

# **A conceptual model of illness-related emotional distress in chronic respiratory disease: a systematic review and synthesis of symptom management models**

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## **Abstract**

**Aim.** To introduce a conceptual model of illness-related emotional distress in the context of symptom management in chronic respiratory disease.

**Background.** In chronic respiratory disease, illness-related emotional distress increases significantly in exacerbations of the disease. However, we do not know what role illness-related emotional distress plays in regard to patient outcomes. A conceptual model is needed to advance the understanding and to inform clinical practice.

**Design.** We performed a systematic search to identify conceptual models. Conceptual models were included that referred to symptom experience and / or management and excluded if they referred to a specific condition and / or lacked clarity.

**Data sources.** Electronic databases MEDLINE, CINAHL, EMBASE and PsycINFO were searched and papers included from inception until June 2017.

**Review methods.** We critically appraised using Kaplan's criteria and their perspective on emotional distress was elaborated. The development of the conceptual model followed theory synthesis.

**Results.** This synthesis, which includes five models and further evidence, yielded a new conceptual model, describing the processes of regulation and symptom self-management in chronic respiratory disease. Identified sources of illness-related emotional distress are new or increased symptoms, additional treatment, new restriction in daily life role performances and increased unpredictability. Patient goals and self-efficacy were identified as further drivers of symptom self-management. The regulation process is embedded in contextual factors.

**Conclusion.** Theory synthesis provided transparent guidance to develop a model to understand of the factors that drive self-management decisions and therefore has potential to guide development of interventions that support symptom self-management in chronic respiratory disease.

## **Keywords**

Systematic review, Symptom Management, Respiratory Nursing, Nursing Models, Self-care, Self-efficacy, Emotions, Adherence

## **Abbreviations**

CF           cystic fibrosis

COPD       chronic obstructive pulmonary disease

## **Summary statement**

### **Why is this research or review needed?**

- Illness-related emotional distress has been identified as independent factor for symptom self-management and outcomes in non-respiratory disease, but its role in chronic respiratory disease is not known.
- (Illness-related emotional distress rises substantially in chronic respiratory disease when patients experience an exacerbation of their chronic condition and)
- Quantitative and qualitative evidence in respiratory disease points to its relevance to explain symptom self-management and long-term outcomes.

### **What are the key findings?**

- New or increased symptoms, additional treatment, new restriction in daily life role performances and increased unpredictability are the sources of illness-related emotional distress in chronic respiratory disease.
- Aside from illness-related emotional distress, patient goals and self-efficacy were identified as further drivers of symptom self-management. However, the role of self-efficacy in acute episodes has to be explored in future research.

### **How should the findings be used to influence policy/practice/research/education?**

- This newly presented conceptual model provides an understanding of the factors that drive self-management decisions if patients experience new or increased symptoms, which is elementary to developing appropriate interventions, especially to support patient decision making.
- Theory synthesis is a promising methodology to develop conceptual models to inform clinical practice.

## INTRODUCTION

Symptoms in respiratory disease, like e.g. breathlessness, are experienced as life-threatening resulting in high symptom distress and overall emotional distress (Giacomini, DeJean, Simeonov, & Smith, 2012). This may even affect long-term psychological outcomes. Thus, patients who experience severe deteriorations of their chronic condition experience increased level of anxiety and depressive symptoms on the longer term (Man et al., 2015; Oliveira et al., 2016; Quittner et al., 2014; Snell, Fernandes, Bujoreanu, & Garcia, 2014; Teixeira et al., 2015). Understanding the role of illness-related emotional distress in symptom self-management in respiratory disease is the basis to develop interventions to support patients' symptom management. Therefore, a conceptualization of illness-related emotional distress is urgently needed.

