least, surveillance occurs in collaboration. Standardized assessment tools are important, and the results are put into a holistic perspective of the patient's condition. Realizing the significance of symptoms and their interconnectedness in the context of how they present and threaten meaningful activities in daily life during the 24h is ongoing. The presentation and impact of symptoms are also carefully examined in relation to potentially emerging lifethreatening exacerbations, with relevant actions actualized accordingly. Securing proper use of inhalers and other medicines, smoking cessation, maximum physical activities, nutritious food intake, quality sleep and quality interpersonal relationships are just some of the activities to attend to and assist patients and families in managing the disease and its treatment.

Rationale

People with COPD have many, complex and difficult symptoms, although dyspnoea, often referred to as breathing difficulties, is the most central one (Bausewein et al., 2010; Disler et al., 2014; Effing et al., 2016; Gardener et al., 2018; GOLD, 2023; Maddocks et al., 2017). Other symptoms include chronic cough and sputum production, activity restrictions, wheezing, fatigue and malnutrition (GOLD, 2023). There are manifold constellations of these symptoms and their fluctuations from time to time, as well as unique presentations in the patients' lives. Pain is an underrepresented symptom with a prevalence ranging from 32% to 60%, with a higher prevalence in patients with a *moderate* compared to the advanced stage of the disease (van Dam van Isselt et al., 2014). COPD seldom presents as the only disease that the person has. Cardiovascular diseases, lung cancer, diabetes mellitus, skeletal muscle dysfunction and osteoporosis are some co-morbidities (GOLD, 2023).

The inconsistent relationship between the perception of dyspnoea and the pathology of the lungs is essential to acknowledge in clinical practice. There is growing evidence of intricate connections



TABLE 1 Examples of challenges that may gain unique significance in the nurse-patient-family dialogue.

Complexity in comprehending disease ramifications

Patients may not associate themselves with the disease pathology or recognize its influences on body functions despite frequent contacts with and attempts of healthcare professionals to inform and explain the nature of the disease to patients and families.

Unexpected deterioration

Approaching death may come as a surprise to patients and their family despite repeated and steadily more severe exacerbations and consequent gradual decline in functioning.

Severity of dyspnoea

Scoring of dyspnoea on routine screening tools often does not reflect the seriousness of the breathing difficulties. Patients may 'adjust' to the limitations that the disease imposes to their furthest extreme and may consequently downplay the seriousness of the difficulties.

Use and types of inhalers

Although patients have used inhaler medicines for years, they may not utilize the devices properly. They may also have prescriptions that do not match their technical capacity.

Pain in the chest wall and pleura

Pain in the chest wall and pleura may have gone unnoticed, sometimes for years. Patients frequently do not complain about it. Even with systematic questioning they may deny its existence.

Anxiety, shame and depression

Difficult emotions, particularly anxiety, shame and depression are common and often serious. What often goes unnoticed is that difficult emotions may hinder patients from facing other health problems that they are dealing with.

Low self-respect and deep-seated difficult experiences

Prior destructive experiences of various kinds, among them disrespectful exchanges with healthcare professionals, may hinder patients from making the most of the nursing care in the beginning.

Multiple and diverse co-morbid issues

Most patients present with complex and extensive health problems of various kinds. Their nature is often unclear and may seem irrelevant to the patients, but with thorough explorations their significance may be understood and put into perspective.

Exhaustion and energy conservation

As COPD may have become a way of life for patients, many lack the energy for daily chores and interests. Prioritization of activities which are to be cherished and those which are not may be delicate to deal with.

Ambiguous patient accounts

Patients may give unclear descriptions of their health condition, especially in telephone calls, and associate them with one of their 'bad days'. Inadequately expressing one's own condition may underestimate the seriousness of it to the extent that it threatens the patients' life. Reading into the nuances in the patients' expressions may be crucial.

'The small things'

Ways and means to support and improve daily functions and patients' well-being may be blurred at the outset of the nurse-patient-family encounters. This may necessitate meticulous and creative searches, often requiring the use of a collection of several and novel approaches.

among mood, prior experience, contextual cues and 'aberrant' learning on the perception of dyspnoea (Pick et al., 2022). A recent approach to understanding the complexity of dyspnoea is the

Breathing, Thinking, Functioning clinical model, which conceptualizes breathing, thinking and functioning as central reactions to dyspnoea, which may cause 'vicious cycles', and thereby maintain or aggravate dyspnoea (Spathis et al., 2017). The goal, therefore, is to understand and reverse the negative spiral. More specifically, careful attention needs to be paid to the difficult experiences of anxiety, depression, feelings of shame, grief and loss, social isolation, loneliness, worries about the future, loss of hope and lack of meaningful activities (Bragadottir et al., 2018; Disler et al., 2014; Gardener et al., 2018; Harrison et al., 2017).

