The experience of hospitalisation in people with advanced chronic obstructive pulmonary disease: A phenomenological study

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Palliative care. The candidate has already achieved 180 credits for assessment of taught modules within the blended learning PhD programme.

Date of submission: October, 2020

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

Acknowledgements

I dedicate this thesis to my loving mother, whose motivation and support encouraged me to embark on this difficult task.

Firstly, I would like to thank God for His everlasting mercy that sustained me throughout the journey of my PhD. According to the scriptures in Psalms 119:105, "Your word is a lamp to my feet and a light to my path", God guided and led me remarkably through every stage of writing my PhD.

A number of people who supported me during the journey of my PhD who I wish to commend include my supervisors: Catherine Walshe and Jane Simpson. I sincerely thank them for their continual guidance and incredible support. I wish to specially thank them for teaching me to preserve through the difficult stages and for their patience as this thesis developed. I would like to thank Katherine Froggatt for tutoring and her early guidance in shaping this thesis.

My sincere gratitude extends towards Dr George D'Souza, for his guidance in the early phase of my research in India. I also thank my peers and friends for their great support and encouragement. I would like to thank all my research participants for being willing to share their experiences which were also an opportunity for me to learn from them.

I am thankful to my family who encouraged me to continue this PhD journey. I specially thank my dear husband who walked with me through each stage of my thesis and for the great confidence he had on me. I greatly appreciate him for his continual support, encouragement and patient listening as this thesis evolved. I thank my loving daughter who waited patiently and sacrificed spending some of the precious moments in life together until the completion.

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Abstract

Background: Chronic obstructive pulmonary disease (COPD) is a chronic disease of the lung and the fourth leading cause of death in the world. People with advanced COPD are frequently hospitalised and have high physical, psychological and spiritual suffering. Hospitalisation caused considerable economic burden on the individuals and countries and a setback in the quality of life. A systematic literature review explored the experience of hospitalisation in people with advanced COPD, utilising a thematic synthesis approach. The studies reviewed focused on the discrete aspects of hospitalisation such as care and treatment, which limited the development of a complete picture of the phenomenon of hospitalisation. Consequently, the research question asked was: 'what is the experience of hospitalisation in people with advanced COPD?'

Method: A qualitative, descriptive phenomenological approach, using unstructured interview was employed to study the phenomenon of hospitalisation. Fifteen participants hospitalised with advanced COPD, in a south Indian, tertiary care hospital were recruited. Giorgi's descriptive phenomenological analysis method guided the analysis.

Results: Five themes were identified: experience of admission, repeated hospitalisation, perception of care, trust in hospitalisation and multi-dimensional suffering. Repeated hospitalisations due to acute breathlessness were often emergency admissions. Although hospitalisation gave a sense of safety, it was perceived to be chaotic. Care influenced trust in hospitalisation and both shaped the experience of hospitalisation. Multi-dimensional suffering was central to the experience, which affected the physical, psychological and spiritual aspects. Persistent suffering, despite repeated hospitalisation negatively impacted the experience of hospitalisation.

Conclusion: Hospitalisation is perceived largely as a negative experience due to the perception of uncertainty and continuing suffering. Integrating palliative care into the routine care of people with advanced COPD is urgently required to improve care.

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Total word count: 39,986

Chapter One

Background: chronic obstructive pulmonary disease and hospitalisation

1.1 Introduction

Chronic obstructive pulmonary disease (COPD) is a chronic, progressive disease of the lung and the fourth major cause of death in the adult population worldwide (Almagro et al., 2017). People with advanced COPD have frequent admissions to hospital due to acute breathlessness and have high symptom burden (Meffert et al., 2015). Acute exacerbation of breathlessness causes high mortality and high healthcare utilisation and associated healthcare cost (Crisafulli et al., 2018). Understanding the experience of hospitalisation in people with COPD is important to improve care. This research explores the lived experience of hospitalisation in people with advanced COPD, in India.

This chapter sets the context for the research by introducing some key characteristics of COPD presentation and its care. First, the epidemiology and clinical characteristics of COPD are presented to understand both the disease presentation and the treatment of COPD. Next, hospitalisation in advanced COPD is discussed in the global, Asian and Indian context which is the research location. Palliative care for advanced COPD is then explained and the need for studying the experience of hospitalisation is justified. My professional background and the structure of the thesis are also explained at the end of the chapter.

1.2. Epidemiology and healthcare burden of COPD

The global prevalence of COPD is 11.7% and the highest prevalent continents in the world are the American region 15.2% and Europe 12% (Adeloye et al., 2015; Soriano et al., 2017). Smoking and air pollution are the major causes of COPD; in particular, smoking is the high-risk factor for COPD in urban population which could also be associated with high mortality in developed countries (Lortet-Tieulent et al., 2019). COPD contributes to high global healthcare burden; the healthcare burden is measured as disability-adjusted life-years which is estimated as the sum of years of potential life lost due to premature mortality plus the years of productive life lost due to disability (Soriano et al., 2017). COPD contributes 2.6% of the global disability-adjusted life-years, which is a higher contribution to global disease burden than other chronic respiratory diseases (Soriano et al., 2017).

Although the overall prevalence of COPD in Asia is lower compared with American and European countries, Asian countries still contribute considerably to the global morbidity and mortality rates, as well as to the global healthcare burden of COPD (Anees ur et al., 2019). India is one of the Asian countries with a steady increase in the prevalence of COPD, with a prevalence of 4.2% in 2016 compared with 3.3% in 2012 (Salvi et al., 2018). However, India has the highest disability-adjusted life-years due to COPD in the world due to late diagnosis of COPD and a higher risk attributed to air pollution than smoking (Salvi et al., 2018). India contributes 32% of the global disability-adjusted life-years due to chronic respiratory diseases, thus posing a high risk for healthcare burden (Salvi et al., 2018). Air pollution and exposure to smoke from biomass fuel are the common causation factors for COPD in India, in contrast to smoking in developed countries; however, smoking is still the highest risk factor in many urban regions (Mahmood et al., 2017). These varied risk factors among different regions and delay in diagnosing COPD challenge the management of COPD in India (Kodgule & Salvi, 2012; Salvi et al., 2012).

1.3 Definition and diagnosis of COPD

Competing definitions have been developed for COPD from different COPD associations. A definition from the Global Initiative for Chronic Obstructive Lung Disease (GOLD) is:

> *'a preventable and treatable disease characterised by persistent respiratory symptoms and airflow limitation that is due to airway and or alveolar abnormalities usually caused by significant exposure to noxious particles or gases and influenced by host factors including*

> *abnormal lung development. '* (Global Initiative for Chronic Obstructive Lung Disease, 2020, p.04).

This definition states that COPD is a treatable disease taking account of various causations of COPD; however, this guideline does recognise the need for palliative care for the end-stage COPD which points out that COPD is a chronic, incurable disease. Also definitions from the American Thoracic Society and European Respiratory Society do not emphasise on the incurable aspect of COPD (Celli et al., 2015). However, a simple definition from the World Health Organization is:

> *'A lung disease characterized by chronic obstruction of lung air flow that interferes with normal breathing and is not fully reversible.'* (TheWorldHealthOrganisation, 2006).

This definition clearly states the incurable nature of the disease, which is important for clinicians to recognise the need for incorporating palliative care from the beginning, rather at the end-stage. This recognition of incurability is essential to guide the treatment goals and to improve the quality of life.

COPD is a complex disease, due to the involvement of pulmonary and extra-pulmonary symptoms. The common pulmonary symptoms are breathlessness and cough with sputum; weight loss, progressive weakness, sleep disturbance and loss of appetite are the most common extra-pulmonary symptoms (Agustí & Celli, 2017). Both pulmonary and extra-pulmonary symptoms worsen as the disease progresses (Agustí & Celli, 2017). People in the advanced stage of COPD suffer from complex symptoms, often affecting the physical, psychological, social and spiritual domains of the individuals (Maddocks et al., 2017). They have a high symptom burden, comparable to people with other chronic illnesses, such as lung cancer (Luckett et al., 2020). Although breathlessness starts in the early stage of COPD, it becomes worse as the disease progresses with acute exacerbation of breathlessness leading to frequent hospitalisation (Lovell et al., 2018). Fatigue with limited mobility and increasing dependency reduce the quality of life in the advanced stage (Maddocks et al., 2017). Anxiety, depression and insomnia are commonly reported psychological difficulties (Pooler & Beech, 2014). Social isolation, perceiving a purposeless life and death and dying concerns are some of the social and spiritual issues reported (Gardener et al., 2018).

The diagnosis and staging of COPD mainly depend on the severity of clinical symptoms, such as chronic breathlessness and assessment of airflow obstruction to establish lung function capacity. The lung function capacity is estimated with spirometry, which is assessed by measuring the ratio between forced expiratory volume in one second (FEV1) and forced vital capacity (FVC); COPD is diagnosed in people with post-bronchodilator FEV1 and FVC ratios of less than 70 percent (Mirza et al., 2018). There are several staging methods used for delineating the different phases of COPD, such as GOLD staging. Each method uses its own criteria for staging, which includes the severity of breathlessness, symptom burden and spirometry values (Jones et al., 2009). For example, GOLD utilises both spirometry measurement and symptom burden for staging. According to the severity of symptom burden, patients are grouped into four categories: A, B, C and D to guide the treatment (GOLD, 2020). Depending on the post-bronchodilator spirometric value, the disease has been categorised into four stages, mild, moderate, severe and very severe; mild stage is FEV1 less than 80% predicted, moderate is FEV1 between 50-80% predicted, severe is FEV1 between 30-49% and very severe is FEV1 less than 30% predicted (GOLD, 2020). Spirometric staging shows the severity of airflow obstruction which may not always correlate with the symptom intensity and therefore, the combination of spirometric and ABCD staging might not reflect the accurate staging and prognosis of the disease; these two categories of staging are mainly used to guide the decision-making in drug management (Bhatta et al., 2020). Therefore, GOLD provides little clarity as to what criteria exactly constitute the advanced stage of COPD.

Although there are different staging methods available depending on the spirometry and symptom severity, challenges remain in identifying the advanced stage. First, the clinical assessment tests used to assess the symptom severity, such as the COPD Assessment Test and the modified Medical Research

Council Scale have some limitations to use in clinical practice (Bestall et al., 1999; Jones et al., 2009). Some tests involve a walking assessment that is not practical to carry out in all clinical conditions and also have a set clinical cut-off point of the tests to determine the staging; this is controversial because the cut-off points do not always correlate with the actual spirometric staging (Karloh et al., 2016). Secondly, predicting prognosis based on clinical symptoms is difficult in COPD because of the unpredictable illness trajectory which is marked by fluctuating episodes of decline and recovery with the possibility of sudden death during exacerbations (Landers et al., 2017; Murray et al., 2005). This unpredictable illness trajectory further complicates the identification of the exact beginning of the advanced stage of COPD. While acknowledging these challenges in determining the advanced stage of COPD, it is still important to have some identifiable, practical and clinical assessment parameters to indicate the advanced stage of illness.

To overcome the difficulty in identifying the advanced stage of COPD, both spirometry and indicators of symptom severity are considered. For this research, people with advanced COPD are defined as those who have GOLD stage III and IV, with the post-bronchodilator value of FEV1 30%-49% and FEV1< 30% predicted, respectively. In addition to this, symptoms such as worsening breathlessness, fatigue, acute exacerbations with frequent hospitalisation, use of a non-invasive ventilator and/or long term oxygen-dependency, are taken into consideration for identifying advanced COPD.

1.4 Treatment of COPD

In general, treatment for COPD is offered depending on the severity of the symptoms and the degree of airflow obstruction. Treatment for the early stages of COPD consists of inhaled bronchodilators, measures to improve exercise capacity and where appropriate, advice on the need for smoking cessation. The treatment for the advanced stage is focused on treating symptoms, mainly breathlessness, cough and extreme weakness. Inhaled corticosteroids and bronchodilators, oxygen therapy and pulmonary rehabilitation are the main treatment components and these are aimed at enabling an independent daily life with an overall aim to maintain the quality of life (Mirza et al., 2018). Acute breathlessness causes repeated hospitalisation in advanced COPD and many people become oxygen-dependent and need therapy with an invasive or non-invasive ventilator (Mirza et al., 2018). Acute exacerbation of breathlessness is defined as:

> *'acute worsening of respiratory symptoms requiring additional therapy.'* (Vogelmeier et al., 2017, p. 588).

People often require emergency admission for acute exacerbation which causes high healthcare utilisation and a setback in the quality of life (Vogelmeier et al., 2017). Although there are guidelines to treat acute exacerbation and to reduce hospitalisation rates, repeated hospitalisation seems to be unavoidable, especially in the advanced stage which is discussed in the next section.

1.5 Repeated hospitalisation and its impact in advanced COPD

Repeated hospitalisation due to frequent, acute exacerbations of breathlessness causes a high healthcare utilisation and expenditure and contributes a considerable financial burden to countries (Iheanacho et al., 2020). A recent systematic review reported a high healthcare cost in COPD primarily contributed by hospitalisation for acute exacerbation of COPD (Iheanacho et al., 2020). Particularly, the hospitalisation cost becomes higher towards the advanced stage of COPD, due to frequent acute exacerbations, number of readmissions and symptom severity (Iheanacho et al., 2020). The European COPD audit reported that the mean length of hospital stay for acute exacerbations as 8.7±8.3 days, which also contributes to the high healthcare cost of hospitalisation (Ruparel et al., 2016). Further, other comorbidities, such as heart failure, diabetes and frailty influence the number of readmissions and length of hospital stay, which add to the cost of hospitalisation in advanced COPD (Iheanacho et al., 2020). High healthcare utilisation and economic burden certainly have implications for developing appropriate healthcare policy to reduce the disease burden of COPD globally (Soriano et al., 2017; Vogelmeier et al., 2017).

The economic burden from COPD is high in Asian countries and this increases the healthcare cost, both for the individual and the policy developers; hospitalisation contributes most to the high healthcare cost in advanced COPD (López-Campos et al., 2016). Studies show that repeated, emergency admissions for an acute exacerbation and the requirement for intensive therapy in the advanced stage of COPD contribute to the high hospitalisation cost in various Asian countries (Li et al., 2018; Ngo et al., 2019; Torabipour et al., 2016; Varol et al., 2013). The length of hospital stay for acute exacerbation in Asia is longer; particularly for intensive care units (ICU) admissions, it is seven days longer than Europe and the US, which indicates a higher hospitalisation cost in Asian countries (Anees ur et al., 2019).

Studies conducted in different states of India have found that high healthcare cost is mainly due to hospitalisation in the advanced stage of COPD (Kallaru et al., 2015; Lakiang et al., 2018; Patel et al., 2014). In India, the length of hospital stay for COPD is extended than other Asian countries, ranging from 9- 12 days and becomes longer for intensive care (Kallaru et al., 2015). The Indian public healthcare system offers free treatment for the poor and subsidised treatment for other socio-economic categories, depending on income status; however, the public hospitals often do not have enough resources to treat patients, therefore, forcing people to seek medical care in private healthcare settings (Pallikadavath et al., 2013). Furthermore, the cost of healthcare in the private healthcare system is not regulated, so charges can sometimes be unreasonably high (Pallikadavath et al., 2013). A study conducted in a tertiary care hospital in south India reports that the mean cost per hospitalisation in advanced stage of COPD is 205£ compared with 62£ in early stages (Kallaru et al., 2015). This high healthcare expense forces people to sell their property and other sources of assets and can frequently lead to poverty (Rijal et al., 2018). Irregularities in healthcare cost which impact the hospitalisation cost of COPD in India impose a great economic burden to individuals as well as to the country; these factors have major implications for policy developers to address the rising healthcare cost of hospitalisation in COPD (Kastor & Mohanty, 2018; Salvi et al., 2018).

1.6 Palliative care for advanced COPD

Evidence shows that people with advanced COPD who have been hospitalised have high unmet needs including physical, psychological and social aspects (Meffert et al., 2015; Schroedl et al., 2014). Despite frequent hospitalisation, people with advanced COPD receive palliative care less often than people with other chronic illness, such as lung cancer, during their hospital stay (Maddocks et al., 2017). Studies conducted in the UK, Australia, US, Taiwan and Germany have all found that people with advanced COPD received palliative care infrequently, had high healthcare needs, prolonged hospitalisation and frequently died in hospital (Bloom et al., 2018; Brown et al., 2016; Chou et al., 2013; Curtis, 2008; Meffert et al., 2015; Philip et al., 2012). Studies investigating the trends of hospital death in advanced illnesses found that people with COPD have a higher hospital death rate than cancer and other chronic diseases (Cohen et al., 2017; Higginson et al., 2017).

However, despite the frequency of death in hospital, a review has shown that conversations about end-of-life care rarely happen during hospitalisation; in a small proportion of cases, the conversation happens near the end-stage, often in intensive care units in a hurried manner (Tavares et al., 2017). There is strong evidence for integrating palliative care into COPD care, which could both reduce hospitalisation rates and improve quality of life (Gomes et al., 2013; Landers et al., 2017; Scheerens et al., 2018; Spilsbury et al., 2017). Studies show that providing specialist palliative care reduced the number of emergency hospital admissions and hospital deaths, enabled the discussion of advance care plan and improved quality of life (Dalgaard et al., 2014; Higginson et al., 2014; Smallwood et al., 2018).

Although palliative care has been proved to be beneficial in advanced COPD, there are challenges in providing palliative care due to COPD's unpredictable disease trajectory and occurrence of sudden deaths (Siouta et al., 2016). Although the GOLD guidelines recommend palliative care for the advanced stage of COPD, they do not clarify what criteria constitute the advanced stage. Hence, challenges in identifying the advance stage impede the scope for providing palliative care for advanced COPD.

1.7 Definition of hospitalisation

Hospitalisation seems to be an umbrella term incorporating varied dimensions, therefore making it difficult to define, due to a lack of clarity on the varied dimensions. The literature implicitly addresses three broad dimensions of hospitalisation: 1) hospital as a physical space; 2) as a facility for treatment and care; 3) as the context for interaction between patients and staff (Andrade et al., 2017; Hughes, 2001; McKee & Healy, 2000; Williams & Irurita, 2005).

The physical environment of the hospital, such as quiet and clean atmosphere, seems to play an important role in satisfaction with treatment and the management of psychological stress of individuals that influences the experience of hospitalisation (Andrade et al., 2017; Williams & Irurita, 2005). A noisy hospital environment is proven to cause sleep disturbances and impacts the recovery of ill people (Robinson et al., 2018). A recent review on the hospital environment showed that poor designing of hospital building, such as in the lighting and windows, certainly plays a major role in the overall well-being of patients (Zhang et al., 2019). Hence, the physical aspects of the hospital seem to contribute to the definition of hospitalisation.

Depending on the facilities available and treatment offered, a hospital could be categorised as a primary, secondary or tertiary care hospital; a primary care hospital offers basic diagnosis and treatment, a secondary care provides specialised treatments and the tertiary care offers long-term and sophisticated treatments for complicated illnesses (White, 2015). Also depending on the funding, hospitals are classified as public and private, which differentially affects the cost of hospitalisation (Liu & Kelz, 2018). Within these varied types of hospitals, care is offered based on the delivery system; primary care hospitals usually provide non-acute care, whereas tertiary care hospitals have a dedicated emergency and accident care (Liu & Kelz, 2018). The distinct types and levels of care offered in these facilities could influence the experience of hospitalisation. This indicates that care and treatment are complex dimensions of hospitalisation that challenges the consistency and comprehensiveness of the definition of hospitalisation.

Communication is an important element of hospitalisation; it facilitates care during hospitalisation and effective communication helps build trust with staff (Elliott et al., 2010). Communication is dynamic and should differ according to individual information needs, patients' expectations and health condition; these variable nature of the communication requirements is challenging to meet the individual's expectation, hence communication may not always have a positive impact on the patients' experience (Rapport et al., 2019). The communicative behaviour of staff seems to influence the psychological stress experienced by hospitalised patients (Andrade et al., 2017). Since the behaviour of staff is both highly variable and subjectively experienced, this dimension remains undefined within the broad spectrum of hospitalisation.

The admission and discharge processes are often not explicitly described as a dimension of hospitalisation rather, viewed as part of the organisational and administrative elements of the hospital. The type of hospital admission could determine the quality of care provided; for example, emergency admissions have been reported to produce a reduced quality of care compared to non-emergency admissions (Symons et al., 2016). These varied types of admission could influence the experience of hospitalisation. Discharge has been studied both with a view to improve patient-satisfaction with care and as an administrative, nursing measure to improve care (Kripalani et al., 2007; Lin et al., 2012).

Effective discharge plans seem to involve adequate information and communication skills which are expected to improve patient care, reduce readmissions and ensure continued care in the community (Lin et al., 2012). Admission process and discharge planning are an integral part of hospitalisation but poorly recognised as part of the varied dimensions of hospitalisation.

These varied dimensions of hospitalisation, ranging from the physical space to human interaction and processes, are complex and dynamic. Also other elements such as admission and discharge process have not been recognised within this broader aspect of hospitalisation. Some of the briefer definitions used in the literature such as ‘healthcare received in acute setting’ are not comprehensive enough to cover the broader aspects of hospitalisation (Mbuzi et al, 2017, p. 40). Therefore these factors challenge the consistent, appropriate and adequate definition of the term hospitalisation.

1.8 Experience of hospitalisation in advanced COPD

The experience of hospitalisation has been studied using both quantitative and qualitative research mainly from the aspect of care satisfaction. A quantitative review has captured the experience of hospitalisation regarding healthcare quality, across six dimensions: safety, timeliness, effectiveness, efficiency, equity and patient-centeredness (Beattie et al., 2013). However, it is still recognised that these dimensions are not complete due to the complexity and the dynamic nature of hospitalisation and the subjectivity of the experience (Beattie et al., 2013). The current health condition of an individual could influence patient-satisfaction, both in a positive and negative manner, which might not be captured by the measures of healthcare quality. This indicates that the experience of hospitalisation is complex.

Many qualitative studies have explored the lived experience of individuals with advanced COPD, studying specific aspects of COPD, such as the experience of breathlessness, anxiety, care needs and treatment experience (Halpin et al., 2015; Harb et al., 2017; Pooler & Beech, 2014; Schroedl et al., 2014). Some of these studies provided evidence for high symptom burden during hospitalisation and its relationship with frequent hospitalisation but do not take account of what hospitalisation means to an individual (Meffert et al., 2015; Pooler & Beech, 2014). Further, other studies focused on some elements of care and treatment, mainly relating to the experience of accessing medical help during acute breathlessness but do not explicate these experience in relation to hospitalisation (Harb et al., 2017). One meta-synthesis (Disler et al., 2014) reporting the experience of individuals living with advanced COPD, discussed the need for frequent hospitalisation for acute exacerbation in the advanced stage of COPD from the community setting, rather than the impact or experience of hospitalisation on individuals with advanced COPD. Hence, the evidence for the experience of hospitalisation could not be drawn from the current evidence. However, the studies conducted in advanced COPD indicated a high, unmet symptom burden during hospitalisation (section 1.6). Therefore, it is important to understand the experience of hospitalisation in people with advanced COPD, to improve the quality of care during hospitalisation. The aim of this research is to explore the phenomenon of hospitalisation in people with advanced COPD in India.

1.8.1 Culture and contextual impact on the experience

Individual experience is shaped by both cultural and social contexts and these can impact the experience of hospitalisation from a number of perspectives. Existing literature on the experience of hospitalisation in people with advanced COPD has been conducted mostly in Western contexts, such as in the UK, US and Europe (Disler et al., 2014). In addition, studies focused on the isolated aspects of hospitalisation are mostly from Western countries (Halpin et al., 2015;Schroedl et al., 2014). Findings from these countries may not be directly transferable to other Asian countries, such as India. One such contextual factor is related to hospital charges which vary within Western countries and could impact the experience of hospitalisation. The centralised healthcare system in the UK provides free healthcare at the point of use which may shape the experience differently from the American context where the healthcare system is decentralised and hospital charges are mainly paid by medical insurance (Light, 2003). In contrast, the existence of both free healthcare in public hospitals and private healthcare which have no regulated hospital charges may play a role in shaping the experience in the Indian context (section 1.5).

Another important factor is the influence of individualism and collectivism on the healthcare system which differs between the Indian and the Western context and culture. Individualism emphasises autonomy and independence whereas collectivism refers to group loyalty and interdependence (Triandis et al., 1990). In Western cultures, healthcare policy and guidelines are typically developed focusing on individualism, but in Asian cultures collectivism is generally emphasised more than individualism. In the Indian healthcare context, important medical decisions and prognosis are generally discussed with the family, as the family pays the hospital bill and are also key caregivers for the patient (Gielen, 2016). Usually, the best possible medical decision is made, considering both family and the individual's well-being (Gielen, 2016). In this context, autonomy is a collective decision of the patient, family members and physician, which is in contrast to the Western healthcare system. These varied cultural and contextual factors could impact the experience and should be taken into account while developing policy and practice guidelines related to hospitalisation in advanced COPD.

1.9 My professional background

In this section, I describe my professional background, in order to bracket my presuppositions about hospitalisation and breathlessness in advanced COPD (chapter 3.6.3.7 & 3.6.4.6).

I am a palliative care physician and have experience in treating people with advanced COPD and providing end-of-life care. I have worked alongside other professionals such as psychologists, counsellors, chaplains and social workers to address the complex needs of people with advanced COPD. I previously worked in the hospital for ten years which is the research setting for this research;

therefore, I am familiar with the hospital routines and admission procedures, but have not worked there for five years. I do have presuppositions about breathlessness in the context of COPD that it is always associated with anxiety that could cause panic attacks and a fear of death. Suffering from breathlessness is associated with a myriad of psychological, social and spiritual problems that are complex to treat. I have found treating people with chronic illnesses with breathlessness is challenging because I felt helpless to watch people suffer through the end-stage and death. These experiences created strong impressions about breathlessness and the complexity involved in addressing this.

I am aware that my cultural and religious beliefs related to the Indian cultures and contexts could also impact my interpretation of the experience of hospitalisation. My cultural beliefs, particularly those related to Indian cultural systems, such as the duty to take care of family members, particularly, the sick and elderly could interfere with the presentation of the phenomenon. Also, my knowledge about Hindu religion such as Hindu religious rituals, relating sickness to past sins, known as ‘karma’, could influence the expression of experience related to illness and hospitalisation. All these assumptions were reflected and bracketed before data collection.

I have observed that people with advanced COPD are frequently hospitalised but continue to suffer from extreme symptoms. This has evoked a curiosity to know what exactly people experience when they are repeatedly hospitalised. I wondered whether they still have hope of cure and reversal of symptoms, or they just buy some time to live by repeatedly getting hospitalised. Although I want to find answers to these questions, the main aim of this study is to gain a deeper understanding of their personal experience of being hospitalised.

1.10 Thesis structure

This thesis is structured with six chapters. In chapter one, the background of the research topic, COPD in the global, Asian and Indian context, which is the specific research location, is described. Hospitalisation in the context of advanced COPD is explored and the need for studying the experience of hospitalisation is explained. In chapter two, a literature review of the experience of hospitalisation, utilising a thematic synthesis is presented. A lack of evidence on the understanding of the experience of hospitalisation is identified to justify the need for conducting this research. In chapter three, the philosophical paradigm and the argument for choosing a descriptive phenomenological approach is explained. The later sections of this chapter explain the data collection and analysis method of this research. The findings of this research are presented in chapter four; the five key constituents of the phenomenon are elaborated and the description of the general structure of the phenomenon of hospitalisation is presented. Chapter five discusses the key findings with other relevant literature. Multi-dimensional suffering is central to the experience of hospitalisation and utilisation of religious coping for psychological distress is discussed in the context of the Hindu religion. The reasoning for perceiving hospitalisation as a negative experience is debated and the conceptualisation of hospitalisation is presented. In chapter six, the contribution to knowledge and practice in the care of advanced COPD and recommendations for future research are discussed.

1.11 Conclusion

Hospitalisation in advanced COPD causes considerable burden on healthcare and economy. Despite frequent hospitalisation, people have high unmet physical, psychological and spiritual needs but receive palliative care less often than other chronic illnesses. There is no clear understanding of the concept of hospitalisation available in the literature and neither does the term hospitalisation have a consistent definition. Some studies on the experience of COPD have explored fragmented aspects of hospitalisation such as care needs, illness perceptions and treatment experience. However, limited evidence has described the experience of hospitalisation in advanced COPD.

India has a high prevalence of COPD, with a higher hospitalisation rate and cost than some other Asian countries, leading to a high economic burden for the individuals and the country. Also late diagnosis of COPD in India suggests that a considerable population of people with COPD might have already been living in the advanced stage with high disability, compared with other parts of the world. Studying the experience of hospitalisation is important to enhance the understanding of healthcare professionals providing care to people with advanced COPD. Hence, this research studies the experience of hospitalisation in people with advanced COPD in India.

Chapter Two

Literature review: The experience of hospitalisation

2.1 Introduction

The purpose of this literature review was to synthesise the available evidence for the experience of hospitalisation in people with advanced COPD, utilising a qualitative synthesis approach. This will enhance the understanding of the experience of hospitalisation and to identify the gap/s in knowledge that set/s the context for conducting this research. Consequently, the review question asked was:

‘What is the experience of hospitalisation in people with advanced COPD?’

2.2 Methods

Qualitative synthesis aims to integrate qualitative studies to provide a formal knowledge synthesis (Zimmer, 2006). Since this review studies the individual experience and seeks to construct a phenomenon, a qualitative synthesis approach was considered appropriate (Gough et al., 2012). Many approaches to synthesising qualitative studies have been described and these can be categorised as either configurative or aggregative synthesis (Barnett-Page & Thomas, 2009; Snilstveit et al., 2012). Among these two approaches, a configurative synthesis approach was considered appropriate for this review focus, as it facilitates a new interpretative synthesis.

In deciding upon a synthesis approach for this particular review question, a number of options were considered. Meta-synthesis is one of the configurative synthesis methods for synthesising evidence from qualitative studies with varied study designs (Sandelowski & Barroso, 2007). Meta-synthesis involves integration and comparison of the findings from the original qualitative studies which are translated to produce a theory and/or a new interpretation (Sandelowski et al., 1997). While this is considered as the strength of meta-synthesis, it has been argued that in the process of developing a theory through translation and abstraction, the original richness of the findings in the included studies can be lost, which can threaten the uniqueness of the interpretive findings presented in the original studies (Zimmer, 2006). The 'whole' phenomenon is illuminated with its constituents, which are the findings of the original studies (Zimmer, 2006). This de-contextualisation of the findings from the original studies compromises the interpretive nature of the qualitative paradigm, which is less suitable for reviews exploring meaning and experience of a phenomenon (Zimmer, 2006). Hence, the synthesis product of meta-synthesis that is more than the sum of its parts seems to be a less suitable method for studying the phenomenon.

It is argued that thematic synthesis is also a suitable method for synthesising qualitative studies with diverse study designs, but without losing the context of the findings from the original studies (Thomas & Harden, 2008). The descriptive themes constructed through the integration and translation of original studies keep the synthesis close to the original studies and preserve the parts of the phenomenon which constitute the 'whole' phenomenon. This is an important consideration here as the phenomenon of hospitalisation has not been elucidated and there is no clear understanding of the phenomenon. On first reading of the potential papers, it seemed that the studies relating to hospitalisation did not seem to provide a direct answer to the review question. Rather, this needed to be synthesised from the findings of the original studies but still preserving the context of the original studies (Thomas & Harden, 2008). Preserving the context is considered important to study the phenomenon of hospitalisation to illuminate both the parts and the sum of the phenomenon. This synthesis method facilitates a new interpretation while preserving the context of the original studies and is more suitable for a review studying the phenomenon. Hence, thematic synthesis is chosen as the review method which is congruent with the aim of this review. This review followed the Enhancing Transparency of Reporting the synthesis of Qualitative research (ENTREQ) guidelines for reporting (Tong et al., 2012).

2.2.1 Search methods

This review adopted the search methods proposed by Thomas and Harden as this is congruent with the review method chosen (2008). The search strategy was designed to achieve the 'conceptual saturation' that was to include a wide range of concepts related to hospitalisation (Thomas & Harden, 2008). In keeping with this view of conceptual saturation, a wide range of electronic databases and grey literature were searched. The following electronic databases were searched: PubMed, CINAHL, PsycINFO, ProQuest and grey literature databases (appendix 1). Indian Social and Science studies database was specifically included in the ProQuest platform, in order to find studies from India which was the research location. The database search was undertaken in October 2016 and was updated in May 2020. There was no time limit set for the search and the period of the search was database specific, so as not to miss any studies indexed. In addition to this, both citation tracking and search of the list of references were done to track the references from the key articles to identify relevant papers, in order to include potential studies with a wide range of concepts (Thomas & Harden, 2008).

The search strategy was built on the key concepts from the review question (Evans, 2002; Greenhalgh & Peacock, 2005). The search term 'hospitalization', in combination with other search terms, reduced sensitivity and yielded a fewer number of studies; therefore, 'hospitalization' was excluded from the final search from all the databases, which improved the number of relevant studies retrieved (appendix 2). In this regard, the search method was iterative, to enable finding a wide range of studies related to the review focus, rather than finding the maximum number of studies (Thomas & Harden, 2008). Qualitative filters were not used because they have been argued to reduce sensitivity (Thomas & Harden, 2008). An example search strategy for PubMed is given in table 1.

Table 1 Search strategy for PubMed

COPD **MeSH** “Pulmonary Disease, Chronic Obstructive” **Free text in Title and abstract** (“Chronic pulmonary obstructive disease” OR “Chronic Obstructive Airway Disease” OR “Chronic Obstructive Lung Disease” OR “Chronic Airflow Obstructions” OR “Chronic respiratory tract obstruction” OR COPD OR COAD). Combined with “end-stage” OR severe OR “palliative care” OR terminal.
Experience **MeSH** (“Sick Role” OR “Illness Behaviour” OR “Attitude to Death”) OR “Adaptation, Psychological”) OR “Quality of Life”) **Free text in Title and abstract** (experienc* OR concern* OR distress OR phenomenolog* OR voice*OR view* OR “quality of life” OR perspective* OR feel* OR understand* OR belief* OR believ* OR worry OR worrie*).
Qualitative studies **MeSH** “Qualitative research” OR “interview as topics” OR Narration OR hermeneutics **Free text in Title and abstract** (questionnaire* OR interview* OR “focus group*” OR “case stud*” OR observ* OR “grounded theory” OR narrative OR phenomenolog* OR “phenomenological studies” OR thematic OR experienc* OR “content analysis” OR ethnolog* OR qualitative OR “field work” OR “semi-structured” OR unstructured OR “in-depth” OR “face-to-face”).