### **Background**

Illness-related emotional distress has been reported as an independent factor in poor self-management and outcomes in chronic diseases: For instance, illness-related emotional distress was found to be correlated with poor self-management and poor glycaemic control in diabetes (Fenwick et al., 2016), and poor adherence to chemotherapy in cancer (Yee et al., 2017). In chronic respiratory disease, illness-related emotional is reported as especially present and high if patients experience an exacerbation of their chronic condition, which they experience as a change in their normal symptoms and deterioration of their condition (Schmid-Mohler, Caress, Spirig, Benden, & Yorke, 2018; Schroedl et al., 2014; Walker, Andrew, Hodson, & Roberts, 2017). Illness-emotional distress again affects symptom self-management and may be a key influencing factor for delayed help-seeking (Andersen, Thomsen, Bruun, Bodtger, & Hounsgaard, 2017; Schmid-Mohler, Yorke, Spirig, Benden, & Caress, 2018). Delayed help-seeking was associated with poor clinical outcomes, such as longer time of recovery, increased risk of hospitalizations and poorer quality of life in COPD (Langsetmo, Platt, Ernst, & Bourbeau, 2008; Wilkinson, Donaldson, Hurst, Seemungal, & Wedzicha, 2004). To foster symptom self-management, especially timely decision-making, the use of action plans are broadly implemented in COPD care with generally good effect on health-related quality of life and hospitalizations (Lenferink et al., 2017). Despite this knowledge, poor adherence to action plans is common and multifactorial. Apart from a lack in knowledge, emotional distress - in form of anxiety and depression - have been identified as risk factors for non-adherence (Choi, Chung, & Han, 2014).

Understanding the role of illness-related emotional distress in patient's decision making and including this factor in interventions, may have the potential to enhance the effectiveness of those widely used interventions. Therefore, a conceptualization of illness-related emotional

distress is needed. The development of interventions shall be guided by a theoretical framework because they follow a set of ideas which can be tested and further refined, consequently enhancing the effectiveness of interventions (Moore et al., 2015).

To advance this knowledge, a conceptual model for respiratory diseases is needed which links illness-related emotional distress with symptom self-management in respiratory disease.

## THE REVIEW

### **Aims**

Our aim was to 1) search and appraise currently available models for symptom experience and management and 2) synthesis the selected models into a conceptual model that links illness-related emotional distress with symptom self-management in chronic respiratory disease. As a conceptual model, we understand a theoretical framework that explains the relationship between a set of concepts, and generally includes a schematic illustration of the relationship (Polit & Beck, 2012).

### **Design**

A systematic literature search and theory synthesis

### **Search methods**

electronic databases MEDLINE, CINAHL, EMBASE and PsycINFO, to identify conceptual models on symptom management was performed in May 2014 and updated June 2017 and included all studies published until June 2017. The search terms were defined according to the BeHEMOTh format (Behaviour of Interest, Health context, exclusions and Models / Theories) (Booth & Carroll, 2015): In a first search, search terms included 'symptom management' (Behavior of Interest) AND 'respiratory disease' (Health context) AND 'conceptual model' OR 'theoretical framework' (Model or Theories). As we could not identify any relevant theory in this search, we broadened our search to generic models. So, in the second search, search terms included 'symptom management' (Behavior of Interest) AND 'conceptual model' OR 'theoretical framework' (Model or Theories).

A pre-search with the terms 'model\* or theor\* or framework\* or concept\*\*' yielded in a high number of non-relevant search results (e.g. animal models, statistical models). After testing several search-strategies, finally, the combination of the two terms 'conceptual model' OR 'theoretical framework' resulted in a high number of relevant studies. No exclusion criteria were

integrated in the search strategy. We extended our systematic literature review with expert consultation (Noyes et al., 2016): We asked three experts about the name of empirically tested symptom management models. Each expert has written at least a doctoral thesis in the field of symptom management,

Inclusion criteria were conceptual models that focused on symptom experience and / or symptom self-management. Exclusion criteria were conceptual models 1) that referred to a specific condition or symptom, and / or 2) that lacked conceptual clarity and consistency (after critical appraisal). Articles were included that described the theory in a first step, as well as updates of the theory of the same author group.

### **Quality appraisal**

The first author critically appraised the conceptual models according to Kaplan's criteria (Smith, 2014) which refer to focus, clarity, consistency and anchoring in empirical evidence (Table 1). Models were excluded if they lacked clarity and consistency: if they did not describe the phenomenon of symptom experience and management in detail, did not provide a definition of the main concepts (symptom experience, symptom management, outcomes, and / or contextual factors) or did not present the relationship between the concepts within a logical model, or did not anchor in empirical evidence.