5.1.2 | Assisting living with the disease

Action

Actively engaging in conversations to understand the meaning of living with the disease—the collective effort to understand the disease and what it entails—is steadfast throughout the nurse-patient-family encounters. An essential part is the undeniable nature of the progression of the disease, which is key to the patient-family dialogue more generally. There is a continuous attempt to seek to understand what may lie ahead, to find possibilities, characterized by openness to the not yet, which may result in new ways of being and doing. Nested within this uncertainty and existential threat, the conversations require a uniquely sensitive approach, having appropriate timing and context, and a clear focus on preserving hope and fostering possibilities. The conversations may take place, for example, in response to comments and concerns raised by patients and/or families or come about concurrent with conversations initiated by the nurse as a part of broader care planning, for example, related to changes in the patient's conditions, such as sudden physical deterioration or changes in the patients' mindset towards living life and their death.

Rationale

The insidious onset and uncertain progression of COPD contribute to difficulties in realizing its existence and the patients' life situations (Giacomini et al., 2012; Maddocks et al., 2017; Marx et al., 2016; Vermylen et al., 2015). The patients may adjust to symptoms without recognizing them as indicators of the disease, frequently claiming that deteriorating health is a normal part of becoming older and intensified by a sedentary lifestyle (Disler et al., 2014) and therefore viewed as 'a way of life' (ibid.). Owing to a lack of knowledge about the disease, shortcomings in acknowledging it and foreseeing its progression, low self-respect, guilt and shame due to smoking, patients may not grasp the reality of their circumstances until a serious infection or exacerbation happens, needing a visit to the emergency room or a hospitalization (Arne et al., 2007; Kendall et al., 2018; Marx et al., 2016; Vermylen et al., 2015). These difficulties underscore the importance of assisting patients and families with 'thinking about the future' (Gardener et al., 2018) in conversations that 'affirm life and regard dying as a normal process' (WHO, 2017) and to live as actively as possible until death, which is in line with the premises of palliative care, advanced care planning and end-of-life care (ibid.).

JAN — WILEY — 7

However, it must be considered that patients may live for some decades after the initial diagnosis.

5.1.3 | Facilitating access to healthcare

Action

Securing reliable and timely access to the nursing practice and other health services—acute care, other outpatient services, rehabilitation, home care, palliative care and social services—is essential, including actively advocating for patients when ordering some health or social services. Dependable access to healthcare requires close collaboration with other healthcare professionals. The nurses are the cornerstone of this collaboration due to their holistic approach to patient care. They provide unique clinical information about each patient and family and their distinctive characteristics and circumstances. This information may be crucial for the amendment of treatment possibilities and, more generally, for clinical decision-making.

Rationale

Patients tend to be late in seeking healthcare. They may consider worsening and even the beginning of an exacerbation as a day-today fluctuation and hope their condition will improve (Giacomini et al., 2012: Jonsdottir, 1998). Alternatively, they consider themselves not worthy of proper care and feel they must deal with the disease on their own (Arne et al., 2007; Kendall et al., 2018). Prior experience of unsupportive interactions with healthcare professionals is reported (Guacomini et al., 2012). The experience of stigma is increasingly associated with the avoidance of accessing healthcare (Chin & Armstrong, 2019). 'Navigating services' is a term Gardener et al. (2018) used to describe activities involved in helping patients access available services, which highlights the weight that needs to be placed on the nurses' identification of the unmet needs of patients and families and the establishment of proactive and appropriate care approaches to facilitate health concurrent with upholding patients' independence and autonomy (Kendall et al., 2018).

5.1.4 | Health experience

The primary goal of the nursing practice is to enhance the health experience. This focus has two intertwined components; the health condition of the patient, which has been described with both quantitative and qualitative means, as well as the patient-family's experiences of the health situation and the nursing care (Ingadottir & Jonsdottir, 2010; Jonsdottir, 2007; Jonsdottir & Ingadottir, 2011). Measures of the health condition of patients include health-related quality of life, smoking status, health status, symptoms of dyspnoea, anxiety and depression, body mass index and proficiency in the use of inhalers. Qualitative descriptions of living with the disease and the meaning of receiving care reveal the experiential approach (ibid.). Additionally, healthcare utilization, particularly the number and length of hospitalizations and use of emergency room visits

reflect cost-effectiveness and the extent to which the nursing care may have spared the patients with exacerbations and undesirable hospitalizations.