Searching for qualitative studies in the electronic databases was challenging due to inconsistent indexing in the databases and the absence of methodological information in the titles and abstracts (Barroso et al., 2003; Wilczynski et al., 2007). Hence, combining the thesaurus terms or Medical Subject Headings (MeSH), free text words and the broad-based term was required to identify the relevant studies to optimise the search (appendix 2).

2.2.2 Eligibility criteria

The review sought original qualitative studies that were based on the empirical data, which studied the experience of hospitalisation in people with advanced COPD. For this review, studies that included individuals who have been hospitalised as inpatients for twenty four hours or more were considered. A minimum of one day stay was considered essential for individuals to experience the varied aspects of hospitalisation. People admitted to care homes, nursing homes and hospice were excluded because of the different purpose of the care approach of these settings.

Studies that included participants with mixed stages of COPD limited the inclusion of some potential studies. Hence, the inclusion and exclusion criteria were revised in order to include studies which had a minimum of fifty percent of population with advanced stage of COPD. The inclusion and exclusion criteria are detailed in table 2. Only studies published in English were included, as there was no resource to translate studies from other languages.

Table 2 Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Participants Adult participants over 18 years of age; GOLD stage III and IV or other equivalent staging and/or clinical staging depending on the symptom severity; studies which included a minimum of fifty percent of participants with advanced stage were included; participants admitted as inpatients for twenty four hours or more.	Participants under 18 years of age. Lived experience of care homes, hospice and community setting.
Aim of the study Studies with primary or secondary focus exploring the experience of hospitalisation, currently or retrospectively.	
Findings Studies reporting findings of patient participants; or if findings of patient participants separable from other participants.	Studies reporting findings other than patient participants (e.g. carers, family members) which were not discreetly presented.

Study design All qualitative approaches were included. Mixed methods studies were considered if qualitative part of study reported the experience of hospitalisation. Original research papers from peer-reviewed journals and grey literature were considered. *Language* Papers published only in English language.	Quantitative studies, systematic reviews, letters to editors, comments and book reviews were excluded.

After excluding editorials and commentaries, twenty nine studies were reviewed with the full-text. A total of eighteen studies were excluded due to one of the following reasons: the absence of clear staging method of COPD, a lack of focus on hospitalisation and inseparable data of patient participants from other participants (appendix 3). Eleven studies were finally included in the review (figure1). The PRISMA flow chart is used to explain the selection process of studies (Moher et al., 2009).

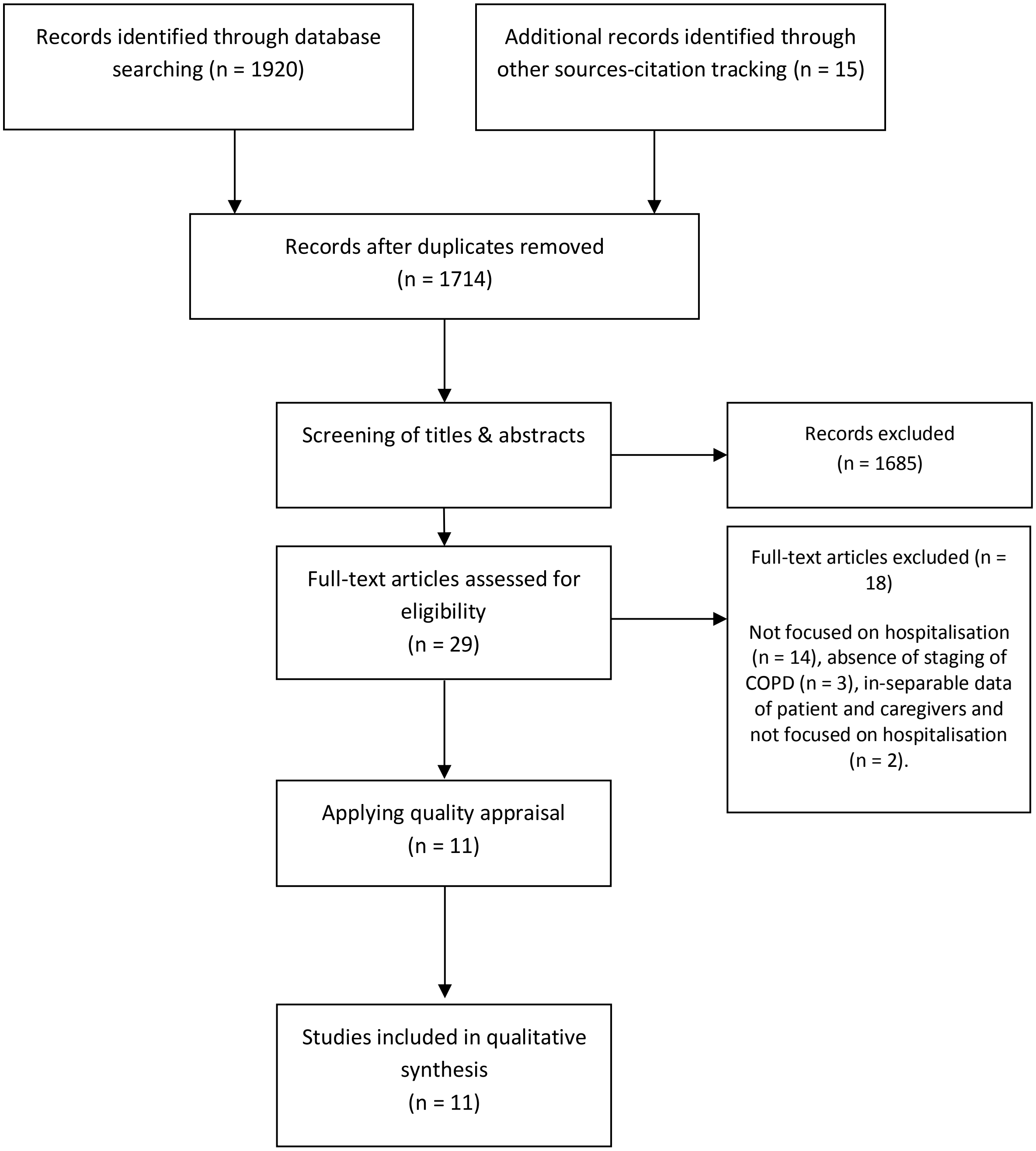

Figure 1

PRISMA flow diagram

2.2.3 Quality appraisal

Quality of the original studies in a synthesis determines the quality of the synthesis product (Carroll & Booth, 2015). The criteria for assessing quality still remains debatable due to the varied epistemological and methodological types of qualitative studies with different reporting styles (Dixon-Woods et al., 2007). Although the focus for determining the quality is to mainly assess the study design, the criteria for assessment may vary according to the purpose of the review (Carroll & Booth, 2015). The purpose of quality assessment for this review was to assess whether the original studies represented the views of the participants related to hospitalisation. Hence, the quality appraisal criteria proposed by Thomas and Harden (2008) was chosen because this is congruent with the aim of this synthesis.

The appraisal tool aims to identify studies that ensured validity and reliability, which relate to credibility and dependability in qualitative research and, which used appropriate methods with a good quality of reporting (Thomas & Harden, 2008). This quality appraisal tool contains twelve criteria under three categories: five related to the *quality of the reporting* of a study such as aim and context; four criteria related to *reliability and validity;* and finally three criteria related to the *appropriateness* of the study methods (Thomas & Harden, 2008). Each criterion was rated either as present or not (a score of 0 or 1 was given); hence, a maximum score of twelve was possible. Studies scored below 5 were considered as poor but were not excluded because each study was considered to have some contribution to the synthesis, irrespective of the quality (Thomas & Harden, 2008). Overall, the studies scores were in the range of 7-12. Four studies scored 7- 9 and seven studies scored 10-12 (table 3). Of the criteria most commonly lacking, ethical issues relating to conducting interviews in vulnerable participants and the validity of data analysis were missing. Two studies which had the lowest score of seven had a poor reporting of the details of the methods; however, their findings were contributive to the synthesis. None of the studies scored below 5 hence, all eleven studies were included.

Table 3 Characteristics of included studies (in chronological order)

Author, country of study	**Study aim**	**Setting**	**Participants**	**Methods**	**Main findings**	**Appraisal score (out of twelve)**
Pang et al., 2004, Hong Kong	Do Not Resuscitate decision making factors in advanced COPD.	Hospital/ICU*	N = 19 Admitted to ICU.	Case study method (Yin's); unstructured interviews, observation and field notes; descriptive statistics, thematic analysis.	Decision making requires shared decision making between physician, patient and family.	10
Yu et al., 2007, China	Experience of recurrent hospital readmission in COPD.	Hospital/ home	N = 5 with repeated readmission.	Qualitative exploratory study; unstructured interviews; thematic content analysis.	Powerless to manage post-discharge period; being a burden to caregiver; socialising atmosphere of hospital.	7
Seamark et al., 2012, UK	Whether hospital is the appropriate place to discuss ACP (advanced care planning).	Hospital	N = 16 Hospitalised for exacerbation within a year.	Qualitative approach; individual semi-structured interviews; Content analysis.	Hospitalisation was a chaotic experience; divided view about whether hospital is a place to discuss ACP; GPs are to initiate ACP discussion.	7

Author, country of study	Study aim	Setting	Participants	Methods	Main findings	Appraisal score (out of twelve)
Kvangarsnes et al., 2013, Norway	The relationship between staff and COPD patients.	Hospital/ICU	N = 10 NIV** for acute exacerbation in ICU.	Narrative inquiry; unstructured interviews; Narrative analysis.	Feelings of vulnerability during acute breathlessness; staff are supportive but at times treatments were forced on them.	10
Sørensen et al., 2014, Denmark	Behaviour patterns of participants with COPD during NIV use in hospital.	Hospital/ICU	N = 21 On NIV treatment.	Glaser's grounded theory; participant observation and structured interviews; constant comparison analysis.	Participants' behaviour related to experience of breathlessness and side effects of NIV.	9
Torheim and Kvangarsnes, 2014, Norway	Experience of care received in the ICU in advanced COPD.	Hospital/ICU	N = 10 Admitted to ICU.	Giorgi's phenomenology; semi structured interview; Giorgi's analysis method.	Being critically ill causes vulnerability; active listening skills improved patients' confidence on the care received.	10

Author, country of study	**Study aim**	**Setting**	**Participants**	**Methods**	**Main findings**	**Appraisal score (out of twelve)**
Lowey et al., 2014, U.S	Perception of timing in seeking healthcare in advanced COPD and heart failure.	Home***	N = 20 (10 COPD & 10 heart failure).	Qualitative descriptive study; semi-structured interviews; qualitative descriptive analysis.	Fear of death; loss of independence; losing control during hospitalisation.	12
Landers et al., 2015, New Zealand	End-of-life issues in advanced COPD.	Hospital	N = 15 NIV treatment.	Grounded theory approach; semi-structured interviews; inductive analysis.	Six illness transition points were identified to help the staff to initiate discussion about end- of-life issues.	10
Harrison et al., 2015, UK	Experience of pulmonary rehabilitation following hospitalisation.	Hospital	N = 10 With acute exacerbation.	Interpretative Phenomenological Analysis; semi structured interview.	Feeling of shame, self-blame and stigmatization reduced health seeking behavior.	12

Author, country of study	**Study aim**	**Setting**	**Participants**	**Methods**	**Main findings**	**Appraisal score (out of twelve)**
Gale et al., 2015, UK	Experience of the process and management of NIV in COPD.	Hospital/home	N = 39 (20 patients, 4 carers and 15 staff) NIV treatment.	Qualitative grounded theory approach; semi-structured interviews; framework analysis.	NIV improved symptoms but lowered QOL; NIV use was felt as mandatory.	8
Chang et al., 2016, Taiwan	Lived experience of COPD following hospitalisation for acute exacerbation.	Hospital	N = 14 With acute exacerbation.	Giorgi's phenomenology; semi-structured interview; Giorgi's analysis method.	Repeated hospitalisation in winter and burdening family members.	11

*ICU-Intensive care unit

**NIV –Non Invasive Ventilation

***Participants were recruited from homecare service and interviewed at home following hospitalisation.

2.2.4 Data synthesis

Data were extracted manually with a structured format using the following headings: data related to study details, demographics and study characteristics such as the type of data collection, sampling, sample size, findings of the primary study and themes or concepts related to the experience of hospitalisation, such as the admission process, treatment and care and communication with staff (appendix 4). All included studies were imported into NVivo 11 software to aid the analysis. Only data related to hospitalisation from the findings section of the original studies were coded; both direct quotes and the explications related to hospitalisation were coded. Data synthesis was carried out following the three-stage thematic synthesis method (Thomas & Harden, 2008). First, line by line coding of the text related to the experience of hospitalisation was conducted. In this process of translating concepts across the studies, relevant texts were coded and each code was given a description to maintain the consistency while coding across the studies. Then these codes were grouped under appropriate categories and descriptive themes were derived from these categories; until this point, themes were kept closer to the original studies in the context from where they emerged (Thomas & Harden, 2008).

The final step of analysis involved the interpretive analysis of descriptive themes to produce analytical themes related to hospitalisation. The analytical themes answer the review question which depends on the researcher's interpretation but also the data from the original studies (Thomas & Harden, 2008). However, 'thin' data from some of the original studies did not allow a deeper interpretation of all the descriptive themes. Thin data in qualitative research is characterised by the absence of rich data that could present the nuanced aspects of the topic studied (Brekhus et al., 2005). Thin data could be identified by the less detailed nature of description with limited illustrative quotes from the raw data (Morse, 2010). For example, the main theme 'the communicative behaviour of the staff' was more descriptive because of sparse data relating to this theme which did not allow the description of nuanced aspects of staff's behaviour (appendix 5). Nevertheless, this theme seemed to answer the review question, hence the level of analysis was considered adequate. In this context, thin data need not necessarily link to the quality, rather it should be viewed as how it answers the review question which directs the analytical aim of the study data (Brekhus et al., 2005). Further, the descriptive themes demonstrated the 'wholeness' of the phenomenon which kept the findings close to the original studies that reflected the parts of the phenomenon and preserved the context of the phenomenon. However, the main theme 'overwhelming distress' was more analytical as it had rich data from many included studies which was demonstrated by many examples of illustrative quotes and in-depth description that also answered the review question. Hence, the level of analysis is influenced by the nature of available data, 'thin versus thick' and also by the review question.

2.3 Findings

A total of 1935 titles and abstracts of the retrieved studies were screened to select the relevant studies. The more recent update of the database search did not yield any new eligible studies. Full texts were sought for twenty nine studies to check their eligibility by applying the inclusion and exclusion criteria. Eleven studies were included in the review, of which, 6 were from Europe, 4 from Asia and 1 from the US. The characteristics of the included studies are detailed in table 3. Three studies used GOLD staging and one used European Respiratory Society staging (Chang et al., 2016; Kvangarsnes et al., 2013; Seamark et al., 2012; Torheim & Kvangarsnes, 2014). The remaining studies used symptom severity and their indicators for staging. All the included studies addressed a certain element of hospitalisation such as end-of-life discussion (Landers et al., 2017; Pang et al., 2004; Seamark et al., 2012), experience of seeking medical help (Lowey et al., 2014), treatment experience (Gale et al., 2015; Harrison et al., 2015; Sørensen et al., 2014), readmission experience (Yu et al., 2007), interaction with the staff (Kvangarsnes et al., 2013; Torheim & Kvangarsnes, 2014) and self-management following discharge (Chang et al., 2016; Harrison et al., 2015). Analysis of the findings from the original papers yielded eight descriptive themes and four overarching themes were identified: unpredictable hospitalisation, perceived benefits and burdens of treatment, overwhelming distress and the communicative behaviour of the staff (table 4).

Table 4 Themes

Main themes	**Sub-themes**	**Example quote**	**Interpretation of quotes**
Unpredictable hospitalisation	*Sudden admissions*	No chance to think, I was whipped in and that was it – you're going.' (Seamark et al., 2012, p.263).	Sudden admissions
		'...it was as though it was the blind following the blind. I couldn't understand how the hell I'd ended up on this ward.' (Seamark et al., 2012, p. 263).	Chaotic admission process
		'The main thing is that going to hospital gives me security… That feeling of security really helps…' (Landers et al., 2015, p. 3).	Feeling safe
	Avoiding hospitalisation	'The hospital symbolized both a loss of control and fear associated with worsening health.' (Lowey et al., 2014, p. 4).	Fear related to hospitalisation
		'They worried about becoming a burden to their families when they were hospitalized.' (Chang et al., 2016, p. 3).	Being a burden
Perceived benefits and burdens of treatment	*Treatment experience*	'It [NIV] helps … I am calm and feel safe… it's easier to breathe.' (Sørensen et al., 2014, p. 1729).	Relief from symptoms
		'That's the worst part of it, the dryness' 'so loud… (Gale et al., 2015, p. 272).	Difficult treatment situation
	Challenges in treatment decision-making	'…they (doctors) know best, and that's it … If they thought it was for the best, then let them get on with it…' (Seamark et al., 2012, p. 264).	Treatment decision-making

		‘Do I go for resuscitation or not, so it’s a lot of things to weigh up.’ (Seamark et al., 2012, p. 264).	End-of-life discussion
Overwhelming distress	*Breathlessness*	‘If you ever notice [that] you lack something, it will be air. You are now about to suffocate! (Kvangarsnes et al., 2013, p. 3066).	Struggle to breathe
		*‘*One thing that happens is when you’re breathing is really bad, your tension goes sky high.’ (Landers et al., 2015, p. 3).	Anxiety
		‘What energy I’ve got I like to put into doing my own things’ (Harrison et al., 2015, p. 753).	Extreme weakness
	Psychological and spiritual distress	‘I’m terrified of the hospital’ because I think I’m gonna die…. (Lowey et al, 2014., p. 6).	Anxiety and fear of death
		‘My mind just wasn’t quite clear. I didn’t talk about anything then. (Torheim and Kvangarsnes 2014., p. 744).	Mental confusion
		‘…there is no hope of cure; just let nature takes its course’ (Pang et al., 2004, p. 138).	Preparing to let go
	Positive behavior	‘They were very helpful and paid close attention – and kind.’ (Torheim and Kvangarsnes 2014, p. 744).	Kind gesture
		‘I didn’t want it on then but the doctor told me, “if you don’t have that mask on, you will die” so I that was it, I kept it on, didn’t I?’ (Gale et al., 2015, p. 272).	Trust in staff

The communicative behavior of the staff		‘To be met as a fellow human being by nurses who understood, was important’ (Torheim and Kvangarsnes., 2014, p. 744).	Being respected
	Negative behaviour	The staff doesn’t know how little one can take when one suffers from severe COPD like I do.’ (Torheim and Kvangarsnes, 2014, p. 744).	Insensitive to participant’s needs
		‘I think sometimes the doctors can be very abrupt with you.’ (Harrison et al., 2015, p.756).	Disrespectful
		‘They did not take me seriously. When I am not heard, or unable to express my opinion, I get livid…’ (Torheim and Kvangarsnes, 2014, p. 744).	Ignoring
		‘There were some nurses who managed to use it to manipulate me...’ (Kvangarsnes et al., 2013, p. 3067).	Distrust with staff

Themes

2.3.1 Unpredictable hospitalisation

Hospitalisations in people with advanced COPD were frequent and sudden due to acute breathlessness. Sudden admissions seemed to cause a chaotic admission process (Seamark et al., 2012). A long waiting time to be seen by a doctor in the emergency department, being admitted to a different ward and checked by a doctor from a different speciality were perceived to cause a chaotic and frightening admission process:

> *"And then they [nurses] stuck me in a room that they put people in when they were dying. And you know how much that terrifies a person?"* (Gale et al., 2014, p. 12)*;*
>
> *"Well they put you in, they boot you and then you wait until somebody comes and assesses you."* (Seamark et al., 2012, p. 264).

Since sudden admissions were usually decided by the healthcare professionals, such as the general practitioner or the ambulance staff, participants felt that they had lost control over the decision of hospitalisation. This poor information of admission decisions was perceived to cause confusion during sudden admissions:

> *"We were whizzed straight into the Medical Emergency or surgical place ...I couldn't tell you."* (Seamark et al., 2012, p. 263).

Despite the fact that sudden hospitalisation caused chaos, participants felt safe due to the immediate help provided for acute breathlessness, which reduced their anxiety and fear of death (Chang et al., 2016; Landers et al., 2015; Pang et al., 2004; Seamark et al., 2012). Immediate medical attention was perceived that the acute situation would be taken care of, which reduced anxiety and helplessness:

> *"…that's a feeling of security. Knowing, that you are going away to get help. I just want to be cared for there is nothing that I can do."* (Landers et al., 2015, p. 03).

As participants felt disabled with breathlessness which reduced their mobility, many of them missed socialising with their friends. For a few participants, hospitalisation also created an occasion to meet with their peers that alleviated their fear:

> *"They [fellow patients] saw me… called out my name loudly…I have many groups to chat with*."(Yu et al., 2004, p. 1759).

Nevertheless, hospitalisation caused fear because of the perceived decline in health and uncertainty of the future. Although participants were hospitalised for a sudden deterioration in health, they felt that hospitalisation itself caused a further decline in health (Lowey et al., 2014; Pang et al., 2004). Progressive deterioration of health was perceived to occur after each hospitalisation:

> *"Because every time I have a bout… I end up on a short stint in the hospital I take one step forward and two back so that I'm always starting over again."* (Lowey et al., 2014, p. 342).

Further, participants who experienced a near-death experience and those who witnessed their relatives die during hospitalisation with breathlessness caused extreme fears about hospitalisation (Harrison et al., 2015; Lowey et al., 2014; Pang et al., 2004). The past painful memories relating to hospitalisation caused anxiety, which became worse when participants had severe breathlessness that mimicked the past episode:

> *"Last time, I was more or less completely gone [nearly died]…"* (Kvangarsnes et al., 2013, p. 3066);
>
> *"I don't even like visiting hospital ... It was my brother in December, when he died.''* (Harrison et al., 2015, p. 753).

Moreover, repeated admissions for breathlessness caused physical and psychological suffering (section 2.3.3). Participants felt that they lived most of their life in hospital in the advanced stage which caused a feeling of uncertainty. Going through fear of death and uncertainty during each time of hospitalisation was sometimes overwhelming:

> *"Going to the hospital would bring a lot of unknowns to participants…whether or not they would be admitted, how long they would have to stay…"* (Lowey et al., 2014, p. 343).

Repeated hospitalisations also caused a feeling of being a burden to participants' family, as hospitalisation caused additional burdens of caring. Care burden was perceived to disrupt the family's routine and also caused financial burden due to hospitalisation:

> *"The daily routine of my son's family was disrupted... I don't want to be a burden to my son and daughter in terms of medical costs or care."* (Chang et al., 2016, p. 3).

On some occasions care giving burden itself caused repeated hospitalisation, as the family felt over-burdened by the demand of care at home in the advanced stage of COPD:

> *"My wife begged the doctor to admit me to the hospital. She was too tired to take care of me…I am her burden."* (Yu et al., 2007, p. 1759).

This indicates that repeated, sudden, hospitalisation caused a mixed feeling of relief and worry about care giving burden to the family members.

In general, the hospital environment was considered dirty due to acutely ill people admitted with cough and breathlessness (Harrison et al., 2015). Also, noise from fellow patients and the breathing machine caused sleep disturbances and contributed to the perception of an unclean environment:

> "*The hospital environment as contaminated and dirty, a place to be avoided until symptoms can no longer be ignored."* (Harrison et al., 2015, p. 753).

The chaotic nature of sudden admission, fear of death due to declining health and an unclean hospital environment created a negative view about hospitalisation; hence, a few participants tried to avoid hospitalisation:

> *"No, no I'm fighting the hospital. Geez if I go to the hospital I'll never come back here…I don't tell 'em the truth. I told 'em no [to being short of breath*]." (Lowey et al., 2014, p. 343).

Some participants tried self-management measures such as modifying life-style and eating habits to reduce the intensity of the symptoms in order to avoid hospitalisation:

> *"I have more sputum within 2 days after eating more tomatoes. I am eating fewer tomatoes now."* (Chang et al., 2016, p. 4).

However, they were aware that hospitalisation was inevitable for accessing treatment for acute symptoms:

> *"I didn't have much choice [about going to hospital].''* (Harrison et al., 2015, p. 753).

While hospitalisation was perceived necessary, the burdens of repeated hospitalisation caused avoidance of hospitalisation.

2.3.2 Perceived benefits and burdens of treatment

In general, the treatment offered for breathlessness was considered effective and quick. Non-invasive ventilation (NIV) is a breathing machine that helps ease breathlessness without the need for intubation. NIV was one of the treatment options offered for acute breathlessness. Participants felt that NIV provided immediate relief from breathlessness and improved their independence:

> *"…it gives me back a normal life…to get me back to a normal existence; it helps me breathe…"* (Gale et al., 2015, p. 271).

Although NIV seemed to relieve breathlessness, it caused unpleasant side effects such as dryness in the throat and difficulties in speaking. (Gale et al., 2015; Pang et al., 2004; Sørensen et al., 2014; Torheim & Kvangarsnes, 2014). Breathing through NIV caused anxiety due to hot air forcefully pumped into the chest, which was perceived as losing control over their breathing:

> *"It's very uncomfortable and awkward… you get anxious and try to avoid the mask, but at the same time you know you need it."* (Sorensen et al., 2014, p. 1729).

Moreover, NIV caused a total physical restriction that limited them from carrying out their daily routine. These discomforts caused frustration, hence, some participants perceived NIV as a punishment that was imposed on them.

> *"...it's sore, it's as if someone has been rubbing your face all night, rawness like, tender… even if the King came to me and said you gotta have one, I'd say no."* (Gale et al., 2015, p. 272).

Nevertheless, participants had to accept NIV, as it seemed to be the treatment of choice for acute breathlessness:

> *"You have no choice, have you? You can't be without it..."* (Sorensen et al., 2014, p. 1731).

Specifically, participants admitted to the ICU who had experienced intubation perceived that it was difficult to endure (Pang et al., 2004; Sørensen et al., 2014). Observing other people who did not regain consciousness after intubation caused fear of death and uncertainty. Being hooked on to the machine and having many tubes connected to their body caused a feeling of losing control over their body:

> "*You need to deal with being cut off from everything and being restrained by the mask… it is really, really tough, but there is no going back, really."* (Sorensen et al., 2013, p.1731).

Both invasive ventilation and NIV treatment for acute breathlessness were appreciated as beneficial but perceived to cause physical and emotional discomfort.

Participants felt vulnerable during acute breathlessness which prevented them from participating in treatment decision-making; hence, some participants preferred their healthcare professionals to decide the treatment of choice (Gale et al., 2015; Kvangarsnes et al., 2013; Landers et al., 2015; Lowey et al., 2014). Also extreme physical weakness caused staff to make the treatment choice:

> *"...perhaps, it is better that they [health personnel] are determined; I was more or less completely gone…"* (Kvangarsnes et al., 2013, p. 3067).

Further, being acutely ill with limited treatment options which were difficult in nature, complicated the treatment decision difficult that restricted the participation in treatment decision-making:

> *"Intubation is unpleasant, and breathlessness is unpleasant too. Both are sufferings to me. I let the doctor make the decision for me*." (Pang et al., 2004, p. 272).

While letting the staff decide the treatment option demonstrated participants' trust in staff, sometimes the treatment decisions taken by staff without participants' involvement caused uncertainty related to their future treatment plan and caused emotional upset:

> *"…that the health personnel had been too forceful in administering the mask treatment. Feeling that she had lost control over her own treatment, the patient became angry."* (Kvangarsnes et al., 2013, p. 3067).

Further, sudden admissions sometimes allowed a short time to decide treatment choices that led to poor explanation of treatment options (Harrison et al., 2015; Kvangarsnes et al., 2013; Pang et al., 2004; Torheim & Kvangarsnes, 2014). Poor treatment information caused a feeling of being neglected by staff:

> *"Physicians discussing further treatment above the patient's head evoked feelings of mistrust in the patient."* (Torheim and Kvangarsnes, 2014, p. 744).

Moreover, poor treatment information caused distrust with the staff which is discussed in section 2.3.3.

Participants reported contradicting opinions about end-of-life discussions during hospitalisation. Some participants reported that the discussion rarely happened during hospitalisation, while others perceived the opposite (Pang et al., 2004; Seamark et al., 2012). In this regard, participants also reported a divided view of whether or not to discuss the end-of-life plans:

> *"No, but I think I'd want it addressed, yeah, I think that it's very important…"* (Seamark et al., 2012, p. 264);
> *"It wasn't discussed and I would have liked to have known more…"* (Seamark et al., 2012, p. 264).

Participants, who perceived that end-of-life discussions had happened during hospitalisation, appreciated the active involvement of them and their family in the discussion. Usually the physician initiated the conversation, but occasionally participants seemed to initiate the discussion with the staff, when they sensed that their illness was progressing:

> *"When I fall down [die], do not rescue me."* (Pang et al., 2004, p.139).

However, some felt that acute hospitalisation was not the right time for discussing end-of-life discussion, as hospital admissions were perceived as chaotic (Seamark et al., 2012). Also participants preferred to discuss the end-of-life plans with their general practitioner (GP), as they perceived GP knew their complete health condition:

> *"Someone with a good knowledge of the condition was also desirable… that person being their GP."* (Seamark et al., 2012, p.263).

This indicated a varied approach to facing end-of-life discussions, which depended on the individual factors such as timing and preference to discussing.

2.3.3 Overwhelming distress

Participants experienced extreme distress during hospitalisation, affecting the physical, psychological and spiritual aspects.

Breathlessness

Breathlessness was the most common difficult physical symptom in advanced stage of COPD. Experiencing a severe breathing difficulty caused suffocation which sometimes was perceived as life-threatening (Kvangarsnes et al., 2013; Sørensen et al., 2014). Some participants described breathlessness as a struggle to get enough air, like breathing through a narrow pipe. Others perceived it as suffocating and an extreme effort to survive:

> *"It is like breathing through a straw and then it is suddenly cut off."* (Torheim & Kvangarsnes., 2014, p. 743);
>
> *"It was terrible…It is a matter of life and death."* (Kvangarsnes et al., 2012, p. 3066).

Experiencing frequent breathlessness required constant breathing support such as NIV. Despite using NIV, participants felt breathless, as the machine tried to blow a lot of air against their capacity to inhale; on some occasions, experiencing a choking sensation caused panic attacks:

> *"…being restrained by the mask was just too much for me, I couldn't breathe… and suddenly I panicked."* (Sorensen et al., 2014, p.1730).

Many people remained anxious, as they were unable to breathe which caused fear of death. Some people experienced confusion during acute breathlessness and were not able to express themselves clearly which caused anxiety. Nevertheless, a few people tried to keep calm to cope with the dual stress of breathlessness and anxiety and some used humour to mask their fear:

> *"Mental strategies for relaxing, calming down and trying to breathe normally could help."* (Torheim & Kvangarsnes., 2014, p.743)*;*
>
> *"I remember getting confused, but I'm confused in any case [laughs]. But all joking aside it was very scary."* (Seamark et al., 2012., p. 263).

An extreme physical weakness accompanied during acute attacks of breathlessness that restricted participants from doing their daily activities (Chang et al., 2016; Harrison et al., 2015; Pang et al., 2004; Sørensen et al., 2014; Torheim & Kvangarsnes, 2014). A few participants even found it difficult to talk and simply were unable to do anything. Many were bedbound, exhausted and completely dependent on others to carry out their daily routines:

> *"Being unable to speak, unable to act, not being able to eat, feeling ill all over."* (Torheim & Kvangarsnes., 2014, p. 743);

> *"I feel that I am living in a prison, being totally restricted in activities."* (Pang et al., 2004, p. 138).

Feelings of isolation caused low self-esteem and helplessness which caused psychological and spiritual issues which are discussed in the next section.

Psychological and spiritual distress

Although breathlessness was the main cause for anxiety, fatigue, nightmares and confusion during acute breathlessness also contributed to anxiety. Anxiety seemed to accompany acute breathlessness because the inability to breathe caused fear of imminent death. Undergoing NIV treatment increased anxiety, as being restrained with the machine caused fear (Kvangarsnes et al., 2013; Sørensen et al., 2014; Torheim & Kvangarsnes, 2014). In particular, being alone in an isolated room with the ventilator further increased anxiety:

> *"I didn't like being in the room. It was horrible with the doors closed..."* (Sørensen et al., 2014, p. 1729).

Nightmares were another source of anxiety; several participants were afraid to fall asleep and wanted to keep the lights on even during the daytime. Fear of death also caused nightmares and disturbed sleep (Chang et al., 2016; Lowey et al., 2014; Pang et al., 2004; Seamark et al., 2012). Feelings of suffocation and other manifestations of difficulties in breathing were vividly experienced in the nightmares. The following is one of the descriptions of a nightmare experienced by a participant:

> *"You are at the bottom of a pool, and you want to get to the surface, but you are not able get up. You just lie there unable to breathe without being able to get to the surface."* (Kvangarsnes et al., 2013, p. 3066).

Following nightmares, participants were afraid to fall asleep and remained anxious; sleeplessness, then, further worsened fatigue which caused dependency. Increasing dependency during hospitalisation disrupted the routines of participants' family and increased the financial demands as well (Chang et al., 2016; Harrison et al., 2015; Pang et al., 2004; Yu et al., 2007). This created a sense of being a burden to the family members which contributed to anxiety:

> *"My family's a big factor... I feel as if I'm actually putting on them.''* (Harrison et al., 2015, p. 752).

Feeling of helplessness, physical dependency and repeated hospitalisation contributed considerable spiritual distress. Although most of the studies reported fear of death during breathlessness, only one study reported death and dying concerns (Pang et al., 2004). Participants expressed fear of death but they were not hesitant to discuss about it:

> *"Who is not afraid of death? It is quite normal to have fear."* (Pang et al., 2004, p. 138).

Some participants realised that repeated hospitalisation did not cure their disease and they expressed a strong wish to die naturally. In a hopeless situation, they sensed that treatments would be in vain (Pang et al., 2004). In this regard, many expressed how they wanted to die; this would be to die spontaneously, as if falling into sleep and to have a peaceful death:

> *"…my concern is to remain clean and tidy when I die... I only want to die in peace, without causing more trouble."* (Pang et al., 2004, p. 137).

Sensing that life was short and that death might occur soon, participants expressed there was nothing to look forward to in life. Reflecting the fulfilment in life, participants felt that they had done what was expected to be done, which gave them a sense of satisfaction:

> *"I am at peace with myself because I did nothing purposely in harming others and I did not owe anybody anything that I did not return in my life."* (Pang et al., 2004, p. 138).

