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**Attitudes, behaviours, and perspectives of people coping with
Chronic Obstructive Pulmonary Disease (COPD)**

Submitted by

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In fulfilment of the requirements for the degree of

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College of Healthcare Sciences

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Statement of Contribution

Contribution	Contributor	Name, Titles, and Affiliations
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Abstract

Chronic obstructive pulmonary disease (COPD) is a progressive lung disease with irreversible obstruction of the airways (Jones et al., 2011; Meier et al., 2011), causing activity limitations, work absenteeism, frequent hospitalisations, and medical emergencies that place a significant burden on patients and healthcare systems. The World Health Organisation (WHO, 2024) ranks COPD as the fourth leading cause of death worldwide.

Prior research has emphasised the importance of adequate coping strategies in dealing with the symptom burden of COPD, but has overlooked the attitudes, behaviours, and perspectives of people coping with the illness. The variations in self-care interventions in daily life are poorly understood, generating the research question guiding this study: “What are the attitudes, behaviours, and perspectives of people coping with COPD that influence variations in self-care interventions in daily life?” The research question is exploratory in nature and is suited to a qualitative methodology.

Data were collected through semi-structured interviews with 11 participants residing in the regional city of Townsville, Australia, between February and August 2024. All interviews were conducted in English, outside the participants' homes, and were audio-recorded and transcribed verbatim by the researcher. The data were organised using NVivo version 12 and analysed following Braun and Clarke's six-step thematic analysis framework (Braun & Clarke, 2006).

Data analysis identified four major themes and nine sub-themes. The analysis of the data revealed that people with COPD went through different phases to manage their disease effectively. The realisation of the symptoms and challenges due to the disease evolved throughout their lives. The process of self-realisation assisted them in discovering their strengths and weaknesses and enabled them to accept the disease. Participants were able to convert negative emotions and feelings into an optimistic approach to tackle the disease. This transformation included various approaches that empowered them to consider disease as a part of their life. Participants were able to utilise the support systems in managing their disease. The action plans articulated by participants, along with using assistive devices, facilitated their management of the symptoms of the disease.

The phases of realisation, acceptance, transformation, and management moulded them to 'Being in Charge' of their disease. These phases also reflected the process of learning, choosing, acting, and sharing. As the participants voyaged through their disease, participants felt motivated. This motivation prevailed to control their attitudes, behaviours, and perspectives to manage the disease and 'Being in Charge' of themselves and their disease.

The findings highlighted the lack of education among study participants about COPD at the early stages of diagnosis, the important role of general practitioners in disease management, and the necessity of support groups for COPD. The in-depth understanding of the experience of study participants may inform the design of educational interventions and frameworks for practice to better support people coping with COPD. Introducing the overarching theme of 'Being in Charge' in one's disease or health, inclusive of the management of COPD, will assist in appropriately educating and empowering patients in collaborative decision-making through advocacy and support.

Exploration and comprehension of the experience of living with COPD have disclosed the distress associated with various physical and psychological symptoms and have raised awareness about coping behaviours adopted by participants. Their strategies offer valuable insights for teaching newly diagnosed patients how to maintain independence, prevent exacerbations, reduce anxiety, and mitigate symptom burden, potentially lessening the healthcare burden on individuals, organisations, and communities.

Introducing educational sessions in collaboration with the multidisciplinary team at the earlier stages of diagnosis can enhance disease awareness and self-management. Introducing COPD-specific support groups and encouraging patients to participate will assist them in sharing their experiences, a catalyst for the participants to be active and an avenue to discuss their concerns. These insights have practical implications for regional healthcare. Tailored education programs delivered at diagnosis, combined with structured peer support networks, can empower patients to engage in collaborative decision-making, reduce symptom burden, and maintain independence. In turn, such strategies may help alleviate the strain on healthcare services in regional communities.

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Table of Publication

Title	Status	Reference
Attitudes, behaviours, perspectives of people coping with Chronic Obstructive Pulmonary Disease: A narrative review	Under review	Appendix N, page 188

Preamble

“I can’t breathe, I can’t breathe”, Margaret (pseudonym) is shouting in fear, and her face has turned purple. Margaret is a patient suffering from chronic obstructive pulmonary disease (COPD) and was admitted to a medical ward in the hospital. Nurses are trying to calm her, increasing oxygen supplementation, giving medications to help her breathe, and contacting doctors for review, but recovery is a slow process. As the frequency of these attacks increases, the recovery time is prolonged. These incidents are frequent scenarios at my workplace.

For nearly nine years of my nursing career, I have cared for patients with respiratory diseases, including chronic conditions like COPD, interstitial lung disease, and cystic fibrosis. Patients with COPD tend to have frequent admissions and usually require noninvasive ventilation (assistive respiratory device) to relieve their symptoms of exacerbation. This always led to extended hospital stays and inconvenience for families and caregivers. Usually, after frequent hospitalisations, patients tend to display friendliness to the nurses caring for them. They know the staff, trust them, and speak about their difficulties due to disease conditions. As a health professional with clinical experience and having worked closely with people suffering from respiratory ailments, I have developed an insight into the difficulties they encounter during frequent hospitalisations. It is heartbreaking to watch someone calling out in fear when they are unable to breathe. The management of fear related to breathlessness and panic attacks is time-consuming and emotionally and psychologically draining for the patients and staff. This is worsened when there are acutely ill patients who require close and constant monitoring. The relief and comfort that patients receive from the support and comforting conversation are invaluable and pleasing for a nurse. Sometimes, these incidents are very frequent and require skilled nurses to be with the patient for a prolonged time, impinging upon the time to care for other acutely ill patients.

Some patients come to the hospital quite frequently, but others do not. I have noticed the frequent hospitalisations and increasing readmission rates of most of the healthcare clients, while a few of them do not have recurrent admission rates. I believe it feels all too familiar to those of us who have been working with patients suffering from COPD. This experience and my clinical curiosity made me wonder if there are any different strategies people use to keep or preserve their quality of life and prevent frequent hospitalisation. I do want us to truly see and understand the

patients' attitudes, behaviours, and perspectives, and how they manage their symptoms at home, and that desire has formed the foundation of this research.

My experiences as a clinician, coupled with the personal narratives of the patients I have cared for, have shaped my motivation for this research. By shedding light on the lived experiences of COPD patients, this study recognised the methods and strategies that study participants used to maintain their independence, continue to maintain their quality of life, prevent exacerbations of the disease, and reduce anxiety and other associated symptoms. This perception may reveal a path to control, adapt or educate future or potential patients in modifying their health behaviours and attitudes and for clinicians to better support their patients.

Chapter One: Introduction

1.1 Chapter Introduction

An understanding of patients' attitudes, behaviours, and perspectives is necessary to develop effective strategies to address or educate people to modify health behaviours and for clinicians to better support patients in any chronic disease, especially Chronic Obstructive Pulmonary Disease (COPD). The chapter aims to establish the research detailed in this thesis. This chapter begins with an explanation of the problem, followed by the narration of background information pertinent to the attitudes, behaviours, and perspectives of people coping with COPD in their daily lives and the significance of this study. The research question to be explored is discussed along with the logic for selecting a qualitative descriptive approach as an appropriate methodology. A recap of the study design chosen for answering the research question is narrated as well. This chapter sums up with a synopsis of all the chapters that are incorporated in this thesis.

1.2 Chronic Obstructive Pulmonary Disease - A Glimpse

Chronic obstructive pulmonary disease is a lung disease with irreversible, progressive obstruction of the airways (Nair & Peate, 2015) portrayed by difficulty in breathing (dyspnoea), persistent sputum production, chest tightness and lethargy (Breland et al., 2015; Marieb & Hoehn, 2015). This lung disease affects the air movement in and out of the lungs, causing persistent airflow obstruction (Robinson & Scullion, 2021). Chronic obstructive pulmonary disease is one of the prevalent respiratory diseases, distinguished by airflow limitation or obstruction, which is slowly progressive and has minimal or poor responsiveness to bronchodilators (Robinson & Scullion, 2021). The chronic airflow restriction, which is specific to COPD, differs from one person to another and progresses at varying rates as time goes on (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2022).

The risk factors for COPD include smoking, occupational exposure to dust and fumes and poor socioeconomic status (Robinson & Scullion, 2021). Tobacco smoke, dust and fumes irritate the bronchial walls, causing the body to produce additional mucous. As part of the body's natural defence mechanism to dissolve irritants, enzymes called proteases are produced by white blood cells (Robinson & Scullion, 2021). The long-term presence of these irritants in the alveoli and the

constant defence by the body eventually destroy the alveolar wall, resulting in emphysema or chronic bronchitis (Robinson & Scullion, 2021). Smoking rates are higher in people with lower socio-economic status and are associated with poor dietary intake and recurrent respiratory tract infections as well. The evidence suggests a positive relationship between poor nutritional intake, poor lung function and COPD (Robinson & Scullion, 2021).

Chronic obstructive pulmonary disease is an inflammatory condition usually involving most of the airways, distinguished by excessive mucous production and chronic cough (Robinson & Scullion, 2021). Excessive mucous production is caused by the increased size and number of mucous glands in the airways and causes chronic cough and sputum production (Burgel & Nadel, 2008). This excessive sputum production leads to mucus plugging in smaller airways, leading to oedematous or swollen airways and damage to the supporting cartilage, which affects breathing (Burgel & Nadel, 2008). The oedema or swelling of small airways results in narrowed airways with increased resistance. This narrowed airway leads to reduced airflow, which is the distinguishing characteristic of COPD (Barnes, 2016). The damaged small airways (alveoli) merge into larger sacs and cause inefficient gas exchange, eventually leading to the collapse of small bronchioles (Robinson & Scullion, 2021). In severe cases of COPD, there will be an extended period of oxygen deficiency. People with COPD experience varying levels of symptoms and activity limitations along with poor health outcomes, despite medical management. At times, because of the complexities of coding and similarity in symptoms, it is difficult to recognise COPD from other respiratory conditions (Robinson & Scullion, 2021).

1.2.1 Background and Significance

Chronic obstructive pulmonary disease has both direct and indirect societal effects and is linked to increased health economic costs (Vogelmeier et al., 2017). Chronic obstructive pulmonary disease causes a notable economic burden, and the relationship between COPD exacerbations and the cost of care increases as the disease progresses (GOLD, 2023). The GOLD report (2023) noted that, in the European Union, more than half of the annual health care budget for respiratory disease (56%) is attributed to COPD, while in the United States of America, it is expected to cost \$40 billion per year. As per the Australian Institute of Health and Welfare (AIHW, 2023), 2.7% of people aged 35 and over were identified as having COPD in 2019. The cost of COPD is

estimated to be \$832 million in 2020-2021 in Australia (AIHW- COPD report, 2024). This cost does not include the value of care provided to people suffering from COPD by family members (GOLD, 2023).

The World Health Organisation (WHO, 2024) identifies COPD as the fourth leading cause of death worldwide, causing 3.5 million deaths in 2021. Reports reveal that the number of COPD patients was approximately 212 million worldwide (Institute of Health Metrics Evaluation [IHME], 2019). Toelle et al. (2013) stated that the prevalence of COPD is 7.5% and 29% in Australians aged 40 years and 75 years, respectively. Consultation rates for COPD are four times more than for angina and are the second most common cause of emergency admission to hospital, with an average length of stay of 7.5 days in the United Kingdom (Robinson & Scullion, 2021).

The severity of the symptoms varies with disease progression, which causes physical limitations in daily activities, including shopping, housework, and other activities, along with psychological problems such as loss of confidence, anxiety, and depression (Robinson & Scullion, 2021). Financial hardship is another significant issue affecting people suffering from this disease because of early retirement or the need for assistance with daily activities. One study stated that approximately 25% of people under retirement age are unable to work because of this disease in the United Kingdom (Robinson & Scullion, 2021). The poor psychological functioning with activity limitation caused by this disease makes people withdraw from professional roles and recreational activities, and become socially isolated (McSweeney et al., 1982).

Anxiety is another problem associated with people suffering from COPD. Yohannes et al. (2010) noted that anxiety and depression are widespread in people with COPD, and some experience clinical anxiety and some subclinical symptoms of anxiety. The self-efficacy, health outcomes and survival rates of people with COPD are related to the timely diagnosis and treatment of anxiety and depression (Yohannes et al., 2010). Psychological functioning, mainly anxiety, varies in people and has a substantial impact on the response to treatment and has different health outcomes for people with the same degree of lung function (Eisner et al., 2010).

The symptoms of dyspnea with social isolation and activity limitation are correlated with anxiety (Eisner et al., 2010) and affect the quality of life (Reardon et

al., 2006). It is noted that depression and anxiety are higher among people with COPD compared to people suffering from other chronic diseases (Felker et al., 2010). Depression and anxiety tend to increase COPD exacerbations, COPD-related hospitalisations, and mortality (Pooler & Beech, 2014). Chronic obstructive pulmonary disease is associated with frequent hospitalisations with exacerbations, specifically characterised by worsening dyspnoea and sputum production (Breland et al., 2015). The associated comorbidities of anxiety and depression lead to impaired physiological and psychological functioning, with frequent exacerbations (Kim et al., 2000; Weaver et al., 1997). The symptoms associated with COPD lead to limitations in daily activities, causing a noticeable extent of disability along with poor quality of life and psychological distress for people suffering from COPD. This leads to enormous strain on healthcare facilities and on patients, including their activity limitations, work absenteeism, emergency presentations to the hospital, frequent hospitalisations, and medical emergencies (Jones et al., 2011; Meier et al., 2011; Yohannes et al., 2010). The effects of the disease and the strain caused by the disease can have extensive consequences for people with COPD, especially in their daily lives.

Medical management of COPD mainly concentrates on approaches to reducing disease progression and managing symptoms (NHS, 2020). Ineffective management of COPD leads to the deterioration of symptoms and influences welfare and quality of life (Miravittles & Ribera, 2017). The importance of self-management programs and coaching by health care providers is emphasised in the GOLD: Executive summary (Vogelmeier et al., 2017). Even though the effects of self-management programs and pulmonary rehabilitation programs are well-researched and supported by the healthcare system, the progress and uptake of these programs are far from ideal (Cravo et al., 2022).

Clari et al. (2017) demonstrated that managing self-care needs and promoting self-care behaviours are indispensable in improving the quality of life, along with the necessity of additional attempts to identify self-care behaviours in people suffering from COPD. A better understanding of related factors and self-management behaviours affecting the quality of life will help clinicians to better support patients with COPD undergoing treatment (Cully et al., 2006; Yohannes et al., 2010). Prior research has emphasised the importance of adequate coping strategies in dealing with the burden of COPD, especially breathlessness, but

research on the attitudes, behaviours, and perspectives of people coping with the illness is not so copious.

Even though attitudes, behaviours and perspectives are interconnected constructs, there are some distinctions between them. Attitude is defined as “a relatively enduring and general evaluation of an object, person, group, issue, or concept on a dimension ranging from negative to positive. Attitudes provide summary evaluations of target objects and are often assumed to be derived from specific beliefs, emotions, and past behaviours associated with those objects” (American Psychological Association [APA] Dictionary of Psychology, nd). Behaviour is defined as “an organism’s activities in response to external or internal stimuli, including objectively observable activities, introspectively observable activities, and nonconscious processes” (APA Dictionary of Psychology, nd). Perspective is defined as “a particular way of looking at events or situations: a stance or philosophical position” (APA Dictionary of Psychology, nd).

Exploring these concepts from the people coping with this illness will help to identify the strategies they are using or trying to prevent exacerbations, anxiety attacks and hospitalisations and will give an insight into the attempt to preserve their quality of living. This insight will assist in recognising the approach towards this chronic progressive disease and the psychological and social strategies adopted by people suffering from COPD. This study may help to recognise the methods and strategies these people use to maintain their independence, continue maintaining their quality of life, prevent exacerbation of the disease and reduce anxiety and other associated symptoms. The study also enlightens the contributing factors for disease progression and reveals a path to control, adapt or educate future or potential patients in modifying their health behaviours and attitudes.

This study explored the attitudes, behaviours, and perspectives of people coping with COPD that influence variations in self-care interventions in daily life. Exploring the attitudes, behaviours, and perspectives of people identified patient-led strategies for disease management. Understanding how individuals navigate their illness can offer valuable insights for clinicians, helping to improve patient care and inform future interventions. Exploration of patient-initiated self-care interventions can assist in formulating interventions to reduce the healthcare burden on people with COPD, the healthcare organisation(s), and the community. The anticipated better understanding of related factors and self-management behaviours affecting the

quality of life may help clinicians to better support patients with COPD undergoing treatment (Cully et al., 2006; Yohannes et al., 2010). The background to the problem, drawing further explanation for the study's significance, is expanded upon in Chapter Two - Literature Review.

1.3 Research Question

The question that guided this research was: "What are the attitudes, behaviours, and perspectives of people coping with COPD that influence variations in self-care interventions in daily life?" Thus, this study aimed to explore the attitudes, behaviours, and perspectives of people coping with COPD that influence variations in self-care interventions other than the well-validated approaches of pulmonary rehabilitation, education programs, smoking cessation, and medication management.

1.4 Methodology and Methods

1.4.1 Methodology

To explore the attitudes, behaviours and perspectives of people coping with COPD, this research is placed within the qualitative paradigm. Qualitative research methodology focuses on the way people perceive their experiences and is usually used to explore the behaviour, feelings and experiences of people and the essence of their lives (Holloway & Galvin, 2016). Qualitative research methodology concentrates on obtaining a deeper understanding of an incident or perception of individuals by observing and describing things as they naturally occur (Nieswiadomy & Bailey, 2018). This methodology enables a researcher to understand the experience, gather rich and in-depth data and generate concepts by interacting with the participants (Holloway & Galvin, 2016). The researcher is interested in the interpretation of events and how those events shape individuals' attitudes, behaviours, and perspectives (Holloway & Galvin, 2016).

1.4.2 Study Design

A descriptive exploratory qualitative approach using semi-structured interviews was chosen to obtain a deeper understanding of the attitudes, behaviours and perspectives of people coping with COPD. An exploratory, descriptive qualitative approach facilitates an advanced exploration of the topic by allowing study

participants to play a part in the development of new knowledge in the specific area (Hunter et al., 2019). This study design was an attempt to fill the gap by obtaining a deeper understanding of the attitudes, behaviours and perspectives of people coping with chronic obstructive pulmonary disease. This study design assisted in understanding the interpretation of people's experience in coping with COPD and how it shaped their behaviour and attitudes. This design assisted in gaining rich and descriptive data about the attitudes, behaviours and perspectives of people.

1.4.3 Recruitment

The study participants included people diagnosed with COPD for more than two years, persons ≥ 40 years of age, persons who were aware of their diagnosis, able to understand the purpose of the study, able to comfortably converse, had a telephone and could speak English. Participants with significant hearing and speech impairments and cognitive impairments were excluded from the study.

After receiving approval from the James Cook University (JCU) Human Research Ethics Committee (HREC), a flyer was distributed to medical centres, community organisations, residential aged care facilities and private practices, along with advertisements via social media accounts of the university, informing people of the study and inviting them to contact the researcher by phone. Participant information sheets were forwarded to those who were deemed to be eligible post-screening over the phone. For those who agreed to participate, a semi-structured interview was conducted via various methods, like in person or by telephone, as per their preference at their preferred place other than their home. Informed consent was signed by the participants before the interview, and consent was verbally confirmed before the recordings.

1.4.4 Data Collection

Data was collected through semi-structured interviews. The questions used for interviewing were developed from the themes identified from the literature review presented in Chapter Two. These questions were open-ended questions about attitudes, behaviours, and perspectives. Minimal socio-demographic data (age, gender, marital status) were also collected. Interviews were audio-recorded on two devices to protect against data loss from technical failure. Data collection was discontinued when data saturation was achieved. Eleven participants consented to

participate in the study and were interviewed. The methodology guiding this study, and the methods used, along with a detailed discussion of data analysis, are discussed in detail in Chapter Three.