INSERT Table 1. Appraisal criteria according to Kaplan (Smith, 2014)

### **Synthesis of existing conceptual models into a new conceptual model**

Our synthesis was guided by the work of Pound and Campbell (2015) which bases on the work of Turner (1991) and followed ten steps (Table 2). Theory synthesis – in contrast to metatheory - is a rather pragmatic approach, in a sense that the approach is concerned in synthesizing theories in order to inform daily practice. As a consequence, it focuses on the theories themselves and is less concerned with the underlying philosophical assumptions of the theorists (Pound & Campbell, 2015).

In contrast to Pound and Turner, we took a deductive approach in summarizing the theories as our aim was to understand the role of 'illness-related emotional distress' in 'symptom management'. As an additional step (step 9), we included the review of the conceptual model by three experts (one clinical nurse specialist and two nurse scientist, one with a special expertise in chronic respiratory disease).

INSERT Table 2. Steps in theory synthesis

## RESULTS

### Search outcomes

An overview of the literature search is provided in Figure 1. A total of 12 relevant conceptual models were identified. Four were excluded because they referred to specific conditions (Finnegan, Shaver, Zenk, Wilkie, & Ferrans, 2010; Mammen & Rhee, 2012; Parker, Kimble, Dunbar, & Clark, 2005; Spirig, Moody, Battegay, & De Geest, 2005). Of the remaining eight models, three were used as the basis for the development of the other five: these three were the Symptom Management Theory (Dodd et al., 2001; Humphreys et al., 2014), the Theory of Unpleasant Symptoms (Lenz & Pugh, 2014; Lenz, Pugh, Milligan, Gift, & Suppe, 1997; Lenz, Suppe, Gift, Pugh, & Milligan, 1995), and the Common Sense Model (Leventhal, Brissette, & Leventhal, 2003; Leventhal, Diefenbach, & Leventhal, 1992; Leventhal, Meyer, & Nerenz, 1980). The other five models (The Symptom Interpretation Model (Teel, Meek, McNamara, & Watson, 1997), the Symptom Experience model (Armstrong, 2003), the Symptom Experience in Time Theory (Henly, Kallas, Klatt, & Swenson, 2003), the Theory of Symptom Self-Management (Hoffman, 2013), and the Dynamic Symptom Model (Brant, Beck, & Miaskowski, 2010; Brant, Dudley, Beck, & Miaskowski, 2016)) used at least one of the previous three models as a basis for their development.

INSERT Figure 1. Flowchart of literature search for the conceptual models

### Quality appraisal

The eight conceptual models were critically appraised using Kaplan's criteria (Smith, 2014) (Table 3).

INSERT Table 3. Critical appraisal of the conceptual models identified in the literature search

Three models, Symptom Experience in Time Theory, Symptom Interpretation Model and Dynamic Symptom Model, had limitations in relation to quality due to the fact that not all concepts were clearly defined or presented in a fully logical model. It was not explicitly stated if these three models evolved through scholarly inquiry and / or patient involvement. Given the lack of clarity, which is a premise for concept building, development of empirical indicators and further testing of the model, these were excluded. Therefore, five models were included in the review: Symptom Management Theory (Dodd et al., 2001; Humphreys et al., 2014), Theory of Unpleasant Symptoms (Lenz & Pugh, 2014), Common Sense Model (Leventhal et al., 1992), Symptom Experience Model (Armstrong, 2003), and Theory of Symptom Self-Management (Hoffman, 2013).