This indicates that participants experienced profound death and dying concerns during hospitalisation.

2.3.4 The communicative behaviour of the staff

Friendly staff motivated participants to remain engaged with their treatment during hospitalisation. Respecting and listening to participants' concerns encouraged them and increased their level of perceived self-control during the acute period of illness (Torheim & Kvangarsnes, 2014). Many participants admitted that having an open conversation with the staff about the disease and treatment plan helped them cope with the difficult treatment:

> "*I participated all the time and most of them were encouraging and open. They listened to what I had to say – what little I had to say.*" (Torheim and Kvangarsnes, 2014, p. 744).

A friendly chat and a sense of humour displayed by the staff even during the critical moments seemed to improve their relationship with staff; they recognised that staff took control during the critical situations and helped them come back to a more normal balance (Kvangarsnes et al., 2013; Torheim & Kvangarsnes, 2014). Particularly, being available and proactive to participants' needs established trust with staff:

> *"That you feel you are in safe hands – that there is control over what is being done and that they know what they are doing."* (Torheim and Kvangarsnes, 2014, p. 743);
> *"They [staff] saw my needs before I noticed them."* (Kvangarsnes et al., 2013, p. 3067).

Consequently, trust in staff helped participants tolerate strange situations such as putting up with difficult treatments.

However, many participants also experienced a negative behaviour from staff, specifically when they were critically ill, which was one of the main sources for losing trust in the treatment. Some participants felt that staff were not listening to their concerns and this caused a feeling of being neglected:

> *"…that she felt she was a nuisance…she said she was put 'on hold."* (Torheim and Kvangarsnes, 2014, p. 743).

In this regard, participants felt that they were not included in the treatment decision-making and perceived that difficult treatments were forced on them which caused distrust with staff (Harrison et al., 2015; Kvangarsnes et al., 2013; Torheim & Kvangarsnes, 2014). For example, one participant tried to test the nurses by keeping the alarm by her side to see whether nurses would attend when she called out. But nurses tried to manipulate the alarm so that it would not ring which angered the participant and disrupted the relationship between them:

> *"...But she [the nurse] threatened [me] a bit with that tablet. I said no. I wanted to be attentive because I might be choked if they do not suck out the slime [in time]. I had to be in control…"* (Kvangarsnes et al., 2013, p. 3067).

Also, treating participants as a nuisance and without respect created distrust (Kvangarsnes et al., 2013; Torheim & Kvangarsnes, 2014). Not just ignoring participants' opinion but neglecting their presence during treatment discussions was perceived to be unprofessional:

> *"And when a doctor stands over you, at the same time making eye contact with a nurse and smiling, thinking I could not hear anything, well that's not nice..."*(Kvangarsnes et al., 2013, p.3067).

Specifically, smokers felt that the behaviour of the staff made them feel shame and guilt for smoking and they deserved such unpleasant treatment for their past behaviour:

> *''…oh perhaps they haven't got much patience with me because it's self-inflicted…"* (Harrison et al., 2015, p. 752).

These unprofessional behaviours caused participants to distrust staff and made them feel at the mercy of staff, which had a negative impact on the experience of hospitalisation.

2.4 Discussion

This qualitative review has provided insight into many aspects of the experience of hospitalisation in people with advanced COPD. A previous review explored the lived experience of advanced COPD, but mainly focused on the experience of individuals living in the community (Disler et al., 2014). In this current review, none of the studies directly addressed the experience of hospitalisation, rather these focused on the discrete aspects of hospitalisation such as treatment, end-of-life discussion and interaction with staff, which were synthesised to present a nuanced understanding of the phenomenon. This review identified four overarching themes related to the experience of hospitalisation: unpredictable hospitalisation, perceived benefits and burdens of treatment, overwhelming distress and the communicative behaviour of the staff. This discussion focuses on comparing these varied aspects of the experience of hospitalisation with other studies conducted in COPD and chronic illnesses such as cancer, chronic heart and kidney disease, to demonstrate the varied perception of hospitalisation.

Hospitalisation is unpredictable due to repeated, acute breathlessness. In line with this finding, studies conducted in individuals with COPD and in advanced respiratory illness have also reported the need for frequent, sudden hospitalisation, mainly because of acute breathlessness (Bartels et al., 2018; Karasouli et al., 2016; Robinson et al., 2018). Acute symptoms such as breathlessness, pain and bleeding in the advanced illness caused unpredictable hospital admissions in people with varied chronic illnesses, such as heart failure and chronic kidney disease (Barello et al., 2015; Kuluski et al., 2013). Further, unpredictable hospitalisation was associated with chaotic admissions due to delays in admission and inadequate treatment information, which was also reported in studies conducted in chronic illnesses (Bailey et al., 2016; Barello et al., 2015).

Hospital is perceived to be a safe place because of its ability to provide immediate relief for acute breathlessness. A study which investigated the experience of hospitalisation in people with palliative care needs found that feeling safe was attributed to immediate symptom relief for difficult physical symptoms (Robinson et al., 2015). Studies conducted in various chronic illnesses such as heart failure, COPD and cancer also found feeling safe was linked to the availability of immediate medical help and attention of the staff (Liu et al., 2017; Spichiger, 2009). Similarly, this literature review showed that feeling safe in hospital was related to the expertise of the staff and immediate relief which depended on the symptom severity at admission.

An unclean hospital environment, noise and fear related to past experience of hospitalisation contributed to the avoidance of hospitalisation. One review which studied the experience of palliative care in an acute hospital setting, found that an unclean and noisy environment was uncomfortable for patients receiving palliative care (Robinson et al., 2014). Noise from the NIV machine and from neighbouring patients causing sleep disturbances during hospitalisation were also reported in studies conducted in COPD and other chronic illnesses (Brereton et al., 2012; Christensen et al., 2017; Oyesanya, 2017; Wang et al., 2009). Further, experiencing unpleasant events such as a near-death experience during the previous hospitalisation contributed to the avoidance of hospitalisation. Studies showed that experiencing severe pain or a distressing symptom during the previous hospitalisation was the reason for avoidance of hospitalisation (Ghafari et al., 2014; O'Leary et al., 2019; Stisen et al., 2016). Avoidance of hospitalisation has a myriad of contributing factors that have a negative impact on the experience of hospitalisation.

Overwhelming physical, psychological and spiritual distress was reported, despite hospitalisation provided immediate symptom relief. Breathlessness and extreme fatigue caused dependency that limited mobility were the most common physical symptoms, which is in line studies conducted in COPD (Gardener et al., 2018; Lovell et al., 2018). This literature review identified that anxiety was the main cause for psychological distress, which was attributed to sudden hospitalisation, breathlessness and difficult treatment. Similarly, studies reported that breathlessness and NIV treatment caused anxiety and fear of death (Christensen et al., 2018; Christensen et al., 2017). However, spiritual distress seemed to be the least reported in this review with just one study reporting death and dying concerns. A review examined the support needs of COPD also found that spiritual concerns were frequently not reported compared with other symptom domains (Gardener et al., 2018). This could be related to the perception that people with COPD may perceive themselves living with COPD rather than dying from it (Pinnock et al., 2011).

The behaviour of staff seemed to influence the experience of hospitalisation. This review found that participants experienced both friendly and unfriendly behaviours of staff during hospitalisation, which resonates with studies conducted in other chronic illnesses (Barello et al., 2015; Black et al., 2018; Kuluski et al., 2013). However, a few studies have reported only the negative behaviours of staff (Ghafari et al., 2014; Mulemi, 2008; Robinson et al., 2014). Friendly gestures, such as being available and listening, helped participants cope with the illness (Black et al., 2018; Kuluski et al., 2013). Further, a friendly behaviour from the staff influenced participants to initiate a discussion about treatment decisions (Black et al., 2018; Giacomini et al., 2012). This review found that staff taking control of the critical situation enabled participants to entrust their treatment to them during hospitalisation. Taking control of the situation not only helped build trust with the doctors but also helped patients include their doctors to plan future care (Barello et al., 2015). However, unfriendly behaviours such as ignoring and disrespect caused distrust with the staff (Barello et al., 2015; Ghafari et al., 2014). Distrust with the staff reduced confidence in hospitalisation and this had a negative impact on the experience of hospitalisation.

This review found that the overall experience of hospitalisation in advanced COPD is a mix of positive and negative experiences which is similar to some studies conducted in other chronic illnesses (Liu et al., 2017; Spichiger, 2009). Feeling safe, being cared for and appreciating the necessity of hospitalisation are some of the positive aspects whereas fear related to hospitalisation, poor communication and unfriendly staff behaviour were some of the key negative aspects of hospitalisation. This indicates that the experience could be varied depending on the complex elements of hospitalisation.

2.5 Strengths and limitations

Strengths

This review synthesised evidence for the experience of hospitalisation in people with advanced COPD, from eleven qualitative studies. Nine electronic databases that included grey literature databases and citation indexes were searched, in addition to citation tracking from the key studies. A wide range of databases were included to locate the studies published from different countries and to find a varied concept of hospitalisation. The database, Indian Social and Science Studies, which indexed studies from India helped search for eligible studies from India which is the study location for this research.

Limitations

Although care was taken to search for all the electronic databases and grey literature, there is still a possibility that some studies might not have been included which could have limited the presentation of the experience. Only studies published in the English language were included which therefore omitted experiences from studies published in non-English languages. The included studies were mostly published from Europe, which might have influenced the presentation of the experience. The findings are therefore, reflect the European culture and context which may not be transferable to other contexts and cultures (Hartog & Hartog, 1983).

Another limitation of this review was that the data from some of the original studies were often ‘thin’ which did not allow deep interpretive analysis of all themes. However, these thin data demonstrated different dimensions of hospitalisation, such as communication with staff, hospital environment and spiritual distress, which helped appreciate the multi-dimensional experience of hospitalisation.

2.6 Conclusion

This review has synthesised the experience of hospitalisation in people with advanced COPD. From the papers reviewed, hospitalisation is unpredictable, mainly due to frequent, acute breathlessness. Hospital is perceived to be a place of safety and yet a place of distress. Hospitalisation is considered as necessary yet would be preferred to be avoided.

This review synthesised specific aspects of hospitalisation, such as care, treatment and interaction with staff. As hospitalisation is a broad, multi-dimensional experience, it is difficult to know whether these findings represent the experience as a whole. It is important to know the experience of hospitalisation from the perspective of people who experienced it, to illuminate the complete picture of the phenomenon of hospitalisation. This would provide a deep insight into the experience and enhance the understanding of the staff involved in the care of people with advanced COPD to improve future care. Further, ‘thin’ data of some of the included studies certainly impacted the depth of analysis of some aspects of hospitalisation, which could have limited the understanding on the depth of the experience. Most of the included studies are from Europe, which has a specific socio-cultural background; this experience therefore, may not be transferable to other countries such as India, as an example of an Asian country which has high COPD prevalence and hospitalisation. Therefore, this research aims to study the lived experience of hospitalisation in people with advanced COPD, in India, in order to further our understanding of the ‘whole’ phenomenon of hospitalisation in the Asian/Indian context and culture.

Chapter Three

Methodology and Methods

3.1 Introduction

In this chapter, the methodology and the methods of carrying out this research are discussed. The methodology is the approach used and methods are specific tools used to study the subject of interest (Bryman et al., 2012). The philosophical underpinning of phenomenology and the methodological approach of descriptive and interpretative phenomenology are explored. The rationale for choosing Giorgi's descriptive phenomenology over the other descriptive phenomenological methods is debated. The data collection methods and analysis using Giorgi's descriptive phenomenology is detailed in the methods section. Quality, rigor and ethical issues concerning this research are discussed.

3.2 Research question

The literature review showed that the experience of hospitalisation in advanced COPD still remains poorly understood. This research aims to study the lived experience of hospitalisation in people with advanced COPD. Research Question:

'What is the lived experience of hospitalisation in people with advanced COPD in India?'

3. 3 Qualitative, phenomenological approach

For this research, the approach that explores the nature of the phenomenon of hospitalisation with the aim to find the universal features of hospitalisation is required. As this research aims to study the individuals' experience, a positivistic approach that utilises strict laws and measurements is not suitable and it needs a different approach. A qualitative approach helps understand the human experiences and illuminates the context and meaning of the experience; this approach considers that subjectivity is important to have an in-depth understanding of the phenomenon such as the lived experience of individuals (Creswell, 2014; Silverman, 2013). Since this research studies the individuals' experience of hospitalisation, subjectivity is considered essential to understand the experience in-depth. Therefore, a qualitative approach is better suited for the aim of this research.

Phenomenology studies the life-world of individuals and explores the phenomenon from the participants' perspective (Giorgi, 1997). A phenomenological approach is suitable for this study because this elucidates the phenomenon which is not known and constructs the universal features or the essence of the phenomenon from the participants' description (Giorgi, 1997). There are also other competing qualitative approaches that could be considered to study the experience of hospitalisation. Ethnography studies the experience of a group of people which is shaped by the social and cultural values, hence it is not suitable for the aim of this research (Christina, 2005). Grounded theory is more oriented to develop a theory and discourse analysis constructs the phenomenon through the knowledge and meaning of the language used, rather than to illuminate the individual experience; hence both approaches do not seem to be suitable approaches (Christina, 2005). The narrative approach which describes the varied experience through narration of story of the individuals is more suited for understanding idiographic experience, rather to find the essence of the phenomenon. Hence, the phenomenological approach is chosen as it lends itself best to this research.

It needs to be acknowledged that the philosophy and methodology of descriptive phenomenology are similar, therefore, it is important to consider its epistemological underpinnings first before the methodology is explored (Finlay, 2009).

3.4 Philosophical underpinning of phenomenology

Epistemology is concerned with the study of knowledge and how knowledge could be studied; ontology is to know the reality that exists about the world and society (Silverman, 2013). The epistemology of

Husserl's descriptive phenomenology does not seem to align with any of the post-positivistic epistemological positions such as constructivism; however, the ontological position seems to closely align with critical realism which is discussed below.

Husserl, the founder philosopher of phenomenology believed that subjectivity as the point of departure from positivism and founded an alternative way to study human experiences (Wertz, 2005). He observed the human experiences through the consciousness of intentionality (Giorgi, 1997). He argued that by intentionally directing one's consciousness towards the phenomenon to be studied, it is possible to unfold the phenomenon; he further argued that removing the prejudices related to the phenomenon which is known as 'epoche or phenomenological reduction' is essential to uncover the essence of the phenomenon in its natural attitude (Churchill & Wertz, 2001; Finlay, 2009; Giorgi, 2005). He emphasized that 'zu den sachen' is to return to the phenomenon in- itself, to clarify the phenomenon, to describe the context and the way in which it occurs (Wertz, 2005). In this research, intentionality is used to study the lived experiences as it appears in the context, to uncover the phenomenon of hospitalisation by interacting with the participant and the phenomenon; phenomenological reduction is followed to avoid the pre-assumptions about the phenomenon to describe the phenomenon as it is described. These features of Husserl's epistemological approach underpin this research to facilitate the presentation of the essence of the phenomenon.

In critical realism, reality is considered to exist independently and could be studied through human interpretation (Fletcher, 2017). The ontology of critical realism includes three levels: empirical, actual and real (Fletcher, 2017). At the empirical level, reality could be known through subjectivity and its meaning, cause and experiences could be explained. Events or phenomena are considered to occur independently whether it is known or not, at the actual level; however, this helps the phenomenon to be studied as it presents in the natural form, in its context. At the real level, the causal mechanism of the reality could be studied to understand the effect of casual factors that caused the occurrence of the phenomenon (Fletcher, 2017). In this research, the phenomenon to be described exists independently and could be known through the researcher who studies the phenomenon, which relates to the empirical level. The phenomenon could be presented in its natural attitude, as it occurs in the context which relates to the actual level. The causation of phenomenon is explicated through the participants who experienced it, which refers to the real ontological level of critical realism. Hence, this research takes the position of critical realism.

3.5 Descriptive phenomenological approach

There are two major contested approaches to phenomenology; descriptive and hermeneutic phenomenologies are debated and the rationale for choosing a descriptive phenomenological approach is discussed. The justification for choosing Giorgi’s descriptive phenomenological approach over the other descriptive phenomenological methods is discussed.

Phenomenology is defined as the study of the experiential world of an individual (Giorgi, 2010). Descriptive phenomenology is developed from Husserl’s concept of consciousness of intentionality (Giorgi, 2012). Consciousness is always present whether one acknowledges its presence or not; the person needs to intentionally direct the consciousness to study the phenomenon in its context to describe the general structure of the phenomenon which Husserl described as ‘the essence’ (Applebaum, 2014). Descriptive phenomenology looks at patterns and similarities among the individuals to describe the essence of the phenomenon, to find a ‘unified variation’ (Giorgi, 1997, 2012). This is especially useful where the phenomenon has not been studied before to give an elaborate description of the phenomenon. This feature of finding the patterns to describe the essence of hospitalisation is the key requirement to give a rich description of hospitalisation.

In order to describe the phenomenon to present in its natural form, previous experiences and knowledge of the researcher related to the phenomenon should be suspended, a process known as 'phenomenological reduction'; this is also known as bracketing (Dowling & Cooney, 2012). Whilst the researcher is still interacting with the phenomenon, Husserl argued that it is possible to withhold one's previous knowledge, in order to avoid the interpretation of the researcher that might dilute the accuracy of presentation of the phenomenon (Ashworth, 1999; Englander, 2016). As a palliative care physician, my assumptions and previous experiences about hospitalisation might obscure the description of the experience of hospitalisation in its natural attitude. Hence, bracketing the assumptions about hospitalisation helps to have a fresh approach to the phenomenon, to understand it as it is described by the participants. Utilising consciousness of intentionality, bracketing and finding patterns are the distinctive features of descriptive phenomenology which are essential to describe the essence of hospitalisation. Therefore, the descriptive phenomenological approach is the appropriate approach for this study.

Hermeneutic phenomenology is developed from Heidegger's concept of 'being there' which means the situatedness of the phenomenon, to know how the phenomenon relates with the context, society and culture (Laverty, 2003). The hermeneutic approach considers to understand the meaning of the phenomenon, rather, to understand the way how the world presents the phenomenon to us in its natural form (Davidsen, 2013; Finlay, 2009; Laverty, 2003). This approach emphasises the importance of allowing prejudice for the explication of the phenomenon, so that the depth of understanding of the phenomenon is expounded by the interpretation (Dowling, 2007). Therefore, integrating researchers' reflexivity is considered essential to contribute to the interpretation of the phenomenon (Wojnar & Swanson, 2007). Interpretative phenomenological analysis (IPA) is developed from hermeneutic phenomenology that explores the meaning of phenomenon to understand how the individuals make sense of their personal and social world (Smith et al., 1997; Smith & Osborn, 2004). IPA mainly examines the dissimilarities to explain how people differ in making sense of a certain experience to present the varied difference among the individuals (Smith & Osborn, 2015). IPA considers that the subjectivity of the researcher is essential to interpret the meaning of the phenomenon (Finlay, 2009; Giorgi, 2010; Smith et al., 1997). This fundamentally differs from the descriptive approach and emphasis upon the interpretation over the description of the phenomenon (Ashworth, 2003). This interpretative approach is more suited for research that aims to find idiographic meaning and a varied presentation of the phenomenon, rather than for research that is focused on finding universal features or patterns. Hence, this approach does not seem to be the appropriate approach for the descriptive nature of this research.

3.5.1 Rationale for choosing Giorgi's phenomenology

Following Husserl's philosophical stance, Giorgi developed the descriptive phenomenological method based on the tenets of consciousness of intentionality and bracketing to discover the phenomenon (Giorgi, 2012). Giorgi laid out a method of analysis on these grounds to describe the general structure of the phenomenon, especially in a field where new knowledge is required (Giorgi, 2012). The lived experience of hospitalisation remains poorly understood and requiring a description of the complete picture of hospitalisation. Therefore, Giorgi's descriptive method suits the goal of this research.

There are other descriptive phenomenological methods developed by Moustakas, Van Kaam and Colaizzi (Davidsen, 2013). Moustakas's method is more suited for a self-enquiry nature of describing autobiography (Moustakas, 1990). The other two include interpretive elements within the descriptive approach such as, appointing judges or returning the text to the participants for feedback; therefore, do not reflect the pure method of a descriptive research (Giorgi, 1997). Not only is this a less suitable method for descriptive phenomenology, but the discovery and the description of experience also requires some expertise and it is not expected that all participants and the experts will have this expertise, in terms of having an experience of a particular phenomenon or investigating such an experience (Giorgi, 2008b). Hence, they are suited for a different kind of a research approach. Giorgi's descriptive phenomenology is chosen as the appropriate method because this reflects the descriptive nature of this research.

3.6 Methods: Giorgi's descriptive phenomenology

In this section, detailed procedures of data collection and data analysis are explained. Bracketing researcher's reflexivity is discussed under both data collection and data analysis to demonstrate bracketing at different stages of the research.

3.6.1 The phenomenon

Giorgi defines a phenomenon as:

> *'whatever is given, present itself and is understood precisely as it presented itself to the consciousness of the person entering the awareness.'* (Giorgi, 1997, p.238).

For this research, the phenomenon of interest is the experience of hospitalisation in people with advanced COPD. Health events that lead to hospitalisation, hospital procedures including treatment and test and interaction with the staff in the context of advanced COPD were considered as the contributors of the experience of hospitalisation.

3.6.2 Study design

Among the different methods of descriptive phenomenology (section 3.5), Giorgi's descriptive phenomenological method is chosen to study the experience of hospitalisation, as this is the suitable approach for the goal of this research, to describe the general structure of the phenomenon from the participants' perspective.

3.6.3 Data collection methods

In this section, the details of data collection methods are set out and the measures taken to ensure the quality of data collection are explained.

3.6.3.1 Population

Adult participants over the age of eighteen years with advanced stage of COPD were included in the study. COPD is common among people over sixty years of age; however, its presence cannot be dismissed among young people, especially in India, as one of the main contributing risk factors is exposure to biomass fuel and occupational pollution (Salvi et al., 2018). Hence, a wide age range of 18 years and above is considered, so as to include the younger population. The inclusion and exclusion criteria are detailed in table 5.

Table 5 Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
COPD patients with GOLD stage III and IV; in addition, clinical symptoms such as worsening breathlessness, fatigue, acute exacerbations with frequent hospitalisation, use of a non-invasive ventilator and/or long term oxygen-dependency were also considered to identify the advanced stage.	Acutely ill participants.
Adult patients > 18 years of age.	Those who are unable to communicate.
Admitted to the pulmonary and geriatric medicine wards for a minimum of 24 hours.	People with cognitive impairment.
Able to communicate fluently in Tamil and or English language.	

3.6.3.2 Settings

This research was conducted in a hospital in a south Indian city with a current population of 12.3 million (UnitedNations, 2017). Both public and private hospitals, ranging from primary to tertiary care with sophisticated treatment facilities are situated in the city.

The hospital setting for this research is a private, tertiary care hospital which has distinguished clinical facilities. It provides advanced medical treatment and represents one of the typical tertiary care hospitals in India. People with advanced COPD are referred here for the management of complex symptoms. The hospital charges a reduced fee for poor people which depend on their income status compared with the fee structure set for people from other socio-economic status. This hospital caters to a wider population on the south part of the city and also to the neighbouring towns and villages from other states/provinces.

3.6.3.3 Sampling

Giorgi (2008) recommends that the researcher should seek participants who have had the same experience of a particular phenomenon, in order to obtain the common features of a phenomenon. A purposive, homogenous sampling method focusing on the particular characteristics of the population helps to find the answer for the research question (Bryman, 2012). Hence, purposive, homogenous sampling was employed, to identify people who share the same characteristics with advanced COPD and experience of hospitalisation, to study the phenomenon of hospitalisation.

3.6.3.4 Sample size

Qualitative studies generally aim to have a small sample size because this enables the collection of subjective, in-depth information about the phenomenon being studied (Englander, 2012). Although the recommendation for sample size is varied, Giorgi (2008) suggests that using a minimum of three participants is essential for a descriptive phenomenological research. However, this is varied depending on the phenomenon being studied and achieving redundancy of themes as an indication for sample sufficiency (Englander, 2012). Previous studies have shown that a sample size of nine to nineteen is sufficient to capture the phenomenon (Bailey, 2004; Pang et al., 2004). Hence, a range of ten to fifteen participants was justified as a sufficient sample size for this study.

3.6.3.5 Recruitment

Participants from pulmonary and geriatric medicine wards were recruited because people with advanced COPD were usually admitted to these wards. Participants were identified from the admission records, by the designated clinical staff who were the gatekeepers. As participants were vulnerable due to their advanced stage of the disease, gatekeepers were considered essential to protect the participants from coercion (Kars et al., 2016). The clinical staff approached eligible participants first, informed them about the study and provided the participant information sheet. Participants usually remained in the hospital for about 3-5 days. I followed them up after a day to answer any queries and to know their willingness. Alternatively, participants informed their decision to the clinical staff. I provided the consent form in participants' preferred language, either in English or Tamil language, to those who were willing to participate; after discussing any concerns, I took written consent in the ward. Participants were reminded that they had an option to withdraw from the study anytime, until four weeks after the data had been collected. Although I worked previously as a palliative care physician in the research setting, I was not employed in this hospital during the time of data collection. Participants were not aware of my previous employment as a physician in this hospital. I explained that family members could accompany the participants during the interview, in accordance with participants' wishes but they would not be able to participate in the interview.

3.6.3.6 Interviews

The rationale for utilising an unstructured interview and challenges in conducting a phenomenological interview is described below.

Unstructured interviews

Individual, face-to-face, unstructured interviews were conducted to capture the phenomenon of hospitalisation. Interviews are the most common data collection method used in descriptive phenomenology, although written accounts were used at earlier times (Englander, 2012; Giorgi, 2012). An unstructured interview is an interview technique in which there are no predetermined questions or answers (Zhang & Wildemuth, 2006). This entirely depends on the interaction between the interviewer and the interviewees; therefore, the interview questions are flexible and modified according to the interviewee's response. This is useful to discover the unanticipated themes that help to shape the researchers' understanding of the phenomenon (DiCicco-Bloom & Crabtree, 2006; McCann & Clark, 2005; Zhang & Wildemuth, 2006). In contrast to the semi-structured interview, the flexible nature of the unstructured interview helps participants describe their experience freely, therefore, allowing participants to have the control on the interview; this may lead the interview out of the focus, nevertheless, it helps extract the unprecedented aspects of the phenomenon in-depth (Whiting, 2008). Since this study aims to describe the lived experience, unstructured interview is an appropriate method to delve deeper into the phenomenon (DiCicco-Bloom & Crabtree, 2006; Zhang & Wildemuth, 2006). When the interview turns into a purposeless direction, it fails to draw the essential information about the phenomenon being studied. Therefore, interviews were conducted with an aide-memoire, which is a broad guide to the key topics to be covered (appendix 6). This is flexible, has open-ended questions, which was modified according to the participants' response; while, this allows flexibility, at the same time it prevents the conversation from deviating from the focus (Zhang & Wildemuth, 2006).

Phenomenological interviews

Phenomenological interviews aim to focus on the phenomenon through the lens of participants' experience. In this research, the interview began with an open question, 'how do you feel about being hospitalised or could you tell me about your experience of being hospitalised?' To explore the phenomenon in depth, descriptive and structural questions are used. Descriptive questions were used to understand the overall experience of phenomenon which opened up the phenomenon freshly in the context that helps to understand the interrelated elements of the context, which led to the experience of that phenomenon (Bevan, 2014; Englander, 2012; McCann & Clark, 2005). The typical occurrence of the phenomenon was explored using structural questions to clarify and to understand the phenomenon; here, questions from the interview guide were used to tease out the nuances of the phenomenon (appendix 6). However, use of these questions was balanced to get an optimum description of the phenomenon. In descriptive phenomenology, the aim of interviewing is to know the phenomenon, therefore, the interviewer focuses on the object of the phenomenon which is mediated through the interviewees (Englander, 2012). While the researcher's main focus was to gather the information related to the phenomenon as conveyed by the interviewees but remaining sensitive to their emotions could limit the description of the phenomenon. For example, a few participants became emotional while talking about being a burden to their family; in this situation, I remained sensitive to their emotions and addressed these first, then, carefully shifted the conversation towards exploring the phenomenon. Hence, this required a balanced shift between the subject-subject to the subject-phenomenon approach (Englander, 2012).

All the interviews were conducted in Tamil language at the hospital either in the counselling room situated adjacent to the ward or at the patient's bedside. Except for six interviews, the remaining nine interviews were conducted at the bedside because participants were unable to walk and were oxygen dependent. Although privacy was ensured at the bedside, staff moving around in the background and noise from the medical equipments may have limited their freedom to share their experience. If patients wished, their family caregivers could be present during the interview to support them. It was made clear to family caregivers that they were not participating themselves in the research, and if they spoke that this would be recorded but not used in the study. The interview length was relatively short in sick participants, as they were unable to talk continually. For sick participants, interviews were recorded with one or two temporary pauses of few minutes, allowing them to manage any breathlessness or cough. Emotional reactions such as being tearful, was another reason for short interviews with a few participants who did not want to talk anymore or at a later time. I provided emotional support to these participants and made a courtesy visit the next day to check whether they required further support. A distress protocol was followed to address the psychological distress (appendix 7). Interviews were audio-recorded in an encrypted digital voice recorder. Data collection and analysis were done simultaneously, so any new topics found from the analysis could be added to the next interview. Data collection was stopped when there were no new themes found.

3.6.3.7 Bracketing in data collection

Bracketing helps prevent the researcher's influence on the phenomenon and, therefore, facilitates a fresh approach to the phenomenon which aids a rich description of the phenomenon (Giorgi, 2012). Bracketing could be demonstrated through keeping a reflective diary, which serves as an audit trail of methods followed and to demonstrate that the findings reflect the participants' experience rather than the researcher's own interpretation of data (Giorgi, 2012; Wall et al., 2004). My knowledge about advanced COPD including textual, experiential knowledge as a palliative care physician might influence the data collection and analysis; hence I wrote them down in the diary and updated it periodically when new thoughts emerged to interpret the participants' description.

An example of practising bracketing is to prevent thoughts from my previous knowledge about breathlessness that emerged naturally to interpret the participants' description of breathlessness. I reflected and wrote down these thoughts in the diary and consciously bracketed it when interviewing topics related to breathlessness. After conducting a few interviews, the familiarity of what previous participants described began to interfere (Wall et al., 2004). This was identified and bracketed, in order to approach the subsequent interviews with a fresh approach. One such issue was participants expressing fatigue during an extreme breathing difficulty. While I heard most of the participants saying this, I decided to listen to their own story of fatigue and what they did to overcome this, which was unique to each participant that helped me overcome the familiarity. These were reflected and diarised; any new situations that emerged following each interview on a specific topic were reflected and suspended; these were also updated in the diary. A section of researcher's diary showing the thoughts about breathlessness is given in appendix 8.

3.6.4 Data analysis

In this section, transcribing and the challenges faced with translation are discussed. Giorgi's data analysis method is explained with working examples. Practicing bracketing during analysis and measures ensuring quality of analysis are discussed.

3.6.4.1 Transcribing

I transcribed all the audio recording verbatim into Tamil. Words in English used by participants were transcribed as such in bold and capitals, to indicate that they were participants' own words and to differentiate it from translation in English. When translating these words into English, the context in which a certain word was used is taken into consideration, to preserve the contextual meaning than to match the literal meaning. Body language signs were written in the brackets to enhance the description. Pause during the interviews and background noises were also noted down to bring the environment of audio recording. Transcribing required much patience and time but it helped me understand the context of experience of hospitalisation from the participant's perspective. Bracketing my own thoughts to avoid interpreting participants' description helped me remain in the participants' description of their lifeworld.

3.6.4.2 Translation

The audio recordings were first transcribed verbatim in Tamil language and then translated into English by the researcher. They were back-translated into Tamil by a bilingual expert to check the accuracy of the translation. Any challenge in translation of certain words or phrases was discussed with the translator and resolved before the final version of the transcript was prepared and this final, verified transcript was taken for analysis. Employing back-translation ensured that the meaning of the translated text in English stayed close to the original language; back-translation not only reduces the translation errors, but also ensures the validity of translation (Chen & Boore, 2010; Santos Jr et al., 2015).

There are different approaches to translation, for example, early and late phase translation (Santos Jr et al., 2015). In early phase translation, all the interview transcripts are translated before the analysis is carried out, whereas in the late phase, the end product of the research which are concepts or themes are translated; early phase translation is advantageous because it preserves the participants' language as it was told and there are opportunities to correct the translation errors or clarifications before proceeding for data analysis (Santos Jr et al., 2015). This method helps stay close to the participants' description of the phenomenon before the transformation of data happens and preserves the data 'life-as told' that meets the requirement of descriptive phenomenology; in the late phase method, the data become 'life-as-interpreted-translated' that might not purely reflect the participants' description (Santos Jr et al., 2015: 139). Although early phase method could be a time consuming and expensive method, it is advantageous to collaborate with the co-researchers or supervisors who are not proficient in the original language, to benefit from their guidance and discussion (Santos Jr et al., 2015).

3.6.4.3 Challenges in translation

Translating from one language to another could lead to loss of semantics and syntax. Occasionally, the translator omit or reduce a part of the text unintentionally, which might be interpreted differently as they are not often oriented to the research problem (Berman & Tyyskä, 2011). The participants' language and their opinion could be diluted by the translator's knowledge and their own opinion about the phenomenon being researched; however, this depends on how much the translator becomes involved in the process of analysis (Temple, 2002; Temple & Young, 2004). Since the translator was involved only in the back translation of transcripts in the English language, there was a least chance of omitting part of the text. Since this study adopted early phase translation, it helped overcome the challenge of interpreting participants' description.

It is suggested to look for the meaning rather than provide equivalent terms, while translating the original language to another language (Berman & Tyyskä, 2011). For example, distress was described using many different terms in Tamil that literally meant, emotional torture, intolerable suffering and heart-breaking. In this context, instead of looking for an equivalent term, words that reflected a close meaning of the terms used by participants were chosen. For certain words in Tamil, there are no equivalent words available in the English language. In this case, the original word was translated as such, so as not to lose its richness. For example, breathlessness was described using many different words, such as pulling for breath, wanting for breath, chasing for wind and tightness of breath; these terms were preserved as such to indicate the diverse explanation of breathlessness.