1.5 Results

Preliminary thematic analysis and initial coding were done alongside the data collection by listening to the recorded interviews. The recorded interviews were transcribed verbatim. Following transcription, the data were organised, and coding was performed with the aid of NVivo 12 software. A six-step thematic analysis, as explained by Braun and Clarke, was used for analysing the data (Braun & Clarke, 2006). The Braun and Clarke Thematic Analysis (TA) has six phases, and each phase helped the researcher to analyse the data by a recursive process (Braun & Clarke, 2006). A reflexive TA approach was the preferred method for data analysis as it is flexible and not bounded by a framework (Braun et al., 2019). All the themes evolved from data analysis were merged into a comprehensive map to represent all perspectives. The final or overall theme was presented as a clear pattern with quotes from interviews to support the findings. This approach allowed the researcher to actively engage in interpreting the data with their ideology and insight, societal obligation, and theoretical knowledge (Braun et al., 2019) and to propagate thoroughly collated results from the summarised data. A comprehensive discussion of the results is presented in Chapter Four.

1.6 Discussion

This research examined the variation in attitudes, behaviours and perspectives of people coping with COPD in their daily lives. However, collectively the findings highlight the various approaches implemented by people in coping with COPD and how they modified their attitudes and behaviours before, during and after the diagnosis of the disease. The findings of this study were scrutinised and collated against the existing literature and theories. A comprehensive discussion of the findings is described in Chapter Five.

1.7 Conclusion

The outcome of this study is extensively considered and has significant implications for healthcare. These findings form the basis for recommendations for policy, practice, education, and research. A comprehensive discussion of the

implications and recommendations raised from this research is described in Chapter Six.

1.8 Thesis Outline

This thesis is collated into 6 chapters, and the summary of each chapter is described in the following sections.

Chapter 1: Introduction and Context. Chapter One established the problem to be explored and addressed the research question. A summary of the background and context of COPD is demonstrated, along with introducing the methodology and methods and research outcomes.

Chapter 2: Literature Review. This chapter is shaped by the background for the study, which was established in Chapter One and creates the foundation for the study design and methods. This chapter includes the narrative literature review conducted to investigate the attitudes, behaviours and perspectives of people coping with COPD. An earlier version of the literature review is under review for publication and is included in the appendices with the taxonomy of contribution. Please refer to Appendix N.

Chapter 3: Methodology and Methods. This chapter justifies the design of this study and details the methods used in data collection and analysis. It describes the recruitment of participants and includes an explanation of the ethical considerations and risk assessments relevant to the study. This chapter ends with the risk management strategies that were utilised in the study.

Chapter 4: Results. The findings that emerged from this research study are presented in this chapter. After beginning with an overview, the findings are examined in detail, with each reporting major themes, subthemes and subsets. These major themes offer a detailed and coherent understanding of the factors that made study participants behave differently in coping with COPD.

Chapter 5: Discussion. With reference to the recognised literature and relevant theories, this chapter untangles the findings to locate them within the broad field of knowledge. A comparison of the study to relevant literature and other theories is provided to validate the quality of the findings.

Chapter 6: Conclusion. In the context of the study findings, this concluding chapter commences with the reflections of the candidate during her candidature. This final chapter then concludes by discussing the limitations and strengths along with the implications arising from the findings of this study and recommendations for research, policy, education and practice.

1.9 Chapter Summary

This chapter presented the problem and background, illustrating the significance of this research. The aim of the research, as well as the methodology and methods applicable to the study, are briefly described and concluded with a synopsis of all the thesis chapters. Building on this foundation, the subsequent chapter unfolds a detailed setting for the research and presents the literature review conducted to explore the attitudes, behaviours and perspectives of people coping with COPD. The succeeding chapters describe the methods and risk assessment related to data collection conducted to answer the research question, followed by a discussion of the results and implications of this study.

Chapter Two: Literature Review

2.1 Chapter Introduction

The previous chapter presented the context and background of the study. It is important to discuss the literature review that led to the development of the research project. This chapter discusses the aim of the literature review, search strategy, appraisal, and synthesis of articles, which led to the development of themes and the foundational concepts of the study.

2.2 Aim of the Literature Review

This literature review aimed to identify literature about the attitudes, behaviours, or perspectives of people with COPD, with a particular focus on patient-initiated self-care interventions other than pulmonary rehabilitation, education programs, smoking cessation, and medication management. The research question guiding this literature review was “What are the attitudes, behaviours and perspectives of people coping with Chronic obstructive pulmonary disease (COPD)?”

2.3 Methodology and Methods

2.3.1 Designs

The narrative literature review was conducted systematically to gather a complete picture of the literature, but did not include a quantitative analysis as would be found in for example, a Cochrane systematic review (Aveyard, 2019). A narrative literature review evaluates the literature and provides theoretical statements without using quantitative methods (Bourhis, 2017). A thematic analysis approach using a literature review matrix method of analysis, as per Aveyard (2019), was used to analyse the studies and generate the themes.

2.3.2 Search Methods

Four databases- CINAHL, Emcare, MEDLINE (Ovid) and PsycINFO were searched. The following combined MESH and keyword searching terms were used to identify a wide range of studies: (“COPD” OR “Chronic obstructive pulmonary disease” OR “Chronic obstructive airway disease” OR “Chronic obstructive lung disease” OR “Chronic airway limitation” OR “Pulmonary disease, chronic obstructive”

OR “Lung diseases, obstructive” OR “Obstructive airway disease” AND “Coping” OR “Coping strategies” OR “Coping behaviours” OR “Coping behaviors” OR “Coping skills” OR “Cope” OR “Coping ability” OR “ Self-management” OR “Self -treatment” OR “Self- nurturance” OR “ Selfcare” OR “Selfmanagement” OR “ Selftreatment” OR “ Agreeableness” OR “ Adjustment” OR “Coping mechanisms” OR “Coping measures” OR “ Self-care” OR “ Resilience” OR “Coping style” OR “ Self-care skills” OR “ Symptom distress”) OR (“COPD” OR “Chronic obstructive pulmonary disease” OR “Chronic obstructive airway disease” OR “Chronic obstructive lung disease” OR “Chronic airway limitation” OR “Pulmonary disease, chronic obstructive” OR “Lung diseases, obstructive” OR “Obstructive airway disease”) AND (“Attitudes” OR “Attitude to health” OR “Attitudes to illness” OR “Perceptions” OR “Opinions” OR “Thoughts” OR “Feelings” OR “Beliefs” OR “Belief*” OR “Behaviors” OR “Behaviours” OR “Perspectives” OR “Knowledge” OR “Practice” OR “Thinking” OR “Emotions” OR “Health beliefs”). There were no limitations placed on the search. The search was conducted until the 6th of March 2022 using the keywords. The search strategies for the four databases are included in the appendices (Appendix A, B, C and D).

2.3.3 Inclusion/ Exclusion Criteria

The literature containing attitudes, behaviours, and perspectives of people coping with COPD, who were above 18 years old, was included in the review. Literature in languages other than English, which was not about human beings and was about children, and adolescents, was excluded from the review. The inclusion and exclusion criteria are detailed in Table 2.1.

Table 2.1

Inclusion/ Exclusion Criteria

Inclusion criteria	Exclusion criteria
Literature containing attitudes, behaviours, and perspectives of people coping with COPD	Literature containing family and clinicians' perspectives only
English language only	Languages other than English
Globally found literature	Literature about not-for-resuscitation
About human only	Literature not about human beings
Aged above 18 only	Asthma as the primary diagnosis
	Children and adolescents

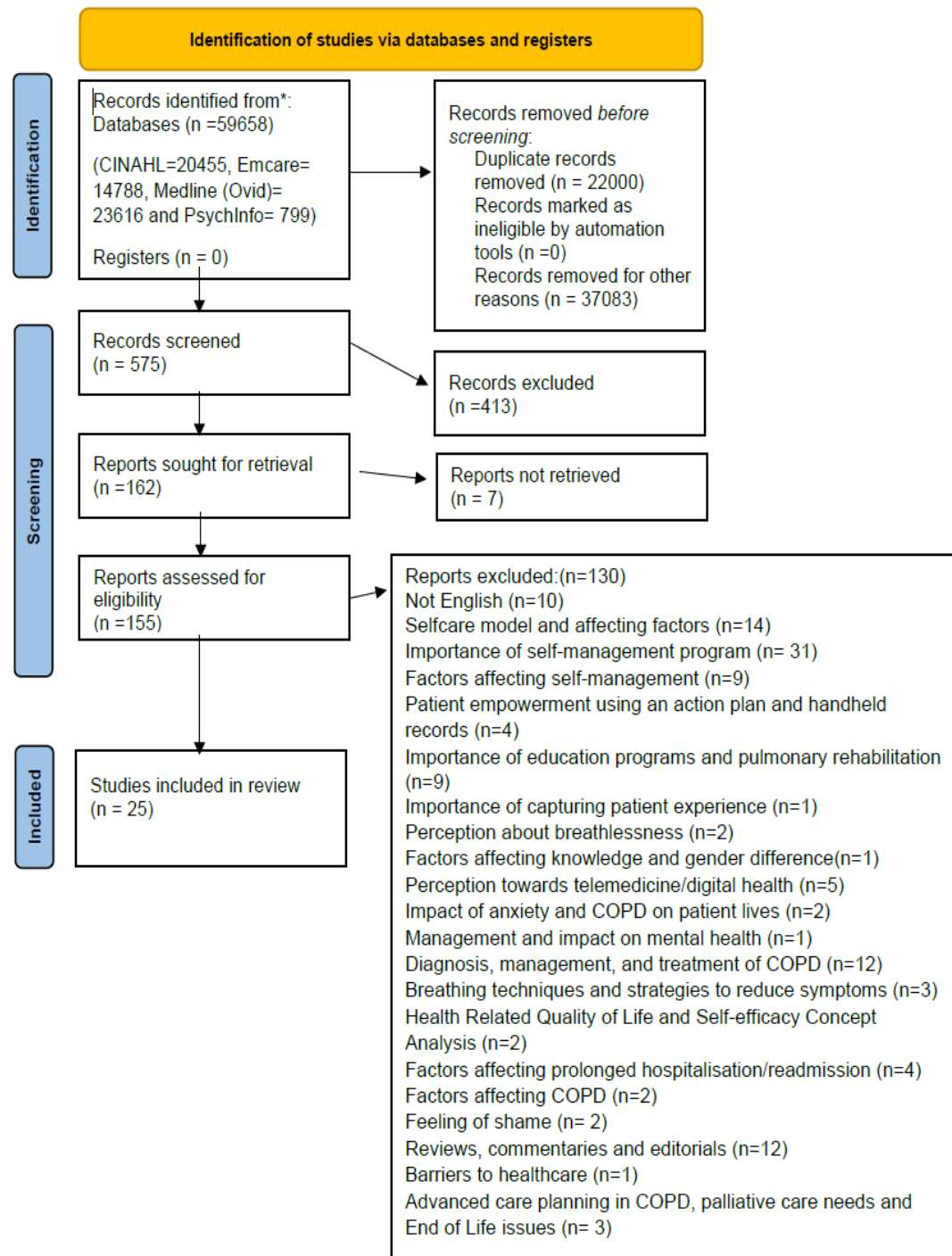
2.3.4 Search Outcome

The search yielded 20,455 papers in CINAHL, 14,788 papers in Emcare, 23,616 papers in MEDLINE, and 799 papers in PsycInfo. After removing the duplicates, 37,658 distinct articles remained. No additional records were identified from the eligible reference lists by manual searching of primary sources. Title screening excluded 37,083 papers. The abstracts of the remaining 575 papers were read, and 413 papers were removed as they did not meet the inclusion criteria. From the remaining 162 articles, seven articles were removed as it was not possible to retrieve the full text. One hundred and fifty-five articles were assessed for eligibility, and 130 articles were removed, leaving a total of 25 articles to be critiqued and synthesised. The Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) 2020 flow diagram, following the guidance of Page et al. (2021), was used for preparation and reporting in this review. See figure 2.1 for the PRISMA 2020 flow diagram, which presents the search and selection process.

2.3.5 Data Abstraction

Figure 2.1

The PRISMA 2020 Flow Diagram



2.3.6 Quality Appraisal

The first author designed the search strategy with the assistance of the co-authors. The keywords and search terms were developed by the first author with the guidance of co-authors and were refined as the search progressed. The first author conducted the search and selected the articles that answered the research question. The co-authors assisted in refining the few articles where the first author was unsure about the selection. The first author excluded the articles as per the eligibility criteria, read each paper, and assessed the quality. The co-authors guided the selection of the quality appraisal tool and assisted in resolving any discrepancies that arose when the first author appraised the quality of each study.

The Critical Appraisal Skills Program (CASP) checklist (Critical Appraisal Skills Program [CASP], 2022) for qualitative studies was downloaded from the CASP website, and individual studies were appraised against the ten questions in the CASP checklist. The quality of these 25 articles was evaluated by the CASP tool for qualitative research (CASP, 2022). These studies were identified as valuable with the appropriate use of methodology, which addressed the research issue and demonstrated a clear statement of findings.

The questions of the CASP checklist assisted in deciding if these studies had a clear statement about the aims and the use of qualitative methodology, and if recruitment strategies were appropriate for these studies. The appropriate relationship between the researcher and participants, including ethical considerations, was identified using the CASP checklist. Data analysis, including a statement of findings and the value of the research, was also evaluated using the CASP checklist.

2.3.7 Synthesis

A simplified thematic analysis approach using the literature review matrix method of analysis, as per Aveyard (2019), was used to analyse the themes by the research team. The lead author created a summary table of the key elements of each of the 25 studies (Table 2.2 shows a summary of the included studies). Once the studies had been critiqued and summarised in the table, a thematic analysis of key findings was conducted. The research team developed themes and subthemes from the extract of key findings.

Table 2.2*Summary of Studies*

Author/ Date	Purpose of the study	Study design	Country/ Sample/ Setting	Method of data collection & analysis	Main findings	Limitations/ Strengths
Ansari et al., 2014	Explore the impact of the new diagnosis of COPD and the reaction towards the diagnosis in the context of multi- morbidity	Qualitative design	Sydney, Australia n=9 males n=9 females Age: 43 to 84 years	Telephone interviews X 16; in person X 1 Semi-structured interview guide Data collection: April to July 2013 Digitally recorded and transcribed verbatim Preliminary thematic analysis and concurrent coding NVivo 10 software	Reaction to diagnosis- shock and denial of the new diagnosis, positive attitude for older participants Impact on function and health behaviour- difficulty with daily chores Factors influencing self-management capacity- less knowledge about the disease Healthcare utilisation – lack of communication among healthcare providers Interplay of comorbidities Suboptimal management caused by minimal awareness of the disease and its long-term implications Socioeconomic status and level of education had an impact on the management of the disease	S: The abstract offered a clear overview L: Newly diagnosed COPD L: Only Caucasian participants L: Small-scale study S: Samples and themes are clearly reported S: In-depth analysis was done L: Self-selection bias S: Sufficient data were included to support the findings

Apps et al., 2014	Describes the perceptions of the impact of the condition and their corresponding attempts to manage symptoms	Qualitative	East Midlands England Primary care COPD registers n=15 (9 female and 6 male) Aged 55-75 years	Face-to-face, semi-structured interviews Digitally recorded and transcribed verbatim A reflective log was kept NVivo software Braun & Clarke's thematic analysis	Feeling frustrated about the condition, lack of knowledge, and limited information from health professionals Participants initiated self-management behaviours such as pacing, adapting activities, distraction, and utilising social support. Participants unknowingly performed self-management behaviours but expressed a lack of confidence in managing their symptoms due to a lack of confidence in their disease knowledge. Importance of family perceptions and involvement in managing COPD.	S: The abstract offered a clear overview L: Selection bias L: Small-scale study, limits generalisability S: In-depth analysis was done S: Samples and themes clearly reported
Brien et al., 2016	To explore and understand variations in experiences and coping strategies in COPD patients across different severities	Qualitative	England Primary and secondary care sites and a patient volunteer database n= 34	Face-to-face semi-structured interviews, Dec 2013 to April 2014 Digitally recorded and transcribed verbatim Textual analysis using pseudonyms Reflexive notes Atlas.ti v5.2 for data storage	Symptoms and impact varied Varied coping strategies- medication management, PR, activity limitation Support needs Poor QOL is evident in people with maladaptation to disease and has worsened behavioural, psychological, and emotional dysfunction.	L: Abstract not offering a clear overview L: Limited description of the sample S: In-depth analysis was done S: Data saturation reached S: Approaches to minimise bias, a

	of disease and disease impact					detailed audit trail, negative and deviant case analysis, cross-checking of coding strategies, a multi-disciplinary research team including patient and public involvement and input from COPD patients
Chang et al, 2016	To explore the lived experiences of people with COPD following hospitalisation for acute exacerbation or pneumonia	Phenomenology	Taiwan The thoracic and geriatric wards of a medical centre n=14, 12 men and 2 women between 63–86	Semi-structured interviews Data collection Jan 2013- 2014 Interview and concurrent data analysis. Data analysis by Giorgi's (1997) method	Impact on daily life Difficulty with tolerance to colds and catching coughs, and infections Being a burden to the family Striving for wellness- smoking cessation, traditional Chinese medicines Tendency to narrow their activities	S: The abstract offered a clear overview L: Single-site study L: Small-scale study S: Samples and themes clearly reported S: In-depth analysis was done S: Rigour maintained
Chen et al., 2008	To explore the self-management behaviours of	Qualitative descriptive	Northern Taiwan Thoracic ward, outpatient	Semi-structured, face-to-face interviews	Patients chose self-management behaviours, based on experience, wisdom and professional guidance. Influence of cultural factors on patients' self-management behaviours.	S: Abstract offered a clear overview L: Results can vary in different settings

	patients with COPD to understand how patients manage their disease.		department, and the respiratory therapy room in a medical centre n=18, men who had COPD for at least 1 year Aged 55–81 years	Data collection from November 2006 to April 2007 Transcription by a research assistant and checked by the first author Data collection and concurrent analysis Miles and Huberman's (1994) three-step method for analysis	Integration of environmental control behaviours into the lives. A variety of behaviours in managing disease and symptoms, along with maintaining quality of life. Participants tended to adopt all five themes of self-management behaviour	L: Small sample, men only L: Facility to attend educational programs S: Data analysis explained in detail S: Samples and themes were clearly reported S: Trustworthiness was established
Cicutto et al., 2004	Understand the day-to-day self-care activities of people living with COPD and the meaning of the activities.	Qualitative Methodology	Canada Focus group Four in Toronto (n = 25) Three in non-metropolitan areas (n = 17)	Recruitment via posting flyers in doctors' offices and rehabilitation clinics, advertisements in community newspapers and newsletters Interview guide with eight open-ended questions Audio recorded and transcribed Verbatim	The impact of daily activities requiring several lifestyle changes was mentioned Emotional adjustment was seen as crucial for survival Support from families, peers, and healthcare professionals plays an important role The support of family to accomplish daily tasks Family support also facilitated self-care and living life.	L: Small-scale study L: Purposive sampling L: Only participants who attended a rehabilitation program were included S: Samples and themes were clearly reported S: Trustworthiness of the data

			June to August 2001	Transcript coded independently by two team members Constant comparative method of data analysis	Importance of peer support in surviving COPD	
Cooney , 2013	To understand the meaning of COPD for people and their response to this disease.	Qualitative longitudinal Grounded theory (Corbin & Strauss, 2008)	Ireland General practices on the western seaboard n= 26	Data collection - face-to-face semi-structured interviews Data analysis- constant comparative technique NVIVO 9 software	Hiding- symptoms were hidden at the beginning. Impact on daily activities Self-initiated steps to reduce symptom burden- participants started to reduce activities to consciously hide symptoms from others Perception of guilt related to smoking Battling- depends on the severity of the disease Daily activities required planning Avoidance of activities at the beginning, and eventually stopped doing them when symptoms got worse Teaching self-management skills improved the burden of hiding and battling Proper education on self-management	S: Abstract offered a clear overview L: Single case study S: Methodological rigour was enhanced by using memos, team discussions, using the kappa coefficient to measure inter-rater reliability and presenting findings to the expert in the field. S: Purposive sampling