A major strength of the five included models was their clarity and consistency, with all concepts being defined at a middle range of abstraction and the relationship of concepts being logically illustrated within each model. A further strength was their anchor in evidence. All were underpinned by empirical evidence and, in each case, published examples of their use in practice or research were identified. An overall limitation of the models was that empirical indicators were not identified for all relevant concepts of the conceptual models, such as symptom experience, symptom self-management and outcomes. As a consequence, the models have not been validated in full, with only the operationalized concepts being validated. Empirical indicators were specified for symptom perception, self-efficacy, and certain outcomes, like health-related quality of life (QOL), as well as partially for influencing factors. Yet, for symptom management strategies, empirical indicators were not identified in the Symptom Management Theory or the Theory of Symptom Self-Management. Those studies measuring symptom management strategies (Humphreys et al., 2014), mostly measure adherence or self-efficacy in performing a certain behaviour. As a consequence, only relationships between operationalized concepts were studied and no model has been validated as whole. Of the five models, none focused specifically on acute episodes and all had been empirically tested mainly in stable phases rather than during acute phases (Dempster, Howell, & McCorry, 2015; Humphreys et al., 2014).

### **Preparation of the synthesis**

*Preparing the theories.* In preparing the five theories for the synthesis, we summarized each theory (step 1) (Supplement 1). Symptom experience, symptom self-management, outcomes of symptom management and influencing factors were identified as the common themes. Then, we extracted the aspects of the theories that referred to emotional distress (step 2) and stated the relationship to the identified common themes (Table 4). In this first step, a working definition for 'illness-related emotional distress' was developed, which was 'an umbrella term for uncomfortable emotions such as anxiety, sadness and others, that arise from illness (such as treatment, symptom or meaning of illness)'. Thus, symptom distress was one aspect of illness-related emotional distress. Emotional distress in general was defined as the interaction between illness-related emotional distress and non-illness related emotional distress (such as stressful life events). Illness-related emotional distress was not used as a fixed term in any of the five models. Each model included conceptually related term. Those were emotional status, mental state or mood, affective reaction, emotions (e.g. anxiety) or psychological state. We extracted the passages that involved any of those terms.

INSERT Table 4. Different theoretical perspectives on symptom and illness-related emotional distress

*Preparing the further empirical evidence.* In reviewing the empirical evidence regarding emotional distress and relationship to concepts of the theory (step 3), we extracted five key statements findings regarding emotional distress in chronic respiratory patient population:

Symptoms, treatment and unpredictability are the sources of emotional distress: Patients with COPD and CF report that deteriorations in their chronic condition, e.g. pulmonary exacerbations, lead to high levels of illness-related emotional distress, whereas distress is due to increased symptom (Abbott et al., 2009; Korpershoek et al., 2016) and treatment burden (Sawicki & Tiddens, 2012). Furthermore, the unpredictability of the situation regarding the future adds to distress (Bailey, 2001; Harrison et al., 2014).

The source and the total level of emotional distress guides decision making: Qualitative data indicates that exacerbation-related emotional distress does affect symptom self-management during the exacerbation. CF patients reported different dimensions of distress for symptoms, treatment and the overall experience during a pulmonary exacerbation that guided their symptom self-management during exacerbation (Schmid-Mohler, Caress, et al., 2018), and reported a close connection between fear and avoidant behaviour (Palser et al., 2016). Similarly in COPD, fear and perceived influence on the course of the exacerbation were reported as guiding symptom self-management (Korpershoek et al., 2016).

Repeated experience of ineffective symptom management, which goes along with high symptom distress, leads to the feeling of powerlessness: The experience of uncontrollable symptoms leads to an overall feeling of powerlessness, helplessness and uncertainty on the longer term (Giacomini et al., 2012; Sheridan et al., 2011). These feelings were reinforced if patients made this experience several times (e.g. in form of exacerbations) (Tracy, 1997). Feelings of powerlessness during an exacerbation may lead to the belief that nothing helps control CF, which in turn may affect symptom self-management in the longer term (Sawicki et al., 2011).

Beside emotional distress, patient's individual life goals drive self-management decisions: Individual aims and goals have been reported as strong driver for symptom self-management decisions. In CF and COPD exacerbations, patients choose self-management strategies that helped them to keep or reestablish normality (Korpershoek et al., 2016; Schmid-Mohler, Caress, et al., 2018).