Researcher translator

For a phenomenological study, the translator should be a native speaker of that language and should have years of living experience in the culture (Squires, 2008; Temple, 2002). Since I have these specified qualities, it is advantageous to understand the context in which the participant used a certain word or phrase and that facilitated the translation close to participants' description. The translating role for a researcher offers an opportunity to look into the meaning within the socio-cultural, as well as in the context of research, thus, the texts could be viewed from an insider-outsider view (Temple, 2002). This insider-outsider view is beneficial particularly where many different dialects are used, which may have a strong socio-cultural relationship. In this study, participants spoke four different dialects, posing challenges to translate words adopted from English and from other local languages which were context specific. Since both researcher translator and the translator have experience of living in the same culture, translating from different dialects became less difficult. The common challenge for a researcher translator is to look for the meaning of a particular word within the research context, rather than thinking what the participant actually meant to say (Temple, 2002). In this context, following bracketing during the data analysis helped translate the texts as described by the participants.

3.6.4.4 Analysis method

Transcriptions were first imported to the NVivo 11 software to enable data management and analysis. Data analysis was conducted according to Giorgi's phenomenological analysis method (Giorgi, 2008; Giorgi, 2012). Data analysis consists of five steps (table 6). Firstly, the text was read to understand its wholeness. Secondly, the researcher assumed 'phenomenological attitude' to suspend all the presuppositions about the phenomenon. The goal of phenomenological reduction is two-fold: to gain a fresh approach to the phenomenon and to give a rich and accurate description of the phenomenon. In assuming the position of phenomenological reduction, initially, the existence of the phenomenon is withheld which helps approach the phenomenon with openness; then, the researcher suspends all the assumptions and previous knowledge and experience about the phenomenon (Giorgi, 1997, 2005). This fresh approach helps the researcher to give a rich, rigorous and precise description of the general structure of phenomenon (Giorgi, 2008a, 2012). Third, the text was re-read to capture the 'meaning units'; meaning units are those parts of the text which are relevant to the phenomenon of hospitalisation. The fourth step is to transform the meaning units into a scientific expression. This transformation is to change the participants' description from the first person to the third person expression, then to a scientific language in order to integrate a similar description across other descriptions.

In the final step, synthesis and description of the phenomenon was written from the transformed meaning units. The list of transformed meaning units was checked to include only the essential elements of the phenomenon, a process known as 'eidetic reduction'. Eidetic reduction helps to find the invariant parts of the structure of the phenomenon, which are known as constituents (Giorgi, 2009). This process is aided by, 'imaginative variation' in which each constituent was interrogated by imaginatively varying the different aspects of it (Giorgi, 2008). Finally, the general structure of the phenomenon of hospitalisation was written from the specific constituents utilising the description given from the transformed meaning units. Carrying out each step of analysis with exemplars is further detailed below.

Table 6 Giorgi's analysis method

Data analysis steps
1. Read and re-read the text 2. Assume the position of 'phenomenological reduction' 3. Delineate meaning units 4. Transformation of meaning units 5. Description of the phenomenon

Analysis with NVivo

NVivo enables storing large volume of data and facilitates analysis of data through the process of coding. NVivo also helps in retrieving, moving, swapping and linking of the codes (Bazeley, 2013). The ability of NVivo to retrieve a large amount of coded text is useful to apply imaginative variation, which is crucial to identify the key constituents and to demonstrate the inter-links between the constituents. Meaning units are segregated from the transcripts using the 'coding' feature of NVivo. Codes of similar content were grouped under nodes, given a description and named according to the content of the codes. After the meaning units were separated from each transcript, they were copied and pasted on to a separate document created in the NVivo. Transformation of the meaning units was done manually after completing coding of each transcript; this process was applied to all the transcripts.

Descriptive coding method is followed because this is congruent with the analysis method of this research. Coding was done by the researcher and was checked by the supervisors; this ensured the process of bracketing in place that I did not force my own interpretations while I coded the texts.

3.6.4.5 Working methods of analysis

Delineating meaning units

The first step is to read the transcript to capture the sense of wholeness of the experience described. The text was re-read to identify parts of the text that demonstrated some meaning related to the phenomenon. An example for delineation is the part of the text that describes the narration of the incident on the day of hospitalisation; they were delineated and grouped under breathlessness, chaotic admission and repeated hospitalisation. Data reduction is a way of simplifying the data where the key meaning is isolated from the text (Miles et al., 1994). Delineating meaning units is not a reduction of data, rather it is a method whereby the large transcripts are simplified to manageable chunks of text (Giorgi, 2012). Hence, delineation is a meaningful dissection of the text, which was aided by bracketing, and guided by the relevancy and content of the text.

Transformation of meaning units

After delineating the meaning units, they were transformed into a non-individualistic, third person format and to a scientific language, so that similar descriptions could be integrated to form the general structure (Giorgi, 2012). The number of transformations required depends on the complexity of the description used; simple meaning units do not need to be transformed into a scientific language but some just need to be changed to a third person format. Some complex meaning units needed both kinds of transformation depending on their complexity (table 7). These transformed meaning units become part of the description of the phenomenon. Transformed meaning unit for a transcript is appended (appendix 9).

Table 7 Example of transforming meaning units

Participants' description	**Transformation**
I: the treatment was good. There was no problem with that.	
Torture… giving injections…. taking blood… see here, it's swollen…. So let me go home….I want to see (my) children;	*Getting injection and undergoing blood tests are torture. Hence, she wants to go home to see her children.*
I: all look after well. But how long this treatment will last. Again tiredness, same story, same sickness... same this...	*Despite getting good treatment she feels that it will not last for a longer time and that all problems will come back soon.*

🟧 Texts that do not need to be transformed

🟥 Texts that needs to be transformed into third person

⬛ Texts that need both a third person and a scientific transformation

Description of the phenomenon

The description of the phenomenon consists of synthesising the meaning units using imaginative variation and eidetic reduction to identify the key constituents of the phenomenon. The order of these steps is not exactly sequential because imaginative variation is employed at different stages, to identify the key constituents and sub-constituents and at last to verify the inclusion of all key constituents from the transformed meaning units. The steps are explained below.

1. Imaginative variation

The transformed meaning units are eidetically reduced which is to identify the essential from the non-essential meaning units with the help of imaginative variation. The different aspects of the transformed meaning units are imaginatively varied to identify the constituents of the phenomenon. A constituent is a part that is considered to be the essential part of the structure of the phenomenon (Giorgi, 2008). For example, sleep disturbances during hospitalisation could be imaginatively varied by checking whether sleep disturbance was due to the physical environment of the hospital, such as noise or difficulties in falling asleep due to breathing problem and/or anxiety, to see if this aspect could fit into the specific context of the individual description and whether this forms the essence of the phenomenon. This process of imaginative variation purifies the constituents by eliminating the non-essential to identify the essentials and finds the similarities across the descriptions to form the general structure of the phenomenon (Giorgi, 2009). An example for using imaginative variation is shown in table 8.

Table 8 Identifying constituents

Transformed Meaning Unit	**Imaginative variation**	**Constituent**
He feels that there is no health reason for him to be in the ICU. He is questioning why he should be there just to get the routine treatment. (P13)	‘Being admitted to the ICU’ is one of the feature of acute hospital admission. ICU is part of the hospital and it is common for acutely sick people to get admitted in the ICU. Here, the participant could not understand the reason for ICU admission, as he felt that he wasn’t acutely sick. This fits the phenomenon of hospitalisation and formed the sub constituent of ‘experience of ICU care’.	Perception of care/Experience of ICU care.

2. Identifying the key constituents

After identifying the constituents using imaginative variation, their essentiality in relation to the general structure of the phenomenon was checked by imaginatively removing a particular constituent from the general structure to see if the general structure collapses or a significant, unacceptable change happens in the structure. In this context, imaginative variation of the constituents helps to identify the key constituents. For example, the sub-constituent ‘experience of ICU care’ was imaginatively removed from the general structure of hospitalisation to see if this significantly alters the structure of the phenomenon or not. Though the experience of ICU care seems to be contextual, removing it from the general structure appeared to lose one of the salient features of hospitalisation because acutely sick patients are admitted to the ICU with acute breathlessness. Therefore, this constituent was considered essential for the phenomenon (chapter 4.5). After all the key constituents were identified, the transformed units were checked once again to verify that all of the key constituents were included. Identifying constituents for a transcript is appended (appendix 9).

These identified key constituents are interdependent and this interrelatedness of constituents is partly due to the overlap of the constituents and how they are perceived in relation to the phenomenon. For example, the key constituent, perception of care influenced trust in hospitalisation, both in positive and negative direction. This depicts the interrelatedness of constituents and how these constituents are related to the phenomenon of hospitalisation. This interrelatedness is further explained in the findings chapter (section 4.5).

3. Description of the general structure

The general structure is written, utilising the transformed meaning units to emphasise the description in a scientific, non-individualised format, so that the typical features of the structure could be presented (Giorgi 2012). This generalisation is important to transfer the findings beyond the context from where it was obtained (Giorgi, 1997). So this is not a summary of the findings, rather, the presentation of implicit structure of the phenomenon.

The description of the phenomenon depends on the participant who described it, the cultural situatedness in which the phenomenon is experienced, the researcher's ability to use the language to transform it into a scientific expression, and the researcher's background and experience that determines the articulation of the experience (Giorgi, 2009). However, the influence on the presentation caused by the researcher is minimised by practising bracketing (sections, 3.6.3.7 & 3.6.4.6).

While it is important to present the universal features, returning to the data to find the atypical nature of the phenomenon is also equally important to portray a different presentation of the phenomenon (Giorgi, 1997). These atypical features are presented within the presentation of individual, key constituents to demonstrate the varied presentation (chapter 4.3), whereas the general structure portrays the universal presentation of the phenomenon (chapter 4.4).

3.6.4.6 Bracketing during analysis

When analysing meaning units related to breathlessness, my own thoughts about breathlessness were consciously bracketed to avoid interpreting the participants' description. Whilst the physical aspects of breathlessness were bracketed, I realised that the emotional impact of breathlessness was hard to be bracketed, as I felt I was being affected by my experience of having discussed these aspects with my patients. In this situation, I immediately stopped analysing and wrote down my thoughts and consciously bracketed them. Any new thoughts related to this were updated in the diary and I reflected on it, in order to avoid from interfering (appendix 8). Bracketing is not the issue of completely eliminating the subjectivity, rather, how to suspend it, in order to get a fresh view of the phenomenon (Chan et al., 2013; Finlay, 2014; LeVasseur, 2003).

There are different viewpoints regarding how long the bracketing should be followed in descriptive phenomenology (Chan et al., 2013; Gearing, 2004; Hamill & Sinclair, 2010). Giorgi (2012) advises that bracketing should be followed until the completion of data analysis (Giorgi, 2012). Bracketing is released at the stage of the description of the phenomenon to reintegrate the data to provide a complete description of the phenomenon (Chan et al., 2013; Finlay, 2014). Releasing bracketing at this stage is essential to allow sufficient subjectivity to interpret the data to give a sensible description of the phenomenon (Finlay, 2014; Giorgi, 2012). In this regard, bracketing is to keep the assumptions in suspension and not completely abandon them (Chan et al., 2013; LeVasseur, 2003). Therefore, to follow a complete bracketing is not only impossible, it would become, rather, observing a position of complete 'objectivity' which does not fit for a scientific phenomenological study (Finlay, 2014).

I followed bracketing until the completion of data analysis. The main aim of bracketing is to get a fresh approach of the phenomenon which was achieved at the end of data analysis. At this stage it is essential to release the bracketing to present the description in a sensible and acceptable way and discuss the findings with related literature (Giorgi, 2008a).

3.7 Rigor in descriptive phenomenology

Rigor in qualitative studies encompasses transferability, credibility, dependability and conformability (Mays & Pope, 2000; Shenton, 2004). Transferability is generalisability of findings to other similar contexts and population (Mays & Pope, 2000). Transferability is determined by giving a thick and rigorous description of the phenomenon which enables the transferability of the findings to a similar context (Shenton, 2004). In order to achieve this, collecting quality data is essential to have a sufficient and rich data. The quality of data is determined by selecting the appropriate, informant-rich participants (Fusch & Ness, 2015; Saunders et al., 2017). The appropriateness was achieved through a purposive, homogenous sampling by selecting participants who could provide rich information about the experience of hospitalisation.

Credibility is referred as the accuracy of operationalization of research and the researcher's ability to produce an accurate data (Shenton, 2004). Credibility is facilitated through imaginative variation which allows the researcher to find out the commonalities and eliminate those elements that do not fit; this serves as a purification method to eliminate the possible misjudgement by the researcher (Giorgi, 1988, 2008a). Going back over the transformed units at the end of identifying key constituents is done to ensure that all the key constituents are included. These two methods are incorporated within the analysis to maintain credibility.

In addition, the sufficiency of the general structure is determined by redundancy in the structure and adequacy of description; redundancy is confirmed when returning to the data do not yield any new constituent; adequacy is ensured by thick and rich description of the phenomenon (Giorgi, 2009). The richness is facilitated by giving an elegant description covering the breadth of different aspects of the phenomenon which is enriched by appropriate quotes from the participant; thickness of description is to capture the depth of the phenomenon (Morse, 2015). In this research, the quantity and the diversity of information provided by the participants reflected the sufficiency and the richness of data; further, the description is strengthened by the participants' quotes that captured the salient aspects of hospitalisation.

Practising bracketing enabled both accuracy and neutrality by avoiding researcher's bias. Also, maintaining a personal diary demonstrated a clear audit trail to facilitate the process of different stages of research for verifying the process of analysis (Silverman, 2013). Hence, member checking, peer debriefing was not considered as a measure of strengthening credibility in descriptive phenomenology. Firstly, it is not expected that all participants and the experts may have this particular expertise to give feedback about the phenomenon; secondly, employing imaginative variation and bracketing served as a method of minimising bias, thus improved the accuracy of this research (Giorgi, 2008b).

Dependability is the replicability of findings when the same methods are employed in the same context (Shenton, 2004; Silverman, 2013). Unlike quantitative research, it is rather difficult to reproduce the same findings in qualitative studies, such as the one which examines the individuals' lived experience, because of the presence of inter-subjectivity in the research process which are varied; rather, replicability depends on the context and the perspective in which the data is examined (Englander, 2012; Giorgi, 2008a). It is recommended that the prescribed steps of the methods adopted should be strictly followed to ensure replicability; hence, precisely employing the prescribed steps of Giorgi's descriptive phenomenology itself facilitates dependability.

Conformability is measures taken to ensure neutrality and devoid of biases in the research (Mays & Pope, 2000). Employing bracketing to avoid researcher's previous experiences and assumptions from interpreting the data avoid researcher's bias. Following bracketing from the stage of designing the research until the data analysis facilitated neutrality of this research (section 3.6.3.7 & 3.6.4.6).

3.8 Ethical issues

Ethics approval was first obtained from the Faculty of Health and Medicine Research Ethics Committee, Lancaster University (ID: FHMREC17006) and then submitted to the Institutional Ethics Committee (ID: IEC/169/2016), where the research was conducted in India (appendix 10). Finally, approval from the Indian Council for Medical Research was obtained (ID: 5/8/4-31), as this was the requirement for research sharing the data outside India (appendix 10).

The research was conducted according to the ethical principles of conducting a biomedical research (Lawrence, 2007). Avoiding coercion, non-maleficence, maintaining confidentiality and anonymity are the ethical issues faced in this research which is discussed below.

Coercion

Although the researcher does not have any dependent relationship with the participants, in terms of providing health care, recruitment was done through the gatekeepers to avoid coercion and to respect participants' autonomy. Participants were given sufficient information and time to make a decision as to whether participate. Twenty four hours was considered appropriate to provide sufficient time to decide participation, whilst acknowledging the short hospital stay. The participant information sheet (PIS) was given in potential participants' preferred language after explaining the study (appendix 11). This facilitated an informed decision so that participants were completely aware of the study details and their role in this research. I obtained the written consent from willing participants and this provided an opportunity to address their concerns or doubts they may have regarding the study and, to explain that their participation in the study was completely voluntary. The option of withdrawal from study is stated in PIS and consent form, which was briefed prior to taking consent (appendices 11 & 12). All reasonable measures were taken to avoid coercion. In order to facilitate autonomy, participants' family caregivers could be present during the interview but they were asked not to participate in the interview. However, when the caregivers spoke, their words were recorded but not included in the analysis.

Non-maleficence

Protecting the physical and emotional well-being of participants was given prime importance in this research and appropriate measures were taken to minimise harm to participants. Participants were first approached regarding participation in the study only after they recovered from acute breathlessness. Also participants were not aware of my previous employment as a palliative care physician in the research setting, which could have impacted their decision around participation and/or withdrawal.

Participants were informed that they were free to withdraw from the study and that this decision will not affect any aspect of their treatment.

Interviews were conducted in a flexible manner with small pauses, in order to minimise any potential physical or psychological distress such as breathlessness and being tearful etc. In such situations, they were given an option to continue the interview at a later time. Participants were reminded about the option of withdrawal, if they were unable to continue the interview due to any physical and psychological distress. A distress protocol was followed to ensure the well-being of the participants (appendix 7).

Confidentiality

Only pooled information of participants was used in the final reporting to protect confidentiality; however, participants were explained that using direct quotes from the interviews to enhance the quality of reporting. Also measures were taken to store the data safely to protect confidentiality. Any identifiable data were stored separately from the interview data. Data were stored in the University's shared drive and a back-up in an encrypted laptop to aid analysis. Any details that could identify the participants were removed and numbers were used in the final reporting to ensure anonymity. The translator was instructed about the confidentiality of data and signed the confidentiality agreement (appendix 13).

3.9 Conclusion

In this chapter, the philosophical and methodological approach of this research and the rationale for choosing a descriptive phenomenological approach are presented. Data collection method is described and challenges faced with the translation and conducting a phenomenological interview are discussed.

Giorgi’s phenomenological analysis method is explained using exemplars. Practising bracketing is described under both data collection and analysis to demonstrate how bracketing was practised during the conduct of this research. Also maintaining rigor in descriptive phenomenology and ethical issues pertaining to this research are discussed. The findings of the analysis are presented in the next chapter.

Chapter Four

Findings

4.1. Introduction

The findings of the experience of hospitalisation in people with advanced COPD are presented in this chapter. The chapter begins with the description of the participants' demographic characteristics. The five key constituents of hospitalisation are explicated with quotes from the interview. Then, the general structure of the phenomenon of hospitalisation is presented. Also the interrelationship of the constituents is explained to demonstrate how the key constituents relate to each other and to the general structure of the phenomenon.

4.2. Demographic characteristics

Sixteen participants were approached and fifteen agreed to participate. Data were therefore collected from fifteen participants; five women and ten men. Their ages ranged from 63-81 years (table 9). Of the five participants who required breathing support, four used NIV and one was on nasal oxygen. The average number of hospitalisations over the past one year was three, with a range of 1-5 times per year. The most common cause for hospitalisation was acute breathlessness and a few participants reported breathlessness associated with cough.

All participants were interviewed in the inpatient ward of the hospital. The mean interview time was 26.06 minutes with a range of 20.16 - 30.47 minutes. No new themes emerged after the twelfth interview; hence, data collection was stopped following the fifteenth interview.

Table 9 Demographic characteristics

Baseline characteristics	**N**	**Mean**
Gender		
Female	5	
Male	10	
Age	61-83	66.2
Religion		
Hindu	11	
Christian	4	
Time since diagnosis of COPD (years)	7-15	
Oxygen therapy		
Non-invasive ventilation	4	
Nasal oxygen	1	
Intermittent oxygen	10	
Co-morbidities		
Hypertension	7	
Diabetes	3	
Heart disease	2	
Dyslipidemia	10	
Number of days admitted	2-18	4.73
Hospitalisation in past one year	1-5	2.26
Route of admission		
Emergency department	10	
Outpatient department	5	

4.3 Explication of key constituents

The general structure of the phenomenon of hospitalisation consists of five key constituents that reflect the parts of the phenomenon and the general structure depicts the sum of the phenomenon. The key constituents are illustrated with quotes from the participants' interview (table 10). Some of the key constituents and their sub-constituents have a short description and others are lengthier, which reflect how the participants described these constituents in less or more detail. However, irrespective of the length of description, each constituent remains important to the phenomenon and indicates the multi-dimensional nature of the phenomenon. The particular order of presentation of the key constituents aims to unfold the phenomenon of hospitalisation.

Table 10 List of key constituents

Key constituent	**Sub-constituent**
Experience of admission	*Emergency admission* *Multi-factorial anxiety*
Repeated hospitalisation	*Familiarity* *Being a burden* *Reluctance towards hospitalisation*
Perception of care	*Rewards and burdens of treatment* *The attitude of the staff* Discussing prognosis
Trust in hospitalisation	*Immediate symptom relief* *Impression as a good hospital*
Multi-dimensional suffering	*Unpredictable breathlessness* *Psychological distress* Incurable illness Anxiety and fear *Spiritual distress* A purposeless life Ambivalent thoughts Perspective about God

4.3.1. Experience of admission

The experience of admission is mainly influenced by emergency admissions because of sudden breathlessness.

Emergency admissions

Most participants had an emergency admission in the advanced stage of the disease because of acute breathlessness, which often required immediate treatment. Delays experienced during emergency admissions were due to delays in transfer to the ward. The delays were either due to unavailability of bed or a long queue of other patients waiting to be admitted:

> *"I came morning 9am to emergency department, evening 8pm only I got bed; I had to wait there for a long time."* (P8).

Sometimes, due to unavailability of beds, participants were admitted to the ward against their preference, either to a private or general ward.

Also delays in making decisions as to whether or not participants need admission contributed to the delay. At times, a long waiting time to be attended by the doctor due to high workload in the emergency department caused delays in the treatment:

> *"ECG got over; all got over; after 4.30, doctor came and I said 'sir, I can't [tearful]then he gave one injection, then I was admitted."* (P15).

A few participants expressed that the emergency department physicians were not aware of their medical history, which delayed the initiation of treatment and caused delays and confusion in the treatment decisions. Further, delays in treatment decisions coupled with poor communication of the treatment plan caused considerable anxiety and uncertainty (section 4.3.3). For example, one participant was upset that the doctors admitted him to the ICU without his consent:

> *“No. Nobody explained, I also did not know… my son called up and asked the doctor to know why I needed ICU treatment…”* (P13).

A long waiting time, poor communication and confusion over getting admitted to the ward contributed to a disorganised admission process. Only a few participants were happy with the quick attention and care provided by the doctors and the fast admission process from the emergency department:

> *”When I came to emergency, there were not many patients waiting… so they checked me quickly and admitted me…”* (P13).

Sometimes this varied experience was perceived by the same participants during repeated hospitalisation and at times this depended on the workload of the emergency department. However, participants who had non-emergency admissions did not report any problems with the admission process.

Multi-factorial anxiety

Participants perceived considerable anxiety during hospitalisation, particularly during repeated, emergency admissions. Anxiety was triggered by acute breathlessness (4.3.5), difficulties in complying with hospital procedures and poor explanation of treatment (4.3.3).

Emergency admissions seemed to trigger anxiety because of acute health condition which sometimes caused a feeling of imminent death. Participants were not able to understand how their current health condition would develop, as some participants experienced a life-threatening condition in the past:

> *“…what would happen next, oh my God! The thought of what is going to happen next gives me fear.”* (P5).

Although many participants got used to the hospital procedures in the course of repeated hospitalisation, such as the routine nursing procedures and tests, a few participants expressed difficulties in complying with the hospital procedures, which caused anxiety:

> *"… but they were not allowing me to go to the toilet; I've never used bedpan. I couldn't pee in the bedpan… I was tensed. "* (P8).

Undergoing tests during emergency admissions was another cause for developing anxiety; both the test itself and the outcome of tests which would determine the treatment plan contributed to anxiety:

> *"…then they took the blood test… they did the entire test; I had to wait not knowing [test results] what will happen."* (P13).

Emergency admissions often involved quick medical decisions and immediate treatment which at times, can be overwhelming and these could cause anxiety. Multi-factorial anxiety caused uncertainty around the future and contributed to psychological and spiritual distress which is discussed in section 4.3.5.

4.3.2 Repeated hospitalisation

Although participants developed familiarity and felt safe during hospitalisation, at times, they were reluctant to get hospitalised.

Familiarity

Most participants expressed a sense of familiarity with the usual places in the hospital, the staff and the routine procedures of hospitalisation during the course of repeated hospitalisation. Familiarity to the usual places in the hospital, such as the emergency department relieved the fear related to hospitalisation:

> *"…this is usual…my usual place [emergency department] that I come and go..."* (P13).

Also being familiar with staff helped developing a good relationship with them, which gave a sense of being cared for:

> *"I know the doctor very well… he came forward to give treatment with great effort."* (P4).

Further, familiarity with staff created a sense of safety that their problem would be taken care of. Feeling safe reduced anxiety and gave a hope around future:

> *“They [doctors] give good treatment during emergencies…I came to this hospital because I had hope in them…now I get the belief that I will survive for some more days.*” (P6).

Feeling safe and being cared for helped developing trust with staff. Some participants felt that immediate attention gave a sense of control that their health condition would improve:

> *“All doctors surround me and check me… whatever needs to be given they give that immediately; they know everything about me.”* (P15).

Having gone through the routine hospital procedures during repeated hospitalisation also created a familiarity for participants. For example, frequent admissions through emergency department seemed to create a familiarity to the routines and procedures regularly performed:

> *“…usual procedures only…as soon as I came, they checked me… they gave me injection, then oxygen, then they took the blood tests…”* (P13).

Also familiarity to the procedures in the inpatient ward such as the nursing routines helped in reducing anxiety related to hospitalisation. Although familiarity to places, people and procedures in the hospital had a positive impact on the experience of hospitalisation, a few perceived the routines and procedures as troublesome, which are discussed under the sub-section, reluctance towards hospitalisation.

Being a burden

Repeated hospitalisation caused a considerable financial burden to participants. Further, frequent emergency admissions were more expensive than ordinary admissions which drained their financial capital. Some participants perceived that the financial burden caused by repeated hospitalisation prevented them from accessing the best care and treatment they wanted, such as being admitted to a private ward, which was considered to provide individualised and immediate attention:

> *“I can’t work. Everyone has financial struggles. So I can’t afford the best treatment.”* (P6);
> *“...now I couldn’t earn anything, so I usually prefer to get admitted in the general ward.”* (P10).

Participants felt that they were burdening their family as the family provided care and paid the hospital bills, in addition to the care they provided at home. Repeated hospitalisation increased both care and financial demands on participants' families:

> *"I keep coming back [to hospital]. Where can I go for money? Why should I be a burden to others?"* (P2).

A few participants expressed that they missed their role in the family while being hospitalised. They felt that they were unable to fulfil their family responsibilities, such as being able to cook for the family and looking after grandchildren:

> *"Because all [family members] go to work, four [grand] children are with me from morning until night...that is what I miss nothing else."* (P13).

Although participants felt being a burden to their family, the involvement of family members in providing care and treatment decision-making was a great encouragement for them. Some participants had support from their friends as well, which helped them cope with repeated hospitalisation:

> *"...my son comes along, my wife comes with me…I've my friends; I will take one of them to the hospital..."* (P1).

Being a burden to others caused a perception of dependency and helplessness and a few expressed a wish to die, which is discussed in section 4.3.5.

Reluctance towards hospitalisation

While hospitalisation provided a sense of familiarity and safety, the perceived burdens related to hospitalisation caused unwillingness for hospitalisation. A noisy hospital environment and the need to comply with hospital routines contributed to reluctance towards hospitalisation. Generally, the hospital environment was perceived as noisy and dirty, which caused a negative impression about hospitalisation. Particularly, noise from neighbouring patients and medical equipments caused sleep disturbance during hospitalisation:

> *"When neighbour patients make noise...snore like 'ghorr.. ghorr' like tearing the whole building apart… I try to tie a towel around my head… I even thought of plugging my ears with cotton…"* (P12).

A few participants expressed that they preferred not to get hospitalised due to the unclean hospital environment:

> *"The murmurs, noises, messes… of course it can happen… but I don't want to get admitted. NO ADMISSION."* (P3).

Complying with hospital routines was perceived as troublesome despite accepting their necessity. Undergoing many investigations and being subjected to frequent tests, such as drawing blood caused inconvenience, although they were perceived necessary:

> "*They take blood tests; wake me up at 4 am in the morning. Then, I go to sleep; again some other staff comes and asks for tests. But they have to do their duty, I can't complain about it.*" (P3).

However, participants seemed to understand the necessity of hospitalisation and, therefore, accepted the inevitability of hospitalisation:

> *"…what can I say…that shall I remain at the hospital because I think that if I am at hospital, I will be fine or shall I remain at home thinking that if I remain at home that I would become alright?"* (P11).

Difficulties in complying with the hospital routines and, unclean hospital environment caused negative impression towards hospitalisation. Nevertheless, it was perceived that these inconveniences were unavoidable during hospitalisation.

4.3.3. Perception of care

Care during hospitalisation underpinned the experience of hospitalisation; the experience of treatment and the attitude of the staff during hospitalisation seemed to influence the care experience.

Rewards and burdens of treatment

The experience of treatment influenced the care experience during hospitalisation. Treatment was regarded as effective if it brought immediate relief and enabled participants to do their daily activities such as bathing, independently. Immediate medical attention was perceived to bring back the ability to breathe normally and relieved the feeling of imminent death:

> "..*immediately the doctor came and gave me injection… otherwise, I would have gone [died] that night itself, isn't it?"* (P7).

Further, timely treatment was regarded beneficial to carry out the daily chores independently, also simple tasks such as being able to speak or walk without other's help:

> *"…immediately…within 12 hours I get ready to the point that I could go for a walk and get up from the bed*." (P13).

Both timely treatment and the expertise of the staff were considered to be efficient treatment. Efficient treatment enabled independence in a short time and to return to normal life:

> *"…for wheezing that is worse, they [staff] give urgent treatment… just two days are sufficient for them… they change me to a normal man and send me..."* (P15).

Most participants expressed a quick relief attributing to the expertise of the staff which also facilitated developing trust with staff, as well as trust in this particular hospital (section 4.3.4).

However, the requirement of repeated treatment caused physical and psychological discomfort. While treatment brought immediate relief, participants were aware that the effect of treatment would not last for a long time and, understood the need for repeated treatment due to the nature of illness:

> *"I am OK now... within two days I will go home; but it may come again. I think so… I know that also."* (P3).

Nevertheless, participants co-operated with treatment procedures and acknowledged that tolerating such difficult treatments were necessary to get well. They withstood uncomfortable postures and, tolerated pain and other intimidating procedures, despite those being difficult:

> *"Sometimes I get irritated when they [staff] frequently ask me to move this side and that side; but I understand the necessity of the treatment."* (P3).

A participant expressed that he decided to tolerate the discomfort of being connected to the NIV machine all through the night:

> *"…they [staff] asked me to take oxygen all through the night, and I followed it; They advised considering my safety only know."* (P10).

The ICU treatment was perceived as difficult, especially the ventilator treatment which caused physical discomfort and anxiety. Having tubes inserted all around the body and being hooked on to the oxygen machine created a sense of isolation:

> *"At times I feel why this hospitalisation? They have put tubes everywhere; I can't move this or that side. It was very painful."* (P4).

Further, facing difficult treatment without being aware of the outcome caused anxiety and a fear of death. A participant expressed that he was not aware of the reason for the ICU admission that caused anxiety and uncertainty:

> *"No… nothing they [staff] said… gave nebulization… and after that they did not come near me; just for nebulization, why should I be in the ICU?"* (P15).

Further, participants expressed that they were not involved in the treatment decision involving invasive ventilator due to physical inability and drowsiness. In this context, participants accepted the decision made by the staff with their family members:

> *“I was unconscious when I was admitted in the ICU… on the machine; it was painful but they [staff] did all that considering my health, so I had to accept it.”(P4).*

While treatment was regarded as beneficial, at the same time, it was also perceives as burdensome.

Similarly, undergoing tests during hospitalisation caused mixed feelings. Participants realised that the purpose of tests was to diagnose the underlying problems which relieved the fear of the unknown. However, at times, the thoughts of a negative outcome of the test, caused anxiety:

> *“I do fear… suppose, if something contrary happens to what I think…”* (P12).

The efficiency in conducting tests was related to a clear explanation of the tests and precision in doing the tests. Participants were happy with the efficiency in conducting tests and felt that they were offered utmost care while undergoing investigations:

> *“Here, for each and every procedure or test, there are concerned people who take care of that...”* (P9).

Overall, participants had a good impression of undergoing tests, although there were difficulties inherently associated with certain types of tests:

> *“I feel so irritated; they [staff] change my positions…keep shifting me to various test”* (P3).

Treatment and tests caused mixed feelings which impacted the experience of hospitalisation variedly.

The attitude of the staff

The caring attitudes of the staff gave a sense of being cared for during acute breathlessness. Immediate attention, providing dedicated care by taking account of every small detail, listening and taking time to explain the treatment plan facilitated both a good relationship and development of trust with staff. Participants felt that the staff provided good care, despite being busy and did everything to restore their health to normal:

> *"The way the doctors treat us and the quick response, that itself makes me feel happy*." (P3).

Timely and dedicated care given during acute breathlessness was much appreciated and gave a sense of being cared for:

> *"…they bring me back alive madam, here, they check all the 'pulse and nerves' ['Naadi narambu'- check everything diligently] and give good treatment; even if I came with the worst illness, they revived me like God."* (P15).

Actively listening to their concerns and involving them in the treatment decision-making were felt essential for good care. Also communicating in the participants' native language was considered to have a clear understanding of treatment that influenced the care experience:

> *"My doctor is super...he listened to everything what I said and spoke in my language."* (P12).

Most participants expressed satisfaction with nursing care that the care was timely and adequate enough to meet the needs of care during hospitalisation. Although there were some minor issues related to care, participants tried to ignore them and acknowledged the presence of imperfections in care due to the care demand imposed on the nurses:

> *"…their [nursing staff] smile, their immediate response and everything was good. I consider it to be the best medicine. Sometimes there were little problems. But I didn't take that as a big issue."* (P3).

The caring attitude of the staff encouraged participants to both engage actively in the treatment and develop trust with them. Participants wanted to follow the advice of staff, although it was hard to follow at times. Participants also felt that their efforts to taking part in the treatment were necessary for good treatment experience:

> *"…they [staff] treat depending on our co-operation… if we co-operate well, the treatment is also good…"* (P12).

On some occasions, the unpleasant attitude of the staff such as not paying attention, ignoring emotional concerns and failing to explain treatment plans caused emotional upset to the participants. Being sensitive to the emotional concerns was perceived to be as important as the need for physical treatment:

> *"…when I have fear, they [staff] don't ask and I don't tell either."* (P2);
>
> *"But at times when I call them they don't respond immediately. Then, I get tensed."* (P6).

One participant recalled a past experience in another hospital where a lack of empathy and an unconcerned attitude of the staff were reported:

> *"At some hospitals, doctors are good but nurses don't speak well, they don't behave well*…" (P12).