Ek & Ternstedt, 2008	To describe the essential structure of the lived experience of living with severe COPD during the palliative phase of the disease	Giorgi's phenomenological method is based on Husserl's theory of intentionality	Sweden Departments of respiratory medicine of two different hospitals n= 8 (women=5 men= 3) Age: 48–79 years	Interviews home x 6; hospital x 2 hospital Interviews are audiotaped and transcribed verbatim Data analysis method Giorgi and Giorgi (2003a)	Limited living space, changed lifestyle, and challenged self-image Lack of physical strength Social isolation Increasing dependence, along with low self-esteem and a challenged sense of identity Lack of knowledge about the effect on family interactions when a family member has chronic obstructive pulmonary disease	S: The abstract offered a clear overview L: Same geographic location L: Small-scale study S: Rich in-depth data obtained
Gabriel et al., 2014	Explores the perspectives of both patients and family members regarding the impact of chronic obstructive pulmonary disease	Exploratory qualitative study with a cross-sectional design	Portugal Primary care centre, district hospital October 2011 to February 2012 n=40 (20 patients)	Interviews with open-ended questions and transcribed verbatim Descriptive statistics using Predictive Analytics Software Statistics version 19.0 for Windows Data analysis - thematic analysis (Miles & Huberman, 1994)	Impact of COPD symptoms on daily personal and family life Negative impacts on family activities Participants felt restricted to their homes (Over)protective family support Difficulties in couple communication are causing an impact on the marital relationship Embarrassed to ask their partners to help in daily activities Financial strain	S: Abstract offered a clear overview L: Selection bias L: Participants were in the chronic phase of the disease S: Actionable outcomes S: Sufficient data were included to support findings

	(COPD) in their family life		and 20 family members)	Two independent researchers (gerontologists) coded and categorised data into themes in three phases: data reduction, data display, and conclusion drawing/ verification	Sense of identity loss Fear of progression Positive reappraisal, search for meaning and problem-solving strategies as coping resources used by patients	
Halding et al., 2018	Explore how persons living with COPD experience transitions related to health, self-management, and follow-up from the healthcare services	Qualitative	Rural Norway Health unit n= 11 (females= 5, males=6) Age: 62–76 years	Interviews audio recorded Transcribed A qualitative content analysis NVivo Pro (QSR International) used	The struggle to keep going, adaptation to a new way of daily living, and the challenges of changing social roles and function Knowledge of disease improved via self-management courses, along with guidance and helped to make contacts that gave possibilities for further follow-up Interaction with the healthcare services varied depending on the services and the professionals. The satisfaction varied depending on the interaction with the individual healthcare worker The feeling of guilt because of the self-inflicted disease	S: The Abstract offered a clear overview S: Credibility strengthened by participatory design S: Sufficient data were included to support findings

					The need for continuity and competent facilitation, like rehabilitation and training, as a kick-off for the everyday drudgery Necessity for a contact for disease management due to a lack of involvement of the primary physician and unawareness of the extent of the disease by the emergency room	
Jarab et al., 2018	To explore how patients with COPD cope with their chronic disease, and their needs and perspectives regarding COPD management and its impact on their quality of life.	Qualitative	Jordan COPD clinic - Royal Medical Services Hospital, Amman n = 28 in five focus groups	Focus group discussions in Arabic Interviews audio-taped and transcribed Transcriptions were translated into English and back to Arabic by two expert and independent translators to guarantee content consistency, and then the English version was utilised. Content analysis-approach described by Lennon et al., for data analysis.	Poor knowledge about their disease and a lack of information about its aetiology and management Physical inability to perform even simple tasks, with a general feeling of exhaustion, tiredness, and slowing down of life Psychological impact of the disease from two perspectives: what they had lost and reliance on medication and hospital intervention. Coping mechanisms: the changes adapted by participants and the need to keep looking on the brighter side of life Physical reliance on family members or hospital staff, at an early stage of the disease Improving patients' knowledge about COPD and its management in future COPD care programs	L: Purposive sampling L: The influence of the researcher's prior beliefs on the interpretation of the transcripts was acknowledged L: The Possibility of the increased impact of censoring and conforming because of a focus group technique S: Samples and themes are clearly reported

					Education is required to stop the patients from panicking	
Johan- sson et al., 2019	Identify and describe the symptom burden and its effect on daily life in people with COPD, based on their own lived ex- periences	Qualitative	Specialist lung or COPD reception at three hospitals Southeast of Sweden March 2015 to June 2016 n=25 (females = 14 males = 11) Age: 58– 82	Individual face-to- face interviews with an interview guide Digitally recorded and transcribed verbatim Quotations were originally in Swedish and translated into English Braun and Clarke's thematic analysis	An altered everyday life that is challenging Prioritising daily activities to cope with energy demands The feeling of being a burden Social isolation Zeal for a curative treatment resulting in the overuse of drugs Fear about the future Feeling of guilt (self-inflicted disease) Challenges in adapting to the opportunities in life Support needs from the next of kin and society	S: Abstract offered a clear overview L: Only people with stage III and stage IV COPD S: Every single interview was treated as a unique unit and added to the data corpus without looking for recognition. S: In-depth analysis was done
Kaptain et al., 2020	To describe how people living with COPD and manage everyday	Qualitative	Denmark n= four females and four males Age – 65- 87 years	Semi-structured interviews based on an interview guide at participants' homes Data collection: October-December 2018	Difficulties in managing everyday life activities with COPD Effects of COPD symptoms Being aware of own body Using extra time and effort in managing symptoms	S: Abstract offered a clear overview L: Small-scale study

	life activities			Interviews were transcribed verbatim alongside data collection Inductive qualitative content analysis (Graneheim and Lundman)	Accepting help while resisting dependence Adjustment of activities	S: Samples and themes were clearly reported
Lander s et al., 2015	To explore patients' perceptions of advanced COPD and their understanding of a palliative approach to care	Qualitative with grounded theory as methodology	New Zealand The Canterbury District Health Board n =15	Semi-structured interview QSR NVivo 10 for data management Structural coding Deceptive analysis	Reduced level of activity- loss of recreation Changes in the home environment due to a decline in health, episodes of hospitalisation, requiring oxygen and help with self-care Patients' perception of living with COPD, not dying of COPD Difficulty in initiating the offer of palliative and end-of-life support	L: Patients with advanced disease only S: In-depth analysis was done S: Sufficient data were included to support findings
Marx et al., 2016	Meaning of living with COPD as an incurable and constantly progressing disease	Qualitative longitudinal	Germany Lower Saxony Lung care clinics and community care n=18	Qualitative face-to-face interviews at home, hospital or at clinic Interviews were audiotaped and transcribed verbatim, but not returned to participants	Difficulty with accepting and feeling of being at the mercy of the disease. Social isolation Limited knowledge Patients try to maintain daily activities Feeling of guilt	L: Purposive sampling S: Samples and themes clearly reported S: In-depth analysis was done

	and reconstructed from the patients' perspective			Field notes were made Codes developed using abductive reasoning (Strauss and Corbin,1990) Data management using MAXQDA Analysed in German A professional translator translated the passages of the interviews from German to English	Increase in activity limitation and social isolation Benefits of early integration of palliative care and volunteers Provides new insights into patients suffering from progressive COPD and end-of-life care	
Molin et al., 2020	Explore attitudes to COPD self-management , perceptions of GP commitment to PR, and	Qualitative	Denmark Municipal database 'Sundhedsportalen' (Health Portal) in Copenhagen 2012–2015	Semi-structured interviews and audio recorded Data generated February–April 2020 Thematic analysis Investigator triangulation Field notes	Self-management involved a social gradient and worry about the future. Inadequate pulmonary rehabilitation support Inadequate information was provided by the GP Disease denial and acknowledgement due to a lack of knowledge Feelings of self-contempt and embarrassment	S: Abstract offered a clear overview L: Strategic sampling S: Investigator triangulation S: Samples and themes clearly reported

	COPD knowledge		n= 14 (8 women and 6 men, aged 69-65 yrs) with moderate COPD	NVivo	Positive relationship between higher education, social network and COPD self-management. Importance of acting at an earlier stage to facilitate activation of patient resources.	S: In-depth analysis was done
Pooler, 2014	To extend knowledge of the experiences of adults living with chronic pulmonary illness, everyday meanings and activities. connections between, individuals experiences and health professionals' practices	Phenomenology	Western Canada Three pulmonary outpatient clinics and programs of a large metropolitan city n=16 (6 females and 10 males, aged 35 to 77 years)	Open-ended, conversational interviews, audiotaped and transcribed Reflexive log with close observation of participants' behaviours, expressions of language, autobiographies, the research literature, and clinical experiences of the researcher Lens of Merleau-Ponty for the interpretation and approach of van Manen for analysis	Impact on daily life Participants found themselves slower than they used to be, and slower than others. Limiting activities to conserve energy Reaction to the disease -feeling frustrated Effect of cold weather	L: Data analysis not reported in detail S: Samples and themes were clearly reported S: Sufficient data were included to support findings

Rubio, 2019	To describe and contextualise the experience of living with severe COPD; inform health care providers of the potentially unmet needs of this population	Interpretative phenomenological analysis (IPA)	Texas Regenerative medicine clinic Documented stage IV COPD confirmed by pre-interview spirometry n=6	Open-ended in-depth interviews with leading and probing questions Audiotaped and transcribed Analysis using IPA methodology	Making sense of diagnosis- awareness of measures, lack of guidance and contributing factors Feelings of guilt for past smoking Being a burden to others Depression, anxiety and social isolation due to the use of oxygen The struggle of daily living to manage activities of daily living, and the effects of COPD on their bodies The perceived quality of life is dependent on an individual's perception of his or her illness	L: Small-scale study L: All the participants were white S: Rigour was maintained by member checking, and transferability S: Prolonged engagement with the cohort facilitated credibility S: Transferability is evident
Sigurgeirsdottir et al., 2019	To explore COPD patients' experiences, self-reported needs, and needs-driven strategies	Phenomenology	Iceland Rehabilitation center n= 10 (3 men and 7 women aged between 59 to 74)	Semi-structured in-depth interviews	Lesser involvement in family and social life, with loss of ability to perform usual activities Requiring multiple breaks to carry out simple tasks and being forced to stay at home Feeling of shame due to procrastination The participant's knowledge about COPD and prognosis was different	L: All participants were recruited from a waiting list for PR, indicating a certain population bias, as only a minority were referred to PR L: Not much description on recruitment

	to cope with self-management				Some felt that education regarding the disease had been provided too late Negatively affected physical and psychosocial well-being, family relationships and social life Financial worries due to the inability to work	S: Sufficient data were included to support the findings
Steindal et al., 2017	The study aimed to explore how women with COPD experience their daily life at home	Qualitative explorative and descriptive design	Norway General hospital Data collection January - June 2014 n = 9, women aged 63-79	Semi-structured interviews with open-ended questions Qualitative content analysis, using the interpretative contexts identified by Kvale and Brinkmann (2012) Investigator triangulation	Enjoyable life with COPD, despite the limitations, is possible Confidence in getting help- aware of who to contact for help, feeling safe at home Trust in hospitals and health care professionals was important Achieving a balance between insight and compliance with management of COPD: sufficient knowledge about COPD, ways to manage, and an available action plan The women experienced a struggle in daily life to comply with COPD management	S: Abstract offered a clear overview L: Urban women only L: Participants from one medical centre only S: Investigator triangulation to enhance credibility S: Data collection and the data analysis were discussed with the other authors, which additionally facilitated discussions of competing interpretations S: Transferability was enhanced by

						descriptions of the participants, the process of data analysis, along with enriched descriptions of the results with relevant quotations and continued discussions among team members
Valencia-Rico & Burbano-Lopez, 2020	To ascertain the meaning of the experiences that individuals with serious and very serious COPD encountered, to provide information relevant to nursing care from the subjective	Qualitative study based on Martin Heidegger's hermeneutic phenomenology	Colombia Health institute in the city of Manizales, Caldas n=10	In-depth interviews focused on an initial question guideline The data were gathered and analysed simultaneously Superficial analysis, in-depth analysis, and triangulation were used The criteria established by Guba and Lincoln were used	Awareness of the disease: All patients knew that their disease was incapacitating and progressing towards physical and emotional deterioration, through a coping mechanism based on problem-solving The symptoms, especially breathlessness, made it difficult to carry out daily activities Constant use of inhalers and oxygen to cope with the symptoms Another coping system described is related to religiousness, which increases as the disease progresses Feeling of anxiety along with disease burden (involving their family members mistreating them, being abandoned, not being considered, and being embarrassed because of the care that has to be given to them by	S: Abstract offered a clear overview L: Small-scale study L: Single-site study S: Credibility was ensured with continued observation of the phenomenon using various interviews S: The mechanism of triangulation was used for auditability or reliability of the information, submitting it to another researcher's analysis

	perspective of those who had this disease				the members of their own family, with whom they do not feel close enough) Limited communication between them and the health professionals Different meanings of symptoms and functional changes in daily moments and times of exacerbation Changes in lifestyle and adaptation strategies	S: Findings were contrasted first with the study question and then with other similar studies S: In-depth analysis was done
Williams et al., 2014	To identify how patients recognise and manage exacerbations at home.	A qualitative, interview-based study	United Kingdom From primary and secondary care settings in Oxford 2012-2013 n= 44 (17 women, 27 men; age range 55–85 years),	In-depth interviews at patients' homes Audio-recorded, transcribed verbatim NVivo 10 to store and organise the data Analysis by the grounded theory approach Constant comparative method; open, axial and selective coding and memo-writing to identify theoretical links and concepts from the data	Difficulty with daily activities Identifying the symptoms Self-managing with inhalers and medications before contacting health professionals Physical limitations were a more important change to patients than respiratory symptoms Uses experiential knowledge to assess both objective signs and subjective 'invisible' chest sensations, including breathlessness and bodily changes Patient's expertise in management should be acknowledged and integrated into care plans by healthcare professionals and clinicians	S: Abstract offered a clear overview L: Purposive sampling L: Limits generalisability as recruitment was part of a clinical trial with strict eligibility criteria S: Analytical processes were discussed in depth throughout the study among the research team members, which enabled credibility S: The Interviewer had extensive training

						in qualitative research methods S: Two interviews were coded by an experienced qualitative researcher external to the project to ensure the rigour of the coding process. L: Results can vary in different settings
Wong et al., 2014	To explore the perceived needs and expectations of patients with regard to their lifestyle, management, and adaptation towards the disease.	Qualitative method	Malaysia Tertiary hospital, urban suburb of Kuala Lumpur 2012 A total of 8 FGDs (4 with a total of 18 male patients and 4 with a total of 18 doctors)	Focus group discussions (FGDs) using a semi-structured topic guide Thematic analysis Transcripts were coded independently by two researchers Discrepancies in coding were resolved through discussions	Knowledge and awareness of COPD-unfamiliarity with the term COPD Effect on daily activities -psychosocial and physical impact The utility of self-management Experience a loss of intimacy (One patient expressed difficulty in performing sexual intercourse) Loss of social interaction and bonding The only study that has examined patients' experiences of COPD from the doctors' perspective	S: Abstract offered a clear overview L: All participants were male L: Convenience sampling by a research assistant S: The focus group discussion was led by a researcher who was not directly involved in the management of the patients

Wortz et al., 2012	To describe the results to guide development of cognitive-behavioural interventions for self-management support of patients with COPD	Qualitative study	From the University of Texas Health Science Centre at Tyler n=54	Interviews Used an inductive approach to code in non-hierarchical thematic categories consistent with grounded theory methods	Loss: loss of normal functioning, independence, and social contacts, and loss associated with other medical conditions Fear: about disease progression and suffocation Lack of self-management support and understanding of their condition leads to opting for improved care	L: Results can vary in different settings S: Samples and themes clearly reported S: Rich in-depth data obtained
Zeb et al., 2021	To understand the lived self-care experiences of patients with COPD and to explore the role of the family	An interpretive phenomenological inquiry	Northern Pakistan Out patient pulmonary clinic at two public hospitals n=13	Semi-structured interview guide The interpretive analysis was based on Ricoeur's interpretation theory (Ricoeur, 1976) The trustworthiness criteria (Guba & Lincoln, 2005) were used to establish rigour	Daily struggles of physical and emotional struggles affect self-care Fear of putting the burden on families for assistance with daily needs Believing in spiritual and traditional healing – spiritual approaches to healing Alternate ways to manage self-care-hospitals, community workers Role of family in patient self-care support	S: Abstract offered a clear overview S: One experienced researcher and the other attended training S: In-depth analysis was done

	in self-care		aged above 30 years Data collection from September to December 2019		Reliance on family and emphasis on traditional interventions for disease management	
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LEGEND: FGD=Focus Group Discussions, L= Limitations, S= Strengths, PR = pulmonary rehabilitation QOL= Quality of Life, GP= General Practitioner

2.4 Results

Twenty-five studies, all of the qualitative design, met the inclusion criteria. The studies were published between 2004 and 2021. The sample sizes of these studies ranged from six to 54 participants, with participants aged 40 - 85 years. Semi-structured interviews were the main method of data collection for 23 studies, while the remaining two studies used focus groups. Non-participant observation and field notes were used along with interviews to collect data in studies. The studies portrayed various stages of COPD, ranging from new diagnosis, mild, moderate, and severe stages, and the perspectives of people after acute exacerbation as well.

All 25 studies reported on people coping with COPD and the numerous behavioural changes and support systems in their day-to-day lives (Ansari et al., 2014; Apps et al., 2014; Brien et al., 2016; Chang et al., 2016; Chen et al., 2008; Cicutto et al., 2004; Cooney et al., 2013; Ek & Ternestedt, 2008; Gabriel et al., 2014; Halding et al., 2018; Jarab et al., 2018; Johansson et al., 2019; Kaptain et al., 2020; Landers et al., 2015; Marx et al., 2016; Molin et al., 2020; Pooler, 2014; Rubio, 2019; Sigurgeirsdottir et al., 2019; Steindal et al., 2017; Valencia-Rico & Burbano-Lopez, 2020; Williams et al., 2014; Wong et al., 2014; Wortz et al., 2012; Zeb et al., 2021). Appropriate research design and data collection methods were used, and all 25 studies had human research ethics approval.

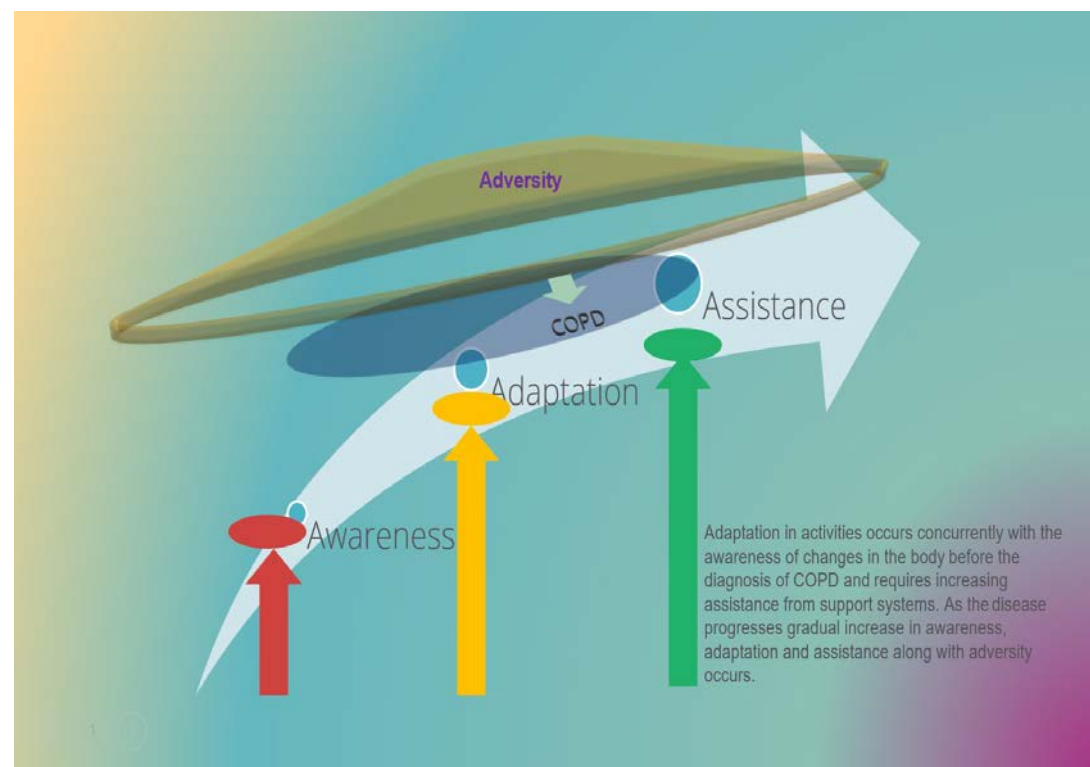
Various qualitative designs were described by the authors. Seven studies used different types of phenomenology (Chang et al., 2016; Ek & Ternestedt, 2008; Pooler, 2014; Rubio, 2019; Sigurgeirsdottir et al., 2019; Valencia-Rico & Burbano-Lopez, 2020; Zeb et al., 2021). A qualitative descriptive design (Chen et al., 2008), a qualitative exploratory descriptive design (Steindal et al., 2017), a qualitative longitudinal design (Cooney et al., 2013), an explorative qualitative cross-sectional design (Gabriel et al., 2014), a qualitative longitudinal design (Marx et al., 2016), and a qualitative interview-based design (Johansson et al., 2019; Williams et al., 2014) were also used. Content analysis described by Graneheim and Lundman (Kaptain et al., 2020), grounded theory (Landers et al., 2015), focus group methodology (Cicutto et al., 2004) were also evident, while the other eight studies used a thematic analysis unrelated to any particular qualitative methodology (Ansari et al., 2014; Apps et al., 2014; Brien et al., 2016; Halding et al., 2018; Jarab et al., 2018; Molin et al., 2020; Wong et al., 2014; Wortz et al., 2012). A summary of the key features of the 25 articles can be found in Table 2.2.