6 | DISCUSSION

The revised practice framework, Partnership-based nursing practice for people with COPD and their families, is characterized by a principal dialogue approach with the patient and family. It has three action-related components: assisting living with symptoms, assisting living with the disease, and facilitating access to healthcare—with the primary goal of enhancing the health experience. The reformations that were made to the original framework were in terms of an increased emphasis on the family within the framework's overarching dialogue in response to our experience and growing evidence of the difficulties that families encounter when a member has COPD (Farguhar, 2018; Miravitlles et al., 2015), as well as the benefits that families have achieved in the partnership-based practice (Jonsdottir & Ingadottir, 2011). The other aspect of the framework that needed revision was to heighten nurses' efforts to help the patient-family come to grips with the progression of the disease (Gardener et al., 2018). The focus on the progression of the disease is relevant for patients at all stages of the disease, albeit intensified at the advanced stages. Our research on the effectiveness of the partnership-based nursing care for patients at the beginning stages showed limited benefits (Jonsdottir et al., 2015). Yet, nursing care and research on patients-families at the beginning stages of the disease warrants more attention. Impeding, even preventing the progression of the disease, is the ultimate goal (GOLD, 2023).

The relationship-based focus assumes engagement in dialogue about what is of significance to the individual patient and family regarding health, which has been valuable to understand and collectively actualize possibilities that previously may have been unheard of (Jonsdottir & Ingadottir, 2011). This engagement normally lasts extended periods (ibid.). The evidence of the effectiveness of continuity of nursing care for people with complex healthproblems is presented in a recent systematic review of nurse-led care of chronically ill people which showed a reduction in hospitalizations and readmissions (Davis et al., 2021). Interdisciplinary collaboration, nested in shared responsibility for patient-family welfare guidance of patients for services in the healthcare and social system, is essential in partnership-based nursing practice. The significance of the role of nurses as leaders in such collaboration in chronic care is noteworthy (Ora et al., 2023).

The framework delineates an extension of conventional specialized respiratory service, which is limited assessing and treating the disease (GOLD, 2023). It embraces the uniqueness of each patient-family in a comprehensive account for what may influence the patient's health problem, for example, access to social and health services, the home environment, co-morbidity and nutrition. Reaching out to families of patients with COPD is seldom reported,

even non-existent in clinical guidelines (GOLD, 2023) despite the wide-ranging influences of the disease on families (Farquhar, 2018).

Early on, research on the effectiveness of nursing care using the framework demonstrated a reduction in the use of hospital and emergency care (Ingadottir & Jonsdottir, 2010). This indicates that patients receiving the care were spared exacerbations of the disease, which is the critical goal for patients and healthcare alike (López-Campos et al., 2016; Zhang et al., 2018). These findings underscore the usefulness of the partnership-based theoretical framework to reflect and bring into light the complex healthcare needs of patients with COPD. The use of the framework might be extended to patients with other complex chronic diseases and their families who frequently present in outpatient and community care, as an exemplar of the much sought after integrated conceptualization of healthcare (Delaney et al., 2022).

7 | IMPLICATIONS FOR NURSING SCIENCE, PRACTICE AND DISCIPLINARY KNOWLEDGE

Nursing is key in healthcare for people with COPD and their families. This contribution must be acknowledged and given the recognition that it deserves. Using the partnership-based nursing practice framework may furnish an enriched life and living with COPD and reduce costly healthcare resources such as hospital care. Employing the framework guides nurses in taking care of patients and their families and provides language to express nursing contributions to health and healthcare. Extending the focus of healthcare beyond the medical treatment of COPD has yet to be actualized on a broader scale. Using the partnership-based theoretical framework has the potential to do so. It illustrates the disciplinary focus of nursing, contributes to interdisciplinary collaboration, and should inspire further research initiatives.

8 | CONCLUSION

The framework, Partnership-based nursing practice for people with advanced COPD and their families, has guided relationship-based, holistic, person-family-centred and seamless care of people with health challenges related to COPD. In the revised framework, the overarching dialogue distinctively includes families in the nurse-patient-family relationship. The action-related component assisting living with the disease was added to underscore the significance of attempting to understand what may lie ahead for the patients and families. The other action-related components remain unchanged. They are assisting living with symptoms and facilitating access to healthcare. The primary goal of the care is enhancing the health experience. Research on this modified form of the framework is warranted.

Using this nursing practice framework in outpatient care can assist people with COPD and their families, particularly at advanced stages of the disease, and possibly other groups of people living with progressive diseases in living with complicated health predicaments

concurrent with reducing the usage of costly healthcare resources such as hospital care.

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DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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