The unfriendly attitude of the staff reduced trust with staff which had a negative impact on the care experience. This experience was varied and depended on the competency of the staff.

Discussing prognosis

In general, not all participants seemed to have a complete understanding of their disease condition. Although participants did not explicitly express an interest to knowing the disease prognosis, they wanted the doctors to initiate the discussion of prognosis, as they felt that only doctors could identify the ideal time to discuss:

> *"I don't ask usually; unless, I am very particular to know about something; they [doctors] are here to tell me, if there is anything that I should know."* (P9).

In this context, participants emphasised the importance of using effective communication skills. A participant, who faced an unpleasant disclosure of his illness, expressed that the doctor was very direct and abrupt; the doctor neither bothered about his wife's presence nor asked the consent of the participant before discussing the prognosis:

> *"A doctor told me that 98% of your lungs are dead [laughs]; my wife cried...for me, nothing [not hurt]; he [doctor] is saying right on my face while my wife was with me."* (P8).

Being insensitive to participants' emotion when communicating their prognosis and failing to discuss future treatment plans were perceived as being indicative of an uncaring attitude. This participant was unhappy with the attitude of the doctor:

> *"…no…doctors didn't say [speak] anything; they give me injection… give tablets; check with machine…"* (P11).

Some participants, especially smokers, perceived that the explanation of the causation of the disease was helpful to modify an unhealthy lifestyle; however, non-smokers felt the causation was not well explained to them:

> *"what I need and don't need' I should know about it; then take the treatment and follow the advice… that's what I expect."* (P12).

However, there was often a lack of understanding of the disease causation and complete picture of prognosis and treatment plan. Some did not know the name of the disease or about the disease course:

> *"Doctor said that 'the illness is like that… because of the rainy season you are affected, I know nothing else."* (P2).

Communication skills seemed to be important in discussing prognosis with the participants. Failure to provide the information about prognosis and future treatment plan seemed lacking and often caused a perception of inadequate care during hospitalisation.

4.3.4. Trust in hospitalisation

Trust in hospitalisation seemed to influence the decision of hospitalisation to access treatment for repeated breathlessness.

Immediate symptom relief

Immediate relief from acute breathlessness improved independence in doing daily activities during hospitalisation and relieved anxiety and fear of death:

> *"…the confidence that I can do things myself... [sighs]… today I can talk without problem…"* (P15);
>
> *"I wouldn't have been alive if I wasn't here in this hospital."* (P7).

For some participants, the feeling that they have reached the hospital itself gave a sense of hope that they will get help for their acute condition:

> *"…no fear because I reached the hospital; the atmosphere itself gives me the confidence that I will be healed."* (P3).

Immediate symptom relief was one of the main reasons for returning to the hospital for continued care, which established trust in hospitalisation. Further, communication skills and attitude of the staff also seemed to be important in developing trust in hospitalisation (section 4.3.3).

Also seeing other people with similar suffering in the hospital encouraged them that they were not alone in their suffering. Observing other people being cared for well and watching those getting better seemed to strengthen participants' confidence in hospitalisation:

> *"…the person next to me also has same problem; he got well by 70%... a good and God's [Christian] hospital."* (P15).

These factors improved trust in hospitalisation itself and also played a role in choosing a particular hospital over the other which is discussed next.

Impression as a good hospital

Decisions about which hospital to attend were informed by good impressions from past experiences and opinion from family and others. A high chance of getting cured and advanced care created a good impression on a particular hospital that helped participants decide which hospital they would access for care:

> *"I come with belief… otherwise, I wouldn't have come here, there are so many other hospitals and I could have gone there."* (P12).

Also participants' previous, good experience of hospitalisation in this particular hospital shaped the trust in hospitalisation. Participants valued a dedicated care provided by the hospital:

> "*If I go to another hospital, leaving this hospital, it won't get better…hmm…. it gets worse and not better."* (P15);
>
> *"Here, they make sure that the patients get relieved. I came to this hospital because I had hope in them*." (P6).

Although most participants were from a Hindu religious background, their personal opinion that Christian hospitals provide good care increased the hope of getting well which influenced the trust that they had in this hospital:

> *"...especially because this is a Christian hospital; I was hopeful that I will get cured..."* (P3).

Further, healthcare cost seemed to be the determining factor for several participants. Participants experienced an unreasonably high healthcare cost and a poor quality of treatment in other private hospitals:

> *"I went to a nursing home [small private clinic with outpatient and inpatient facility] and they kept on giving me IV fluids and charged me with 249£; here, they don't do like that…"* (P8).

Also facilities available in the varied types of hospital, public and private and, expertise of the staff also influenced the decision of choice of the hospital. Participants had an unpleasant experience due to incompetency of the staff in both private and public hospitals:

> *"No.it is neatly done here…all equipments are available here…drawing blood is pretty smooth. In private clinics… they employ trainees… they pricked me somewhere and all." (*P8);
>
> *"I was admitted in some government hospital earlier; I didn't like it even a bit... they don't look after well…"* (P9).

Opinion from other people who were admitted previously to this hospital encouraged trust in the particular hospital where the study was conducted. The opinion of family members and friends also played a role in the decision-making of choosing this particular hospital. The main reason for family members to recommend this particular hospital seemed to be the belief that this hospital holds the value of Christian religion which suggested offering good care and the belief of high chances of getting well, compared with other hospitals in the city:

> *"…that belief that this is a Christian hospital. Also my mother-in-law has faith in this hospital."* (P12).

Both individuals' experience and their family's opinion about the hospital, which relates to the perceived moral and religious values of the hospital, seemed to be important to develop trust in hospitalisation and also in a particular hospital.

4.3.5. Multi-dimensional suffering

Suffering is multi-dimensional affecting the physical, psychological and spiritual aspects of the individuals.

Unpredictable breathlessness

Participants suffered from breathlessness constantly in their advanced stage, with frequent, acute exacerbations of breathlessness requiring hospitalisation. Breathlessness was often sudden and its unpredictable nature and severity devastated participants' daily life. Participants described the experience of breathlessness in many different ways: a choking sensation in the throat, a pulling sensation in the chest, a sensation of heaviness and or tightness, perception of a rock-like chest or extreme difficulty in inhaling air. For some it was an intense struggle just to take a breath. Following descriptions depicted the severity of breathlessness of individuals:

> *"I feel as if it is blocked [breath]; air is not getting inside; it keeps coming outside [of the breathing passage]."* (P7);
> *"…'haa..haa. huss' like that [showing it] it pulls; it keeps pulling like this; never stops…"* (P12).

At times, participants faced embarrassing situations as episodes of acute breathlessness were unpredictable; for example, getting breathlessness in the toilet or in similar situations seemed to impact their dignity, as they hesitated to ask for help, especially the male participants from the female nurses:

> *"… it comes suddenly [breathlessness]. What am I supposed to do then? Whether I am going to pee or poop now [without control], that kind of feelings."* (P1);

> *"…when it (wheezing) comes, in the toilet, sometimes I think it is better to die…"* (P8).

Most participants experienced anxiety during breathlessness, which is further discussed under psychological distress.

Fatigue accompanied breathlessness which limited participant's mobility. Fatigue restricted the ability to do the simple daily tasks, such as eating, which caused dependency on others. Extreme fatigue also changed the way they used to do a certain task, which caused psychological distress:

> *"…if I walk a quite a small distance, to the toilet, then, my chest is blocked. I have to sit for a while, before I walk again…"* (P10);
>
> *"…I wish no one suffers like me. Nobody should have like this."* (P6).

Further, extreme fatigue caused physical dependency that caused feelings of helplessness. Feeling of low self-esteem and being a burden to others seemed to prevail during fatigue:

> *"…if I sit, I can't get up…can't walk…can't take bath…can't wash my face."* (P11)*;*
>
> *"Why am I like this? How long my children will take care of me?"* (P2).

Another concern was losing one's role in the family due to weakness that impacted participant's self-worth. The following conversation sheds light on the participant's inability to play the role of a grandfather that he wanted to be:

> *"'WASTE'…. I can't carry my grandson here [showing the chest, tearful]. I make him sit over here [showing the shoulders]."* (P8).

Fatigue with dependency had a negative impact on the psychological and spiritual aspects of the individual which is discussed in the following section.

Psychological distress

Incurable illness

Participants realised over time that their illness was incurable; this was because of deterioration of their health, despite treatment and recurrent, acute physical symptoms that caused progressive weakness. Enduring fatigue and dependency seemed to be the indicators of incurability:

> *"…my life has become somewhat [pause] illness is there. Tiredness is there. It has been there [for a long time]…"* (P11).

Some participants perceived a strong indication from their fellow patients that their illness would not be cured:

> "*I don't have belief. Nobody has that belief… it can't be cured. No. I have seen 150-200 people.*" (P1).

Interestingly, most of the participants did not seem to have had a discussion about their health condition (section 4.3.3).

A few participants expressed their understanding of the incurability of illness through metaphors. The following interview excerpt explains a participant's view about the nature of illness and the need for optimum treatment. If rice is boiled too much it won't get cooked; in the same way, if the illness is over-treated the body may not tolerate it; if water is added when the rice is boiled, then it cools down the temperature, also allows sufficient time to cook well; similarly, the treatment needs to be given to bring down the intensity of symptoms:

> *"when we add water, we do it because the rice is cooked; when it boils down, if we add water then it will cool down; rice also gets cooked completely; it's like that; this illness also like that; when it is more, we have to take treatment; otherwise, just leave it; try to reduce it; if we try to over treat it, it doesn't take; whatever is inside will come out."* (P2).

This indicates the self-realisation of incurability through participants' personal experience of living with the illness rather than a discussion with their doctors.

Anxiety and fear

Fear and anxiety were the most common forms of psychological distress experienced during hospitalisation. In general, participants expressed anxiety during breathlessness due to varied reasons. Some thought that it was natural to get scared during breathlessness, as severe breathlessness itself was thought to cause fear and anxiety:

> *"…when you can't breathe, getting scared is natural, isn't it? when I can't do anything about it; then I get scared."* (P7).

For a few participants, being alone in the hospital bed during breathlessness caused fear; in this situation, fear was relieved when they talked to someone or called for immediate medical attention. The fear of the unknown sometimes triggered a panic attack and uncertainty. A participant described a panic attack during breathlessness, especially being alone when breathless, as following:

> *“when I have fear I don’t know what’s happening to me…fear…fear…only fear is more… nothing else…!”*(P11).

Also perceiving acute breathlessness as life-threatening caused fear of death:

> *“...I get scared because of that… what might happen later… how things...”* (P11).

However, participants felt that they could not express their fear to anybody during hospitalisation, as they felt staff may not be able to help with the fear and the staff were primarily to take care of physical symptoms:

> *“I don’t tell anybody; what can they do, even if I tell…nobody can do anything about my fear…”* (P14).

Perception of incurability and sensation of imminent death during acute breathlessness caused considerable spiritual distress, which is discussed below.

Spiritual distress

Feeling a purposeless life caused death wishes during acute breathlessness. Searching for the purpose of suffering through individual’s religious belief helped accept suffering.

A purposeless life

Participants reflected on the purpose of life when they experienced immense suffering while being hospitalised. Being useful to the family and others and the ability to lead an independent life without burdening others were perceived to provide a purpose in life; however, considering that they might have a purposeless life caused anguish. Perceiving life was purposeless created a sense of emptiness in life and also questioned the value of life:

> *"Why should I be alive? So far I've worked hard; what am I going to earn hereafter? Am I going to buy some land or a car? Why should I be alive? [pause]. Or am I going to work hard like carrying heavy loads? Or am I going to defend when strong men come to pick up a fight with me? why should I be alive? whatever it is, let me end here [his life]."* (P9).

Considering the view that life was purposeless, participants wanted to let go of life. Some individuals expressed that they were not afraid of dying and would like to live until the time meant to live for individuals by God. Some participants perceived death was better than living with suffering every day, while a few other perceived living with suffering differently. They wanted to help others, rather, being helped by others so that they could see a purpose in living:

> *"…when the time comes, I will go; if my time is good, I will be alive for some more time."* (P9);
>
> *"…no no; I don't depend on anybody, I want to help others but do not want to take help from others…"* (P13).

Perceiving that life was purposeless, participants searched for the meaning of life. Reflecting on the fulfilment in life encouraged them to have hope for future. For most participants, being able to complete their family duties, such as raising children, providing education and seeing them married were regarded as important duties in the Indian culture. Reflecting on completing the family responsibilities gave a sense of fulfilment in life:

> *"I raised my children all alone. I gave my two children a good education..."* (P7)

Thoughts of fulfilling family duties were helpful in overcoming the feelings of purposelessness and seemed to find meaning in life. However, these thoughts were often shadowed by despair and a wish to die.

Ambivalent thoughts

For participants, life goals were centred on their family and being able to complete family responsibilities seemed to provide the source of hope. Living until completing these responsibilities encouraged hope and participants looked forward to enjoying the milestones of the family:

> *"…whether it becomes cured or not, I need to be alive now; I have to get my son married, I have to be around."* (P2).

Although the desire to live encouraged the hope for a longer future, uncertainty of illness seemed to take away that hope, so participants were caught between a glimpse of hope and worries about the future. These thoughts seemed to alternate and reoccur, with some participants feeling constantly being caught in contradicting cycles of despair and hope:

> *"What is this illness and cough; I wish to do something to end my life [pause] let me see for another two or three years; I want to see my grandchildren; then, I will lay that idea back."* (P9).

For some individuals, letting go of life triggered death thoughts during extreme breathlessness and created a sense of helplessness and vulnerability. Furthermore, some participants thought that it was natural to think of dying during extreme suffering. Feeling worthless and being a burden to others seemed to cause a death wish:

> *"…what can I do hereafter? That's why, I don't want to be alive. I want to die."* (P2);
>
> *"I want to die [laughs loudly].I am not useful for anybody [pause] for people who look after me also difficult...that's it."* (P8).

While realising that the end was approaching sooner, the desire to be around to see the family milestones encouraged the participants to strive to live; a few participants expressed their wish to live well, with whatever time remained to live. To live well meant, to love and to be loved by others and not being a burden to others:

> *"… even if a few days that I live I want to be happy. I want to make peace with all my enemies and friends and love every people whom I meet."* (P6).

Realising a purposeless life caused death wishes, but finding meaning in life brought a desire to live well until death. The ambivalent feelings of a 'wish to die and to live' and, 'despair and hope', seemed to co-exist.

Perspectives about God

Participants from both the Hindu and Christian religions showed faith in God that God was in control of their lives and nothing can happen without God's control. Hindu participants seemed to relate their suffering to 'karma' which is the belief that suffering happens due to sins committed in the past life; this belief in karma helped them accept the suffering:

> *"…[sighs]… I don't know what 'karma' I have done in the past [sins of the past life], god has confined me [with illness]."* (P11).

Christians viewed their suffering as punishment for their sins and they wanted to seek forgiveness from God and others. For this participant, restoring a harmony in relationship with both God and others seemed important:

> *"I pray to God that if I have done any mistakes let the world forgive me. If the mistake was unintentional I'll get forgiveness. If the mistake was intentional then I will be punished for that..."* (P6).

Many participants believed that disobeying God could be the reason for suffering but having faith in God could answer their prayers for a wish to live. A few participants felt that trusting God was to surrender everything to God and, continuing to trust God, despite the suffering, realising that only God could save them from their suffering. Both Hindu and Christian participants believed that having undoubted faith in God could answer the prayer for healing:

> *"…despite I am suffering like this, I am building a temple with the help of my friends… I want to go there."* (P1);
>
> *"He [God] may or may not cure you. But He shows you the path. He may not give prescription for this and that problem. Instead He shows you the ways that's all; and we are supposed to follow that path."* (P6).

Also performing religious rituals were considered to bring answer to prayers and also to gain control over the situation by performing rituals. Hindu participants also believed that performing rituals as a way of purifying their sins and prepare them to eternal life:

> *"I want to go to the temple and worship to get some 'punya' [cleansing of sins]…'Oh Shiva [name of a Hindu god]. I am unable to do that now…what to do."* (P11).

Although participants showed faith in God, a few participants questioned God due to the constant suffering they had to endure. However, they continued to believe in God, despite suffering:

> *"…what is this God? Either take away [my] life or cure… do it at once. I don't want this pain [disease] Only God is there to save me [tearful] [pause] Why God did this to me?"* (P4).

Thoughts of death and dying seemed to connect with the religious beliefs held by the participants. All participants seemed to accept death as part of life and that God controlled both one's life and death. In general, participants were not worried about death but rather the way death would happen. Having a peaceful death such as dying in one's sleep and without much suffering was considered as a good death:

> *"I don't worry about death; even today itself if I die when I am asleep, no problem; I shouldn't die being ill and bed ridden"* (P12).

Both Hindu and Christian participants seemed to find meaning even in their suffering and that suffering was a way to 'moksha' which is eternal life. For a few participants death was viewed as a way of ending the suffering:

> *“I consider that God has given me this as redemption for my sins. When I take my last breath let Him give me the good place. ”* (P7).

In general, religious belief helped people accept suffering and death as part of the life and participants continued to trust God despite suffering, to have a peaceful death and eternal life.

As per Giorgi’s analysis method, the general structure of the phenomenon of hospitalisation and the interrelationship of five key constituents are presented in the next sections.

4.4 General structure of hospitalisation

The experience of hospitalisation is characterised by repeated hospitalisation, which is frequently an emergency admission because of repeated, acute breathlessness. Emergency admissions are perceived to be chaotic, due to delays in admission and treatment and poor communication, which caused anxiety. Repeated hospitalisation provides immediate symptom relief and creates a familiarity towards hospitalisation. Nevertheless, the feeling of being a burden to the family in terms of care and financial support and, difficulties in complying with the hospital procedures causes reluctance towards hospitalisation. Perception of care underpinned the experience of hospitalisation which is shaped by both care and treatment provided and, the attitude of the staff. The care experience is varied, both positive and negative, depending on the expertise and the attitude of the staff. Trust in hospitalisation is determined by a good care experience and a good impression about the hospital which was informed by the values and principles held by the hospital. Progressive illness and repeated, acute breathlessness cause multi-dimensional suffering affecting the physical, emotional and spiritual aspects of individuals during hospitalisation. Repeated, acute breathlessness is associated with anxiety which causes uncertainty. The dual feelings of wishing to ‘live and die’ and ‘despair and hope’ reflect the oscillation of emotions during intense suffering. Faith in God and following religious rituals are helpful to cope with the suffering during hospitalisation.

4.5 Interrelationship of constituents

The interrelationship of constituents is explained using imaginative variation (chapter 3.6.4.5) to demonstrate how the key constituents connect with each other and to the general structure of the phenomenon.

Experience of admission sets the beginning of experiencing care in the hospital, as this is usually the first point of contact for hospitalisation. Participants begin to experience the sense of hospitalisation from the time of admission. The initial care experienced during emergency admission differs from that of a routine admission, as emergency admission requires immediate attention. Imagining the general structure of hospitalisation without the experience of admission might obscure the care provided in the emergency department, which is an essential aspect of care during hospitalisation. Therefore, removing this constituent could cause a deficiency in the core structure of hospitalisation.

Repeated hospitalisation is the main feature of the experience of hospitalisation because acute breathlessness required repeated hospitalisations, which are mostly emergency admissions. Removing the constituent of repeated hospitalisation from the general structure would also lead to the removal of experience of the admission because repeated hospitalisation necessitated the admission process. Furthermore, removal of these two constituents from the general structure could lead to the collapse of the general structure of hospitalisation, as these two constituents set the context for the experience of hospitalisation. Therefore, repeated hospitalisation and experience of admission are interrelated and together they contribute to the phenomenon of hospitalisation.

Perception of care is the core element of hospitalisation as participants required a continuum of care for recurrent breathlessness. Good care during hospitalisation seems to improve the trust in hospitalisation, as care is the main decision-making factor for choosing a particular hospital. Insufficient care reduces the trust in hospitalisation. Hence, care during hospitalisation seems to influence the trust in hospitalisation and these two constituents have a bidirectional relationship (figure 2). Therefore, removal of this constituent from the structure of hospitalisation could lead to the removal of trust in hospitalisation, which may impact the general structure. In addition, perception of care has indirect connections with the experience of admission, as care begins from the time of admission. Hence, these three constituents, the experience of admission, care and trust in hospitalisation, together establish a strong connection to the structure of hospitalisation.

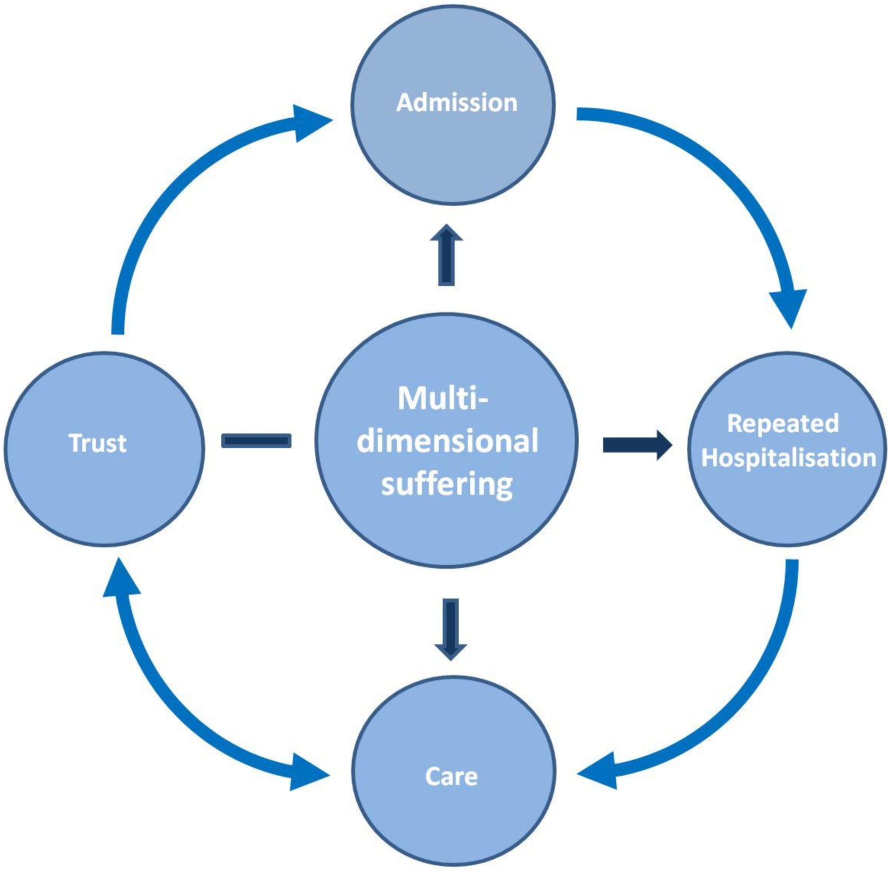

Figure 2

Interrelationship of key constituents

The ongoing suffering requires a continuum of care which shows the connection between the constituents, perception of care, repeated hospitalisation and experience of admission (figure 2). In this context, care during hospitalisation is essential to relieving the suffering, which determines the trust in hospitalisation that plays a major role in deciding on a particular hospital to access treatment. It is, therefore, understandable that multi-dimensional suffering has a complex relationship and interplay with other constituents of hospitalisation, repeated hospitalisation, experience of admission, perception of care and trust in hospitalisation. Hence, multi-dimensional suffering is the central constituent that has a considerable contribution to the general structure of hospitalisation along with the other four constituents.

4.6 Conclusion

The findings demonstrated that multi-dimensional suffering is central to the experience of hospitalisation. Care and suffering, have a bidirectional relationship and both have a considerable impact on the experience of hospitalisation. The description of the general structure of hospitalisation is presented to understand the universal features of hospitalisation. The interrelationship of the constituents showed the relationship between the key constituents and their collective contribution to the general structure of hospitalisation. The findings are analysed with other literature and presented in the next chapter.

Chapter Five

Discussion

5.1 Introduction

The research aims to study the experience of hospitalisation in people with advanced COPD. The findings show that the phenomenon of hospitalisation has five key constituents: experience of admission, repeated hospitalisation, perception of care, trust in hospitalisation and multi-dimensional suffering. In this chapter, the findings of hospitalisation are discussed in relation to literature in other chronic illnesses, with a special focus on psychological distress and coping. The reason for the perception of hospitalisation as a negative experience is explored and the conceptualisation of hospitalisation in advanced COPD is discussed.

5.2 Repeated hospitalisation and anxiety

The important feature of hospitalisation in advanced COPD is repeated hospitalisations which were often emergency admissions due to acute breathlessness. Globally, acute breathlessness in advanced COPD is the second most common cause for repeated, emergency admission, which resonates both with the literature review and the findings of this empirical research (Bartels et al., 2018; Bottle et al., 2018). This empirical research found that repeated hospitalisation is associated with anxiety which is multi-factorial and contributed by acute breathlessness, uncertainty and difficult treatment.

Many studies have found that breathlessness and anxiety in advanced COPD are interconnected (Gardener et al., 2018; Maddocks et al., 2017; Pooler & Beech, 2014). This empirical research found that anxiety was associated with acute breathlessness during hospitalisation. Acute breathlessness was perceived at times as life-threatening, which triggered anxiety, which in turn increased breathlessness; this sets in place a vicious cycle of breathlessness and anxiety (Baliley, 2004). Anxiety caused the perception of loss of control over the situation which leads to uncertainty for the future (Lovell et al., 2018). In this empirical research, experience of loss of control during acute breathlessness blurred the participants' future view of their health condition, as many of them had experienced breathlessness in the past which became serious. Sense of powerlessness seemed again to increase anxiety and persistent anxiety increased breathlessness (Rosa et al., 2018). People experienced an intense loss of control and hopelessness at the end stage of COPD because of the unpredictability of breathlessness and declining health (Lovell et al., 2018; Rosa et al., 2018). However, the perception of uncertainty was prominent while being hospitalised with acute breathlessness. The inability to plan events, due to the unpredictability of breathlessness and its outcome, caused uncertainty and expectations of a bleak future (Lovell et al., 2018). This empirical research showed that participants could not plan events such as visiting shrines which caused a perception of a purposeless life. This indicated that the perception of uncertainty was one of the strong triggers of anxiety during repeated hospitalisation (section 5.6). Acute breathlessness, feeling of loss of control and perceived uncertainty contributed to anxiety during hospitalisation.

Difficult treatment and poor explanation of treatment plans were the other contributors of anxiety during hospitalisation. Undergoing difficult treatments such as NIV or ICU treatment caused anxiety because these treatments created considerable physical and psychological discomfort and a financial burden (Christensen et al., 2018). Participants expressed anxiety and a sense of isolation when being treated with the ventilator which also caused a considerable financial burden to the participants and their family (chapter 4.4.3). Secondly, a lack of information about the treatment plan caused anxiety (section 5.3). People with advanced respiratory illness experienced poor communication especially during emergency admissions which reduced trust with the treating staff (Bailey et al., 2016). Reduced trust caused anxiety and increased uncertainty around the future (Rosa et al., 2018). Although hospitalisation provided immediate treatment for acute breathlessness which relieved anxiety, the requirement for repeated treatment for breathlessness increased anxiety. Persistent anxiety after discharge was one of the main causes for repeated hospitalisation and had a negative impact on psychological well-being (Halpin et al., 2015; Karasouli et al., 2016; Rosa et al., 2018). Moreover, anxiety was associated with prolonged hospital stay in advanced COPD (Pooler & Beech, 2014). Multi-factorial anxiety caused uncertainty, which contributed to a negative perception of hospitalisation, which is discussed in section 5.6.

5.3 Care during hospitalisation

Care is the key element of hospitalisation which is shaped by the treatment and communication skills and attitude of the staff, which are essential components in delivering the crucial information needed to make important end-of-life care decisions.

Having a clear treatment plan is important because frequent, acute breathlessness demands immediate attention. Shared decision-making is where patients are informed about the treatment options and supported to make a feasible treatment-decision, with the active involvement of both doctor and patient (Bomhof-Roordink et al., 2019). Shared decision-making in COPD has been shown to improve patients' disease knowledge and reduces treatment-decision conflicts (Basile et al., 2018; Collinsworth et al., 2018). Although treatment decision-making ideally involves the physician, patient and their carer, this triadic decision is not always possible in the acute care setting of COPD (Karasouli et al., 2016). Usually, doctors seem to decide the treatment option during acute medical conditions because of lack of time for discussion and difficulties in identifying the beginning of the advanced stage which has limited treatment options (Jerpseth et al., 2018; Karasouli et al., 2016). In this empirical study, doctors made the treatment decisions on occasions where intensive treatments were required without involving the participants. Physical weakness impedes patients' ability to participate in the treatment decision-making during acute hospitalisation (Alqahtani & Mitchell, 2019). In the empirical study, fatigue and confusion was reported during extreme breathing difficulty, which reduced the overall energy and the ability to communicate. In such situations, either the staff or the family members make the decision on behalf of the participants and patients have to accept the treatment decision which was taken with consideration of their well-being (Wilson et al., 2019). This leads to accepting the difficult treatment options such as ventilator treatment. This indicates that shared decision-making is limited by several factors, such as the criticality of illness, time availability and the feasibility of patients' participation.

Evidence showed that people with COPD suffer from significant psychological and spiritual concerns such as anxiety, loss of meaning and hope and, death and dying concerns during hospitalisation (Schroedl et al., 2014). This empirical study found that psychological and spiritual concerns such as anxiety, purposeless life and death wishes were not addressed, despite repeated hospitalisation. A systematic review examined the support needs of COPD found that the spiritual dimension did not emerge as one of the care needs (Gardener et al., 2018). It was not clear whether spiritual concerns remain unaddressed due to lack of effort from staff to elicit them or there was a reluctance on the part of patients or staff in discussing these concerns (Gardener et al., 2018). One study showed that patients rather than staff initiated the conversation regarding spiritual concerns (Wittenberg et al., 2017). Although addressing spiritual concerns is considered as part of the end-of-life discussions, studies found that clinicians felt vulnerable when addressing this issue with their clients, which could be the reason for lack of initiation from staff (Houtepen & Hendrikx, 2003; Puchalski et al., 2006). Further, communication skills play a major role in eliciting spiritual concerns in addition to a lack of training in eliciting spiritual concerns (Wittenberg et al., 2017). This empirical study identified spirituality as a considerable contribution to distress and negatively impacted the experience of hospitalisation.

Discussing end-of-life care requires good communication skills on the part of all staff involved in care. Studies have confirmed that end-of-life care discussions happened rarely during hospitalisation in people with advanced COPD (Carlucci et al., 2016; Jerpseth et al., 2018; Momen et al., 2012; Philip et al., 2012). In general, discussing end-of-life care is challenging and further complicated in acute care settings due to the demands of immediate attention and care (Collins et al., 2018). This empirical research identified that although participants felt that the discussion regarding end-of-life should be initiated by the physician, but such discussions rarely happened during hospitalisation. Evidence for who should initiate this discussion seems to be divided; healthcare professionals wanted their patients to initiate this discussion perceiving such discussion could be painful to patients (Momen et al., 2012). On the contrary, evidence indicated that people preferred their physicians to identify the ideal time to discuss prognosis (Collins et al., 2018). Nevertheless, both patients and healthcare professionals agreed that it is necessary to discuss prognosis preferably at a time when both could have a relaxed and calm discussion, ideally at an outpatient consultation following hospitalisation (Gott et al., 2009; Philip et al., 2012). Since these sensitive conversations can destroy the hope of participants, maintaining hope while communicating, avoiding confrontations and setting realistic short-term goals, could facilitate this sensitive conversation (Philip et al., 2012; Smith et al., 2017). In addition to finding the right time and utilising communication skills effectively, the unpredictable disease journey of COPD complicates the identification of advanced stage, which further contributes to a lack of communication regarding end-of-life care discussions during hospitalisation.

5.4 Trust in hospitalisation

Apart from acute symptom presentation, the constituent, trust in hospitalisation, influences the decision for hospitalisation. Trust in the context of healthcare is multi-dimensional, with varied definitions between and among different disciplines of social, political and healthcare, hence it is difficult to define (Pearson & Raeke, 2000). Trust encompasses a wide range of dimensions, including confidence, compassion, competency, maintenance of confidentiality and dependability, which mainly refers to the interpersonal trust between the physician and the patient (Pearson & Raeke, 2000). Most definitions of trust in the healthcare context are based on this aspect of interpersonal trust. In keeping with this view, trust has been argued to be a social construction of patients’ expectations, which is the expectation of goodness, advocacy and competency of the physician (Goold, 2002). Although patient-physician trust is the main component of trust, trust in associated healthcare system also shapes the trust in the healthcare context (Krot & Rudawska, 2016). The empirical research showed that the staff attitude and competency are the core dimensions of trust, in addition to the trust in the Indian healthcare institutions, public and private.

Trust could be categorised at three levels: meso-level trust which is a system-trust, i.e. trust in the healthcare system; macro-level trust is trust in the institution, such as a specific hospital or clinic; and micro-level trust is interpersonal trust between a patient and a physician (Krot & Rudawska, 2016). Meso-level trust reflects the participants’ opinion about the various healthcare systems of India, both public and private. Trust in these two major types of Indian healthcare system was dependent on the principles of and beliefs on the public and individual private healthcare systems. Trust in private healthcare was dependent on the successful operation of the organisation and the healthcare cost. In general, public healthcare systems seemed to be not well trusted by the participants of this research because of lack of material and expert resources to treat major and long-term illnesses. For this reason, many participants sought healthcare in a private institution. This reflected that meso-level trust shaped the experience of hospitalisation.

Participants of the empirical research based their trust in a hospital on their understanding of the belief and moral values that the healthcare institution imparts in the society. The belief that a Christian religious hospital provides a good care with high chances of getting well is based on both the participants’ past experience and the opinion of their family members, which shaped the macro-level trust. This macro-level trust played a role in the choice of a particular hospital for treatment. This indicates institutional trust or macro-level trust is primarily related to the principles and values held by the healthcare institutions (Krot & Rudawska, 2016).

Good communication skills and competency of staff influenced trust with the healthcare professionals during the course of repeated hospitalisations. The empirical research showed that participants who had an unpleasant interaction with staff during previous hospitalisation did not prefer to go back to the same hospital for further treatment. This reflects that the micro-level trust played a role in choosing a certain hospital, which was developed over time during repeated hospitalisation. Further, micro-level trust indicates trust, knowledge, loyalty and regard for healthcare professionals that influence satisfaction with healthcare provision (Chipidza et al., 2015; Ridd et al., 2009). Satisfaction with healthcare provision, in turn could improve the treatment outcome and bring symptom improvement (Birkhäuer et al., 2017). The empirical research identified that participants' micro-level trust was instrumental in developing a rapport with their physicians, which contributed to treatment satisfaction and had a positive impact on the experience of hospitalisation. This demonstrates that meso, macro and micro-level trusts all seemed to play a role in developing trust in hospitalisation which impacts the experience of hospitalisation.