The generalisability of the results was limited due to small-scale studies (Holloway & Galvin, 2016). In these 25 studies (Ansari et al., 2014; Apps et al., 2014; Brien et al., 2016; Chang et al., 2016; Chen et al., 2008; Cicutto et al., 2004; Cooney et al., 2013; Ek & Ternestedt, 2008; Gabriel et al., 2014; Halding et al., 2018; Jarab et al., 2018; Johansson et al., 2019; Kaptain et al., 2020; Landers et al., 2015; Marx et al., 2016; Molin et al., 2020; Pooler, 2014; Rubio, 2019; Sigurgeirsdottir et al., 2019; Steindal et al., 2017; Valencia-Rico & Burbano-Lopez, 2020; Williams et al., 2014; Wong et al., 2014; Wortz et al., 2012; Zeb et al., 2021). These 25 studies were from varied geographic locations, and results may not apply to other areas due to cultural differences.

Four main themes emanated from the synthesis of the findings related to the aim of this literature review. These themes were awareness, adaptation, assistance, and adversity, which portrayed the lives of people coping with COPD. The evolution of these themes across the progression of the disease can be found in Figure 2.2.

Figure 2.2

Themes across Disease progression



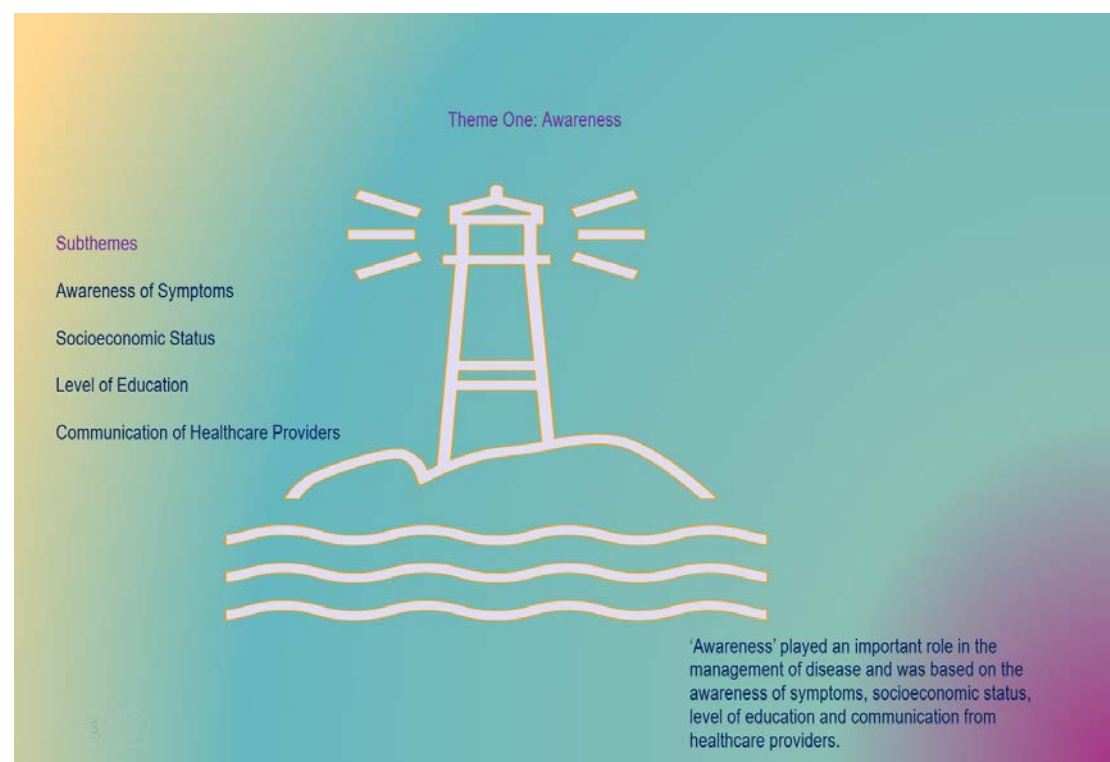
2.4.1 Theme 1: Awareness

The theme 'awareness' revealed that the consciousness of symptoms, socioeconomic status, level of education, and communication of healthcare providers played an important part in the timely management of symptoms. The participants had awareness of symptoms, as there was something different noted in their bodies. Depending on their socioeconomic status and education, they anchored correct or incorrect meanings to those symptoms. At some point after the encounter with healthcare providers, they realised the meaning of the symptoms and the disease process in their bodies. Those encounters assisted them in understanding the disease process and initiating ongoing communication and follow-up with healthcare providers to manage the disease effectively.

The subsets of the theme 'awareness' include awareness of symptoms, socioeconomic status, level of education and communication of health care providers. These subsets are portrayed in Figure 2.3 and elaborated further in the following sections.

Figure 2.3

Theme 1 Subthemes



2.4.1.1 Subtheme 1: Awareness of Symptoms. It is evident from the studies that the awareness of symptoms started before the proper diagnosis of the disease (Cooney et al., 2013; Halting et al., 2018; Jarab et al., 2018; Kaptain et al., 2020; Valencia-Rico & Burbano-Lopez, 2020; Williams et al., 2014). The participants were not able to recall the actual onset of symptoms (Cooney et al., 2013). They did not realise that the changes in their body were related to a disease process and only became aware of the disease during the hospital stay (Jarab et al., 2018; Valencia-Rico & Burbano-Lopez, 2020) and this awareness assisted in identifying exacerbations along with their bodily knowledge (Williams et al., 2014). Being proficient in understanding the symptoms associated with the disease gave them a feeling of confidence and security (Kaptain et al., 2020) and their awareness grew gradually (Halting et al., 2018).

2.4.1.2 Subtheme 2: Socioeconomic Status. Three studies found that socioeconomic status played an important part in the awareness and management of disease (Ansari et al., 2014; Molin et al., 2020; Zeb et al., 2021). The view of participants about health was impacted by their socioeconomic status (Ansari et al., 2014). Participants with limited or no resources were continuously battling poverty and struggling for better health, and did not have sufficient finances for medications, follow-up visits, or hospital admissions (Zeb et al., 2021). Resourceful participants selected choices that reflected the suggestions for COPD treatment, while participants with fewer resources preferenced their choices for avoiding discomfort rather than for disease management (Molin et al., 2020).

2.4.1.3 Subtheme 3: Level of Education. The relationship between participants' education and the understanding and management of symptoms was evident in two studies (Ansari et al., 2014; Molin et al., 2020). A competent approach to the management of symptoms was evident in participants with higher education (Molin et al., 2020). Participants' level of education appeared to impact the way they experienced and managed health conditions: especially those with tertiary education perceived the magnitude and severity of the disease accordingly and prioritised their disease more coherently than others (Ansari et al., 2014).

2.4.1.4 Subtheme 4: Communication from Health Providers.

Communication from health providers varied and affected the understanding and confidence of participants (Ansari et al., 2014; Apps et al., 2014; Chen et al., 2008; Cicutto et al., 2004; Halting et al., 2018; Molin et al., 2020; Sigurgeirsdottir et al., 2019; Steindal et al., 2017; Valencia-Rico & Burbano-Lopez, 2020). Advice from healthcare professionals played an important role in establishing faith in the treatment and prompting adherence to the management strategies (Apps et al., 2014). Healthcare providers played an important role in persuading participants to take part in educational activities, which helped them to be more accountable for their behaviours (Chen et al., 2008). Communication and relationship with healthcare providers not only gave them the latest information and treatment options but also the confidence that everything was alright, and cultivated a supportive decision-making ability as well (Cicutto et al., 2004). Participants wished for contact with a health professional with a good relationship to meet their needs individually in a caring manner, which reflected the importance of trust and confidence in the system (Steindal et al., 2017). The continuity in professional healthcare was considered vital by some participants (Sigurgeirsdottir et al., 2019), while a few participants mentioned the limited communication and were displeased with the 'inhuman treatment' by healthcare professionals (Valencia-Rico & Burbano-Lopez, 2020, p. 315). The information provided by primary care physicians was inadequate (Ansari et al., 2014; Molin et al., 2020) while participants received a better understanding from the specialists (Molin et al., 2020) and expressed a lack of confidence in their primary care physician (Halting et al., 2018).

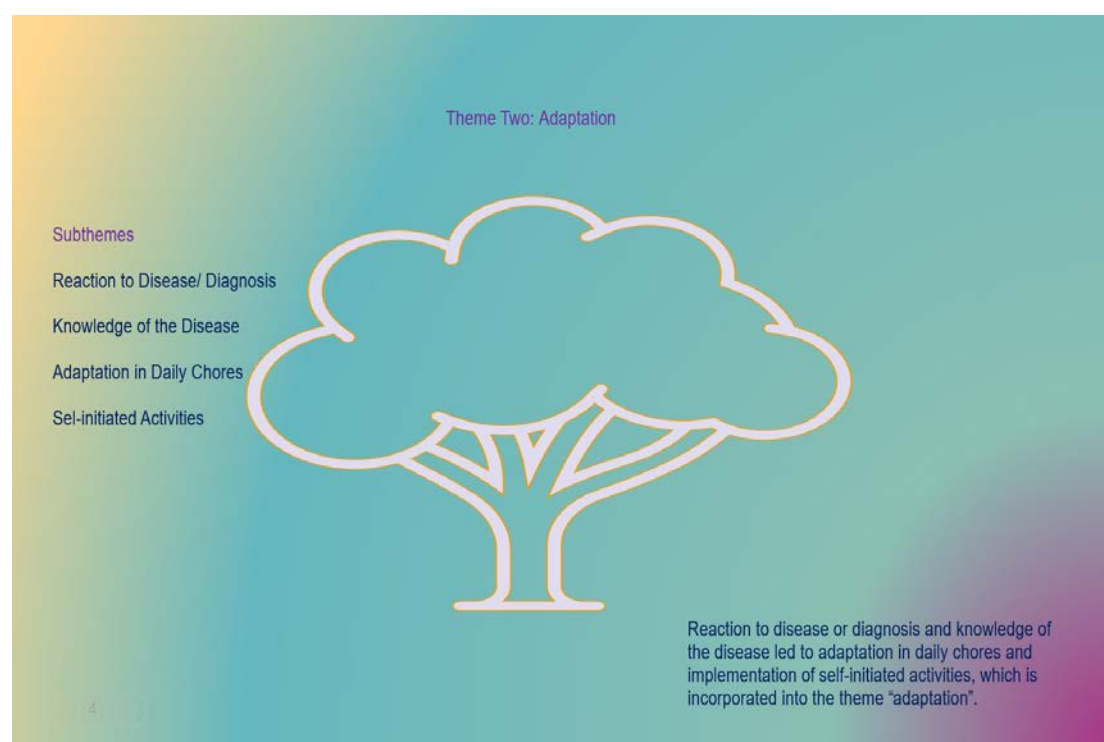
2.4.2 Theme 2: Adaptation

Reaction to disease or diagnosis and knowledge of the disease led to adaptation in daily chores and implementation of self-initiated activities, which are incorporated into the theme of adaptation. Adaptation to the disease began before the diagnosis of the disease but evoked a strong reaction at the point of diagnosis. After being diagnosed with the disease, the existing level of knowledge may change in response to the consciousness of the disease. Once the understanding or perception increased, changes occurred in emotional reactions, and this is reflected in how they manage the activities of daily life. Further in the adaptation process, people living with the disease tried to initiate other activities to improve their quality of living.

The factors incorporated in the theme 'adaptation' include reaction to disease/diagnosis, knowledge of the disease, adaptation in daily chores and self-initiated activities. These subsets are illustrated in Figure 2.4 and further described in the subsequent sections.

Figure 2.4

Theme 2 Subthemes



2.4.2.1 Subtheme 1: Reaction to Disease/ Diagnosis. It is evident from the studies that being diagnosed with COPD led to various reactions (Ansari et al., 2014; Chang et al., 2016; Cooney et al., 2013; Ek & Ternestedt, 2008; Gabriel et al., 2014; Halting et al., 2018; Marx et al., 2016; Pooler, 2014; Rubio, 2019; Valencia-Rico & Burbano-Lopez, 2020; Wortz et al., 2012). Some of the participants were in shock, while some were in denial, but participants aged in their seventies and eighties had a cheerful outlook on the disease (Ansari et al., 2014). A theme found by Chang et al. (2016) was "trapped in an invisible cage" (pp.468), while Cooney et al. (2013) found that participants tried to hide the symptoms from others. While some tried to make sense of their diagnosis (Rubio, 2019), others mentioned a feeling of meaninglessness and wanting to die (Ek & Ternestedt, 2008), but some feared death (Valencia-Rico & Burbano-Lopez, 2020). Feelings of sadness and loneliness

(Gabriel et al., 2014), fear of disease progression and prognosis (Halding et al., 2018; Wortz et al., 2012), a feeling of being at the mercy of the disease (Marx et al., 2016) and difficulty accepting the diagnosis and disease (Pooler, 2014) were also evident in the studies.

2.4.2.2 Subtheme 2: Knowledge of the Disease. It is apparent that participants had varying levels of understanding of COPD prognosis and management, and this affected their confidence in managing the disease (Ansari et al., 2014; Apps et al., 2014; Chen et al., 2008; Halding et al., 2018; Jarab et al., 2018; Kaptain et al., 2020; Marx et al., 2016; Molin et al., 2020; Sigurgeirsdottir et al., 2019; Steindal et al., 2017; Valencia-Rico & Burbano-Lopez, 2020; Williams et al., 2014; Wong et al., 2014; Wortz et al., 2012). Participants' knowledge about COPD and prognosis varied (Sigurgeirsdottir et al., 2019) and only a few participants knew what their lung condition was called, and were confused about the symptoms (Ansari et al., 2014). Participants were confused and frustrated because of the lack of understanding of their condition, and wanted to learn more about self-management (Wortz et al., 2012). Participants had poor knowledge about the disease and a lack of information about management before the diagnosis of the disease (Jarab et al., 2018; Marx et al., 2016; Wong et al., 2014), but people with higher education and good social networks had greater understanding and good self-management (Molin et al., 2020). Some had sufficient knowledge about COPD, but struggled to know what they had to change in their lifestyles (Steindal et al., 2017). The knowledge level impacted their confidence in managing medications and acute events (Apps et al., 2014), but some used strategies from their previous experience (Chen et al., 2008). Participants' knowledge and experience were important in developing self-management skills (Halding et al., 2018).

2.4.2.3 Subtheme 3: Adaptation in Daily Chores. All of the studies supported that participants had to adapt their daily chores in response to their disease and symptoms (Ansari et al., 2014; Chen et al., 2008; Cicutto et al., 2004; Cooney et al., 2013; Ek & Ternestedt, 2008; Halding et al., 2018; Johansson et al., 2019; Kaptain et al., 2020; Marx et al., 2016; Pooler, 2014; Rubio, 2019; Steindal et al., 2017; Valencia-Rico & Burbano-Lopez, 2020; Wong et al., 2014; Zeb et al., 2021). Participants encountered physical and emotional struggles in their daily lives (Rubio, 2019; Zeb et al., 2021) and these struggles led to modifications of behaviours (Ansari et al., 2014; Chen et al., 2008; Cooney et al., 2013; Ek & Ternestedt, 2008; Pooler, 2014). Cooney et al. (2013) mentioned, “the tasks became military operations requiring strategic planning” (p. 990), while Wong et al. (2014) mentioned about breaking down the tasks into small steps. Participants became constant observers of symptoms to adjust their behaviours to lessen the intensity (Valencia-Rico & Burbano-Lopez, 2020), but required planning their daily lives to accommodate the changes (Halding et al., 2018; Johansson et al., 2019; Kaptain et al., 2020). This included planning, pacing and prioritising activities by changing from an active to a passive role (Cicutto et al., 2004), whereas some used a positive outlook by prioritising the current situation and not worrying about the future (Marx et al., 2016; Steindal et al., 2017).

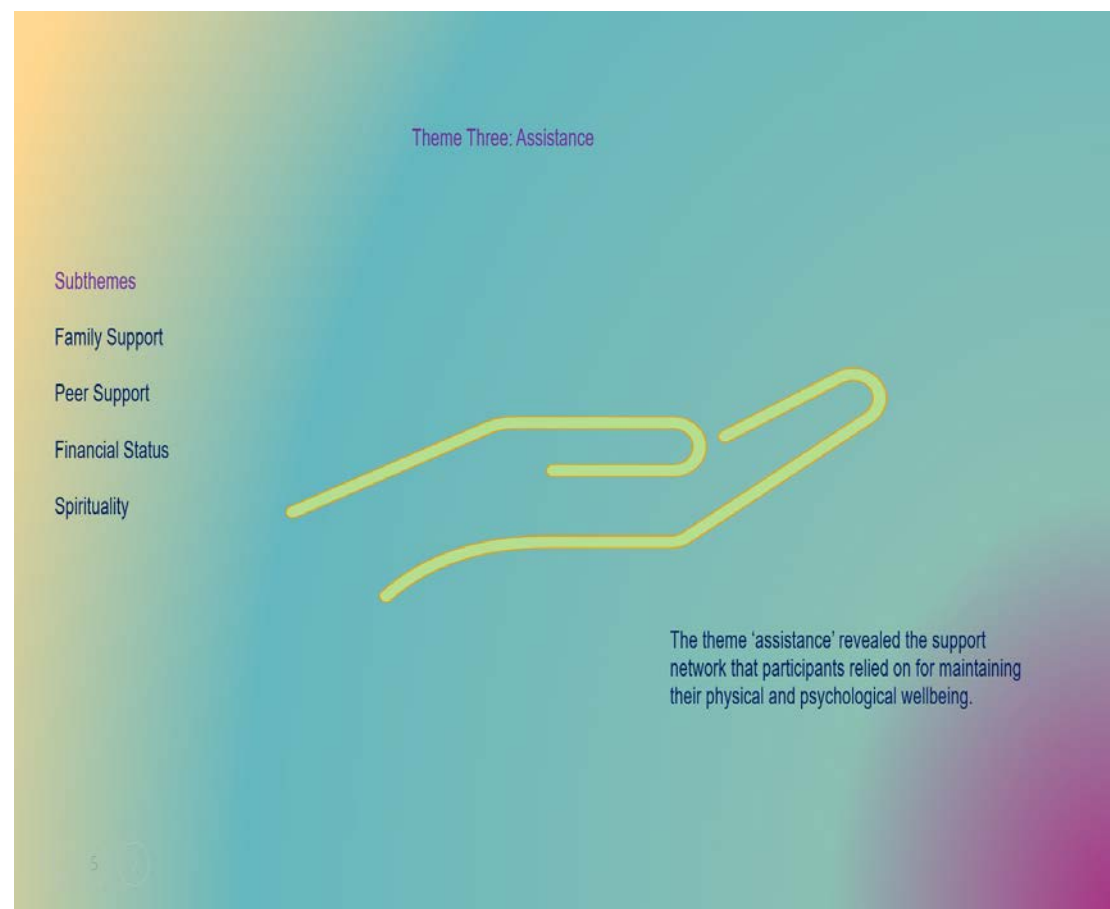
2.4.2.4 Subtheme 4: Self-initiated Activities. Experiencing various symptoms in their daily lives eventually led participants to self-initiate symptom management activities to overcome or adapt to the disease (Apps et al., 2014; Chang et al., 2016; Chen et al., 2008; Cicutto et al., 2004; Pooler, 2014; Valencia-Rico & Burbano-Lopez, 2020; Williams et al., 2014; Wong et al., 2014; Zeb et al., 2021). It is noted that self-management strategies were initiated without any instructions from health professionals (Apps et al., 2014). Participants adopted various strategies like taking a few steps at a time, breaking up tasks, taking more time, reducing activities, planning and pacing (Chang et al., 2016; Chen et al., 2008; Cicutto et al., 2004; Williams et al., 2014; Wong et al., 2014). Participants paid attention to food and used traditional therapies (Chang et al., 2016; Zeb et al., 2021). Some took measures to avoid cold weather to reduce the symptoms (Chang et al., 2016; Chen et al., 2008; Pooler, 2014) while constant use of inhalers to control external factors, alteration in food and avoiding strong odours (Valencia-Rico & Burbano-Lopez, 2020) were also mentioned.