*Points of convergence and divergence of the theories and further empirical evidence.* After breaking the theories and empirical evidence on simple propositions on a common level of abstraction (step 4), we reviewed point of similarity, convergence and divergence (step 5).

The five models converge that symptom distress is the emotional aspect of symptom experience. It is expressed as bothersomeness, upset and / or suffering. Symptom distress is a result of a cognitive evaluation of the symptom, taking severity and frequency of the symptom into consideration. The overall evaluation criteria is the meaning of the symptom(s). The meaning is formed by beliefs about the symptoms and includes the perception of restrictiveness in daily life and threat and control.

Illness-related emotional distress was not used as a term in the five models. Each model included conceptually related term. Those were emotional status, mental state or mood, affective reaction, emotions or psychological state. They were either outcomes (Symptom Management Theory, Symptom Experience Model) or influencing (Theory of Unpleasant Symptoms) or moderating factors (Common sense, Theory of Symptom Self-Management) or outcomes of symptom experience or management. So, the models converge that emotional distress is a relevant component of symptom experience and management, but diverge where its place is. Empirical evidence in chronic respiratory disease highlights that illness-related emotional distress is a moderating concept between symptom experience and symptom self-management. In addition to symptoms, also treatment is reported as relevant stressor.

The relationship between symptom distress and emotional distress is described in the Symptom Experience Model. There, the meaning of the symptom or a symptom cluster contributes to emotional distress, not only on the symptom level but on a situational or even on an existential level. The perception of the symptoms is embedded in a broader, existential meaning which includes the patient's own perception of his or her own vulnerability and mortality and contributes to illness-related emotional distress (Armstrong, 2003). Empirical evidence in chronic respiratory disease is in line with the models, that important evaluation criteria are perceived threat and control of the illness situation and the perceived restrictions in daily life due to the illness. It adds that symptoms and treatment are evaluated against these criteria, which results in symptom distress and treatment distress. Whereas symptom or treatment burden are the main source of emotional distress due to illness, the level of emotional distress is not restricted to symptom and treatment burden, but which applies to the totality of experiences and their meaning (Davidson et al., 2007; Devins et al., 2006; Higham et al., 2013; Knight & Emanuel, 2007). It shapes the person's experience of symptoms and influences the subsequent self-management treatment (Gazzaniga et al., 2013).

The Theory of Symptom Management included the concept 'self-efficacy' and states that a person appraises the situation twice. Initially, the person judges the potential harm that can be caused and then he or she assesses the potential to control the situation, whereby the latter is influenced by the person's perception of self-efficacy in managing the symptom (Hoffman,

2013, p. 21). Empirical evidence in chronic respiratory disease adds that repeated experience of ineffective self-management leads to the feeling of powerlessness, which may impact self-efficacy negatively on the longer term.

Hoffman's work is based on the Social Cognitive Theory (Bandura, 1982, 1998), in which symptom distress or treatment distress is not explicitly mentioned. However, it can be concluded that 1) low self-efficacy expectations in managing symptoms and treatment, 2) receiving or having to do treatment / therapy that is not believed to be beneficial or necessary, (indicating low outcome expectations), or 3) not achieving one's self-efficacy outcome expectations (e.g. improvement in symptom status) lead to symptom distress or treatment distress (Bandura, 1982, 1998; Resnick, 2014). Empirical evidence adds that patient goals are strong drivers for self-management decisions.

In summary, the five models focused predominantly on symptoms as a source of emotional distress. They highlight that patients appraise symptoms within an overall situational context of illness and life, attributing a meaning to the symptom but also to the overall situation. This overall meaning leads to symptom-related distress, but also to distress associated with the overall situation, referred to as 'illness-related emotional distress' in this new model.