5.5 Psychological distress and religious coping

Studies show that people with advanced COPD experience considerable psychological distress including anxiety, depression and fear of death (Boston et al., 2011; Lee et al., 2013; Pooler & Beech, 2014). However, studies report that psychological distress is not addressed during hospitalisation, which could be one of the causes for readmission in people with advanced COPD (Rosa et al., 2018; Schroedl et al., 2014). Similarly, this empirical research also showed considerable psychological distress such as fear and anxiety, which remained unaddressed during hospitalisation. Many attempts have been made to define the term 'psychological distress', with different definitions reflecting on the varied approaches to understanding distress. For example whether the definition should include only those with a recognised psychological disorder, such as depression or anxiety, or whether it is more dimensional and including psychological states, such as low mood (Barry et al., 2020; Tran et al., 2020). However, these two approaches do not have to be mutually exclusive. Since psychological distress will necessarily affect the emotions of the individual, it could be argued that the perception of distress is dependent on the appraisal of the individual (Ridner, 2004). This research demonstrated a number of examples of different forms of psychological distress, such as anxiety and fear, sadness, helplessness and feelings of vulnerability, with varying intensity across the participants. Considering this, the following definition was chosen to define psychological distress:

> *'the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person.'* (Ridner, 2004, p. 539).

Stress is an event or situation which is perceived unfavourable to person-environment relationship that might change in intensity over time (Lazarus, 1993). The main trigger for stress in people hospitalised with chronic illnesses such as COPD is, stress related to the illness, repeated, sudden hospitalisation and entry into the hospital environment (Andenæs et al., 2006; Andrade et al., 2017; Medinas-Amorós et al., 2012). Similar to the empirical study, other studies conducted in COPD showed individuals experienced considerable stress during acute breathlessness, stress related to hospitalisation such as undergoing difficult treatments such as NIV and to the physical environment of hospitalisation (Andenæs et al., 2006; Christensen et al., 2017).

Lazarus and Folkman developed the transactional theory to conceptualise the coping response to stress in chronic illnesses and this theory was later elaborated by Folkman and Greer (Folkman & Greer, 2000). Folkman and Greer's theory argues that coping is a response to the perceived stress that affects the emotional and cognitive behaviour of the person and there is a constant appraisal of stressors to maintain harmony (Folkman & Greer, 2000). Appraisal of the intensity and type of stressors help identify the appropriate coping response. Appraisal depends on the individual's ability to appraise the emotional intensity and to regulate it, finding the appropriate problem-solving solutions, and to resolve the demands of the external environment to restore the harmony between the individual's and the external demands. Primary appraisals consider the nature of stressor in terms of harm, challenge and threat. Secondary appraisals initiate the appropriate coping response and both problem and emotion focused coping are implemented to restore the positive emotion. Distress is perceived when the stressor is appraised as a threat and the coping initiated has not been successful. The perception of distress depends on the individual's ability to appraise and cope. In this situation, meaning focused coping can be used to change the appraised meaning of the situation and this can then help cope with less controllable situations (Folkman & Greer, 2000). Religious coping is an extension of meaning focused coping, which utilises religious beliefs and values to cope with the stressor. According to Pargament, religious coping is defined as:

> *"religious coping occurs when a stressor related to a sacred goal arises or when people call upon a coping method they view as sacred in response to a stressor."* (Cummings & Pargament 2010, p. 30).

The concept of religious coping has undergone further development and researchers have found evidence for both positive and negative religious coping (da Silva et al., 2018; Nascimento et al., 2020). Positive religious coping is using a benevolent religious approach and to have a secure connection with the divine to cope such as closeness to God; negative religious coping represents having a less secure connection with God and is often associated with spiritual struggle and tension within oneself and with God (Cummings & Pargament, 2010). According to Pargament, religious coping has five major functions: discovering meaning, gaining control, closeness with God and others and life transformation, which have been later incorporated into the RCOPE religious coping assessment scale (Pargament et al., 2001). This scale also includes negative religious coping elements, such as demonic reappraisal and religious discontention to comprehensively assess religious coping strategies (Pargament et al., 2001). Most of the studies on religious coping are conducted in the western culture, mostly in the Judeo-Christian religion and there is limited research in other religions of the world such as Hinduism (Tarakeshwar et al., 2003).

5.5.1 Hinduism and the karmic doctrine

Research conducted in Hindu participants has shown that the principle of Hinduism, ‘karma’, has unique implications for the psychological well-being of individuals with major stress related to life (Anand, 2009; Tarakeshwar et al., 2003). Karma means ‘deed’ or ‘act’ and the karmic doctrine, refers to the cause and effect of one’s own action, which is central to the Hindu belief (Anand, 2009). Karma has two components: one is that the current situations of life are determined by the sins of past life and second is that current deeds will justify the future life, reincarnation, which is the cycle of rebirths (Davidson et al., 2005). Hindus believe that doing their duties related to family and God and doing good deeds would help them rectify current suffering and in doing so, escape from reincarnation to enter ‘moksha’ which is eternity (Thrane, 2010; Whitman, 2007).

Limited studies have been conducted on the effect of karmic doctrine in coping, especially, in the health and illness context. A series of studies conducted in hospitalised people with varied chronic medical illnesses in India showed that there is a positive relationship between karmic beliefs and psychological well-being (Dalal, 2000). Similarly, studies conducted in Indian cancer patients in both north and south Indian cities, showed that people related karma and God’s will to their illness and this helped them accept the suffering, which had a positive impact on their psychological well-being (Gielen et al., 2017; Simha et al., 2013). However, a study conducted in hospitalised cancer patients in India showed no relationship between karma and psychological well-being (Kohli & Dalal, 1998). This study was conducted in women with cervical cancer from a Indian rural hospital, which probably shaped the illness and the treatment beliefs differently that illness causation was related to 'karma' and or the influence of evil power (Kohli & Dalal, 1998). These contextual factors could be attributed to the varied perception of karma and illness of the individuals, which also could depend on the socio-cultural context within the Indian karmic belief system. With these being the only studies, it is not possible to make a more definitive conclusion on the effect of karma on coping and psychological well-being in the Hindu context. The findings from the current empirical study relating to the utilisation of Hindu religious beliefs and practices are consequently further discussed to understand how Indians have used religious coping to cope with psychological distress during hospitalisation. The karmic doctrine is discussed from the perspective of religious coping, according to Pargament's five elements of religious coping in the following sections (Pargament et al., 2001).

Discovering meaning

People searched for the meaning of life and tried to make sense of their purpose in life when they perceived intense suffering. Studies have found that religious coping helped find global meaning of suffering and situational meaning. Global meaning is finding meaning for the suffering as the world views it, situational meaning is finding a personal meaning and beneficial consequences for individual suffering such as getting closer to God and strengthening of faith (Cummings & Pargament, 2010). Hindu participants in this empirical study related suffering to 'karma' to make sense of their suffering; that their suffering was due to sins committed in their past life and this helped them accept suffering. This view of relating suffering to karma shows that how global meaning making of the stressful situations helped them cope. Two studies conducted in Hindu cancer patients in India also found that this similar way of making sense of suffering through karmic deeds was helpful in accepting suffering (Bhatnagar et al., 2017; Simha et al., 2013). In contrast, studies done in the western, Christian population showed both global and situational meaning (Pargament et al., 2004; Tarakeshwar et al., 2006). This could be attributed to the Hindu karmic belief and cultural system and how individuals within this belief system interpret stress. This element of discovering meaning had a positive impact on people who perceive loss of purpose with the advance of an uncertain illness condition, particularly, in an illness such as COPD with its unpredictable illness trajectory.

Gaining control

Practising religious rituals such as prayers, visiting temple and offering special prayers at the temple are considered very important in gaining control over the current situation of suffering for participants during hospitalisation. Participants in the empirical study believed that only God could determine how the karmic deeds were justified in an individual's life, which helped them to surrender the control to God through offering prayers and rituals; this gave them some level of perceived control over the less controllable situation. Studies conducted in Hindu participants showed that religious rituals, yoga and meditation helped gaining control (Ramanakumar et al., 2005; Tarakeshwar et al., 2003). In contrast, surrendering control to God or somebody in whom they can trust such as doctors also seemed to be an effective religious coping strategy in Hindus with chronic illness during hospitalisation (Dalal & Singh, 1992). Both gaining and surrendering control over the stressful situations are helpful coping strategies in Hindu people with stress during hospitalisation.

Closeness to God

Offering regular prayers and observing religious rituals are considered important for sick people to develop faith in God which can then build a close connection with God (Anand, 2009; Gielen et al., 2017; Ramanakumar et al., 2005). This close connection with God seemed important to people to please God and some even adopted this as the way of life during old age (Soneja et al., 2007). Most participants in the current empirical study mentioned that rituals and reciting the prayers gave a sense of security and connectedness with God. Also studies conducted in Hindu patients with cancer also reported that rituals and prayers seemed to draw a close connection with God (Bhatnagar et al., 2017; Gielen et al., 2017; Simha et al., 2013). Feeling connected with God helped participants cope with the fears and worries of illness particularly, fear of death during acute breathlessness. Apart from being connected to God, participants felt rituals also helped in religious purification and to lead a life according to the karmic principles.

Closeness with others

A few participants expressed the significance of developing closeness with others in the empirical study. Offering special prayers with family members and others was considered a way of strengthening the relationship with God and others (Tarakeshwar et al., 2003). A participant from the empirical study mentioned that visiting a shrine with his friends was important to get closer with God and with them. He believed that building a temple in his village with the help of friends gave a feeling of closeness with God and with them; this imbued him with a purpose to live and to spend his last days in that temple that he would build. This indicates that religious practices were not just done with the purpose of complying with karmic deeds alone but go beyond that to develop harmonic relationship with God and others. Interestingly, none of the Indian studies mentioned about closeness to others as a religious coping strategy (Dalal, 2000; Pandey et al., 2003; Simha et al., 2013).

Life transformation

Transformation of life refers to a major change in life goals and the way the changes effect achieving those goals. Pargament described three elements which indicate transformation: religious purification, religious forgiveness and religious conversion (Pargament et al., 2001). Of these three elements, only religious purification is explicitly discussed by the participants in this empirical study. Religious purification is attained through religious actions such as performing special rituals that are considered as a remedy for a particular sin. The religious priests are invited to conduct these special rituals which are considered highly sacred among Hindus (Shanmugasundaram et al., 2010). Attaining religious purification is considered important to gain eternity and to have a life pleasing to God. In contrast, other studies conducted with Hindus found that none of the participants expressed religious forgiveness or purification in their study (Simha et al., 2013; Tarakeshwar et al., 2003). Transformation seems to be a positive religious coping strategy although not all of its elements are visibly practised in this empirical research.

5.5.2 Positive and negative religious coping

Positive religious coping

Positive religious coping strategies seem to be helpful in coping with the stress of illness in people with advanced COPD during hospitalisation. Studies conducted to understand karmic beliefs in chronic illness in India found that elements of positive religious coping, such as closeness to God, perceived control, and discovering meaning were associated with psychological well-being (Dalal & Singh, 1992; Garg et al., 2018; Gielen et al., 2017; Pandey et al., 2003; Simha et al., 2013; Soneja et al., 2007). However, none of these studies showed a positive relationship with collaboration with God, which is not a well demonstrated belief in Hinduism which is different from Christianity. In contrast, studies conducted in COPD, in Christian and western cultures, found positive religious coping approaches such as benevolence and collaboration with God were associated with improved health related quality of life, reduced depression and anxiety (Burker et al., 2004; da Silva et al., 2018; Nascimento et al., 2020). Although these studies provide evidence for positive religious coping, they do not interrogate the five functional elements of religious coping in detail. In contrast, this empirical study found that all five functional elements were helpful coping strategies, but there were variations in the way they have been utilised to cope. Gaining control over the situation was seemingly an important religious coping strategy for Hindu participants who were hospitalised but few participants expressed both gaining control and surrendering control as the coping mechanisms. While gaining control through performing religious rituals gave a sense of perceived control, people believed that God was in ultimate control of life situations, which led to participants surrendering the control to God and indicated both were effective religious coping mechanisms utilised. Transformation of life through karmic deeds is valued, especially religious purification, because it is believed to be pleasing to God. The other two elements of transformation, i.e. religious forgiveness and religious conversion, were not reported in the empirical study. Religious forgiveness is not a common practice in Hinduism; although people perform rituals as a remedy to past sins, confessing sins explicitly is not common. This differs from the Judeo-Christian religious belief of confessing sins, which is not present in Hinduism (Tarakeshwar et al., 2003). Pargament et al (2004) found that religious purification, forgiveness and religious conversion were associated with a decline in physical function and quality of life and increased depression in hospitalised medically ill people, but these elements helped some individuals have positive stress-related growth and improved spiritual outcomes (Pargament et al., 2004). This relationship between religious coping and stress-related growth in the western, Christian population, is not yet well demonstrated in studies conducted in the Asian, Hindu, karmic believers.

Negative religious coping

Unlike positive religious coping, only a few elements of negative religious coping examples were reported in the current, empirical study. Discovering the meaning of suffering through karmic doctrine related suffering as a punishment for the past karmic deeds. Despite this interpretation as a punishment, all Hindu participants showed having a religious focus and getting closer to God as important. Only two participants expressed anger towards God asking ‘why me?’ but acknowledged that continuing the religious rituals and prayers would help get released from the reincarnation. This could be hypothesised as being consistent with the idea that negative religious coping is transitory and it soon changes to positive religious coping (Cummings & Pargament, 2010). This transitory negative coping could be further explained as the simultaneous occurrence of positive and negative emotions during stress by Folkman and Greer (Folkman & Moskowitz, 2000). Similarly, this empirical research found the dual feeling of wishing to die and live which could be due to the simultaneous occurrence of positive and negative emotions. Also the karmic doctrine emphasises the completion of duty in the current life which includes completing family responsibilities (Shanmugasundaram et al., 2010). The stressor, wishing to die, is reappraised by changing the meaning of the situation, in which people found meaning to live until a family milestone such as to living until the son's wedding or the grandson was born. This meaning making of the perceived stressful situation changed the negative emotion to a positive emotion that helped them to look forward to the future with hope. Similarly, Gielen et al (2017) reported the contradicting positive and negative emotions in Indian cancer patients that people continued to believe in God despite the negative spiritual feelings of 'why me?' (Gielen et al., 2017). Interestingly, none of the other studies conducted to study the karmic beliefs in chronic illness in India reported negative religious coping (Dalal & Singh, 1992; Garg et al., 2018; Pandey et al., 2003; Simha et al., 2013; Soneja et al., 2007). However, studies conducted with individuals with a psychiatric illness showed that negative religious coping had a positive correlation with depression and anxiety but did not explain what aspects of negative religious coping were related with the depressive symptoms (Kataria et al., 2016). This indicates that religious coping is dynamic and depends both on the illness and cultural contexts of individuals therefore, coping response may vary accordingly.

5.5.3 Karmic belief and end-of-life

The practice of karmic principles not only gives meaning to the present life through performance of religious rituals but also gives hope to look forward to live the full, rather than living waiting to die. Belief in the karmic principles seemed to connect the past, present and future life of participants; they were able to accept the suffering of the present life as a connection to the deeds done in the past life and looked forward to the hope of living by doing the rituals in order to have eternal life. According to karmic beliefs, one is judged by one's own deeds, which determine their destiny (Inbadas, 2017). Destiny meant reincarnation in which people are reborn in different hierarchies, as humans or in other forms, such as animals, which is purely determined by the karmic deeds (Shanmugasundaram et al., 2010). Participants believed in doing good deeds, such as building a temple, would help them have eternal life. Also doing the right deeds, especially completing family responsibilities were considered important duties for men before dying (Tarakeshwar et al., 2003). Participants in this empirical research who had not completed their family duties wanted to live until the family milestones; others who completed the family duties were ready to let go of life. Participants found meaning of life through completion of their duties and deeds, which also prepared them for death. In contrast, a study done in hospitalised people with chronic illness in India showed that karmic beliefs helped see the past and present but not the future; people seem to trust in God's will and the physician's treatment for their future life and recovery (Dalal & Singh, 1992). This linkage of past, present and future life depends on individuals' view on the future through the lens of karmic beliefs in the illness context during hospitalisation.

Although death is accepted as part of rebirth, people experienced fear of death during breathlessness. In this empirical study, fear of death was related to the way how death might happen with minimal suffering. A study in cancer patients in India showed that people accepted death as part of the cycle of rebirth and a transit to enter a new life (Simha et al., 2013). Also, people were more open to talk about death which is a similar finding to the empirical study. Participants preferred a good death, which meant to die during sleep with no struggle or pain. For many, dying at home was important as the home environment facilitated both the necessary completion of religious rituals during the time of dying and more importantly being with their family (Shanmugasundaram et al., 2010). Good death was connected to karmic deeds as a common belief in Hinduism is that a good death will happen for people who have done good karmic deeds (Sharma et al., 2013).

There is a high association reported between religious coping and intensive care preference in people with advanced cancer during terminal illness (Balboni et al., 2013; Loggers et al., 2013; Maciejewski et al., 2012; Phelps et al., 2009). This preference for intensive treatment could be attributed to the Christian religious beliefs of miracles and perseverance in suffering (Cummings & Pargament, 2010). This indicates that religious coping in the context of end-of life, which is mainly drawn from a Christian, western population may not be directly related to the Indian culture and religion. In general, Hindus prefer less intensive treatment and refuse pain medication during dying due to the belief that being conscious when dying and enduring pain is important for the karmic belief of reincarnation or 'moksha' (Shanmugasundaram et al., 2010; Sharma et al., 2013). Also Asian-Pacific and western cultures differ in the way they view illness: Asians accept death while Europeans seem to fight death (Spathis & Booth, 2008). Studies from Europe showed that people look for options to extend life because of the perception that living with COPD is a 'way of life' (Pinnock et al., 2011). Seeking self-management is a common practice in the western culture in contrast to relying on God and family support, which was perceived to be more important than self-management for people living with COPD in the Asian-Pacific culture (Nicholas et al, 2010). This indicates a different viewpoint of illness in the western and Asian cultures; illness is viewed as a biophysical entity in the western culture but Asians view it as a holistic view of mind, body and spirit embedded in the natural context (Uba, 1992). This fundamental viewpoint determines how Indians cope with the psychological and spiritual distress from chronic illness, utilising religious values and beliefs as a natural coping response to illness related stress. Hence, culture and religion determine the way in how people appraise and cope with stress in chronic illness. Positive religious coping is a more helpful coping strategy than negative religious coping in people with advanced COPD during hospitalisation. But not all of the elements of religious coping are relevant to the followers of Hindu Karmic belief, which indicate the coping responses are drawn from individuals' religious belief, culture and appraisal of stress.

5.6 Hospitalisation as a negative experience

This empirical research found that the overall experience of hospitalisation was perceived as negative. Studies conducted in COPD and in chronic illnesses also found a similar negative experience; this was attributed to poor communication and inadequate treatment information, staff attitude and high symptom burden, which caused intense suffering (Benham-Hutchins et al., 2017; Oyesanya, 2017; Robinson et al., 2014; Wang et al., 2009). The reasons for this perception could be that hospitalisation offered temporary symptom relief, rather than providing a cure. Although people live with suffering at the end stage of the disease, multi-dimensional suffering seems to be intense during hospitalisation and not all the dimensions of suffering seem to be addressed by the healthcare professionals. Lack of a comprehensive treatment plan, coupled with poor communication, created poor clarity regarding disease prognosis. Continuing suffering and unclear disease prognosis seemed to contribute uncertainty, which caused a negative perception of hospitalisation.

Uncertainty is the inability to make sense of the events, such as hospitalisation, or illness prognostication (Etkind et al., 2017). Uncertainty is commonly experienced by people who had both emergency and non-emergency admission for breathlessness, which confirms with the findings of the literature review (chapter 2). Studies investigating uncertainty in chronic illness indicated that lack of information and complexity of the disease presentation were the main contributors of uncertainty, which confirms with the findings of this empirical research (Etkind et al., 2017; Smith et al., 2017). Uncertainty seemed to be experienced during repeated hospitalisation, due to high symptom intensity, which has a multi-factorial causation and, attributed to repeated, unpredictable hospitalisation, anxiety (section 5.2), and, poor communication of treatment and prognosis (section 5.3).

The complexity of the disease presentation is contributed by unpredictable breathlessness, which is the main reason for repeated, emergency hospitalisation which increased anxiety. Fatigue and dependency during acute breathlessness further contributed to psychological and spiritual distress. This indicates physical, psychological and spiritual distresses are inter-related and influenced the severity and the presentation of symptoms in each other domains. In addition, the unpredictable illness trajectory of COPD prevents clinicians from providing a clear picture of prognosis and treatment plan from the varied, complex treatment options available which caused uncertainty around the future (Landers et al., 2017; Murray et al., 2005). A lack of information regarding treatment and prognosis is further complicated by sudden, acute breathlessness, which at times could be life-threatening. Unpredictable breathlessness seems to be underpinning the causation of uncertainty in people with advanced COPD.

These attributes of uncertainty relate to the core concept of uncertainty measurement: ambiguity, lack of information, complexity and unpredictability (Mishel, 1999). Ambiguity refers to the unclear illness presentation, complexity refers to varied, multiple treatments and systems of care, lack of information refers to inadequate and inconsistent information regarding prognosis and treatment plan and unpredictability refers to inconsistency between the occurrence of illness, treatment and its outcome (Mishel, 1981, 1999). These four elements could be simplified as treatment and illness-related factors: complexity and lack of information are related to treatment factors and, ambiguity and unpredictability are related to illness. The inter-related role of these factors to the contribution of uncertainty is described in figure 3. The perception of uncertainty during hospitalisation is the main reason for a negative perception of hospitalisation.

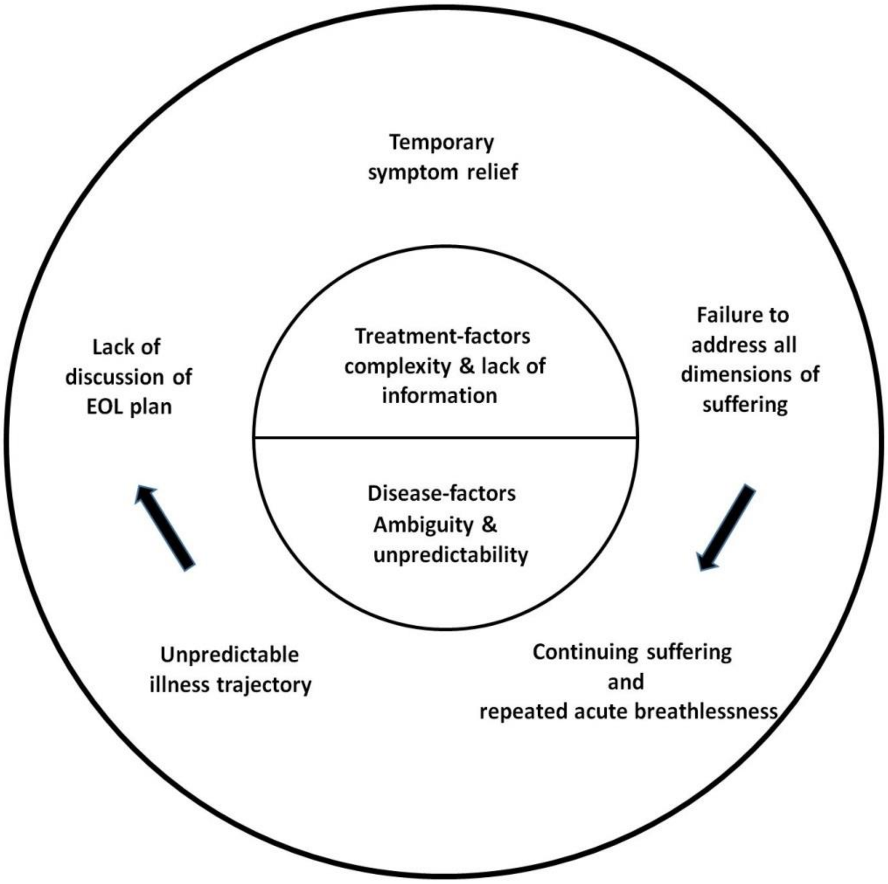

Figure 3

Uncertainty and experience of hospitalisation

Many studies indicate the elements of uncertainty present in varied chronic illness during hospitalisation (Caruso et al., 2014; Etkind et al., 2017). The presence of uncertainty indicates ongoing suffering and maladaptation to the illness, which is detrimental to the well-being of individuals with chronic illness (Caruso et al., 2014; Wright et al., 2009). In the empirical research, uncertainty also affected the personal and social domains of individuals, in that participants perceived that there was no future and were unsure if they would be present for important milestones of the family; hence, attaining short-term future goals, such as visiting their favourite shrines or making a useful contribution to people around them, helped overcome the feeling of uncertainty. Interestingly, uncertainty need not always reflect a negative effect, but it could protect against a negative view of the future; that not knowing what would happen, could give them hope to live, as opposed to knowing the exact time left to live that might destroy hope (Etkind & Koffman, 2016). This view explains the ambiguity between wanting to know more information about prognosis versus 'just the right' amount of information. While having the right amount of information helped focus on the present, wanting more information helped plan the future (Etkind & Koffman, 2016). In contrast, participants from the empirical research wanted to know the prognostic information to plan their future to be present for their family milestones, thus, the view that uncertainty as a protective measure could not be confirmed. The perception of uncertainty had a negative impact on the psychological well-being and caused a negative view of the experience of hospitalisation.

5. 7 Conceptualisation of hospitalisation

There is limited evidence for what constitutes the concept of hospitalisation. In the literature, the hospital is described as a physical place and a facility which is an important element of the healthcare system (Hughes, 2001; McKee & Healy, 2000). Hospitalisation has been studied both in varied chronic illness conditions and in various hospital settings, from acute care to ordinary inpatient care, but mainly from the care and treatment perspective; nevertheless, there is a lack of comprehensive description of the concept of hospitalisation taking these varied dimensions into account (Benham-Hutchins et al., 2017; Black et al., 2018; Katsakou et al., 2012). The findings of the literature review of this empirical research also reflect these elements of care, treatment and interaction with the staff. From the empirical research, the conceptualisation of hospitalisation seems to include two main elements: firstly, the hospital as a physical place and a facility for the sick; secondly, being hospitalised which includes the multi-faceted aspects of administration, treatment, trust and communication. These two main elements are integral parts of each other but their sub-elements may be varied and together they contribute to the experience of hospitalisation.

In terms of hospital as a physical space, the environment of the hospital plays an important role for care and healing (Hughes, 2001). Studies conducted in chronic illnesses and the literature review of this research have shown that the noisy hospital environment is detrimental to the recovery of acutely ill patients (Robinson et al., 2014). Participants of this empirical study experienced insomnia and increased fatigue due to the noisy environment. Secondly, facilities provided in the hospital determine the care experience and satisfaction with treatment (McKee & Healy, 2000). This empirical research showed that participants' experience on the choice of hospital, such as private or public hospital, which was influenced by the facilities available.

The second element, being hospitalised, has varied dimensions related to the administrative process, treatment and care, communication and trust. The admission process was largely perceived as chaotic, especially for emergency admissions, because of poor communication and a long waiting time in the emergency department. Although both admission and discharge processes are considered as the administrative process of hospitalisation, no specific issues relating to discharge emerged in this empirical research. This could be due to participants' expectation to go home rather than being in the hospital for a long duration; hence, the discharge process does not seem to have an impact on the experience of hospitalisation in this particular set of participants. However, this may be perceived variously in a different context. Care and treatment play a major role in determining the experience of hospitalisation which is perceived variously by individuals. These differing perception could be due to the requirement of dynamic care and the expertise of the staff. Communication is another main factor, which also has a dual experience and perceived variedly by different participants. Care and communication, seemed to have a contrasting perception, both positive and negative, and, share a bidirectional relationship, which indicates the dynamic nature and complexity of these sub-elements. The complexity of these elements mainly depend on the nature and the depth of care required, the expectation of the individuals and the competency of the staff involved (Benham-Hutchins et al., 2017; Black et al., 2018). In addition to these dimensions of hospitalisation, this empirical research identified trust in hospitalisation as one of the elements for the experience of hospitalisation. Meso, macro and micro-level trust influenced the choice of a particular hospital for care which shapes the experience of hospitalisation (section 5.4).

These varied dimensions of the experience of hospitalisation are dependent on individuals who access care, the health condition of a particular individual, their culture and religion (figure 4). For example, this empirical research showed that the participants from the Hindu religion interpreted illness and death differently from other religions. Similarly, participants who had emergency admissions perceived a chaotic admission experience than who had non-emergency admission. This conceptualisation of hospitalisation, should therefore, be understood from the context where the research was conducted, the particular set of participants who shared their experience, the cultural and religious contexts which is drawn from the perspective of repeated and often emergency hospitalisation for a serious, chronic and advanced stage of illness. These dimensions in themselves are not complete, as hospitalisation is a broad, varied and complex phenomenon and could be conceptualised differently in other contexts and cultures.

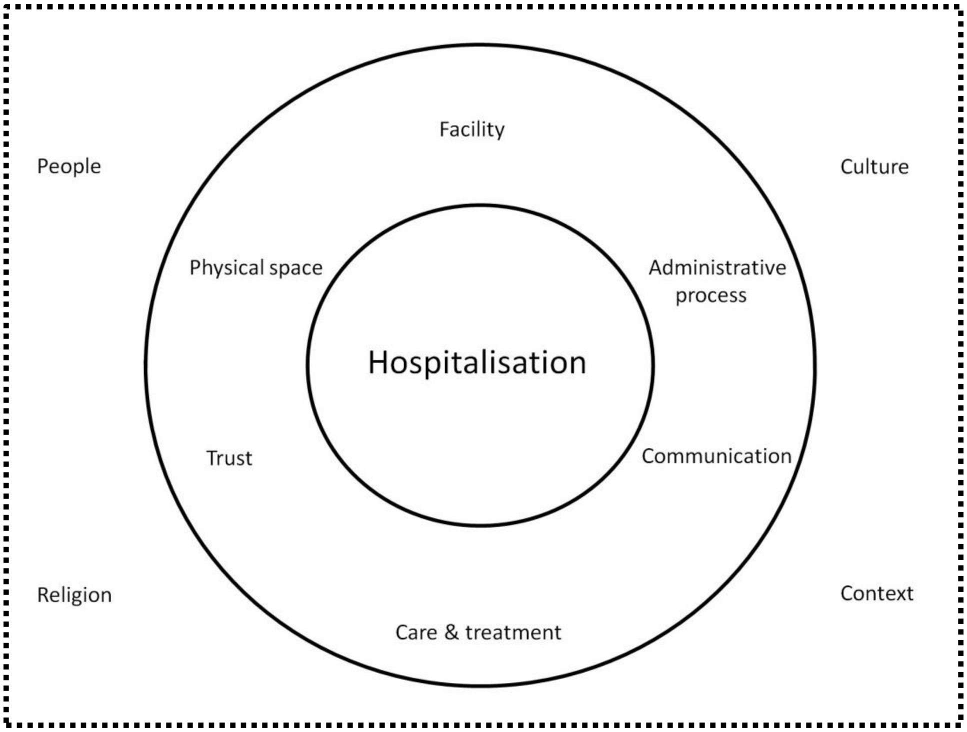

Figure 4

Conceptualisation of hospitalisation

5.8 Conclusion

The main feature of hospitalisation for people with advanced COPD is repeated, unpredictable, which is frequently as an emergency admission. Exploration of psychological distress in the context of religious coping showed that positive religious coping strategies were more helpful in coping than negative religious coping. Karmic beliefs are central to the Hindu participants in coping with stress during hospitalisation. The experience of hospitalisation is perceived as a negative experience because of persistent symptoms, uncertainty related to disease progression and future and unrelenting suffering.

The conceptualisation of hospitalisation in advanced COPD demonstrates that hospitalisation includes two main elements, hospital as a physical place and facility and hospitalisation as a multi-dimensional phenomenon, which is shaped by the context, culture, people and religion. The implications of the findings for contribution to knowledge and practice are discussed in the next chapter.

Chapter Six

Conclusion

6.1 Introduction

This research was conducted to understand the experience of hospitalisation in people with advanced COPD in south India. This research identified that trust in hospitalisation was an important element of hospitalisation and multi-dimensional suffering was central to the experience of hospitalisation. In this chapter, the implications of the findings to knowledge and practice and recommendation for future research are discussed. The strengths and limitations of this research are also discussed.

6.2 Contribution to knowledge

This research identified meso, macro and micro levels of trust in hospitalisation as an important element of the experience of hospitalisation; this is a new knowledge contribution. Three other main contributions are identified: trust in hospitalisation influenced the decision-making regarding hospitalisation, suffering was central to the experience of hospitalisation and positive religious coping was helpful for spiritual distress in the Indian context.

6.2.1 The phenomenon of hospitalisation

This research offered a unique insight into the phenomenon of hospitalisation in advanced COPD and presented a general structure of the phenomenon of hospitalisation in the Indian context.

Earlier studies conducted in various chronic illnesses such as cancer and heart failure had focused on the care and treatment, mainly from the perspective of patient-provider satisfaction during hospitalisation and or did not specifically focus on the experience in the advanced stage of illness (Benham-Hutchins et al., 2017; Liu et al., 2017; Mulemi, 2008; O'Leary et al., 2019). Although the literature review of this research included studies with individuals with advanced COPD, most of the studies again focused on the care and treatment aspects. The main elements of the phenomenon of hospitalisation of this empirical research resonated with the literature review of this research, which indicates that the commonality of the experience of hospitalisation is similar across countries.

This research identified trust in hospitalisation as an important element of the phenomenon of hospitalisation. Meso and macro level trusts are grounded in the beliefs and moral values that the healthcare system and institution imparts to the society, which played a major role on the choice of hospital for treatment. This was reflected in participants' choice of selecting a private over public hospital and a Christian religious hospital over other private hospitals of different religious backgrounds. The empirical research found that all three levels of trust, macro, meso and micro, were important in shaping the experience, which differs from the literature review which identified that only micro level trust, that is interpersonal trust, influenced the experience.