2.4.3 Theme 3: Assistance

The theme 'assistance' revealed the support network that participants relied on in their daily lives, which either had a positive or negative impact. This included family and peer support, financial stability and spirituality, which helped participants in maintaining physical and psychological well-being. The subsets of the theme 'assistance' are portrayed in Figure 2.5 and elaborated upon further.

Figure 2.5

Theme 3 Subthemes



2.4.3.1 Subtheme 1: Family Support. Some of the studies found that family support played a crucial role in maintaining the well-being of participants (Apps et al., 2014; Chen et al., 2008; Cicutto et al., 2004; Jarab et al., 2018; Johansson et al., 2019; Kaptain et al., 2020; Sigurgeirsdottir et al., 2019; Valencia-Rico & Burbano-Lopez, 2020; Zeb et al., 2021). Participants acknowledged the support from family and friends (Sigurgeirsdottir et al., 2019), especially with tasks at home, but also noted that the family can be overprotective (Johansson et al., 2019; Kaptain et al., 2020). It is evident that there was an over-reliance on family members in managing the disease (Jarab et al., 2018), but this reliance was a challenge at times when it created conflict, and yet a positive source of support for some participants (Apps et al., 2014). Participants relied on caregivers for continuous assistance with basic activities (Valencia-Rico & Burbano-Lopez, 2020) and compassionate family support was evident in physical, psychological, financial, and emotional needs (Zeb et al., 2021). Some participants mentioned family as the only cause for sustaining the challenges (Cicutto et al., 2004), and it is a joy to note that the “family first ideology” encouraged family members to support their family member’s health (Chen et al., 2008, p. 601).

2.4.3.1 Subtheme 2: Peer Support. Peer support was pivotal in surviving COPD (Cicutto et al., 2004; Sigurgeirsdottir et al., 2019) and participants were content to talk openly about the disease and support each other (Sigurgeirsdottir et al., 2019). They mentioned that the new insight and knowledge from their peers was inspirational and made it easier to solve problems (Cicutto et al., 2004).

2.4.3.1 Subtheme 3: Financial Status. Having adequate financial resources made a substantial difference in the ability of people with COPD to manage their disease. Financial status played a major role in the diagnosis and management of COPD (Ansari et al., 2014; Zeb et al., 2021). Financial restrictions led to delayed management of the disease due to affordability issues (Ansari et al., 2014). Zeb et al. (2021) mentioned about participants who did not have enough money to buy medications, afford follow-up visits, and travel to hospitals. Retired participants had better financial stability because of concessions than those employed or people on benefits (Ansari et al., 2014).

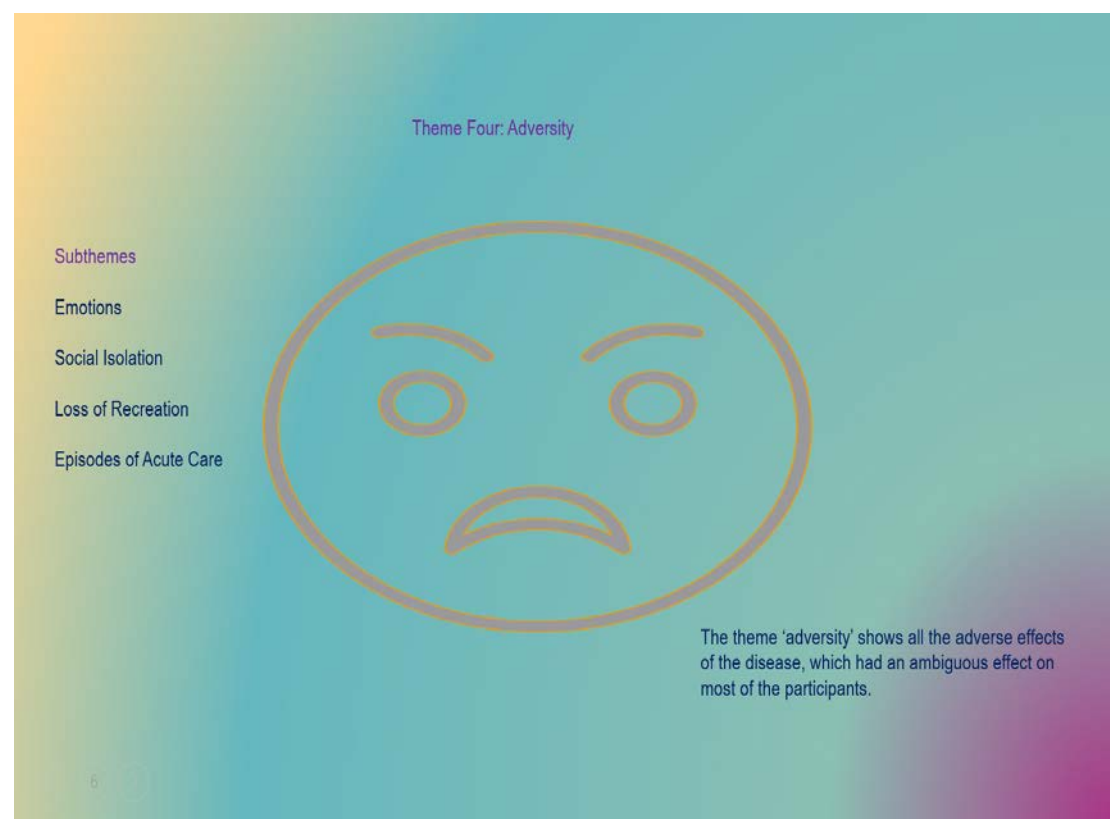
2.4.3.1 Subtheme 4: Spirituality. Spirituality was an efficient survival approach for participants (Valencia-Rico & Burbano-Lopez, 2020; Zeb et al., 2021). Spirituality had a positive impact and served to promote inner peace and comfort (Valencia-Rico & Burbano-Lopez, 2020) and those beliefs gave them the power and courage to manage the negative effects (Zeb et al., 2021).

2.4.4 Theme 4: Adversity

The theme 'adversity' illustrated all the adverse effects of the disease on participants. The emotional changes included a feeling of guilt and frustration, anxiety, worry about being a burden, and worry about finances, along with social isolation, loss of recreation, and episodes of acute care were portrayed in the theme of adversity, which had a cryptic effect on most of the participants. The subsets of the theme 'adversity' are portrayed in Figure 2.6 and elaborated further.

Figure 2.6

Theme 4 Subthemes



2.4.4.1 Subtheme 1: Emotions. The COPD had a psychosocial impact, and participants attempted to control emotional disturbance by changing negative thoughts into positive ones (Chen et al., 2008). Participants mentioned the change in emotional state while living with COPD and implemented different strategies like self-talk, acceptance of the condition, and laughter for emotional adjustment (Cicutto et al., 2004). Participants encountered a sense of meaningfulness, but at times with challenged self-esteem, felt worthless and desired death (Ek & Ternestedt, 2008). Shortness of breath made the participants frightened (Gabriel et al., 2014), while some felt fearful when left alone at home (Williams et al., 2014).

2.4.4.1.1 Feeling of Guilt and Frustration. Participants felt frustrated and confused about their condition, and it was worsened by inadequate information from healthcare professionals (Apps et al., 2014). Participants expressed guilt and negative emotions about the self-inflicted disease (Cooney et al., 2013; Halting et al., 2018; Johansson et al., 2019; Rubio, 2019) and experienced psychological burden (Marx et al., 2016). Frustration was also caused by inadequate coping (Jarab et al., 2018; Landers et al., 2015) and because of the dependence on others for daily activities (Kaptain et al., 2020). Participants mentioned feeling embarrassed (Molin et al., 2020) and felt frustrated because they were forced to do less (Pooler, 2014).

2.4.4.1.2 Anxiety. Panic and anxiety were common among participants related to breathlessness (Jarab et al., 2018) or worrying about oxygen and social isolation (Rubio, 2019), while some participants became “maddened with fear” (Sigurgeirsdottir et al., 2019, p. 1036). Participants reported that COPD triggered their anxiety, causing panic attacks that, at times, restricted their lives (Brien et al., 2016), and they felt they might die during panic attacks (Wong et al., 2014).

2.4.4.1.3 Worry About Being a Burden. Participants were concerned about creating trouble for their families (Chang et al., 2016) and were reluctant to ask for help because of the uneasiness of being a burden on their family (Zeb et al., 2021). They also felt that they were a burden, with an inability to participate in social activities and socialise with family because of low energy levels (Johansson et al., 2019). The support from family and friends led to a feeling of burden on their support system (Landers et al., 2015) because of their disease (Rubio, 2019) and with the loss of independence, which strengthened the feelings of uselessness and desperation (Valencia-Rico & Burbano-Lopez, 2020).

2.4.4.1.4 Worry About Finances. Financial worry was mentioned in association with the inability to work and earn money (Sigurgeirsdottir et al., 2019). Financial strain was also attributed due to early retirement and the need for costly medications (Gabriel et al., 2014). These affected men, losing their leadership qualities and ability to make decisions at home, because of the lack of economic productivity (Valencia-Rico & Burbano-Lopez, 2020). Participants asked for advice from the healthcare professionals in their community and built connections with an aim of free advice, and requested assistance from community pharmacists for free medications because of the lack of funding for renewing medications and follow-up visits (Zeb et al., 2021).

2.4.4.2 Subtheme 2: Social Isolation. Participants reported loneliness despite close relationships (Ek & Ternestedt, 2008), while some reported the negative effect on family activities and felt restricted at home (Gabriel et al., 2014; Johansson et al., 2019; Marx et al., 2016; Wong et al., 2014; Wortz et al., 2012). Participants tended to avoid family gatherings and other activities (Gabriel et al., 2014; Johansson et al., 2019; Marx et al., 2016; Wong et al., 2014; Wortz et al., 2012) and some were worried about wearing oxygen delivery equipment, which led to social isolation (Rubio, 2019).

2.4.4.3 Subtheme 3: Loss of Recreation. Loss of recreational activities and devoting time to spending with family were other hardships associated with the advancement of COPD. The advancement of COPD affected the intimacy with others, and participants were heartbroken (Landers et al., 2015).

2.4.4.4 Subtheme 4: Episodes of Acute Care. The necessity for acute care in managing the disease was another unpleasant situation, but most of the participants expressed faith in the hospital system (Landers et al., 2015). The acute hospital was perceived as a “haven or place of security” by the participants (Landers et al., 2015, p.15043).

2.5 Discussion

This literature review examined the attitudes, behaviours, and perspectives of people coping with COPD. There were areas of agreement and disagreement

between the 25 studies included in the review. However, collectively the findings highlight the various approaches implemented and revealed that people with COPD start modifying their attitudes and behaviours before the diagnosis of the disease (Cooney et al., 2013; Halding et al., 2018; Jarab et al., 2018; Kaptain et al., 2020; Valencia-Rico & Burbano-Lopez, 2020; Williams et al., 2014). Awareness of the disease is dependent on the socioeconomic status of people with COPD (Ansari et al., 2014; Molin et al., 2020; Zeb et al., 2021), level of education (Ansari et al., 2014; Molin et al., 2020) and communication with healthcare providers (Ansari et al., 2014; Apps et al., 2014; Chen et al., 2008; Cicutto et al., 2004; Halding et al., 2018; Molin et al., 2020; Sigurgeirsdottir et al., 2019; Steindal et al., 2017; Valencia-Rico & Burbano-Lopez, 2020).

Awareness and knowledge are reflected in emotional and behavioural changes and assist in building confidence in initiating and modifying activities to improve quality of life (Ansari et al., 2014; Chen et al., 2008; Cicutto et al., 2004; Cooney et al., 2013; Ek & Ternestedt, 2008; Halding et al., 2018; Johansson et al., 2019; Kaptain et al., 2020; Marx et al., 2016; Pooler, 2014; Rubio, 2019; Steindal et al., 2017; Valencia-Rico & Burbano-Lopez, 2020; Wong et al., 2014; Zeb et al., 2021). As participants acquired more knowledge about the disease and changes, they sought assistance from family and friends (Apps et al., 2014; Chen et al., 2008; Cicutto et al., 2004; Jarab et al., 2018; Johansson et al., 2019; Kaptain et al., 2020; Sigurgeirsdottir et al., 2019; Valencia-Rico & Burbano-Lopez, 2020; Zeb et al., 2021) and found it inspirational, and that it made problem-solving easier (Cicutto et al., 2004).

Financial stability played a vital part in supporting the needs of participants (Ansari et al., 2014; Zeb et al., 2021), along with spirituality, which helped them to adopt a positive outlook towards life (Valencia-Rico & Burbano-Lopez, 2020; Zeb et al., 2021). The unpleasant effects of the disease, including feelings of guilt, frustration, and anxiety, along with being a burden, financial worry, social isolation, loss of recreation, and episodes of acute care, have not only affected participants and family but also the healthcare system (Brien et al., 2016; Chang et al., 2016; Gabriel et al., 2014; Jarab et al., 2018; Johansson et al., 2019; Landers et al., 2015; Sigurgeirsdottir et al., 2019; Valencia-Rico & Burbano-Lopez, 2020; Wong et al., 2014; Zeb et al., 2021).

This review reinforced the idea that the symptoms of the disease, along with activity limitations and associated anxiety, adversely affected the quality of life, leading to an increase in COPD exacerbations and COPD-related hospitalisations and correlated with the findings of other studies (Breland et al., 2015; Cully et al., 2006; Eisner et al., 2010; Reardon et al., 2006; Yohannes et al., 2010). It is apparent from the literature review that the rate of anxiety and depression among people with COPD is high, which was also found in another study (Felker et al., 2010). This review reinforced the correlation between anxiety and impairment in physiological and psychological functioning, leading to frequent exacerbations and corresponding with other studies (Kim et al., 2000; Weaver et al., 1997). It is evident from this review that the activity limitations, work absenteeism, emergency presentations to hospital, frequent hospitalisations, and medical emergencies resulted in extensive demand on healthcare facilities and patients, a finding confirmed in other studies (Jones et al., 2011; Meier et al., 2011; Yohannes et al., 2010).

This review underlined the importance of knowing the disease for better self-management behaviours and to facilitate engagement in shared decision-making with healthcare providers, and is supported by previous studies (Hibbard & Greene, 2013; Hibbard et al., 2007). The poor knowledge of participants and the lack of information and support from healthcare professionals about the management of the disease, especially from primary healthcare physicians, is highlighted. This review revealed participants' preference for having a contact health professional to discuss their needs in a caring manner reflected their trust and confidence in the system. Effing et al. (2016) stated the importance of coaching and education by healthcare providers in transforming health behaviours and developing skills. Blackstock et al. (2016), which was a randomised controlled trial, stated that disease-specific education will facilitate health-related quality of life.

The literature review emphasised that information and advice provided by health care providers played an important role in persuading participants to take part in educational activities and to build confidence in supportive decision-making and is slightly different from the GOLD report (2022), which disclosed "Physicians and healthcare providers need to go beyond pure education/ advice giving (didactic) approaches to help patients learn and adopt sustainable self-management skills" (p. 97).

2.5.1 Recommendations arising from the Literature Review

The role of healthcare providers, especially primary care physicians, cannot be replaced in the management of the disease. It is evident from the review that changes in professional practice and empowerment through education at the primary level are necessary for the proper diagnosis, management of the disease, and support of healthcare clients.

The review reinforced the necessity of proper educational activities for participants, as the poor knowledge of the participants and the lack of information about the management of the disease are evident (Ansari et al., 2014; Jarab et al., 2018; Marx et al., 2016; Sigurgeirsdottir et al., 2019; Wong et al., 2014; Wortz et al., 2012). Implementation of practice changes to support improved communication, assessment of needs, and maintaining continuity of care to achieve a holistic person-centred approach in the management of the disease is crucial. Educational activities and coaching by healthcare providers should aim to motivate, engage, and coach patients to confidently transform their health behaviours (Effing et al., 2016) and to enhance skills to improve well-being (Blackstock et al., 2014). The review has highlighted the need for health providers to be a point of contact to discuss the issues in a caring and friendly manner, rather than the traditional role of being a healthcare provider.

The provision of training and education, and a more structured approach to improve the knowledge and expertise of clinicians, should be encouraged. Education should focus on enhancing clinicians' potential to increase awareness and provide systematic assessment and education to patients. The provision of training and educational activities for clinicians should be encouraged by healthcare organisations and be made mandatory by policy, which will have a positive impact on clinical practice. This review has highlighted the need for ongoing training and educational activities to broaden the skills and knowledge of clinicians and the empowerment of patients.

Even though the included studies exposed the influencing factors in coping with COPD, most of the studies have focused on structured interventions such as pulmonary rehabilitation programs or educational sessions. These approaches provide valuable support, yet they do not fully capture the attitudes, behaviours, and perspectives that shape how individuals manage their illness outside formal

healthcare settings. Scant research has investigated the variation in self-care strategies people adopted beyond prescribed programs to cope with symptoms, maintain independence, and prevent hospital readmissions. This lack of research into this facet of the variation in coping indicates the need to explore this topic in further studies for clinicians and policymakers to design patient-centred and contextually relevant interventions. In particular, the knowledge about how patients in regional areas develop coping strategies, or how families and healthcare providers might influence these processes, is not very well understood either. Addressing this gap is essential for building a more systematic and holistic framework for COPD management that integrates the lived experiences of patients, their support networks, and clinicians.

2.5.2 Strengths and Limitations

This is a comprehensive review of the literature about attitudes, behaviours, and perspectives of people coping with COPD to inform conclusions about the gaps and future opportunities. A key limitation of the review is that of the total 25 studies directly relating to the research question, all were qualitative in nature and thus ranked lower in all established hierarchies of evidence (Joanna Briggs Institute [JBI], 2014; The Centre for Evidence-Based Medicine [CEBM], 2011); The National Health and Medical Research Council [NHMRC], 2023). Despite having predefined search criteria tailored to each of the four databases (Aveyard, 2019; Efron & Ravid, 2019), no quantitative studies were retrieved. The measures to maintain the rigour of this review were: no limitations on search strategy; a clear, predefined research question; and predefined inclusion and exclusion criteria.

2.6 Chapter Summary

This chapter has presented the findings from a review of the literature pertaining to the attitudes, behaviours, and perspectives of people coping with COPD. The interrelatedness of numerous factors is evident in the diagnosis and management of this debilitating disease. The awareness of the disease empowered the person to adapt to the symptoms and situations with assistance from support systems to reduce or overcome the adversities. Despite advances in the management of this disease, people still experience high levels of symptom burden and require frequent hospitalisations related to exacerbations. The symptom burden varies in different patients and underlines the importance of collaborative healthcare

based on education, respect, and effective communication to manage this disease and enhance patient well-being. The next chapter introduces the research question of this study and details the methodology and methods used to address the research question.

Chapter Three: Methodology and Methods

3.1 Chapter Introduction

Chapter Two presented a review of the literature, which led to the development of the research project. The study design, including methods used in the research along with ethical considerations, is explained in this chapter. This chapter begins by reiterating the research question, followed by a description of the methodology underpinning the study. The methods are then described – study design, participants, and recruitment processes, followed by a detailed description of data collection and analysis processes. The management of the data and ethical considerations of the study, along with the risks involved and risk management strategies, are also described.

3.2 Research Question

The research question for this study was: “What are the attitudes, behaviours, and perspectives of people coping with COPD that influence variations in self-care interventions in daily life?” The research question is exploratory in nature and is suited to a qualitative methodology (Kelly, 2016).