### **Synthesis and refinement: The new model of 'Managing illness-related emotional distress'**

In a final phase, we combined the different aspects in one conceptual model (step 6 and 7). After review by three experts (step 8), we refined the conceptual model (step 9). The new model offers an explanation of why illness-related emotional distress is of special relevance in acute episodes and how patients' experience of illness-related emotional distress affects symptom self-management decisions. The model is presented in the following paragraphs:

Most people with a chronic condition may not perceive themselves as ill if they have no symptoms, no new symptoms or do not perceive any disruption to their usual level of function (Benner & Wrubel, 1989; Selby et al., 2011). This perception changes if the condition exacerbates, cannot be controlled by the daily medical regimen and / or if normal daily life is disrupted (Corbin & Strauss, 1992; Reed & Corner, 2015). As a consequence, illness-related emotional distress increases substantially. Figure 2 illustrates the areas in which emotional distress increases during acute phases and which areas lead to a substantial increase in overall illness-related emotional distress: symptoms, treatment, unpredictability and restriction in daily life.

INSERT Figure 2. Increase in regular level of emotional distress during acute phases

Based on the previously presented theories and further empirical evidence, we define '*illness-related emotional distress*' as the interaction between *symptom distress*, *treatment distress*, *distress due to restrictions in daily life roles*, and *distress due to unpredictability*. *Distress due to unpredictability* involves the evaluation of the overall (illness) situation as regards feeling threatened and perceived control. The definitions for each kind of distress are provided in Table 6.

The degree of distress has a powerful impact on which symptom self-management strategies, including coping and help-seeking strategies, will be chosen as a consequence (Leventhal et al., 2003). It is embedded within a process of regulation, as illustrated in Figure 3.

INSERT Figure 3. Regulation process of illness-related emotional distress during acute episodes

The self-regulation process is shaped by contextual factors. Based on Symptom Management Theory and Theory of Unpleasant Symptoms (Humphreys et al., 2014; Lenz & Pugh, 2014), these are distinguished as illness-related, personal, social and environmental factors. *Illness-related factors* include severity of the acute episode, treatment modality, severity of disease, and comorbidities. *Personal factors* refer to habitual behaviour, past experience, self-management skills, spiritual beliefs and goals in life. *Social factors* summarise social context, expectations from social context, and the peer community. *Environmental factors* include working situation, living situation, access to specialised health-care team, and trust of health-care team. These factors vary from patient to patient and explain the variation in the exacerbation experience between patients.

A noticeable change in bodily symptoms or a measurable sign mark the start of the regulation process, whereas '*Bodily symptoms*' are defined as the experience of one or multiple bodily symptoms, including energy-related symptoms and '*Signs*' are measurable expressions of the medical condition such as fever, weight, lung function, blood sugar, or laboratory values. In contrast to the Symptom Management Theory (Dodd et al., 2001), perception in this new model forms before conscious or cognitive interpretation of the information. Therefore, dimensions here are severity, frequency and quality, and emotions are not involved.

Patients evaluate the symptoms, signs and treatment. '*Evaluation*' is understood to be the meaning that the patient assigns to one or several symptoms as well as the overall situation (Armstrong, 2003). The evaluation of symptoms are formed by patient's belief about identity, cause, treatability, and consequences of the symptom or symptom cluster (Dodd et al., 2001; Leventhal et al., 1992). Those beliefs frame the patient's evaluation of the predictability of the situation which itself is based on the patient's evaluation of how threatening or controllable the

overall situation is (Hoffman, 2013; Leventhal et al., 2003) and the overall perception of restriction in daily life, respectively normality (Armstrong, 2003). This evaluation strongly influences the degree of illness-related emotional distress the patient then experiences.

Based on perceived distress, patients decide whether to manage with or without the support of health professionals. The reaction includes a conscious or unconscious decision on how to proceed and as a result, includes decisions on which symptom *self-management strategies* to undertake. This decision is either made by the patient alone or in conjunction with his or her environment, e.g., family. Furthermore, decision making is greatly influenced by a patient's *internal goals regarding outcomes* and his or her *self-efficacy* beliefs (Table 5): The patient chooses those symptom self-management strategies that will help achieve his or her aims, and which he feels confident he can perform (Hoffman, 2013; Resnick, 2014). Based on clinical experience, patients often apply symptom self-management strategies to address the overall illness-related distress, instead of addressing one single symptom (Jarden, Nelausen, Hovgaard, Boesen, & Adamsen, 2009).