This research clarified yet another two distinctive elements which constituted the phenomenon of hospitalisation, that is, the hospital as a physical space and a facility and being hospitalised (chapter 5.7). These two core elements of the phenomenon of hospitalisation form the structure of hospitalisation but their sub-elements could be varied and influenced by the context where the research was conducted, the particular set of participants who shared their experience, the cultural and religious backgrounds and by the illness context, such as advanced stage of a serious, chronic illness. This research identified the universal features of hospitalisation, which remain similar across countries, yet illuminated the subtle variation in the experience, depending on these factors. Although the earlier studies and the literature review of this research mentioned some of these two elements, the integrated nature of these elements have not yet been recognised and discussed.

This research found that the overall experience of hospitalisation is negative which contrasts with the finding of the literature review, but resonates with other studies conducted in individuals with chronic illnesses (chapter 5.6). This varied perception indicates that the experience of hospitalisation is complex and influenced by the dynamic nature of care requirement during hospitalisation, participants' experience and illness context. However, identifying this varied perception is important to improve care for people with advanced COPD.

6.2.2 Multi-dimensional suffering

This research has found that persistent, multi-dimensional suffering is the core experience of hospitalisation in people with advanced COPD. Healthcare delivery in COPD is still symptom-oriented and, psychological and spiritual distress are neglected which caused continuing suffering. This indicates a lack of holistic care for people with advanced COPD while being hospitalised, which confirms with the literature review of this research.

This research contextualised multi-dimensional suffering during hospitalisation, in an Asian, multi-cultural and multi-religious country. This research contributes an innovative finding in that the followers of Hindu karmic belief do not show negative religious coping. The elements of positive religious coping strategies were influenced by karmic belief, which differs from the studies conducted in the western, Christian perspective (Burker et al., 2004; da Silva et al., 2018; Nascimento et al., 2020). Although Hindu participants related suffering to karma and Christians perceived suffering as redemption for their sins, they both accepted their suffering. This varied interpretation of suffering helped participants accept suffering and death, which is in contrast to the western approach to fight death (Spathis & Booth, 2008).

6.3 Recommendations for practice

This research identified that poor communication, especially during emergency admissions and a lack of psychological and spiritual support during hospitalisation are areas that require improvement; the implications for practice are discussed below.

6.3.1 Emergency care during hospitalisation

Emergency department staff should be trained to display adequate communication skills and acquire the expertise to communicate a clear treatment plan to people with acute breathlessness. This research highlighted a poor communication of treatment plan, especially during emergency admission. This emphasis on the need for communication training for staff, specifically in discussing end-of-life care, has been established in studies conducted in chronic illnesses from different countries (Carlucci et al., 2016; Knauft et al., 2005; Momen et al., 2012; Vermylen et al., 2015). Also the staff should identify the right time to discuss the treatment plan with the patient and their family, despite the acute symptoms requiring immediate medical attention.

The emergency staff should seek the support of palliative care specialists when required. A recent review showed some evidence for integrating palliative care in the emergency department to improve the quality of life (Wilson et al., 2019). However, there are challenges identified to integrate palliative care for non-malignant conditions in the emergency department because of not having a consensus among the staff about the end-of-life care plan, insufficient communication skills and lack of space and privacy (Alqahtani & Mitchell, 2019). While these factors can impede the integration of palliative care, the emergency staff should take support from palliative care when required which could improve the experience of hospitalisation.

6.3.2 Addressing psychological and spiritual distress

Appropriate psychological therapy such as cognitive behavioral therapy (CBT) could be helpful for psychological distress experienced during hospitalisation. Anxiety triggered by acute breathlessness is the main form of psychological distress identified in the research. CBT has been shown to reduce anxiety, especially anxiety in ‘dyspnea-anxiety-dyspnea’ cycle in people with COPD, by identifying the catastrophic interpretation of breathlessness and planned exposure to situations that trigger anxiety (Heslop-Marshall et al., 2018; Livermore et al., 2010; Yohannes et al., 2017). CBT could be offered during hospitalisation along with the routine care for COPD, with the help of psychologists from the hospital.

Screening of spiritual distress should be included in the routine care of people with advanced COPD to identify spiritual distress. This research highlighted that spiritual distress was a major concern which remained unaddressed during hospitalisation. A questionnaire developed for Indian patients could be helpful to identify spiritual distress in the Indian context (Bhatnagar et al., 2016). Spiritual screening tools such as the Rush protocol for spiritual screening, Spiritual Injury Scale, have been used in routine clinical practice in other international settings (Berg, 1994; Fitchett & Risk, 2009). People identified with spiritual distress should be referred to the multi-faith chaplain service for a detailed assessment and intervention (Balboni et al., 2017).

Identification of self-regulated coping strategies could be considered to minimise spiritual distress. This research identified that self-regulation using coping strategies such as performing religious rituals was helpful for spiritual distress. Identifying and developing self-management measures, such as culturally and religiously appropriate prayers and meditation, can be helpful to reduce spiritual distress. Involving a multi-disciplinary team including pastoral care would be helpful to offer specialised support for complicated spiritual issues.

6.4 Recommendations for policy

1. Guidelines for the care of people with COPD should be expanded to include a focus on the care of those with advanced COPD, including palliative care and the experience of frequent hospitalisations.

- Current Indian COPD guidelines focus on the diagnosis and management of COPD, rather than recommendations for the management of advanced COPD, which is similar to the focus of other Asian guidelines (Gupta et al., 2013). Hence, existing COPD guidelines should be expanded to include palliative care in advanced COPD.
- Current COPD guidelines give indications for hospitalisation in an acute exacerbation of breathlessness for those with stable COPD, rather than advanced COPD (Gupta et al., 2013). No guidelines address hospitalisation in the advanced stage. It is recommended that indications for hospitalisation in advanced COPD to be included in the guidelines, which could help improve care and may avoid unnecessary hospitalisation.
- Guidelines regarding co-ordinated care between pulmonary, palliative and emergency care should be developed with a particular focus on care delivery in the emergency department (section 6.3.2). Models of integrated care which have already been studied could also be considered to be adopted both at the Indian and Global policy level (Payne et al., 2017; Maddocks et al., 2017).

2. Guidelines for the provision of palliative care need to take account of the specific needs of those with advanced COPD. Such guidelines need, again, to take account of the likely frequent hospitalisations, and the need for integration of care between palliative care and respiratory specialists.

Indian palliative care does not have a palliative care program for COPD (Gupta et al., 2017). The National Program for Palliative Care developed by the health ministry of India largely focuses on cancer and other chronic diseases but does not consider implementation of palliative care for people with COPD (National Program for Palliative Care, 2012). Palliative care for people with advanced COPD in India should be developed with a focus on the following:

- Multi-dimensional suffering is likely to require care from a wide range of professionals across a multi-disciplinary team. Most palliative care centres in India have a lack of comprehensive multi-disciplinary professionals (Gielen et al., 2016). It is recommended that palliative care centres in India develop specific guidelines to address these issues, with the involvement of a multi-disciplinary team, including, for example, physiotherapists, psychologists and pastoral care staff.
- Developing appropriate spiritual care in the Indian multi-cultural and religious context should be incorporated in the development of palliative care for people with COPD.
- As the illness trajectory of COPD is unpredictable, specific end-of-life care plans for people with advanced COPD should be developed. These guidelines particularly should address timely initiation of end-of-life care conversations, including advance care planning.
- Efforts should be taken to develop methods to integrate palliative care into the routine care of COPD in the Indian context, taking account of the varied socio-cultural and healthcare contexts, such as public and private. This will ensure the delivery of early palliative care which could minimise the ambiguity in identifying the initiation of the end-of-life care plan. Integration would largely depend on the healthcare context of the country, varied service provision, such as primary to tertiary care levels, and types of service provision such as hospice, community and institution based care (De Regge et al., 2017; den Herder-van der Eerden, et al., 2018). Hence, policy developers should take account of these aspects, in addition to the individual socio-cultural context.

The followings are recommended, in the global context:

- Spiritual care

International policies on palliative care for people with COPD should have an emphasis on, where appropriate, identifying and addressing spiritual distress, following guidelines already published in spiritual care education (Best et al., 2020).

- Advance care planning

The preference to discussing advance care planning might vary in other international settings, for example, some people may want less or more information on advance care planning. The timing of the initiation of discussion, the location and the preference that who should initiate the discussion, such as participants or physicians (pulmonologist or palliative care or general practitioner) are still debatable (Seamark et al., 2012). Hence, policy developers and clinicians should consider these contextual factors which would help tailor the discussion and information provision according to individual preference and need (MacPherson et al., 2013).

6.5 Recommendations for future research

Qualitative research exploring the experience of hospitalisation in people with advanced COPD in a wide range of cultural contexts should be studied. Such research might expand this understanding to other areas of India, but also potentially to areas with a range of different contextual and cultural considerations including forms of service provision and, religion and religiosity. This understanding of the experience of the hospitalisation will inform future policy and care provision.

Research enabling clinicians to identify milestones that indicate the advanced stage of COPD should be considered to facilitate the initiation of end-of-life care discussions. The research findings indicated that participants wanted their physicians to initiate end-of-life care discussions. Some of the ‘milestones’ to identify the disease progression such as long-term oxygen dependency and episodes of acute breathlessness leading up to repeated hospitalisation, have been helpful in identifying the appropriate time to initiate the discussion (Landers et al., 2017; Vermylen et al., 2015). However, there is no evidence available regarding the consistency of these ‘milestones’ in indicating the advanced stage of COPD. A longitudinal, prospective study to identify the milestones to determine the advanced stage of COPD should be an immediate international research priority (Caruana et al., 2015).

Research exploring the varying perceptions of positive and negative experience of hospitalisation should be undertaken. The literature review of this research showed a mixture of positive and negative perceptions of hospitalisation but the current empirical study showed largely a negative perception. Similarly, studies relating to hospitalisation in chronic illnesses showed varied perception of positive and negative experience (Liu & Kelz, 2018; Rapport et al., 2019; Spichiger, 2008). Most of these studies, as well as this empirical study captured the experience as a snapshot of repeated hospitalisation during the advanced stage, which may be the reason for the varied perception. A longitudinal, qualitative study involving interviewing the same participants repeatedly over an extended time should be considered to understand the experience over time of repeated hospitalisation, which would provide insight into this varied perception (Murray et al., 2009).

Qualitative research to study the views of healthcare professionals to address spiritual distress in the Indian culture and religion should be considered. Currently, there is no culturally and religiously appropriate and proven spiritual intervention available for Indian people with spiritual distress. A study conducted in Indian cancer patients recommends that people should find their own personal spiritual support from their spiritual teachers and priests, due to the lack of pastoral service in Indian palliative care settings (Gielen et al., 2016). Hence, studying the views of the healthcare professionals to address spiritual distress, through a qualitative approach would help the development and implementation of culturally and religiously appropriate interventions.

Research to enable the development of palliative care programmes for advanced COPD in the Indian context should be conducted. Palliative care in India is still focused on the cancer population and palliative care for non-malignant conditions remains underdeveloped (Gupta et al., 2017). The negative experience of hospitalisation indicates a lack of a holistic approach, therefore developing palliative care programmes specific for advanced COPD, to address the complex needs should be studied. Specifically, developing an integrated care plan, which focuses on the needs through coordinated care, would ensure the continuity of care as patients often require a transfer between pulmonary and palliative care (den Herder-van der Eerden et al., 2017). The feasibility of adopting an integrated care plan and the benefits and challenges in implementing this plan, needs to be researched in the Indian context.

6.6 Strengths and limitations of this research

Strengths

This qualitative research has been conducted to understand the experience of hospitalisation in people with advanced COPD. This experience reflects the experience from one of the Asian countries and could be transferable to other Asian countries with a similar socio-cultural context.

Interviews were conducted in the hospital, while participants were being hospitalised, to capture the phenomenon afresh. This helped overcome the challenge of relying on the memory of participants in studies conducted in the post-discharge period. Studies show that poor recall memory after hospitalisation for acute conditions impacts cognition, therefore previously hospitalised patients were unable to capture all the details of being hospitalised (Seamark et al., 2012; Torheim & Kvangarsnes, 2014). Interviewing at the hospital facilitated the exploration of real-time experience and the time-space dynamics in hospitalisation, which help narrating all the nuanced aspects of the phenomenon (Kjellsson et al., 2014).

This research included participants with varied socio-cultural and religious backgrounds that enriched the experience of hospitalisation. Different social and cultural backgrounds determine how a patient behaves with the illness and hospitalisation, which influence the experience of hospitalisation (Hartog & Hartog, 1983). Culture shapes both certain principles and the values of the hospital, which both have an impact on patient-satisfaction and this was specifically demonstrated in trust in hospitalisation (Braithwaite et al., 2017). This empirical research captured the experience of hospitalisation from people from Hindu and Christian religious backgrounds who interpreted suffering variously that complemented the experience. Hindus linked suffering as a punishment to past sins, 'karma', whereas Christians viewed it as redemption for their sins but both set of participants accepted that suffering as a way to eternal life, 'moksha'.

This research captured spiritual distress in-depth, in the Indian context, compared with the literature review of this research and studies conducted in COPD, which showed a lack of evidence on this aspect (Gardener et al., 2018). This demonstrates the extent of the spiritual distress and the need for a holistic approach to care.

Limitations

This research captured the phenomenon of hospitalisation in a south Indian city but the experience may be varied in different regions due to the diverse socio-cultural background of the country. This research finding represent the experience from an urban hospital in India, therefore, this experience may be varied in other hospital settings, such as non-acute hospital setting. Also this experience may not be generalised to non-Asian countries with varied socio-cultural contexts.

The sample had more male participants than female and the experience of hospitalisation might be different for men and women, which might have influenced the description of the experience. Studies show that women with COPD have a different illness experience, such as feeling a loss of role as a homemaker, altered physical appearance and, a lack of confidence to cope with the illness alone (Steindal et al., 2017). Although this research captured the experience of several women, those previous findings did not emerge. It is possible that women with COPD have had a different experience of hospitalisation that could have influenced the presentation of the phenomenon.

The length of the interviews (*M* = 26 minutes) was shorter compared with interviews conducted in other qualitative studies. This could be due to inherent challenges of interviewing participants with breathlessness and extreme physical weakness which could have limited the depth of exploration of certain aspect of the experience. Short interviews are an intrinsic problem associated with research conducted in the advanced stage of COPD (Liew et al., 2019). The short interviews could reduce the breadth and depth of information on the intended topics to be uncovered which might impact the richness of the experience (Liew et al., 2019). To overcome this issue, multiple interviews with the same participants could have been conducted; however, this was not possible because of relatively short stay of hospitalisation in this research setting.

Emotional upset is common when interviews covering sensitive topics, such as illness experience; this might reduce participants' ability to coherently present the experience or lead to an inability to continue the conversation (Silverman, 2013). One example of this was psychological distress occurred while talking about the illness that prevented further conversation. The interview was paused for a short time to allow the participants to handle the emotions and the interview was resumed. A few participants did not want to continue the interview, which could have limited the depth of information obtained on a particular topic.

Another limitation is that both the literature review and the empirical research did not capture experience of discharge process, which is one of the elements of the phenomenon of hospitalisation (Lin et al., 2012). As participants were still hospitalised, the discharge aspect did not emerge during the interview.

This research captured the experience of hospitalisation as a snapshot in the advanced stage of COPD, which might have limited the presentation of the experience. Since hospitalisation is a complex and dynamic experience, which is influenced by multiple factors such as the intensity of symptoms, studying the experience at one point of time may not be adequate to understand the varying perception of positive and negative experience of hospitalisation.

6.7 Concluding remarks

This research illuminated the experience of hospitalisation in people with advanced COPD in south India. Hospitalisation does not have a consistent definition owing to its complex and multi-dimensional nature (chapter 1.7). Much of the research on the experience of hospitalisation has focused on the care aspects, which is the core experience of hospitalisation. Hence, it was difficult to draw definitive conclusions from the literature review of this research on the actual experience. This empirical research was conducted to find out whether the experience of hospitalisation related to certain aspects alone, such as care and treatment or whether other aspects were also present and which either were not given importance or did not emerge due to the methodological and socio-cultural context of the earlier studies.

The findings of this empirical research showed that the experience of hospitalisation resonates with the literature review of this research, which indicates that the universal features of hospitalisation in people with advanced COPD remains similar across the world. However, the experience is shaped by the individual socio-cultural and religious context which is reflected in the constituent, suffering during hospitalisation. This adds to the existing knowledge that individual socio-cultural aspects should be considered while developing policy and guidelines related to hospitalisation in chronic illnesses (Weech-

Maldonado et al., 2012). Also this research contributes to the body of knowledge to the Indian policy developers in chronic illnesses, as there is very limited evidence in this area.

The overall experience of hospitalisation is perceived as negative due to persistent suffering despite repeated hospitalisation, which indicates a lack of a holistic approach to people hospitalised with advanced COPD. However, it is surprising that participants utilised positive religious coping methods which are unique to the Indian culture and religion to manage the psychological and spiritual distress. Further, a lack of end-of-life discussion could lead to ICU and other intensive treatments which may be futile and increase the burden on the healthcare system and the financial burden of both the individuals and the country. Developing a palliative care programme specific to advanced COPD and the associated early integration of palliative care into the routine care of people with COPD is urgently required to improve the care of advanced COPD in India.

7. References

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8. Appendices

Appendix 1 Electronic databases search

Date searched	Name of the database	Date Range set	Total no of articles retrieved	No of articles selected
20.10.2016	PubMed	1970-present (No limit)	57	19
08.11.2016	CINAHL-EBSCO	No limit	622	9
09.11.2016	PsycINFO-EBSCO	No limit	147	8
19.11.2016	British Nursing Index	No limit	11	0
17.11.2016	Nursing and allied-ProQuest	No limit	236	3
06.10.2016	India data base-ProQuest	No limit	38	0
11.10.2016	Dissertation & Thesis-ProQuest		552	0
11.10.2016	Social Sciences-ProQuest	No limit	13	0
13.10.2016	Social science citation Index-Web of sciences (WOB)	No limit	127	0
13.10.2016	Conference proceedings citation index-WOB	No limit	18	0
14.10.2016	Open Grey	No limit	183	0
14.10.2016	Networked Digital Library of Theses and Dissertations (NDLTD)	No limit	27	0
14.10.2016	Open access thesis and dissertation	No limit	26	0

Search was updated on May 2020 and no new studies were found.

Appendix 2 Search terms used for database

Concepts	PubMed	CINAHL (EBSCO)	PsycINFO (EBSCO)	ProQuest*
COPD	**MeSH** "Pulmonary disease, chronic obstructive" OR **Free text** **"**Chronic pulmonary obstructive disease**"** OR "Chronic Obstructive Airway Disease" OR "Chronic Obstructive Lung Disease" OR "Chronic Airflow Obstructions" OR COPD OR COAD	**Mesh** ("Pulmonary disease, chronic obstructive") OR **Free text** (**"**Chronic pulmonary obstructive disease**"** OR "Chronic Obstructive Airway Disease" OR "Chronic Obstructive Lung Disease" OR "Chronic Airflow Obstructions" OR COPD OR COAD)	**MeSh** ("Chronic obstructive pulmonary Disease") OR **Free text** (**"**Chronic pulmonary obstructive disease**"** OR "Chronic Obstructive Airway Disease" OR "Chronic Obstructive Lung Disease" OR "Chronic Airflow Obstructions" OR COPD OR COAD)	**MeSh** ("Chronic obstructive pulmonary disease" OR Emphysema) OR **Free text** (Chronic Obstructive Airway Disease OR Chronic Obstructive Lung Disease OR Chronic Airflow Obstructions OR COAD)
Experience	**MeSh** "Experience, life" OR Sick Role" OR "Illness Behavior" OR "Attitude to Death" OR "Adaptation, Psychological" OR "Quality of Life" **OR** **Free text** experienc* OR concern* OR distress OR phenomenolog* OR voice*OR view* OR "quality of life" OR perspective* OR feel* OR	**MeSh** ("Adaptation, Psychological") OR ("Behavior and Behavior mechanism") OR ("Attitude to Death") OR ("Quality of Life") OR **Free text** experienc* OR concern* OR distress OR phenomenolog* OR voice*OR view* OR "quality of life" OR perspective* OR feel* OR	**MeSh** ("Illness Behavior" OR "Death Attitudes" OR Psychology OR "Emotional Adjustment" OR Adjustment OR "Emotional Adjustment" OR "Social Adjustment" OR "Well Being" OR "Quality of Life") OR **Free text** experienc* OR concern* OR distress OR voice*OR view* OR "quality of life" OR perspective* OR feel* OR understand*	**MeSh** Hardship OR ("Quality of life") OR **Free text** (experienc* OR concern* OR distress OR voice*OR view* OR "quality of life" OR perspective* OR feel* OR understand* OR belief* OR believ* OR worry OR worrie*)

	understand* OR belief* OR believ* OR worry OR worrie*	understand* OR belief* OR believ* OR worry OR worrie*	OR belief* OR believ* OR worry OR worrie*	
Qualitative study	**MeSh** “Qualitative research” OR hermeneutics OR “focus group” OR “interview as topic” OR “personal narratives as topic” OR narration OR **Free text** qualitative OR ethnograph* OR interview* OR “content analysis” OR “constant-comparative-method” OR “audio-recording” OR “grounded theory” OR phenomenolog* OR “field work” OR “semi-structured” OR unstructured OR “in-depth” OR “face-to-face” OR questionnaire*	**MeSh** (“Grounded theory”) OR (“Qualitative studies”) OR (“Phenomenological research”) OR (Interviews) OR (“Quality of life”+) OR **Free text** (qualitative OR ethnograph* OR interview* OR “content analysis” OR “constant-comparative-method” OR “audio-recording” OR “grounded theory” OR phenomenolog* OR “field work” OR “semi-structured” OR unstructured OR “in-depth” OR “face-to-face” OR questionnaire*)	**MeSh** “Qualitative research” OR **Free text** (qualitative OR ethnograph* OR interview* OR “content analysis” OR “constant-comparative-method” OR “audio-recording” OR “grounded theory” OR phenomenolog* OR “field work” OR “semi-structured” OR unstructured OR “in-depth” OR “face-to-face” OR questionnaire*)	**MeSh** (“Grounded theory” OR “Qualitative research” OR “Action research”) OR **Free text** (questionnaire* OR ethnograph* OR interview* OR “focus group*” OR “case stud*” OR observ* OR “grounded theory” OR narrative OR thematic OR experienc* OR “content analysis” OR ethnolog* OR Qualitative OR phenomenolog* OR “field work” OR “semi-structured” OR unstructured OR “in-depth” OR “face-to-face”)

*Nursing and Allied, Indian Social and Science studies and Dissertation and Thesis

Appendix 3 Characteristics of excluded studies

	Author	**Study characteristics**	**Study aim**	**Reason for exclusion**
1	Avsar et al, 2010	Population- COPD participants Stage of disease- mix of mild to severe COPD Setting-Hospital	Exploring COPD’s impact on daily lives.	Mixed stages of COPD. Not focused on hospitalisation.
2	Barnett et al, 2005	Population- COPD participants Stage of disease-mixed stages of moderate & advanced COPD Setting- Chest clinic	Experience of living with COPD.	Mixed stages of COPD. Not focused on hospitalisation.
3	Cooney et al, 2012	Population-COPD participants Stage of disease- not stated Setting- primary care	Exploring meaning of living with COPD.	COPD stage is not stated. Not focused on hospitalisation.
4	Coventry et al, 2014	Population-COPD, heart disease and Rheumatoid arthritis. Stage of disease-mixed stage Setting- hospital	Exploring lifeworld of people living with multi-morbidity.	Mixed participants with chronic illnesses. Inseparable data of mixed participants. Not focused on hospitalisation.
5	Dunger et al, 2015	Population-COPD and lung cancer participants. Setting- hospital Stage of disease- advanced COPD and lung cancer	Comparing the experience of breathlessness in COPD and lung cancer.	Mixed participants with COPD & lung cancer. Not focused on hospitalisation.
6	Fraser et al, 2007	Population- COPD participants Stage of disease- advanced COPD. Setting- hospital	Experience of old people living with advanced COPD.	Not focused on hospitalisation.
7	Willgoss et al, 2012	Population- COPD participants	Experience of anxiety in COPD.	Not included advanced COPD.

		Stage of disease- mild COPD Setting- Out-patient clinic		Not focused on hospitalisation.
8	Gabriel et al, 2014	Population- COPD participants and their family. Stage of disease –mild Setting –hospital	Experience of impact of COPD in daily life.	Not included advanced COPD. Not focused on hospitalisation.
9	Strang et al, 2014	Population-COPD participants Stage of disease- severe and very severe COPD Setting- out-patient clinic	Experience of guilt in COPD.	Not focused on hospitalisation.
10	Gardiner et al, 2009	Population- COPD patients Stage of COPD-moderate and advanced COPD Setting-primary care	Palliative care needs and concerns about death and dying of COPD.	Mixed stages of COPD. Not focused on hospitalisation.
11	Gullick et al, 2007	Population-COPD participants and their family Stage-severe COPD (emphysema) Setting- Hospital	Conscious body management of COPD patients.	Not focused on hospitalisation.
12	Elofsan et al, 2004	Population –COPD Stage-Not stated Setting- home care	Meaning of elderly people living with severe COPD.	Inadequate reporting of staging. Not focused on hospitalisation.
13	Panos et al, 2013	Population- COPD stage –not specified Setting-Primary care	Perception of COPD patients about the disease and impact on life.	Stage of COPD not stated. Not focused on hospitalisation.
14	Kanervisto et al, 2007	Population-Advanced COPD participants and their spouses Stage – advanced COPD Setting- hospital	Coping strategies of patients and their spouse with COPD.	Inseparable data of patient and family members.
15	Sridsman et al, 2010	Population-COPD Stage of disease- mild to severe Setting- Hospital	Experience of wellbeing of COPD patients.	Mixed staging. Not focused on hospitalisation.

16	Philips et al, 2012	Population- COPD participants & healthcare professionals Stage- mild to severe COPD. Setting-hospital	End-of-life decisions in COPD.	Mixed staging of COPD.
17	Lohne et al, 2007	Population-COPD participants Stage- III and IV COPD. Setting-hospital	Experience of pain in COPD.	Not focused on hospitalisation.
18	Skillbeck et al, 1998	Population-COPD participants Stage-advanced stage Setting-hospital	Palliative care needs of end-stage COPD and their carers.	This mixed methods study does not have sufficient qualitative data on the experience of hospitalisation.

Appendix 4 Data extraction sample

Item	Data details	Comments
Study details	Author Year Country	
Study characteristics	Aim Study design Ethics approval Setting Population	
Demographics	Age Gender Stage of COPD Reason for hospitalisation	
Data collection methods	Interviews (face to face, telephonic etc.) Focus groups	
Data analysis	Content analysis, thematic analysis etc.	
Main findings	Themes and concepts	
Findings related to experience of hospitalisation	Admission process, treatment and care and communication with staff etc.	

Appendix 5 Example for thin data
Data related to the theme ‘the communicative behaviour of the staff’ (highlighted)

Narratives of breathlessness in chronic obstructive pulmonary disease

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https://doi.org/10.1111/jocn.12033

Abstract

Aims and objectives

To explore patient perceptions of chronic obstructive pulmonary disease exacerbation and the patients' experiences of their relations with health personnel during care and treatment.

Background

Patients suffering from acute exacerbation of chronic obstructive pulmonary disease often experience life-threatening situations and undergo noninvasive positive-pressure ventilation via bi-level positive airway pressure in a hospital setting. Theory on trust, which often overlaps with the issue of power, can shed light on patient's experiences during an acute exacerbation.

Design

Narrative research design was chosen.

Methods

Ten in-depth qualitative interviews (*n* = 10) were conducted with patients who had been admitted to two intensive care units in Western Norway during the autumn of 2009 and the spring of 2010. Narrative analysis and theories on trust and power were used to analyse the interviews.

Results

Because of their breathlessness, the patients perceived that they were completely dependent on others during the acute phase. Some stated that they had experienced an altered perception of reality and had not understood how serious their situation was. Although the patients trusted the health personnel in helping them breathe, they also told stories about care deficiencies and situations in which they felt neglected.

Conclusions

This study shows that patients with an acute exacerbation of chronic obstructive pulmonary disease often feel wholly dependent on health personnel during the exacerbation and, as a result, experience extreme vulnerability.

Relevance to clinical practice

The findings give nurses insight into building trust and a good relationship between patient and caregiver during an acute exacerbation of chronic obstructive lung disease.

Results

The results show how 10 patients who had recently had an acute exacerbation of COPD and had received mask treatment experienced this acute phase and their relationship with health personnel during treatment in an ICU. Two main themes emerged, and they were breathlessness and the trust/power dimension. The two themes were closely related and had an inner context. We found that breathing problems led to a situation where patients experienced both situations of trust and power. Subthemes were also identified that showed story patterns, which in turn provided a more detailed understanding of the main themes.

Breathlessness

One pattern that emerged from the data is the patients' perception that having breathing problems was the main reason for their admittance to an ICU. The patients expressed that their illness made them feel totally dependent upon the care of others.

Completely dependent on the care of others

Most of the informants remembered little from the acute phase. The phrase ‘I don't remember anything’ is illustrative for what many of the informants said. Other typical statements included the following: ‘It was terrible. I was more or less completely gone’ (N8), ‘It is a matter of life and death – you got to get enough air’ (N6) and ‘I was completely paralysed’ (N2). The statements convey a sense of being completely dependent on others. In the following interview excerpt, one informant describes a traumatic situation:

Researcher: What happened when you got the exacerbation?

N8: After I got the attack, I stood there for about three to four hours without being able to do anything, not call, nothing.… So, if my wife hadn't called … she was at work. I managed to pick up the phone and said she had to come.

It was this man's belief that he was able to get in contact with the health service because his wife had called him. The patients had experienced increasingly heavy breathing before being hospitalised. Several said that because they did not understand the seriousness of their situation, they did not feel any particular anxiety. One patient, who had been diagnosed with COPD for a long time and who felt mentally able to cope with the acute exacerbations, remarked, 'At hospital, they say that I am calm, and I think I cope with it fairly good. They say so, the people in the ambulance. They say I am the calmest COPD patient they ever had' (N10).

Altered perceptions of reality

Several patients noted having nightmares during an exacerbation. One patient used a drowning metaphor to express how he had experienced the situation:

It seems like you enter a kind of dream world. You are at the bottom of a pool, and you want to get to the surface, but you are not able get up. You just lie there unable to breathe without being able to get to the surface. (N6)

Another patient described her phantasms as follows:

In the evenings, there was a woman with one ball down on the floor and one on the ceiling, and then she [would] spread a net with all the colours of the rainbow. I particularly remember black and bright blue. She frightened me, and, afterwards, I did not allow them [the healthcare workers] to turn off the light or the TV because I was so afraid that this woman should return to make her net again. It was scary. (N7)

Other informants said that colours, furniture and people appeared distorted during an exacerbation. When describing these incidents, patients typically used negatively loaded words and phrases, such as *frightening*, *scary*, *ugly*, *choking* and *not able to breathe*.

Trust and power

All the informants described situations in which they had to trust health personnel. But trust implies power, and if power is misused, distrust will be the consequence.

Trust

One patient (N2) stated, 'Yes, I just had to give in. I was totally dependent upon that what was about to happen with me, would be in my best interest'. Another patient (N9) described the situation as follows:

I had to start mask treatment at once. Now there is no resistance, so, perhaps, it is better that they [health personnel] are determined. If you get choking sensations, then … But when it comes to breathing, fear is the worst enemy. If you ever notice [that] you lack something, it will be air. You are now about to suffocate!

The patients noted the degree of professionalism displayed by nurses and doctors when administering mask treatment. With regard to breathing assistance, they expressed complete trust in the health personnel in the ICU. The patients used expressions like *first-class cooperation* to convey their gratitude for the assistance they received in a life-threatening situation. Several patients expressed the opinion that the nurses working in the ICU had a higher degree of competence than those in other units. All patients had a positive experience with the mask treatment. One patient (N5) commented, ‘I think that [the] mask [treatment] was very good for me; it really eased the pressure in my chest’. Another patient (N6), noting the helpfulness, kindness and attentiveness of the nurses in the ICU, made the following insightful comment: ‘They saw my needs before I noticed them’.

Patient participation during treatment in the acute phase is often difficult. The patients in this study experienced situations in which they lacked control. Several patients expressed complete trust in the health personnel in the ICU and wanted them to make decisions regarding the administration of treatment. Even though the patients relinquished control of decision-making about treatment to the health personnel, they still were able to interact positively with the nurses and to participate actively in much of what was happening to them.

Distrust and power

In addition to stories of trust, patients in the present study revealed those of distrust. Specifically, they described situations in which they had not been administered medication they felt that they should have had and had received promises of food from the health personnel that were not fulfilled. One patient (N3) described a night on the ventilator as follows:

> They would give me sleeping tablets because I had not been sleeping well. But I am a sound sleeper, so I thought it was not necessary. But she [the nurse] threatened [me] a bit with that tablet. I said no. I wanted to be attentive because I might be choked if they do not suck out the slime [in time]. I had to be in control; I just could not be asleep. ‘Oh no, this is not necessary’, the woman said. ‘I will look after you all the time’. During the night, I did start to get blocked, and [at first] I thought I was not going to say anything—[I had planned to] just test her out to see if they looked after me. They did not. I had to call. I had not taken a sleeping tablet. I was very blocked with a lot of slime.

In her story about the nurse, the patient used the word *threatened*, which expresses strong modality and, in this context, clearly describes the pressure the patient felt in this situation. As evident from the story, the patient initially distrusted the nurse and, thus, felt that she had to test the nurse before she could trust her. However, by failing to show up when the patient needed someone to suck out the slime, the nurse did not pass the simple ‘test’ that the patient had devised. Another patient (N7) described a situation in which she did not have access to an alarm:

> [The] most important [thing] to me was the alarm. It had to be with me all the time.… There were some nurses who managed to use it to manipulate me – to get some peace, of course – and that was scary because I could not talk. My only way of getting help was through that alarm.

In this story, the patient used the word *manipulate* to express how she perceived her interaction with the nurse. From this patient's perspective, the alarm represented not merely the only means by which to summon help but also a sense of security.

One patient (N4), who felt that she was not getting the kind of care she needed because she did not have the ‘right’ disease, made the following remark: ‘My disease was my own fault, so this served me right. I felt … just like that now and then’. The same patient (N4) also described a typical situation in which she felt that the health personnel patronised her because she had impaired hearing: ‘And when a doctor stands over you, at the same time making eye contact with a nurse and smiling, thinking I could not hear anything, well that's not nice. An educated man should know better than that'. A different patient (N1), who told a similar story about not being taken seriously, made the following comment: ‘They neglected me and ignore what I say’.

One patient (N2) recounted a situation in which she believed that the health personnel had been too forceful in administering the mask treatment. Feeling that she had lost control over her own treatment, the patient became angry. From this patient's perspective, a doctor and a nurse had exercised too much force in administering treatment. During the interview, she called upon all health personnel to listen to patients in situations such as this one.