3.3 Methodology

Methodology reflects the researcher’s philosophical approach to seeking answers, structured by assumptions, interests, and purposes (Taylor et al., 2016). Methodology enables a researcher to select suitable methods and tools for data collection and analysis, thereby adding credibility to the study (Jha, 2024). Methodology is the explanation of the approaches for answering the research question in a particular way, and is different from the methods, which are the techniques used to collect and analyse the data (Pope & Mays, 2020). Jha (2024) argues that the method includes the execution of strategies and techniques in an orderly manner. The selection of research methodology is dependent on the research problem or issue being explored, the methods used for data collection and analysis, and the researcher’s personal experience or philosophical worldviews (Creswell & Creswell, 2023).

Cresswell & Creswell (2023) noted that the philosophical worldview of the researcher is shaped by their professional expertise, cultural experiences, past research experiences, including research advisors. Making this worldview explicit in the study allows the reader to evaluate the research and understand the influencing factors and attitudes of the researcher (p.7). Ontology encourages researchers to understand that the topic being explored is independent of their interpretation or that it exists because of their belief, while epistemology directs the researcher to learn more about the topic to produce valid evidence (Pope & Mays, 2020). Researchers need to understand their views, beliefs, and values, as researchers' views about epistemology and ontology influence the approaches and methods of the study (Pope & Mays, 2020).

The researcher's primary interest was to understand the attitudes, behaviours and perspectives of people coping with COPD to explore the external reality which existed beyond the researcher's understanding. The researcher adopts a realist ontology and aligns with a subjectivist epistemology and an inductive approach, enabling exploration of lived experiences to generate meaningful insights (Pope & Mays, 2020). This research examined and noted the attitudes, behaviours, and perspectives of people coping with COPD and is positioned within the qualitative paradigm. Qualitative research looks for the meaning of participants rather than having a predefined concept (Polit-O'Hara et al., 2001). Qualitative research is an approach to gathering and interpreting data, which includes words, visuals, or descriptions of the meaning that people connect to their experience of the world and the way people make sense of those experiences (Pope & Mays, 2020).

Kelly (2016) noted that "if the research questions are about what people think or know or do, then qualitative methods often offer the best solution" (p.936). As per Jha (2024), qualitative methodology is exploratory and seeks perceptions or purposes to streamline the broad and vague problem. The familiarisation with the problem through data collection and analysis, with flexibility involving non-probability sampling methods, facilitates uncovering the concepts and theories (Jha, 2024).

Qualitative research methodology focuses on the way people perceive their experiences and is usually used to inspect the behaviour, feelings, and experiences of people and the essence of their lives (Holloway & Galvin, 2017; Pope & Mays, 2020). Qualitative research methodology concentrates on obtaining a deeper

understanding of an incident or perception of individuals by observing and describing things as they naturally occur (Nieswiadomy & Bailey, 2018). The researcher is interested in the interpretation of events and how those events shape individuals' attitudes, behaviours, and perspectives. This methodology enables a researcher to understand the experience, gather rich and in-depth data, and generate concepts by interacting with the participants (Holloway & Galvin, 2017).

Qualitative research delves into human actions and interactions, examines people's views to gather information and data about their behaviour, and allows the researcher to rethink participants' perspectives. The collected data is rich and reflects the behaviour and perspectives that sometimes people are not aware of or have thought about until someone has questioned them or reflected on the behaviour with them (Kelly, 2016). This methodology explores the nature of social phenomena rather than simply accepting the concepts. It can be done in day-to-day settings and does not require artificially created or experimental settings (Pope & Mays, 2020). Studying people in naturalistic settings allows the researcher to collect data by observation, interviews, focus groups, informal chatting, and documentary analysis and allows for a deeper understanding of social phenomena (Pope & Mays, 2020).

An exploratory research design investigates the ideas and insights to produce explanations and new knowledge (Jha, 2024). The ideas and insights provided by an exploratory research design serve as the drive to identify and describe the relationships, characteristics and effects of different variables in a descriptive research design (Jha, 2024). A descriptive exploratory qualitative approach using semi-structured interviews was selected to obtain a deeper understanding of the attitudes, behaviours, and perspectives of people coping with COPD, which allowed study participants to contribute to the development of new knowledge (Hunter et al., 2019). An exploratory, descriptive qualitative approach enables further understanding of the topic being explored and allows study participants to contribute to the development of new knowledge in the specific area (Hunter et al., 2019).

3.4 Study Design

A descriptive exploratory qualitative approach using interviews was chosen as this design assisted in understanding the interpretation of people's experience in

coping with COPD and how it shaped their behaviours and attitudes. This study design was an attempt to fill the gap by obtaining a deeper understanding of the attitudes, behaviours, and perspectives of people coping with COPD. The semi-structured interviews facilitated the capture of rich and descriptive data about the attitudes, behaviours, and perspectives of people coping with COPD.

The question that guided this research was: “What are the attitudes, behaviours, and perspectives of people coping with COPD that influence variations in self-care interventions in daily life?”. Thus, this study aimed to delve into the attitudes, behaviours, and perspectives of people coping with COPD to understand the diverse self-care interventions they used to maintain a quality of life. The rich descriptive data obtained by the semi-structured interviews were analysed by a six-step thematic analysis, as explained by Braun & Clarke (Braun & Clarke, 2006). “Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p.79). Braun & Clarke (2006) suggest that thematic analysis is not bound by any theoretical frameworks and differs from other analysis methods, which describe patterns across qualitative data.

As per Braun et al. (2019), thematic analysis has three different approaches: the coding reliability approach, the reflexive thematic analysis (TA) approach and the codebook TA approach. The process of data analysis is guided by a codebook and multiple coders to ensure accuracy and reliability in the coding reliability approach, while a structured framework is used in the codebook TA approach (Braun & Clarke, 2021). A logical and compelling analysis, driven by data with a flexible approach, is the merit of the reflexive TA approach (Braun et al., 2019). Braun et al. (2019) describe “the researcher as a storyteller in the reflexive TA approach, who interprets the data through the lens of their own cultural and social values, ideologies and knowledge” (p.848-849)

A reflexive TA approach was the preferred method for data analysis as it is flexible. As the reflexive TA approach was not bound by any framework and recursive in nature, the researcher was able to immerse in data to look for the interesting factors, connections among participants, making notes and being curious about the data, which made the rest of the analysis enjoyable (Braun et al., 2019). The phases of data analysis are explained in detail in section 3.7.3.

3.5 Quality/Validity of Research and Researcher Characteristics

The validity of the study was maintained through various approaches. The research team maintained reflexivity throughout the study. Reflexivity involves researchers' awareness of their own beliefs, personal experiences and knowledge, which might influence or shape the research process and findings (Pope & Mays, 2020). Pope and Mays (2020) argue that researchers should keep a record of events and their interpretation to enhance credibility (p.219). The researcher conducted each interview, and field notes were kept after each interview. The interview recordings were transcribed by the researcher. The interview transcripts were distributed among the team members and were discussed at regular team meetings along with the characteristics of the participants. The use of memos and team discussions enhanced the rigour of the study. A reflexive log was maintained, which included the notes about participant comments and the researcher's thoughts during the interview. The researcher transcribed the audio recording as soon as possible after each interview. The reflexive log was updated regularly after conducting each interview within 1-7 days. A clear explanation of the data collection and analysis process helped the reader to assess the findings by comparing them to the ways data was collected and analysed (Pope & Mays, 2020).

Transferability indicates that the findings may be transferred to another setting or group and is evidenced by the detailed description of the context (Stenfors et al. 2020). Transferability was enhanced in the study by descriptions of the participants, the process of data analysis, along with enriched descriptions of the results with relevant quotations and continued discussions among team members. Credibility of the study was maintained by the justification of appropriate methodology and selection of apt methods for data collection (Stenfors et al. 2020). Analytical processes were discussed in depth throughout the study among the research team members, which enabled credibility.

The researcher is an experienced registered nurse who was working as a clinical trials coordinator at the time of data collection and had previous experience caring for people with respiratory ailments in an acute care setting for over nine years. The researcher was not known to any participants of this research study before undertaking the study and was not undertaking any activities in clinical areas. Her own clinical experience was deemed beneficial in understanding what the participants were talking about in their experience of coping with COPD. As a

researcher, all conscious efforts were made not to influence the research process by her assumptions and beliefs. Interview questions were asked in a neutral, non-judgmental tone so that participants could share their perspectives. The researcher always asked clarifying questions to better understand participants' responses, and this approach helped to avoid misinterpretation.

3.6 Participants

3.6.1 Inclusion/ Exclusion Criteria

To be eligible for the study, the participants had to meet all the inclusion criteria. People diagnosed with COPD for at least two years were included in the study. People were at least 40 years old, aware of their diagnosis and were able to understand the purpose of the study. Along with these criteria, the person was able to comfortably converse in English and had a telephone as well. People with speech, hearing, or cognitive impairments who were not able to understand the information sheet or were unable to converse were excluded from the study. People with acute COPD exacerbations were excluded as well. The data about the ethnicity and race of study participants was not collected. The interview guide submitted for ethics approval did not contain the specific questions about race and ethnicity. The research team were mindful of the potential identification of participants by disclosing their race and ethnicity, compromising the confidentiality and privacy.

3.6.2 Participant Recruitment

3.6.2.1 Recruitment Process. Recruitment commenced in February 2024 after obtaining ethical approval from the James Cook University Human Research Ethics Committee (Appendix E). Several strategies were used to recruit the participants. The researcher contacted the Primary Health Network for support in facilitating the process of contacting general practices or medical centres to distribute the flyers (Appendix F). A list of general practices/medical centres across Townsville, Queensland, was prepared. The practice managers of the selected general practices/medical centres were contacted by the researcher to assist in distributing flyers. A few general practitioners and a respiratory physician were also directly approached by the researcher to assist with flyer distribution.

Flyers were distributed to the medical centres and private practices informing people of the details of the purpose of the study, what their involvement entailed, and

any potential risks or benefits to their participation and inviting them to ring the researcher to see if they were eligible to participate. A log was kept detailing the general practices/ medical centres, practice managers, and general practitioners who were approached for recruitment, their responses, and follow-up about recruitment. This log also assisted in ensuring all these details were captured in this dissertation.

A few general practitioners advised that they preferred to hand out the flyers to their patients because they valued their personal connections with patients. This approach also assisted in filtering participants who fit the eligibility criteria and enhanced recruitment. Other general practitioners preferred to display the flyers at the medical centres; prospective participants could directly contact the researcher.

The flyer was also advertised via the social media account of James Cook University (JCU) to enhance recruitment. Three people contacted the researcher via email after noticing the advertisement on the JCU social media account. After screening, these potential participants were excluded as they did not meet the eligibility criteria.

Recruitment was slower than anticipated, and the Human Research Ethics Committee approved an amendment (Appendix G) in April 2024 to display the flyers in community pharmacies and other community organisations, including support groups, senior citizens' clubs, retirement villages, rotary markets, clubs, and religious organisations. This strategy resulted in the recruitment of additional participants.

Potential participants contacted the researcher to indicate their interest after seeing the displayed flyers. The researcher then asked screening questions to determine their suitability and eligibility for participation. The screening questions allowed the researcher to assess the extent of the potential participants' disease, their age, and their ability to converse in English. The screening questions are included in the appendices (Appendix H). People with acute COPD exacerbations who were unable to comfortably converse with the researcher were excluded at this time but were encouraged to contact the researcher once they were able to comfortably converse.

If the interested persons met the inclusion criteria, the Participant Information Sheet was explained over the phone. Participants were made aware that they could

elect face-to-face, phone, or online interviews according to their preference. It was explained that the researcher was able to meet at any place as per the participant's preference, which was not noisy or with any distractions, to facilitate audio recording. Interviews were not able to be conducted in the individual's home, consistent with the conditions of the Ethics approval.

Verbal consent was sought, and a tentative appointment one to two weeks in the future was scheduled during the screening phone call. The Participant Information Sheet and Consent Form (Appendix I and Appendix J) were emailed to the participants for face-to-face interviews. The Participant Information Sheet and Consent Form were posted to the participant with a stamped self-addressed envelope for the participant to post the signed consent form back to the researcher for phone or online interviews. If the potential participants were not interested in being interviewed, the researcher thanked them for their time, wished them well, and requested them to share the information about the study with their acquaintances.

Potential participants were contacted the day before to confirm their readiness to be interviewed. On the day of the interview, before consenting, the researcher answered any further queries that participants had regarding the research study. The consent forms were signed before commencing the interview. Consent to participate was confirmed verbally again at the start of the recording. Interviews were concluded after seeking participants' feedback and expressing gratitude for their involvement.

Recruitment was open for approximately seven months, and different methods were used to enhance recruitment. The location of recruitment was a regional city. Consistent with qualitative research processes, it was not possible to pre-determine the sample size. It was decided by the research team to discontinue recruitment once data saturation occurred. It was anticipated that approximately ten to twelve participants would be interviewed for data saturation to occur. The sample size of eleven was appropriate for the exploratory nature of this qualitative study, as no new codes or ideas were emerging from the interviews, indicating that data saturation had been reached. Preliminary data analysis happened concurrently with recruitment and data collection, with the researcher and supervisory team reviewing transcripts after each interview. By the ninth interview, the major categories and codes were consistently recurring; two further interviews were conducted to confirm that no new themes were identified, strengthening the credibility and rigour of the

findings. Once recruitment was completed, the researcher contacted all the general practices, community pharmacists, and organisations that displayed the flyers, along with the general practitioners who assisted with recruitment via email and in person. The researcher confirmed with all the institutions that the flyers were no longer on display and thanked them for their support.

3.7 Data Collection

Data was collected through audio-recorded semi-structured interviews. An interview guide was developed, and interviews were conducted by the researcher, who was unknown to participants and had no clinical involvement with them at the time of the study's data collection phase. Participants knew the interviewer's clinical curiosity and experience motivated the project, and these were viewed as beneficial in understanding the participants' discussions.

The interview guide included questions about demographics, participants' awareness of the disease, the effects of symptoms on their lives, along with strategies they used to relieve those effects. The interviewer also enquired if the participants had any advice for someone newly diagnosed with COPD and feedback for the interviewer regarding the interview process. The detailed interview guide can be found in the appendices (Appendix K).

3.7.1 Practice Interviews

Before conducting interviews with study participants, the researcher undertook practice interviews with colleagues who were experienced research coordinators and registered nurses. Out of six practice interviews, two were face-to-face, two were over the phone, and two were online. The interview questions for the practice interviews were the same as the interview guide used for interviews with actual participants. Harerimana et al. (2024) argue that mock interviews help to support novice researchers in identifying required training needs, improve communication by using interview questions in a suitable way, and identify any technical issues. These practice interviews improved the researcher's interview skills, boosted the researcher's confidence in undertaking interviews, and allowed for checking the recording device for clarity and quality of recordings. "Researchers should always 'pilot' the interviews to ensure the appropriateness and suitability of the questions and sequencing" (Kelly, 2016, p.937). During practice interviews, the

researcher obtained feedback from practice participants for improvement in anticipation of the data collection phase. This feedback from the practice interviews led to minor changes to the interview guide, such as changing the phrases to ensure participants could answer in detail about their experience.

3.7.2 Participant Interviews

The interviews with the study participants were conducted via a mutually agreeable method (in person, via phone, or online) as per the participant's choice. Participants were made aware that even though the video would be recorded during online interviews, only the audio component of the recording would be saved. The participant's willingness to partake in the study was verified, and all queries were answered before signing the consent form. A copy of the signed consent form was provided to the participant before the interview. Participants were asked about their interest in knowing the study findings at the conclusion of the interview.

Interviews were audio-recorded and transcribed verbatim by the researcher. A reflexive log was kept for each interview. This assisted the researcher in assessing the interview process for any required modifications and evaluation of their own experiences. As per Kelly (2016), using a reflexive log for data collection benefits the inexperienced interviewer to evaluate their performance. The interviews took between 15 and 45 minutes, including rest breaks or pauses. Participants were reassured at the start that they had the right to skip or not answer any questions. The interview schedule included open-ended questions about attitudes, behaviours, and perspectives (such as "tell me about how you manage your COPD on a daily basis"). Minimal socio-demographic data (age, gender, marital status) was also collected. Interviews were audio-recorded on two devices to protect against data loss from technical failure by the researcher. The recordings were uploaded into Microsoft OneDrive and NVivo software version 12, and the original files were deleted from both recording devices. A copy of the recording was kept in an external drive as well. Data collection was discontinued when data saturation was achieved. Along with audio recordings, field notes were also collected.

3.7.3 Data Analysis

The recorded interviews were transcribed verbatim by the researcher, and the data was organised within NVivo software version 12. A copy of the transcription

was kept in One Drive and on an external hard disk as well. OneDrive is a cloud-based storage service provided by Microsoft, which can only be accessed through one's own Microsoft account. This secure drive is password-protected. Apart from the researcher, only the research team members could access the specific files that contained data in the researcher's One Drive. Analysis of qualitative data can be daunting with the volume of data, and it is recommended to use NVivo, a qualitative analysis software for large volumes of data, to assist the researcher (Kelly, 2016). Preliminary thematic analysis and initial coding were done alongside the data collection by listening to the recorded interviews.

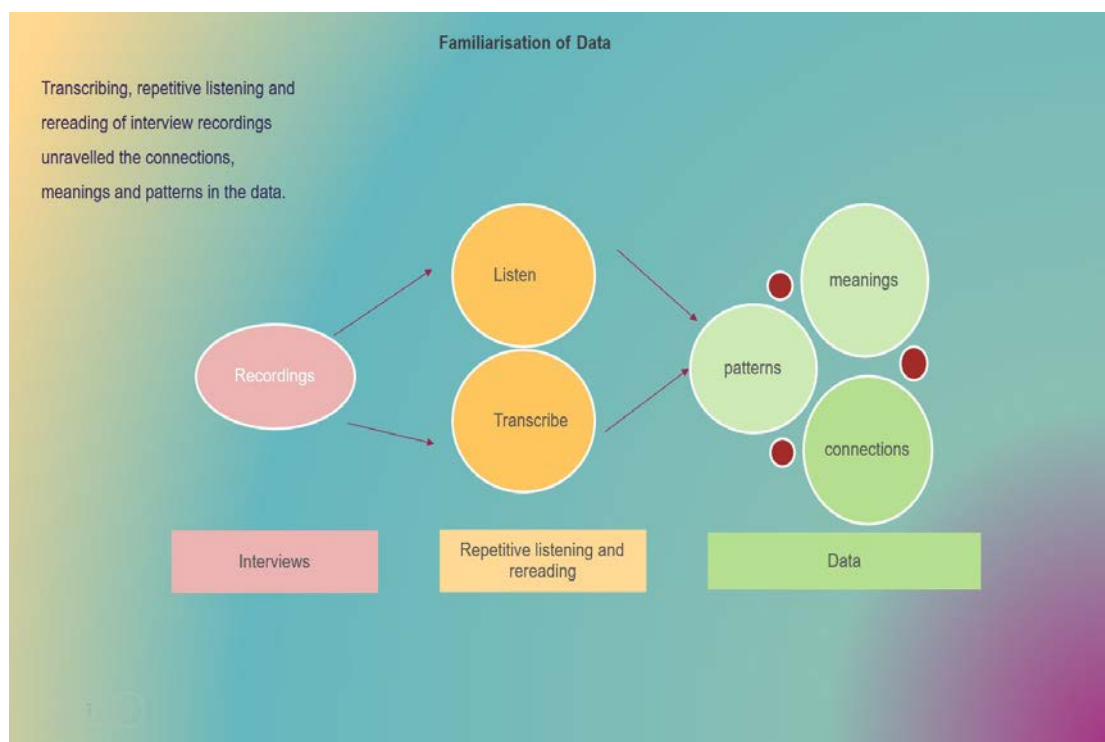
A six-step thematic analysis, as explained by Braun and Clarke, was used for analysing the data (Braun & Clarke, 2006). The process started during data collection, as the researcher noticed patterns of meaning (Braun & Clarke, 2006). The researcher was able to familiarise herself with the data to develop codes for each data extract and arrange codes into meaningful patterns, which produced themes, and ongoing analysis of themes was refined to produce the final analysis of selected extracts (Braun & Clarke, 2006, p.87).