As mentioned above, goals regarding outcomes differ from patient to patient. Whereas the overall *outcome* is a decrease in emotional illness-related distress, which particular type of distress is most relevant may differ from one individual to another. It may be a reduction in symptom distress, treatment distress, or distress due to restriction in daily life. An overall goal is to achieve distance from perceived threat and regain control, whereby the areas addressed may differ greatly (Gazzaniga et al., 2013), as described above. Illness-related emotional distress is very likely a proxy for other outcomes such as performance in life roles (Lenz & Pugh, 2014).

Patients evaluate the effectiveness of the various strategies in reducing distress. If the strategies are effective, distress stabilizes and eventually decreases. If the strategies are not effective, distress increases. Whether effective or not, it impacts the degree of distress as well as the goals and self-efficacy beliefs of the patient, and the resultant decisions regarding self-management strategies.

INSERT Table 5. Definition of concepts

## DISCUSSION

Guided by theory synthesis, different perspectives on emotional distress were explored and synthesised into a new model which provides a comprehensive focus on patients' symptom management of acute phases in chronic respiratory disease, with illness-related emotional distress as the key concept.

Our new conceptual model shows a regulation process that begins with symptoms and treatment as stressors, which are evaluated in terms of their potential threat, controllability, and potential for restrictions in daily life, and which result in emotional distress. Patient symptom self-management, with reducing distress as its aim, is guided by the level of emotional distress, the extent of self-efficacy and the patient's individual goals. The new model describes the relationship between symptom perception, symptom self-management and outcomes, which makes it to a promising framework both to analyze patients' self-management decisions in clinical practice and to underpin interventions to support patients' symptom self-management.

Although self-efficacy has been described in research as an essential driver, it can be hypothesized that decisions taken in acute phases are more driven by patients' goals, as the disease and the treatment are routine matters and high self-efficacy is already a given. Patients reported organisational issues, ambivalence about treatment and avoidant coping as potential barriers (Goss, Edwards, Ramsey, Aitken, & Patrick, 2009; Shipman, White, Gysels, & White, 2009) illustrating that goals may be a more important driver. The role of the various components remains to be explored. A better understanding of the factors that contribute to decision-making in acute phases of chronic disease could help to develop patient-centred interventions while reducing negative outcomes and costs.

The literature review of conceptual models which followed the BeHEMOTh format, resulted in an very high number of non-relevant studies, which has been reported previously (Noyes et al., 2016). We regarded the use of exclusion criteria as problematic as it may threaten sensitivity and has to be adapted for the different databases. Our search approach with restriction to 'conceptual models' and 'theoretical framework' excluded irrelevant studies, indicating high specificity, but probably involved the risk of not having identified all relevant papers. To minimize this risk and considering that theories may have been published in non-digital databases (such as books), we asked expert in this field. However, future research should determine an appropriate combination of search strategies and provide guidance for an optimal balance between specificity and sensitivity in the literature search for theories.

Our theory synthesis followed the procedure by Pound and Campbell (2015) and Turner (1991) and involved nine of ten steps. This approach provided a transparent and feasible guidance for the development of a conceptual model that describes the role of 'illness-related emotional distress' in symptom management in chronic respiratory disease. In contrast to the method used described by Pound and Campbell (2015), we applied a combination of inductive-deductive approach of synthesis and integrated further scientific evidence in order to describe the relationship between the concepts. The integration of theories with further scientific evidence led to the refinement of the position of 'illness-related emotional distress' and

'symptoms'. The model and its potential to inform clinical practice will be tested in a next step. The development of a patient-reported outcome measure that assesses illness-related emotional distress in respiratory disease is in progress.

## CONCLUSION

Thematic synthesis provided suitable guidance for the development of a conceptual model of illness-related emotional distress and its role in symptom management in chronic respiratory disease. The new model provides an explanation why illness-related emotional distress increases substantially if new symptoms arise or existing symptoms worsen and describes drivers for symptom self-management. Understanding the regulation of this process may help healthcare professionals support patient's' symptom self-management during acute episodes of a chronic respiratory disease. Furthermore, the model provides a framework to develop a patient-reported outcome instrument.

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