Appendix 6 Interview guide

Study Title: The lived experience of hospitalisation in people with advanced Chronic Obstructive Pulmonary Disease in India.

This interview guide contains two parts; Part 1 is socio-demographic profile of the participant and part 2 is the interview guide**.**

Part 1 Socio-demographic profile

Name:

Age:

Gender:

Occupation:

Contact details:

Diagnosis:

Reason for hospitalization:

Number of days admitted on the day of interview:

Any other co-morbidities:

Number of times hospitalised within the last six months:

Part 2
Interview guide

The interview will use a broad, open question to begin the interview. It will use indicators to extract the information from the participant. Some of the indicators that might be used in the interview are stated below.

Opening question

Can you please tell me about your experience of being hospitalised?

Indicators/Prompts

1. Can you tell me more about it?

2. How does that make you feel?

3. Could you describe it in little more detail?

4. How exactly does that affect you?

5. What made you feel like that?

Appendix 7 Distress Protocol

Study Title: The lived experience of hospitalisation in people with advanced Chronic Obstructive Pulmonary Disease in India.

This distress protocol will describe the steps to manage participants' physical and emotional distress arising during the interview of this study.

1. Emotional distress

If the participants experience emotional distress during the interview and indicate that they are experiencing a high level of stress or emotional distress then, the following measures will be employed to address the emotional distress.

Step 1

The interview will be stopped and the researcher will provide immediate emotional support.
The emotional status of the participants will be assessed by asking the following questions:

- Tell me what thoughts are you having?
- Tell me what are you feeling right now?
- Do you feel that you will be able to go on about your day?

Step 2

If participants are able to carry on, then, interview will be resumed. If participant is unable to carry on and/ or show any acute emotional disturbance, then, the interview will be discontinued and the following measures will be taken:

- The clinical staff will be notified about the participant's emotional distress, who will take measures to have a consultation with the psychologist.
- The limits of confidentiality will be briefed to the participant.

Step 3

Follow up

- The participant will be asked to inform the responsible clinical staff, in case of experiencing repeated emotional distress.
- OR they may contact the researcher, if they wish to discuss further and researcher's working phone number will be provided.
- If participant does not want to continue, they can withdraw from the study.
- Later, the researcher will make a courtesy call to check the participant's emotional well-being.

2. Physical distress- breathlessness

If participants experience severe breathlessness or cough and unable to continue the conversation, the following measures will be taken;

Step 1

- The interview will be stopped
- The researcher will make sure that the oxygen supply is adequate by adjusting the oxygen pressure in the participants' portable device.
- If breathlessness has reduced and the participant feels alright to continue, the interview will be resumed and conducted in short episodes, permitting a minimum of two interruptions at a time.

Step 2

In case of experiencing severe breathlessness,

- The interview will be discontinued.
- The researcher will check the vital signs and immediately call the clinical staff for further help to treat breathlessness.
- If participant recovers and willing to continue the interview, then, the interview will be rescheduled for another day, within the period of hospitalization.
- If participant does not want to continue, they can withdraw from the study.

Appendix 8 Researcher's diary

Breathlessness

Breathlessness brings a mixed feeling in my mind. In my experience, patients with breathlessness suffered immensely in their body, mind and soul. The search for air never ends and there is no prediction when the intensity of search for air would increase. Being threatened by choking and the miserable feeling of 'passing away' is indescribable. The rock like chest that restraining the lungs from breathing the air, break every effort that patient takes to breathe. Even in patients with NIV, I have seen the struggle to breath continue to threaten the patient. Here, I terribly fail as a doctor who is not able to help but to see my patients continue to suffer despite giving the so called 'treatment'. I have to draw my courage to tell them that this is how it feels even with the machine and that the available medical technology only could help this much. In extreme breathing difficulty, I had to resort to morphine to help with the helplessness of the patient and their family who watch them suffering helplessly.

Watching the fear filled faces, hooked on to the NIV machine, I really search for words of encouragement to speak to my patients (and to myself). That this suffering will not last longer, which indirectly meant that you are ready to be released from the suffering (on earth). I feel happy that some of my patients are smart enough to understand this fact and with them my conversation seems to be brief. But for others who don't understand this fact, I have go through with them (I literally feel this way), their fears about death, being haunted with nightmares, fear of leaving the family behind, unsettled business in life, unsustainable finance, regretting their past behaviours, seeking for forgiveness etc. and the list goes on.

The one thing that most of my patients wanted me to do for them or they desired to achieve after they have been treated in the hospital, was to be independent enough to do their daily tasks. I feel that they are not asking for too much, like others who expect a complete cure. This was an important treatment goal to achieve for me, as well as for my patients but both my patients and I were disappointed over this. As the days go by I have seen patients needed more and more support to carry out daily routines. It was awful to ask someone to help you to walk you to the toilet and walk with the fear of expecting a breathing attack any moment and rely on the oxygen machine as if that is your last hope and support. Many patients literally wanted and begged to have a sudden, peaceful death (like you go to sleep and you never wake up the next day). Again, this was disappointing as many of my patients died with terrible breathing difficulty.

Bracketing

This is my experience but this need not be the one for the patients that I am interviewing! Every experience could be different and unique and bring a different perspective to the phenomenon being studied!

Appendix 9 Identifying constituents from transformed meaning units (P13)

Participant's description	Transformation	Constituents
As soon as I came, they check the oxygen level and they gave me oxygen. They give drips and also give injection, then, it becomes OK. They usually keep me here for 2-3 days… give injection also. When I come, I come with difficulty… after I come here….my doctors who look after me all are good. As soon as I come, they check me well…immediately…. Within 12 hours I get ready…. whatever it is 12hrs or 24 hrs they make me well… to the point that I could go for a walk and get up from the bed, they bring me to that level….	Participant gets quick attention and care as soon as he comes to the hospital. When he comes with difficulty doctors give all necessary treatment that he is independent and returns to normal life within a short time. All the doctors who take care of him are good and pay quick attention.	Caring attitude of doctors/ Immediate attention.
I also would become ready… whatever is required to get better I will also do…. I don't say that I don't want this or I don't like this…I don't do this…. whatever is advised by doctors, I just do it.	He co-operates with the treatment and follows whatever is advised by the doctors.	Experience of treatment/complying with the treatment.
much difficulty…When I came it was bad… cough… I couldn't breathe.. I can't walk….then, immediately they made me well.	When he came to the hospital, his breathing was bad but doctors cured him.	Caring attitude of doctors/ Immediate relief
in my body, somewhat…. When I have bad breathing difficulty, the sides of the lungs (chest) pains and also my back starts aching…	He gets pain on the sides of both chest and back during breathlessness.	Perception of breathlessness

cough.		
when I come to the hospital during breathing difficulty in the auto (a three wheeler vehicle), it gets better partly… but sometimes that itself worsens it.	When he comes to the hospital during breathing difficulty in a three wheeler vehicle, it gets better partly… but sometimes that itself worsens it.	Perception about breathlessness
it was very … very fast… see it was like this (showing how he breathed) and I kept sitting like this (showing sitting leaning forward)….	Breathing was very fast that forced him to sit leaning forward.	Perception about breathlessness/struggle to take a breath.
When I came to emergency, breathing difficulty was more; they first pay attention to the breathing difficulty patients only… hmm… they checked me and then made me lie down in the couch… they gave me injection, then oxygen, then they took the blood test… they did all the test… checked oxygen level… then I went to x-ray… after the x-ray (was taken) they told me that i have some problem and should get admitted.. I got admitted.	Patients with breathing difficulty get doctors' attention immediately in emergency. They checked him in detail and took various tests and said that he has some problem and needs admission.	Care in emergency/quick attention; caring attitude of doctors.
doctor admitted me… I don’t know the doctor’s name… hmmm…. They asked me all the details that ‘how long I have been having this problem; what treatment you have taken? Do you smoke? How long you have been smoking? What do you eat?’ All usual questions they asked me.	The doctor in emergency checked all the details about his illness, then, he was admitted.	Experience of admission in emergency/Caring attitude of doctors.
hmm… usual procedure only….. all doctors advised the same thing… Ok…. I can’t say no… I	The admission procedure is as usual. Doctors advised him the same thing like the earlier times.	Caring attitude of doctors/ Illness information.

have never said I won't do this or that… all aged doctors (senior doctors).	He couldn't refuse their advice as they are all senior doctors.	
I come here to know how not to get this problem again….but circumstances, that and this, food, water all that together bring this problem….i don't go (deliberately do something) to get into problem…	He comes to hospital to learn how to prevent this illness. But there are other factors that could not be controlled which could be causing this illness. He did not do anything intentionally to get this illness.	Information about illness causation; loss of control over getting illness.
my doctors knew about me…that I have only breathing difficulty, don't have sugar or heart problem…. That's why there is no need for ICU treatment… even in ICU they gave only nebulization.. then there was no necessity… if they gave some additional treatment, it was OK to stay in the ICU.	His doctors know his health problems very well that he did not require ICU care. In the ICU, he just received the routine treatment for breathing difficulty. He felt that there was no necessary for him to be in the ICU.	Trust in doctors; Experience of ICU care/ Unnecessary admissions to ICU.
No.. they (doctors) said that I got infection in the lungs and have to be admitted…but doctors here (ICU) thought so, I think… they got me in ICU…anyways I got better and here I am now.	The doctors in the emergency advised admission because of lung infection; probably doctors in the ICU thought that he needed ICU care. Nevertheless, he is relieved that he got better now.	Experience of ICU care/unnecessary admission to ICU.
No.. Nobody explained…I also did not ask… my son called up and asked the doctor to know why I needed ICU treatment… to him they said that 'at least he needs to be there in the ICU for half a day'…So I don't know why I was in the ICU.	None of the doctors explained the need for ICU care. When his son enquired, they told him that he needed to be in the ICU for a short time. But he is puzzled why he was in the ICU.	Inadequate explanation about treatment decision/Unnecessary admission to ICU.
In ICU, it was like this…like a general ward… everybody was coming and going… ICU means ,	That ICU seemed to be a busy place with people moving in and out all the time. That did not give	Experience of ICU care/ Busy place.

nobody (visitors/family members) should come inside… but it was not like that here… people come and go, see, bring things…. that is a busy place…	him a feeling of ICU environment.	
Aha… everybody has got… (laughs) not everybody is same …. everybody have some problem… for their problems they have to see, isn't it? (pause)	He thinks that everyone in the ICU has different health problem and they have to be in the ICU to get well.	Experience of ICU care /Impression about others being cared in the hospital.
aha…. Only bad things I thought.. (laughs) why should I think like that? Isn't it? No chance for thinking anything.	While he was in the ICU, he thought about only bad things. He feels that there no necessity to think negatively because he is not currently very ill like other in the ICU.	Worries about illness.
bother means… see, if I have some problem to be in the ICU and because of that I was admitted, then I need not have to worry. I have no such problem to be in the ICU.. why should I simply lie down in the ICU.. isn't it? just for nebulization, why should I be in the ICU?	He feels that there is no health reason for him to be in the ICU. He is questioning why he should be there just to get the routine treatment.	Experience of ICU care/Inadequate treatment information/Lack of participation in the treatment decision.
Like for others, they were feeding milk through a tube into the nose…like that if had happened to me…. Then … doctors stay there.. no such… for me no such problem… then why I need to be there? Isn't it? (Sounds upset and angry)…. If it is like that for me, then OK… but I was not like that….so I don't have the necessity to be there? Isn't it? If it's like that I will be there… isn't it? See, people are there are those with problem,	If he was sick like others who are admitted in the ICU, then there is a good reason for him to be admitted to the ICU. But he was simply admitted there without having any such issue.	Experience of ICU care/Unnecessary admission to ICU; confusion over admission.

couldn’t eat, couldn’t get up (coughs)… for them ICU is needed… if I was like that I would have been there and I wouldn’t have come here (to the ward)… without having any problem, I was simply admitted there (laughs) …		
No… nothing they said…. They removed my dress and checked everything… gave nebulization… and after that they did not come near me...	The doctors in the ICU did not explain his condition. They just examined him once and after that nobody paid attention to him.	Experience of ICU care/poor attention in ICU.
in emergency, when I was there were, there were no patients waiting…only one or two… doctors were free….they checked me quickly and sent me…. it was easier for them and for me too…	While he was in the emergency, he was examined and admitted by the doctor quickly as there was no other patient waiting.	Care in emergency/ Quick attention.
in ICU all doctors and nurses were busy… because they were busy, they were just doing their job and I didn’t know anything and no one came to me (paid attention)…. Even if I was like those kinds of patients then they would have come to me….. they were busy with their patients …. even doctors just came, saw and then go away…..	In the ICU, doctors and nurses were busy taking care of their patients and nobody came to check on him. He thought because he was not sick like other patients to pay close attention.	Experience of ICU care/poor attention in ICU.
no no.... if I had something then they would have come to me…	If he had some problem doctors would have come to check on him.	caring attitude of doctors/Trust in doctors
this is usual.. my usual place that I come and go… so… nothing…	He feels that hospital is the usual place for him that he didn’t have any different feeling about being	Familiarity/repeated hospitalisation.

	there.	
what thoughts.. that no one is there to look after the children… Because everybody is working for 24 hrs, all go to work, 4 (grand) children are with me from morning until night….that is what I miss nothing else…	He is missing to be with his grandchildren due to hospitalisation and that there is nobody to take care of them.	Inconveniences due to repeated hospitalisation.
I have belief in God… HE is the one who brings me here takes me back home (smiles) I think… no problem… I don't think bad things (laughs) neither good things.. Whatever is there that is how it is… god is there…	He believes in God that He takes care of him. He takes things as it is whether it is good or bad.	Perceptions about God/Faith in God.
Aha (nodding no) I don't think to that extent, no such thoughts… it will be OK; even if not, breathing only know, somehow will adjust; I have adjusted for 40 years, and now for a little while; isn't it… for sure I know that this will not leave my body…isn't it?	He never had thoughts about the chronicity of his illness. He thinks it will be alright. He had it for a very long time and he doesn't mind tolerating it for a little more time. He knows for sure that the illness won't be cured.	Realisation of incurability/perception of illness.
otherwise, it should have got alright… now, when one hand is broken, they give 15 days' time. And hand gets better; if it is not getting better, then, what to do with the broken hand or leg? You have to walk limping; this is also like that; if not getting alright, you have to limp, you have to come for treatment often, and go isn't it? There are many diseases that get cured and those don't get cured; I think this is under the category of not getting cured; even kids of 1 or 2 year old are affected with	He compares the incurability of his illness to a broken hand. If it is not getting alright, then you have to live with it. This illness affects every age group and can't be managed without medications. But he doesn't know why it is incurable.	Views about curability/ /Metaphors about incurability

this; if I have to then, I can be without medicine even for three years.. but if it comes back again, then I don't know… why is it like this…		
no no..… all this is natural…what do we inhale… blanket or pillow some dust whatever inhale… when I was alright, and clean up the dust, nothing happened…. Sometimes it happens so..	He thinks it is natural to get this illness due to things inhaled like the dust.	Living with illness/Reasoning for illness.
see, now, I f I remain without doing that job then I am OK; but if I think that if I don't do it.. who else will do it, so have to do it…and do that job, it affects me.	He can prevent getting the problem by avoiding doing things that triggers it. But when there is one around to help him with then, he has to do that work which affects him.	Living with illness/Reasoning for illness.
no no no… I don't depend on anybody… I make my own tea…I don't even tell my wife…that sugar…she doesn't drink tea and do not know how much sugar to add…because of that I make tea and keep it in the flask and drink.. I want to help others but do not want to take help from others…	He feels that he is not dependent on anybody. He is the kind of person who wants to help others but don't like to take help from others.	Living with illness/being independent
when I get into dangerous condition; I have not yet reached that stage; I am 72 years now…hmm adjusting… what will happen hereafter… God's grace…	He feels that he is not in advanced stage of illness and that he is able to tolerate it until now. He doesn't know how it would be in future and that he trust in God's grace.	Living with illness/ letting go off life: Perception about God/Faith in God.

Appendix 10 Ethics approval

Lancaster University

Applicant: Barathi Bakthavatsalu
Supervisors: Katherine Walshe and Katherine Froggatt
Department: Health Research
FHMREC Reference: FHMREC17006
07 September 2017

Dear Barathi,

Re: The lived experience of 'being hospitalised' in people with advanced Chronic Obstructive Pulmonary Disease in India

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

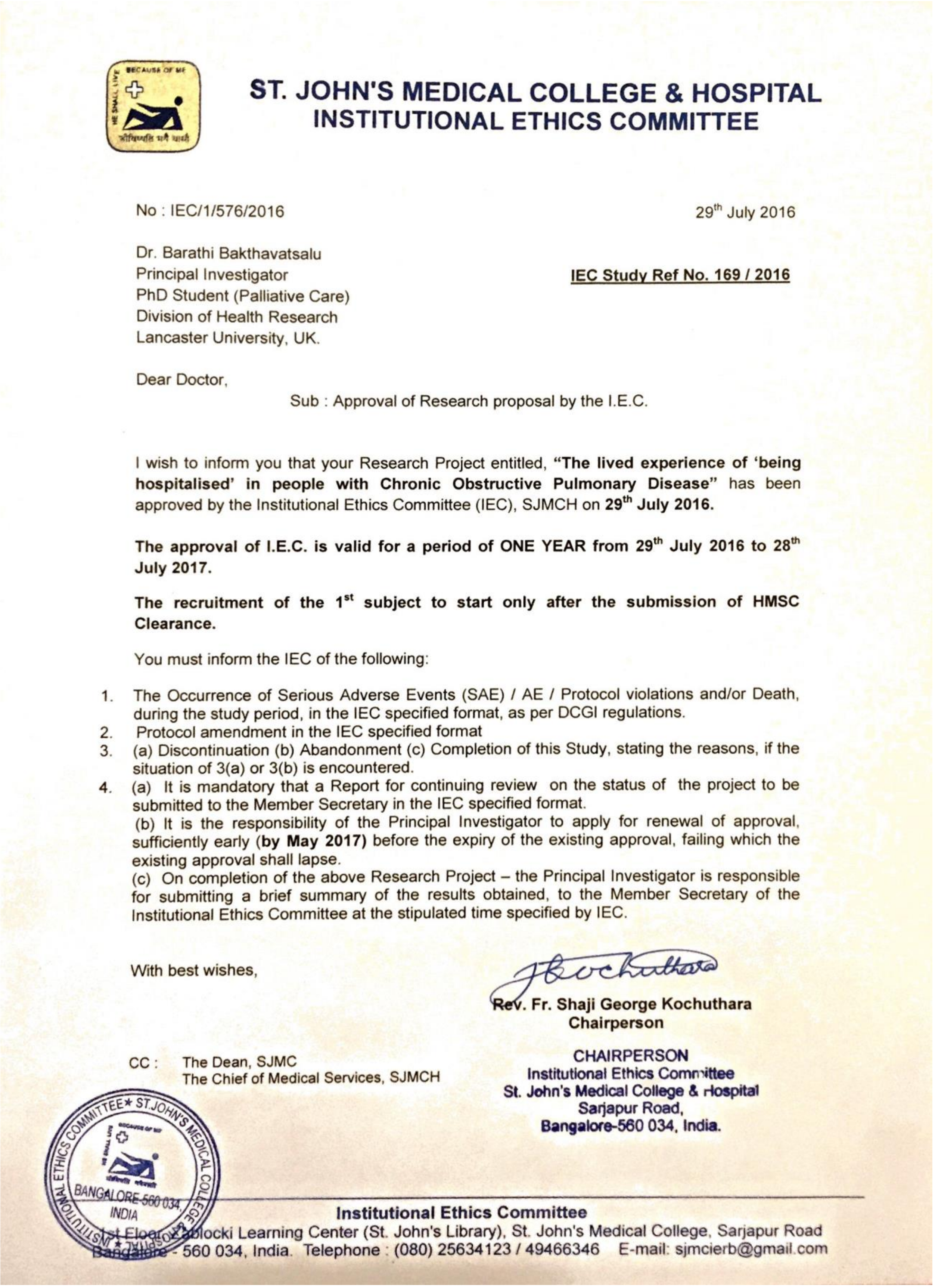
- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.
Tel:- 01542 592838
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Diane Hopkins

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC



ST. JOHN'S MEDICAL COLLEGE & HOSPITAL
INSTITUTIONAL ETHICS COMMITTEE

No : IEC/1/576/2016

29th July 2016

Dr. Barathi Bakthavatsalu
Principal Investigator
PhD Student (Palliative Care)
Division of Health Research
Lancaster University, UK.

IEC Study Ref No. 169 / 2016

Dear Doctor,

Sub : Approval of Research proposal by the I.E.C.

I wish to inform you that your Research Project entitled, **"The lived experience of 'being hospitalised' in people with Chronic Obstructive Pulmonary Disease"** has been approved by the Institutional Ethics Committee (IEC), SJMCH on **29th July 2016.**

The approval of I.E.C. is valid for a period of ONE YEAR from 29th July 2016 to 28th July 2017.

The recruitment of the 1st subject to start only after the submission of HMSC Clearance.

You must inform the IEC of the following:

1. The Occurrence of Serious Adverse Events (SAE) / AE / Protocol violations and/or Death, during the study period, in the IEC specified format, as per DCGI regulations.
2. Protocol amendment in the IEC specified format
3. (a) Discontinuation (b) Abandonment (c) Completion of this Study, stating the reasons, if the situation of 3(a) or 3(b) is encountered.
4. (a) It is mandatory that a Report for continuing review on the status of the project to be submitted to the Member Secretary in the IEC specified format.
   (b) It is the responsibility of the Principal Investigator to apply for renewal of approval, sufficiently early (**by May 2017**) before the expiry of the existing approval, failing which the existing approval shall lapse.
   (c) On completion of the above Research Project – the Principal Investigator is responsible for submitting a brief summary of the results obtained, to the Member Secretary of the Institutional Ethics Committee at the stipulated time specified by IEC.

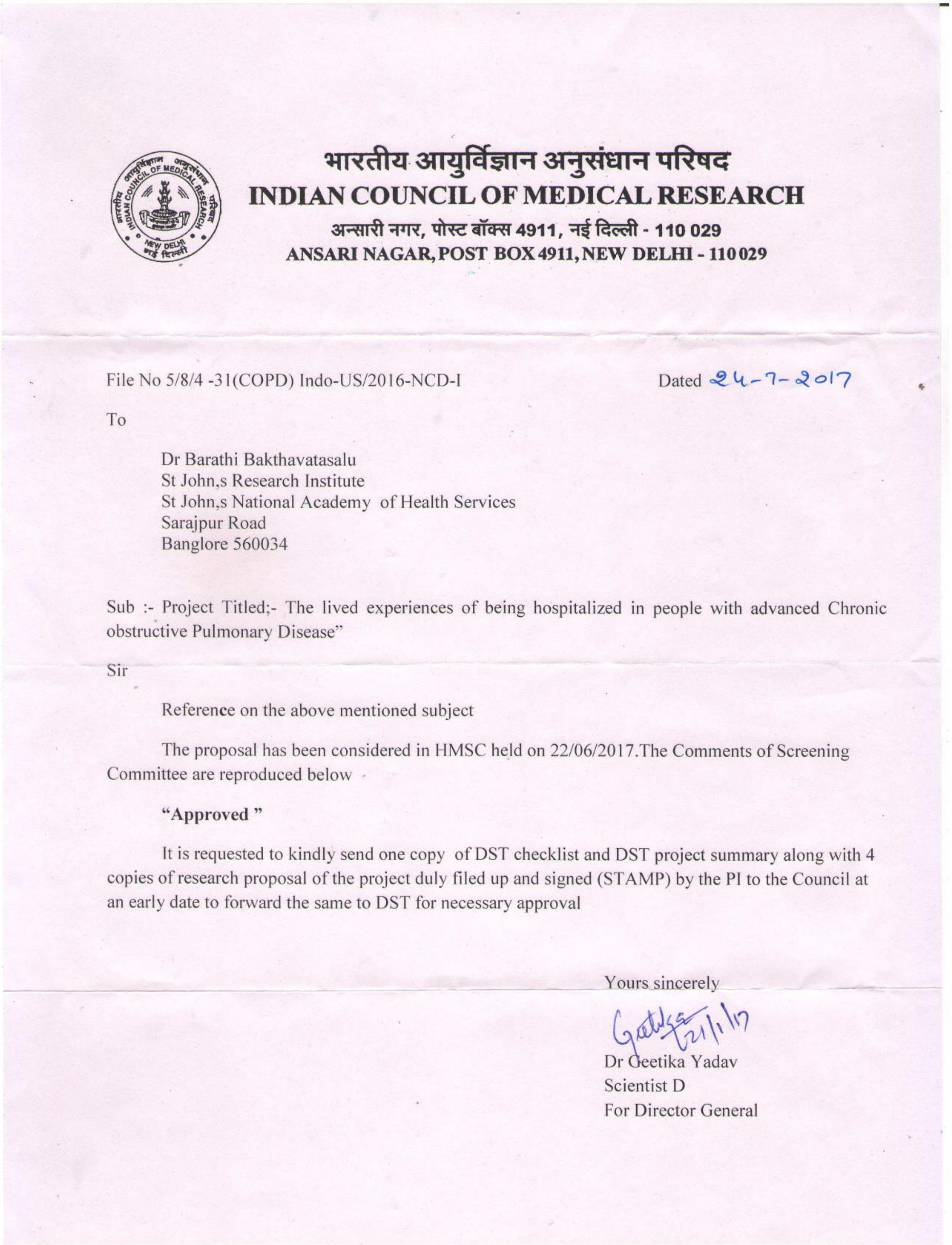
With best wishes,

Rev. Fr. Shaji George Kochuthara
Chairperson

CHAIRPERSON
Institutional Ethics Committee
St. John's Medical College & Hospital
Sarjapur Road,
Bangalore-560 034, India.

CC : The Dean, SJMC
The Chief of Medical Services, SJMCH

Institutional Ethics Committee
1st Floor, Zablocki Learning Center (St. John's Library), St. John's Medical College, Sarjapur Road
Bangalore - 560 034, India. Telephone : (080) 25634123 / 49466346 E-mail: sjmcierb@gmail.com



भारतीय आयुर्विज्ञान अनुसंधान परिषद
INDIAN COUNCIL OF MEDICAL RESEARCH
अन्सारी नगर, पोस्ट बॉक्स 4911, नई दिल्ली - 110 029
ANSARI NAGAR, POST BOX 4911, NEW DELHI - 110 029

File No 5/8/4 -31(COPD) Indo-US/2016-NCD-I Dated 24-7-2017

To

Dr Barathi Bakthavatasalu
St John,s Research Institute
St John,s National Academy of Health Services
Sarajpur Road
Banglore 560034

Sub :- Project Titled;- The lived experiences of being hospitalized in people with advanced Chronic obstructive Pulmonary Disease"

Sir

Reference on the above mentioned subject

The proposal has been considered in HMSC held on 22/06/2017.The Comments of Screening Committee are reproduced below

"Approved "

It is requested to kindly send one copy of DST checklist and DST project summary along with 4 copies of research proposal of the project duly filed up and signed (STAMP) by the PI to the Council at an early date to forward the same to DST for necessary approval

Yours sincerely

Geetika 21/1/17

Dr Geetika Yadav
Scientist D
For Director General

Appendix 11 Participant Information Sheet

Title of the study

The lived experience of 'being hospitalised' in people with advanced Chronic Obstructive Pulmonary Disease in India.

My name is Barathi Bakthavatsalu and I am conducting this research as part of my PhD programme at Lancaster University, Lancaster, United Kingdom. The participant information sheet is available in Tamil.

Summary

This study is about understanding the experience of 'being hospitalised' in people with advanced Chronic Obstructive Pulmonary Disease (COPD) which is one of the 'chronic lung disease'. This involves interviewing people with advanced COPD and the opinions of individuals are analysed together to understand the experience of what is it like to being hospitalised. The findings help to enhance the understanding of the healthcare professionals who are involved in care of people with advanced COPD.

What is the study about?

The purpose of this study is to understand the experience of 'being hospitalised' in people with advanced COPD.

Why have I been approached?

I am inviting those with COPD who are admitted to this hospital if they would like to take part.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. I encourage you to look at the study details here so that you understand as much as possible about the study before you make your decision. If you chose not to participate in the study, your treatment and the care you receive will not be affected.

What will I be asked to do if I take part?

You would be interviewed individually and asked to share your experience about your experience of being hospitalised with this illness. The interview may last about for 30-45 minutes and your conversation will be audio recorded. If you would like one of your close family members to be present with you during the interview, you can do so. Please, note that they will not be participating in the discussion during the interview. Every effort will be taken to delete the accidentally captured audio data of the family members, unless, it is recorded alongside the conversation between yourself and the researcher.

Will my data be Identifiable?

- Your audio recorded conversation will be kept securely, and only identified by a code number, not your name. The typed version of your interview (transcripts) will be made anonymous by removing any identifying information including your name. Your opinion will be pooled with other participants and will be anonymised as any information in your interview which might identify you will be taken out. Quotes from participants will be used in reports and publications, but these will only be associated with a code number, not a name.

- The research team at the Lancaster University and the translator who will help in translating the transcripts will have access to this data; the translator will sign a confidentiality agreement form.

- With your permission, the anonymised transcripts will be stored securely, to enable researchers to use the data for further research.

- Your personal data will be kept separately from your interview responses, in the University's secured shared drive and will be destroyed after publication.

- There are some limits to confidentiality: if what is said in the interview makes me think that you or someone else, are at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in my thesis and may be submitted for publication in an academic or professional journals of palliative care for dissemination. The findings will also be presented at palliative care conferences and to the academic association of Pulmonary Medicine Association in India.

Are there any risks?

I do not anticipate there to be any risks with participating in this study. In talking about your illness, there is the possibility that you may experience some emotional distress. If you experience an emotional distress, the interview will be paused, until the time you feel comfortable to resume. The clinical staff will help you to meet with the psychologist, if required. You are also encouraged to contact the resources provided at the end of this sheet. If you find the interview difficult because you are breathless, we will try interviewing you in short episodes. Should you feel unable to continue, the interview will be rescheduled for another day, whilst you are still in the hospital.

What is the procedure to withdraw from the study?

You can tell the researcher or any member of your clinical team that you wish to withdraw from the study at any time, without giving a reason. If I have already interviewed you, I will ask if I can keep your interview data for the study. If two weeks or more have passed since your interview I won't be able to remove your study data as your opinions will have been analysed together with those of other participants.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University. This study has also been reviewed by the Institutional Ethics committee, St. John's National Academy of Health Sciences at Bangalore, India.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:
Barathi Bakthavatsalu
Work mobile number: XXXXXXX

Supervisors

Dr. Catherine Walshe
E-mail : c.walshe @lancaster.ac.uk
Prof. Katherine Froggatt
E-mail :k. froggatt@lancaster.ac.uk

Complaints

If you wish to speak to someone outside of the PhD in Palliative care Programme, you may also contact:

Professor Roger Pickup
Associate Dean for Research
Faculty of Health and Medicine, (Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG
Email: r.pickup@lancaster.ac.uk
Tel: +44 (0)1524 593746

For any ethics related queries, contact:

Dr. Jayanthi Savio
Member Secretary
Institutional Ethics Committee
St. John's Medical College
Bangalore – 560 034
Ph.: 080 – 49466346 / 48

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

The Head nurse
Work mobile number: XXXXXXX

Thank you for taking the time to read this information sheet.

Appendix 12 Consent Form

Study Title: The lived experience of ‘being hospitalised’ in people with advanced Chronic Obstructive Pulmonary Disease in India**.**

We are asking if you would like to take part in a research project which will explore the lived experience of ’being hospitalised’ in people living with advanced Chronic Obstructive Pulmonary Disease (COPD) which is one of the ‘chronic lung disease’. This will enhance the understanding of health care professionals to improve the quality of care delivered to people with advanced COPD. Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. The consent form will be available in Tamil. If you have any questions or queries before signing the consent form please speak to the principal investigator, Dr BARATHI BAKTHAVATSALU.

Please initial each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study. ☐

2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐

3. I understand that my interview will be audio recorded and made into an anonymised written transcript. ☐

4. I understand that the transcription will be translated in to English by a bilingual expert. ☐

5. I understand that my personal data will be stored separately in a secured place from the interview response and deleted after publication; the original transcripts will be kept securely until 10 years; the back-up copy of the audio recording stored until transcription; the original recording and the back-up copy of the transcripts will be stored until thesis is examined. ☐

6. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

7. I understand that once my data have been anonymised and incorporated into themes, it it might not be possible for it to be withdrawn from the study. ☐

8. I understand that the information from my interview will be pooled with other participants’ responses, anonymised and may be published. ☐

9. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐

10. I understand that the anonymised data set will be accessible to other interested researchers on request, to allow dissemination and further research. ☐

11. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with her research supervisor. ☐

12. I understand every effort will be taken to delete the accidentally captured audio data of my family member who is present during the interview. However in situations where the family member's data is inseparable from the data collected from me or the researcher, I consent to retain them. I fully understand that in this case, the audio data of my family member will not be analysed and all cautions will be taken to store them securely to ensure confidentiality. ☐

13. I consent to the research team at Lancaster University and the translator having access to the data. ☐

14. I consent to take part in the above study. ☐

Name of Participant__________________ **Signature**____________________

Date ____

In case of consent signed by a participant who is not able to read or write, and verbal consent, an unrelated witness signs the following :

I hereby, agree that the participant was given sufficient information to make an informed decision and the participant gave voluntary consent.

Name of the witness: **Signature** ____________________

Name of Researcher: Dr BARATHI BAKTHAVATSALU **Signature** ____________________

Date:

Appendix 13 Confidentiality Agreement for the Translation of Qualitative Data

Name of Study:	The lived experience of advanced Chronic Obstructive Pulmonary Disease in hospitalized patients in India.
Study PI:	BARATHI BAKTHAVATSALU

In accordance with the Research Ethics Committee at Lancaster University (UREC), all participants in the above-named study are anonymised. Therefore any personal information or any of the data generated or secured through transcription will not be disclosed to any third party.

By signing this document, you are agreeing:

- not to pass on, divulge or discuss the contents of the transcripts provided to you for translation to any third parties
- to ensure that material provided for translation is held securely and can only be accessed via password on your local PC
- to return translated material to the research team when completed and do so when agreed in password protected files
- to destroy any audio and electronic files held by you and relevant to the above study at the earliest time possible after the translation has been provided to the research team, or to return said audio files.

Your name (block capitals) MARY BRIDGET PUSHPA

Your signature DMary

Date 20th August, 2016.