A reflexive TA approach (Braun et al., 2019) was the preferred method for data analysis as it is flexible and not bound by a framework. The researcher was able to familiarise the data by reading and re-reading each interview transcript several times. Initial coding was carried out after familiarising with the data. After re-reading the codes, interconnected themes were generated. The themes were cross-checked with the coded extracts and the data. After finalising the themes, a thematic map was generated. All these themes were integrated to form a comprehensive map that represented all interviews. Data analysis involved constant moving backwards and forward between the entire data set and the phases explained below, which is consistent with the six-step thematic analysis explained by Braun & Clarke (Braun & Clarke, 2006).

3.7.3.1 Familiarisation of the Data. The researcher collected the data via semi-structured interviews; all of them were interactive in nature. This involvement by the researcher gave an understanding and prior knowledge before diving into data analysis (Braun & Clarke, 2006). In addition, the researcher elected to transcribe the recorded interviews herself, and all the transcriptions were done on subsequent days of the interview. This assisted the researcher in recalling all the associated events and participant characteristics, and the researcher was able to make notes for future reference. Doing her own transcription also assisted in checking the accuracy of transcriptions against the recordings and being more familiar with the data. This prior knowledge was beneficial during the later phases. During and after transcription, the researcher was engrossed in the data by listening to the audio recordings and repeated reading of transcripts, which allowed the researcher to figure out the possibilities and connections among the data. This process assisted in gaining greater insight into the participants' experiences and attitudes and searching for meanings and patterns in the data. This led to taking notes and marking ideas for coding. The steps involved in this stage and the outcome can be found in Figure 3.1.

Figure 3.1

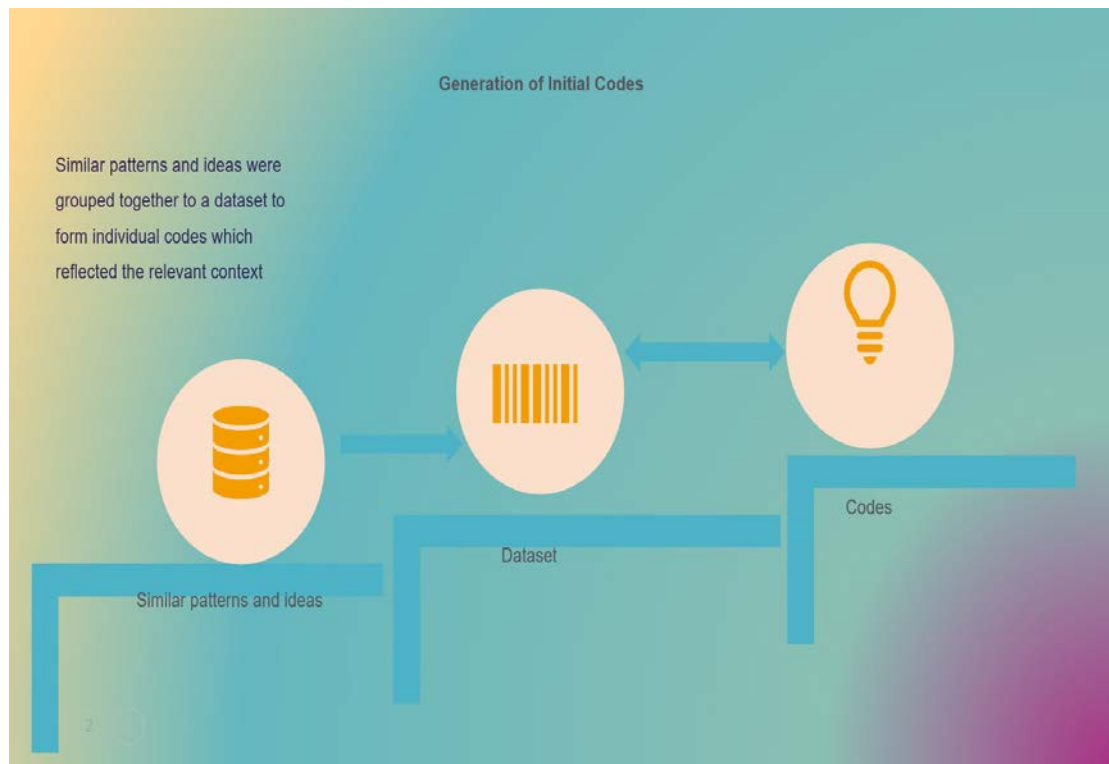
Familiarisation of the Data



3.7.3.2 Generation of Initial Codes. Re-reading the transcripts and repetitive listening of recordings made the researcher more familiar with the data and assisted the researcher in engaging with the data in detail. The initial list of ideas from the previous stage was further evolved, and data with similar meanings and patterns were identified. Potential patterns were identified and matched with the data extracts. Similar patterns or meanings were grouped together, and the contents were reduced to chunks of text, and each pattern was named or coded. After identifying the codes, they were compared against the data set that demonstrated the codes. These codes were identified across the dataset attentively and were coded by tagging and naming the text related to each data item. All the potential patterns were identified and coded in this phase. Data was coded in a way that reflected the relevant context. Some data sets were processed into multiple codes, as they reflected many codes (Braun & Clarke, 2006). Figure 3.2 incorporates the activities involved in this phase.

Figure 3.2

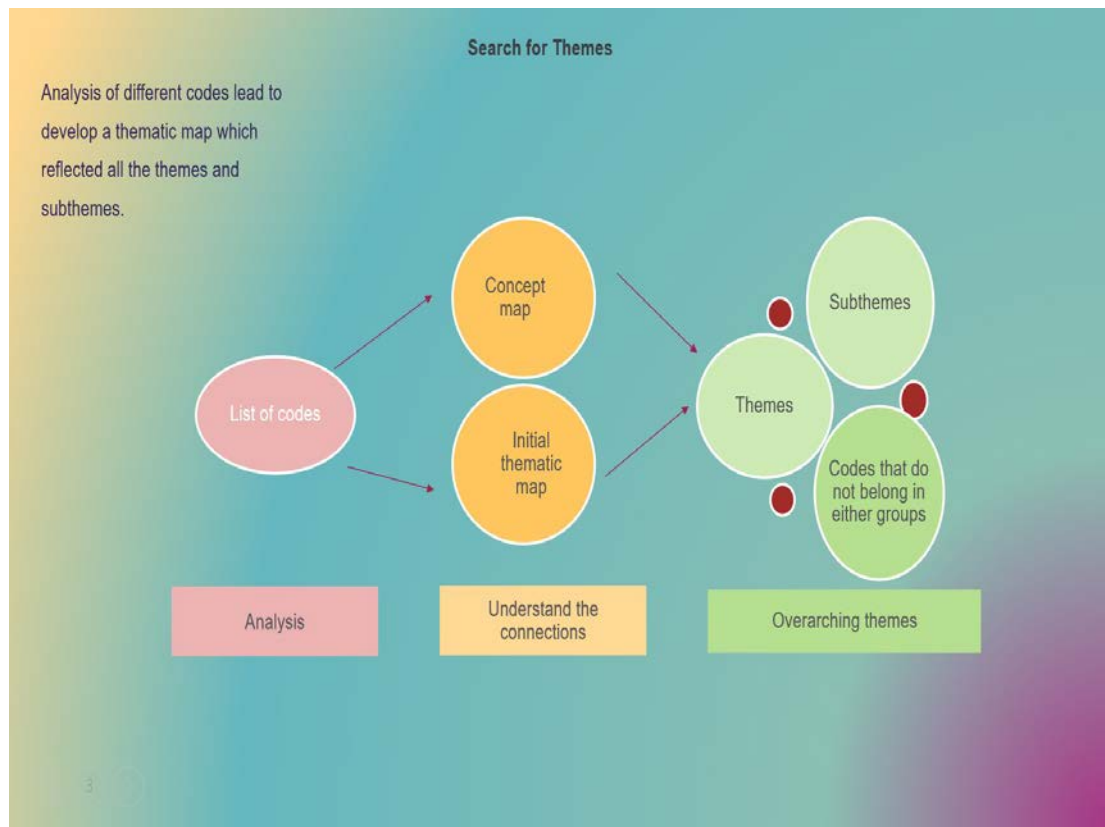
Generation of Initial Codes



3.7.3.3 Search for Themes. All data that was previously coded and organised resulted in a long list of codes. These lists of codes were reviewed, and this led to combining codes with similar meanings and patterns (Braun & Clarke, 2006). A few codes were not able to be grouped and were kept as separate under the theme “miscellaneous”. This process evolved further, and the codes were grouped to form a single overarching theme. There were multiple overarching themes called candidate themes (Braun & Clarke, 2006). Candidate themes consisted of subthemes that were related to each other. Figure 3.3 integrates the steps involved in this phase.

Figure 3.3

Search for Themes



This analysis was facilitated by a concept map and assisted us in understanding the connections among the codes, different themes and different levels of themes. The concept map reflected multiple themes and subthemes in relation to the data.

A Concept Map, showing Multiple Themes, Subthemes and Standalone Themes

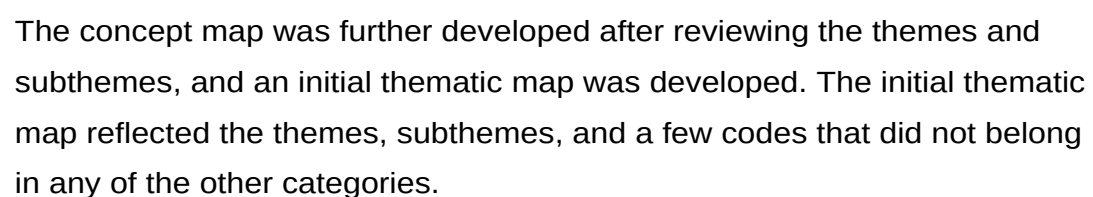
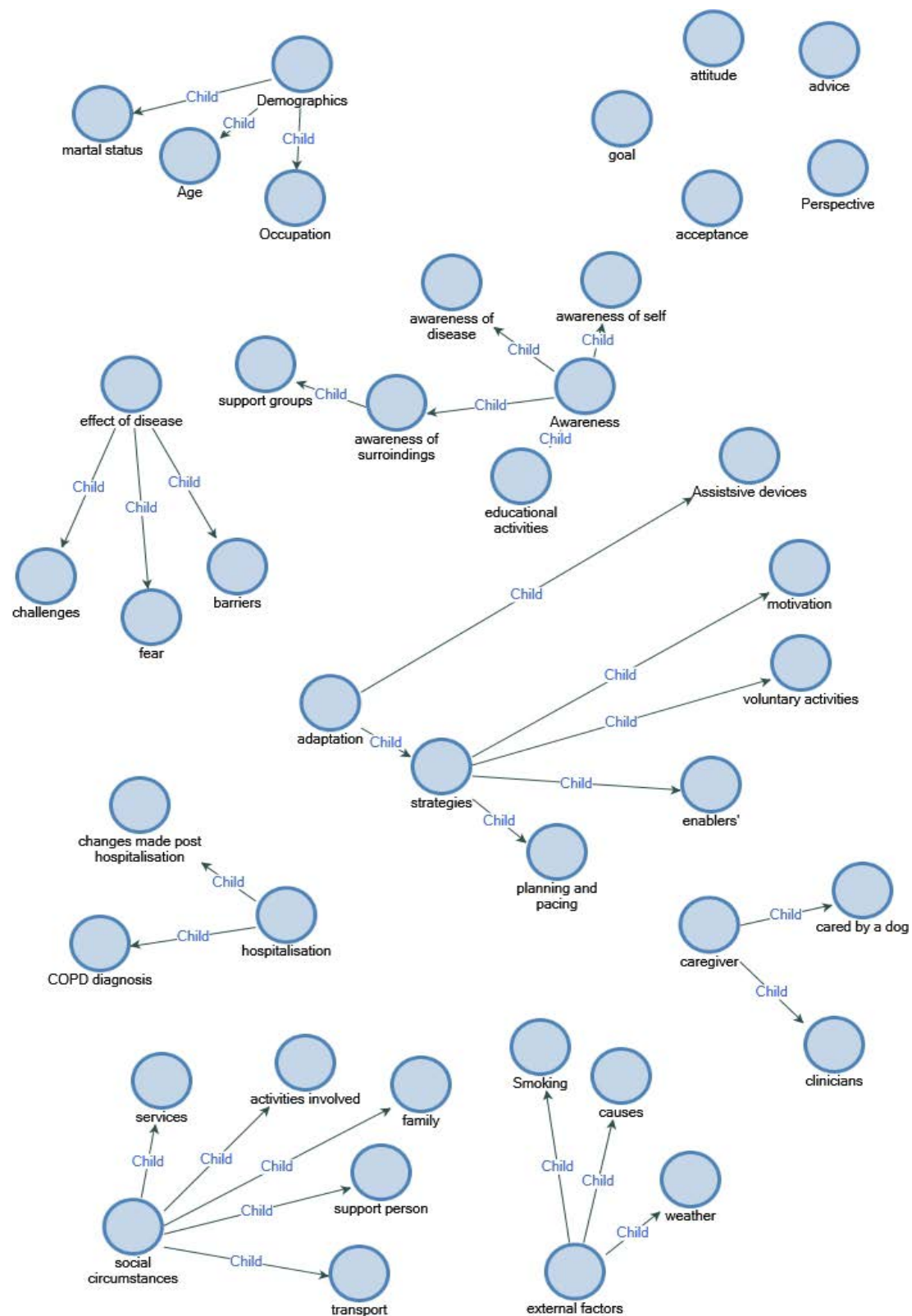


Figure 3.5

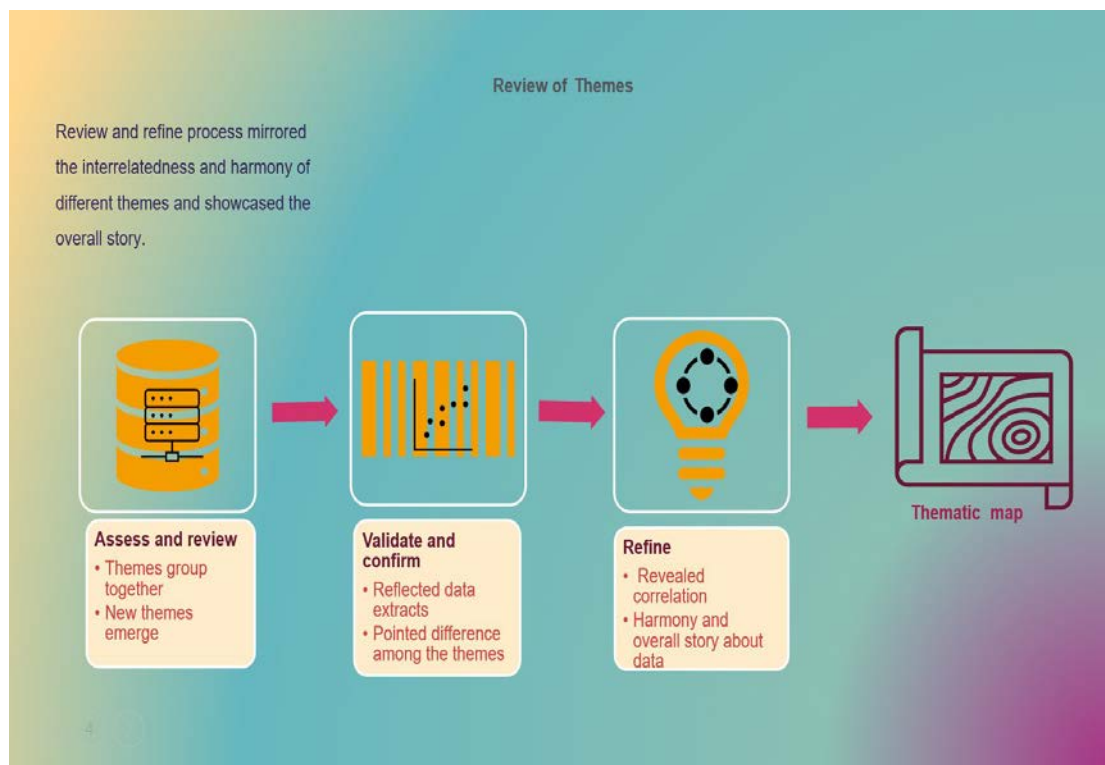
The Initial Thematic Map



3.7.3.4 Review of Themes. The themes that were formulated in the previous step were assessed in detail to confirm that the themes had enough data to support them. This made the researcher understand that a few of those themes were not “real themes” as they didn’t have enough data to support them. A few themes were collapsed together to form a single theme, and other themes were broken down into separate themes (Braun & Clarke, 2006). The themes were validated to confirm that a coherent pattern was formed, which reflected the data extracts and had clear differences among them. This pattern of themes was refined again in relation to the data set. This required constant reviewing and refining of the codes. A thematic map was developed, which reflected the meaning evident in the dataset as a whole. The reviewing and refining process enabled the researcher to understand different themes and their interrelatedness and harmony, along with the overall story they tell about the data (Braun & Clarke, 2006). A thematic map evolved after reviewing the themes and is included in the subsequent chapter. The steps involved in the review of themes are incorporated in Figure 3.6.

Figure 3.6

Review of Themes



3.7.3.5 Define and Name Themes. A satisfactory thematic map was produced in the previous step. The themes were defined to identify the essence of each theme and the aspect of data reflected by each theme. This was later organised with a narrative. For each individual theme, a detailed analysis was conducted to make sure it reflected the story and fitted into the overall story, and this process was written in detail. As part of refinement, sub-themes were identified from the themes. In the latent stage, final themes and subthemes were developed, and themes were named, which gave a sense of what the theme was about (Braun & Clarke, 2006). The final themes and subthemes are narrated in successive chapters. The sequence of steps involved in producing final themes and subthemes can be found in Figure 3.7.

Figure 3.7

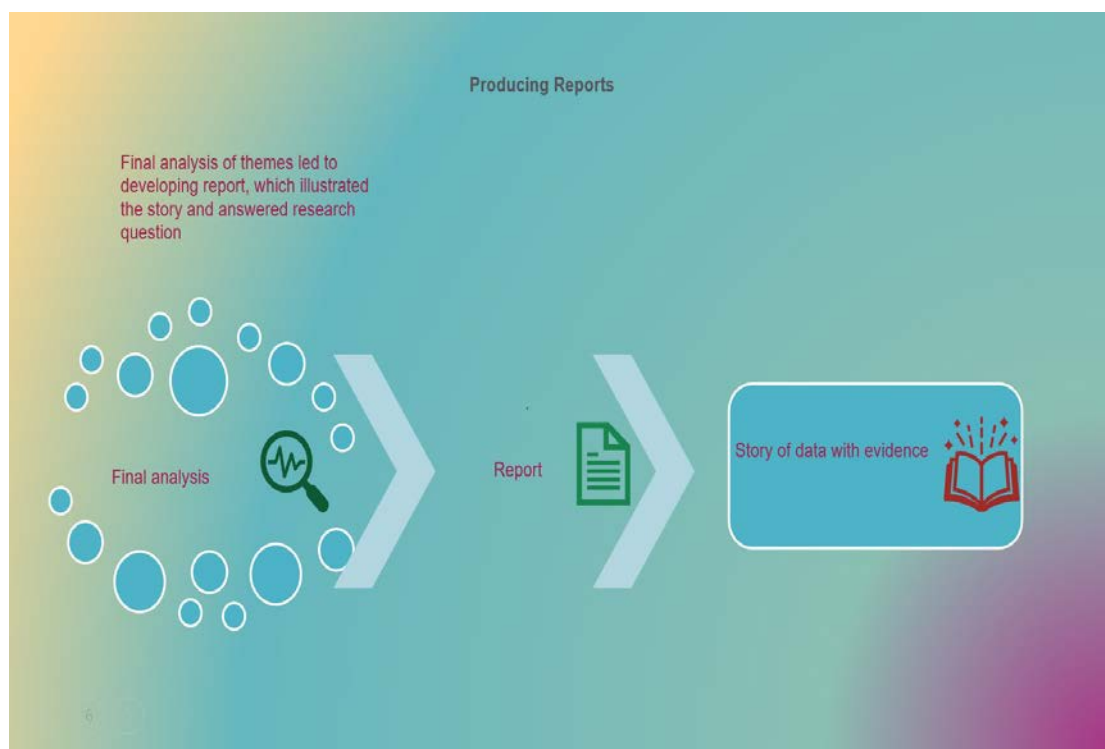
Define and Name Themes



3.7.3.6 Producing the Report. The themes that were developed in the previous steps aided in the final analysis and in writing the report. This report illustrated the complicated story of the data with supportive evidence of themes within the data (Braun & Clarke, 2006) which answered the research question and can be found in subsequent chapters. Figure 3.8 illustrates the process involved in this final phase of data analysis.

Figure 3.8

Producing Reports



3.7.4 Data Management

A research data management plan was created, which detailed what data was created; the owner of the data and the persons who had access to the data; what data management practices were used; what facilities and equipment were required; and the responsible person for each of these activities. The researcher always had a locked briefcase with informed consent, a participant information sheet, and recording devices while interviewing participants. The collected data were stored in cloud storage, on a hard drive, and as hard copies to prevent any permanent data loss and were password-protected or encrypted. The data were then organised and

stored as working data. Identifiers were removed from this working data; file names/code names were used, which included project name, date of interview, location, and version number. Only members of the research team had access to the data once collected and during data analysis. NVivo 12 plus software was used for effective and efficient data collection and management of the transcribed data.

A data record was created in Research Data JCU, which included information about the data used to reach the findings and the location of the master copy of the data used in the active stage of the research project. The physical data (consent forms) was stored in archive boxes onsite in Townsville. Raw digital data was stored in Research Data JCU. De-identifying data by removing names and applying code names cannot adequately de-identify the participants, given that recruitment was conducted across the limited population of the regional city of Townsville. Transcripts may still be identifiable, as recruitment was in a specific area and asked for detailed, specific life stories. Therefore, the research team determined the data to be too personal and distinctive for any data sharing with other researchers. The richness of data depends on the participants' trust in the interviewer, which leads participants to be vulnerable and open in sharing their life stories with the interviewer. The common demographic for this health condition included people between 40 to 70 years old who have not grown up sharing their life details on social media and thus may decline to participate if they do not feel their privacy is adequately protected by the data management protocol. This was consistent with the information provided in the Participation Information Sheet and James Cook University Human Research Ethics Committee (JCU HREC) approval. Due to the potential identification of participants by the distinctive sound of their voices, audio files were not archived in the Research Data Management at JCU.

3.8 Techniques to Enhance Trustworthiness

Various approaches were used to maintain the trustworthiness of this study. The researcher ensured prolonged and varied field experience by spending a significant amount of time with participants at the location of the interview. Spending time with the participants before commencing interviews helped to build rapport. Field notes were taken by the researcher. In anticipation of data collection, the researcher conducted practice interviews with colleagues. The sampling method was purposive, and there was no prior selection involved. Personal logs and memos were

kept. Consensus discussions about the codes were done between research team members.

3.9 Ethical Issues

Any research involving human beings must consider ethical principles of respect, justice, beneficence and research merit and integrity (National Health and Medical Research Council [NHMRC], 2023), which are explained in detail below.

3.9.1 Ethical Principles

3.9.1.1 Respect. The research project aligned with Australia's NHMRC guidelines for human research (NHMRC, 2023), and all the ethical principles were adhered to in conducting this research project. Participation in the study was voluntary, and no participants were coerced into participating; all knew that they could withdraw from the study during the data collection phase as well. The research study was designed with appropriate facilities and resources to ensure respect for all participants.

Participants were reminded that they would not be identified in any transcribed data or publications, as the researcher would be using codes when transcribing the interview recordings. Only members of the research team had access to the data once collected and during data analysis. It was decided by the research team members that data would not be shared for any future research to protect and respect the privacy of participants. This was consistent with the information provided in the Participation Information Sheet and JCU HREC application.

The Participant Information Sheet explained the research project in lay language that participants could understand. A consent form was included, and written consent was obtained before commencing interviews. Consent was confirmed orally before interviews and included at the start of the recording of interviews. The written consent and recording of oral consent helped to respect participant confidentiality and privacy, and assisted in omitting the requirement of any other witnesses for consenting (Nieswiadomy & Bailey, 2018).

3.9.1.2 Justice. The aim of the research and eligibility criteria for the study were explained in detail. Participation in the study was in accordance with the conditions of ethics approval from the James Cook University Human Research Ethics Committee. Even though the selection of participants was compromised due to the conditions of restricted locations for the interview (not at participants' homes), with ethical approval, all efforts were made to maintain a fair approach to recruitment. There was no exploitation of participants, and the welfare of participants was maintained. A fair approach was used to recruit participants, and there was no special consideration for age, culture/ethnicity, sex, location, or profession (NHMRC, 2023).

3.9.1.3 Beneficence. The researcher was mindful of the potential risks and distress to study participants, offset by the potential benefit of being heard and having their experience acknowledged (NHMRC, 2023). The discomforts encountered by the participants were inconvenience and loss of time. The likely benefit of the research outweighed this discomfort, and all possible measures were taken to eradicate or minimise the harm.

3.9.1.4 Research Merit and Integrity. The project was developed using appropriate methods to achieve the aims of the research proposal based on the study of literature, and contributed to the new knowledge to improve individual and social welfare (NHMRC, 2023). This project also improved the skills of the researcher. The respect for participants was not compromised during the study. The study was conducted using appropriate facilities and resources following the principles of research.

3.9.2 Ethical Approval

Approval to conduct this study was obtained from the JCU HREC (HREC reference number: H9144) in August 2023 and included in the appendices (Appendix E). An amendment application was submitted seeking approval to distribute flyers to community pharmacies, and other community organisations, including support groups, senior citizens' clubs, retirement villages, rotary markets, clubs, pulmonary rehabilitation centres and religious organisations, along with community care at Kirwan Health Campus to enhance recruitment and to finalise the project on time. Approval was granted in April 2024 to display flyers in the rest of the areas except

the community care at Kirwan Health Campus, as this falls under a different ethics committee. Please see the appendices for the amendment approval. (Appendix G).

3.9.3 Consent

The consenting process was guided by the NHMRC (2023) *National Statement on Ethical Conduct in Human Research* to ensure study participants were adequately informed and understood the research. Participation in the study was voluntary, and informed consent was obtained to participate in the study. Participants initiated contact with the researcher if they were interested in participating in the study.

At the screening phone call, the Participant Information Sheet was explained over the phone, and verbal consent was sought. A tentative appointment that was at one or two weeks in the future was scheduled, and an information sheet was forwarded to them via post or email. The Participant Information Sheet had information to reflect and protect the rights of participants about voluntary participation and the right to withdraw consent at any time. Potential participants had adequate time to consider their participation and to ask questions. Potential participants were contacted the day before the appointment to confirm their readiness to be interviewed. The consent form was signed before the interview, and a copy was given to the potential participants. Oral confirmation of consent was also sought and included at the start of the recording.

3.9.4 Confidentiality, Privacy, and Anonymity

NHMRC (2023) *National Statement on Ethical Conduct in Human Research* states that researchers should use methods to reduce identification of participants by collecting minimal information on participant characteristics, separation and separate storage of identifiers and contents and by separating the roles of data manager and data analyst (pp.34). The confidentiality and privacy of study participants were protected throughout this study. Participant confidentiality was maintained by deleting all the information that allowed participant identification. The participant identifiers, audio recordings and the interview transcript were stored separately.

The collected data was stored in cloud storage, hard drive and as hard copies to prevent any permanent data loss and was password-protected or encrypted. The

data was de-identified, and file names were used, which included the project name, date of interview, location, along with the version number. Only members of the research team had access to the data once collected and during data analysis. It was decided by the team that data would not be shared for any future research to protect and respect the privacy of participants. The data was de-identified, and a code was assigned to transcripts used in the thesis, articles and seminar presentations.

3.9.5 Risk Management

A risk assessment (see 3.9.5.4) with contingency plans was established at the beginning of the research. The risk assessment facilitated the timely identification and minimisation of risks. The risk assessment discussed possible risks to the participant, the researcher, and the project, along with the mitigation strategies and is unfolded in detail.

3.9.5.1 Risk to Participants. The accessibility of participants if they were hospitalised or the difficulties communicating with worsening symptoms was identified as a constraint. The possibility of physical and psychological discomfort and inconvenience to the participants was identified as a risk. Loss of time and loss of privacy were other risks to participants.

The researcher always confirmed with the participants that they had a COPD action plan for emergencies. The Participant Information Sheet included information about the project, potential risks, and benefits of participating in the project, and their right to withdraw from the study at any time in a language that participants could understand. The choice to stop the interview, have a rest and resume, or resume the interview at a later day was explained to participants before commencing interviews.

3.9.5.2 Risk to Researcher. Coverage of mobile phone service was crucial while doing fieldwork. Inclement weather and the location for conducting the interview were identified as a risk. Doing interviews at the participant's home was deemed as a risk to the researcher, and approval was not granted by the university HREC. Mutually agreed-upon locations like parks and libraries were chosen to do interviews. These locations were unfamiliar to the researcher, who had to visit the places before the interview to rule out any safety issues for both the interviewer and participants. The researcher always notified the advisory panel about the time and location of interviews and ensured the coverage of mobile phones while doing field work. Regular meetings with the advisory panel were conducted to discuss recruitment. The researcher conducted practice interviews with colleagues to improve interview skills and attended training to improve data analysis skills.

3.9.5.3 Risk to Project. Insufficient recruitment within a reasonable time, along with the skill of the researcher, were identified as risks to the project. The location selected for conducting interviews was a threat as it was mainly based on the participants' choice. Noisy surroundings and the presence of others potentially affected the interview process.

In the first phase of recruitment, the researcher contacted the Primary Health Network for support in facilitating the process of contacting general practices or medical centres to distribute the flyers. The practice managers of GP clinics, outpatient clinics, medical centres, a few general practitioners, and a respiratory physician were also contacted by the researcher for flyer distribution along with advertisements via social media accounts of the University. The practices were supportive in facilitating the process. To increase the rate of recruitment, an amendment was requested to expand recruitment in Apr 2024.

In the second phase of recruitment, the researcher contacted religious organisations and support groups to display the flyers. The researcher attended training and in-service to gain knowledge and self-upskill.

3.9.5.4 Risk Management Strategy

Potential Risk	Strategy
<i>Risk to Participants:</i>	
Experiencing discomfort during an interview	Pause the interview until the participant feels more comfortable. Resume at another time if the participant prefers.
Location of the interviews	Mutually agreeable place apart from home, as per the participant's choice. Noisy surroundings. Presence of others.
Coerced or pressured to participate.	Informed consent was obtained at the beginning of the interviews. Participation was voluntary, and they could withdraw or discontinue. The researcher always built a trusting relationship during interviews. Confidentiality and privacy were maintained by de-identifying data.
<i>Risk to researcher:</i>	
Inclement weather	Postpone the interview.
Unfamiliar location	Familiarise the surroundings. Contact the advisory team to notify the location. Coverage of mobile phones and other measures to ensure safety.
<i>Risk to the project:</i>	
Insufficient recruitment within a reasonable time	Snowball sampling. Data collection on nonworking days. Using technology Ethics amendment to expand recruitment.
Location of interview	Depends on the participant's choice. Noisy surroundings. Presence of others.
Skill of a novice researcher	Regular meetings with the advisory panel. Upskill by attending training.

3.10 Chapter Summary:

This chapter described the methodology and methods used to address the study's research question. It began with a clear statement of the research question and described the research elements, the participants, data collection, and data analysis methods. The following chapter will present the study findings, including a full description of the themes arising from the interview data. The final chapter will discuss the findings in relation to the literature and include the implications of the findings and recommendations for future research.

Chapter Four: Findings

4.1 Chapter Introduction

The previous chapter described the study's methodology and methods. The management of the data and ethical considerations of the study, along with the risks involved and risk management strategies, were also described in the previous chapter. This chapter presents the findings that emerged from this research study. The chapter commences with a detailed description of the participants, followed by the themes that emerged from the analysis of the interviews. Throughout this chapter, quotes from participants are used to support the analysis of the data and serve as a forerunner for discussions in the subsequent chapter.

4.2 Participants

Eleven participants were recruited and interviewed. All the participants were residing in the regional city of Townsville, Australia, at the time of data collection. Some of the participants had two or three hospitalisations for COPD since they were diagnosed. Five participants had COPD for more than five years, while three participants had COPD for approximately twenty years. Three participants were not definite about how long they had been living with COPD. The diagnosis of COPD was incidental for all the participants, either during hospitalisations for other diseases or via their general practitioners, because of ongoing symptoms. Demographic data were collected, including gender, marital status, cohabitation, and occupation (previous and current) of all participants. Table 4.1 provides characteristics of study participants, including their code, biological sex, and a brief description of participants.

Table 4.1*Characteristics of the Participants*

Code	Biological Sex	Brief Description of Participants
P1	Female	A middle older adult living alone had COPD for more than 5 years
P2	Female	A younger older adult living with spouse, had COPD for more than 5 years
P3	Female	A middle-aged adult living with the child had COPD for 20 years
P4	Male	A younger older adult living alone had COPD for more than 5 years
P5	Female	An oldest-old adult living with spouse, had COPD for 20 years
P6	Female	A middle older adult living with spouse, had COPD for 10 years
P7	Female	A middle older adult living alone, unsure of the duration of COPD
P8	Female	A middle older adult living with a dog had COPD for 10 years
P9	Female	A middle older adult living with the child had COPD for 20 years
P10	Female	A middle older adult living with dogs, unsure of the duration of COPD
P11	Male	A younger older adult living alone, unsure of duration of COPD

Notes: Middle-aged adult: 40 – 65 years old; A younger older adult: 65-74 years old; A middle older adult: 75-84 years old; An oldest -old adult: over 85 years old

Codes were assigned to participants to protect their identity and privacy in each of the interview transcripts. The study findings are supported by these interview transcripts, and the quotes can be found along with corresponding themes and subthemes throughout this chapter. A description of the demographic data is included in the following sections.

4.2.1 Age

The age of participants ranged from 55 to 87 years. One participant was in their 50s, one in their 60s, six in their 70s, and three others in their 80s.

4.2.2 Gender

There were nine female participants and two male participants, even though equal accessibility and opportunity were available for both men and women. The research team were mindful that better male representation would have strengthened the findings. Despite having multiple recruitment phases and equal opportunities, with time constraints for completing the project within the timeline and achieving data saturation, recruitment had to be stopped. Both male participants were 70 years old and were living alone. One of them had COPD for more than five years, and the other participant was unsure of the onset of COPD, as they had respiratory ailments since childhood.

4.2.3 Living arrangements

The living arrangements varied for each participant. Six participants were living alone, two of whom did have dog(s) living with them. Several participants lived with other family members who supported them throughout their disease. Three participants were living with their husband, another lived with their daughter, and another lived with their son. All participants except one were permanently living in Townsville, Australia. The participant, who was a temporary resident, spent their childhood in Australia but had spent the rest of their life outside Australia and returned to Australia for medical treatment.

4.2.4 Employment status

The previous or current employment status of the participants was also collected. All the participants were retired, two of whom had to retire due to their COPD illness. Three participants expressed that their previous occupation was a contributing factor for their COPD.

4.3 Themes

Analysis of the data revealed that the participants' realisation of the symptoms and challenges due to the disease evolved throughout their lives. This understanding and awareness of symptoms and challenges contributed to accepting the disease. The reaction to the disease varied for participants and evolved from negativity to a positive view. The process of self-realisation assisted them in discovering their strengths and weaknesses and enabled them to convert negative emotions and feelings into an optimistic approach to tackle the disease. This transformation included various approaches that empowered them to consider the disease as a part of their life. The approaches to address the disease were made smoother by accepting the disease, which altered their concepts about life. The realisation gave them a purpose to move forward in life and empowered them to make alterations in life. With this attitude and realisation, participants were able to utilise the support systems in managing their disease. The action plans articulated by participants, along with using assistive devices, facilitated their management of the symptoms of the disease. The themes and sub-themes that evolved from the analysis of data are illustrated in Figure 4.1. The themes and sub-themes, along with all included sub-sets, are elaborated further in the following sections.

Figure 4.1

The Themes and Sub-themes



Table 4.2*Themes, subthemes and subsets*

Themes	Sub-themes	Sub-sets
Theme 1: Realisation and Reaction	The Diagnosis/Realisation of Disease	COPD Diagnosis Hospitalisation Changes after hospitalisation Education about COPD
	Acknowledging the Disease	Symptom Awareness Self-Awareness Awareness of challenges Existing or Lack of Systems in Place Other causative factors Own negligence Smoking
	Reaction to Disease	Fear from breathlessness Effect of Disease Negativity Frustration Positive Outlook Being Active
Theme 2: Acceptance	-----	-----
Theme 3: Transformation and Empowerment	Adapting to the effects of disease through self- realisation	Insight into the disease or view Goal in life Advice for others
	Support from people	Involvement in support groups Support at home/services Role of general practitioners
Theme 4: Symptom Management	Action plan to manage the symptoms of the disease	Being active Approaches to manage symptoms

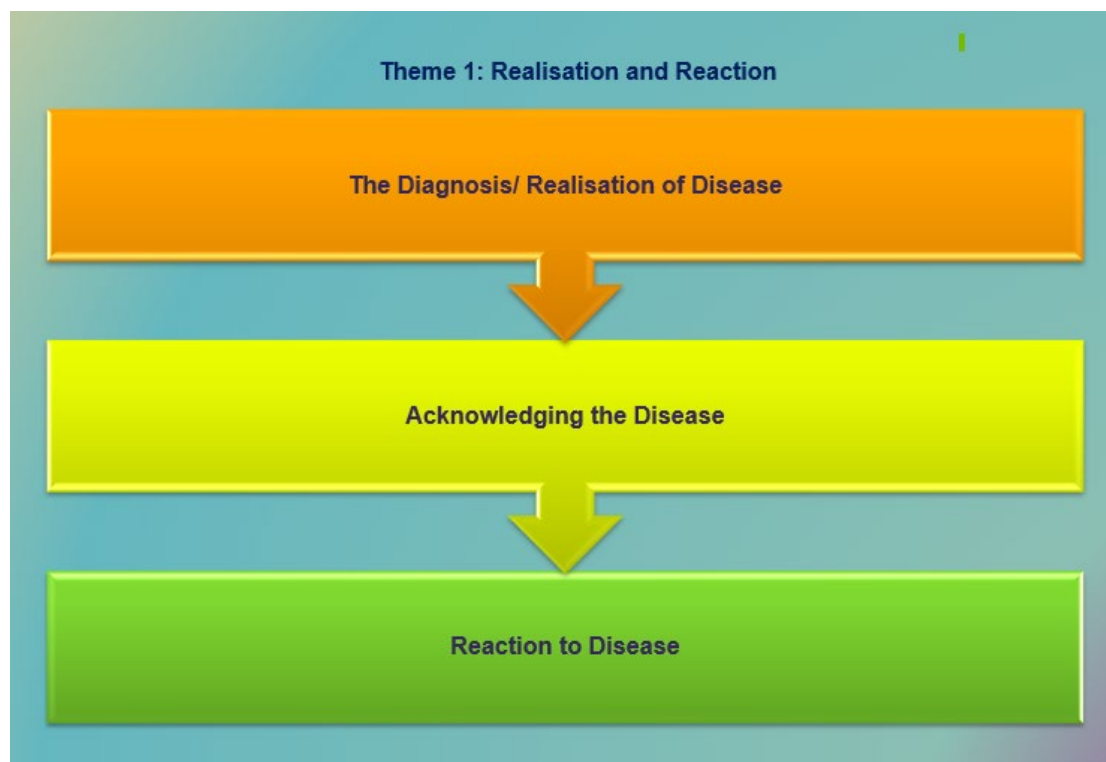
		Preventing infections Planning and pacing Awareness of worsening symptoms Effect of external factors
	Using assistive devices	Using inhalers to help with breathing Other devices to help with breathing Home modifications

4.3.1 Theme 1: Realisation and Reaction

The theme realisation and reaction incorporated the emerging awareness of participants about their disease and their reactions towards the disease. This awareness occurred when they received the diagnosis of COPD either during hospitalisation or from their general practitioners. During this journey, participants discovered self, the effects of the disease, challenges in their day-to-day lives, and how their negligence and other factors contributed to the disease. This awareness was reflected in the changes they made in their lives to manage the disease. Participants had mixed feelings towards the diagnosis: most participants expressed fear and other negative reactions, but eventually had a positive outlook, which was reflected in managing their disease. The sub-themes embodied in this theme are illustrated in Figure 4.2 and explained in detail in the following sections.

Figure 4.2

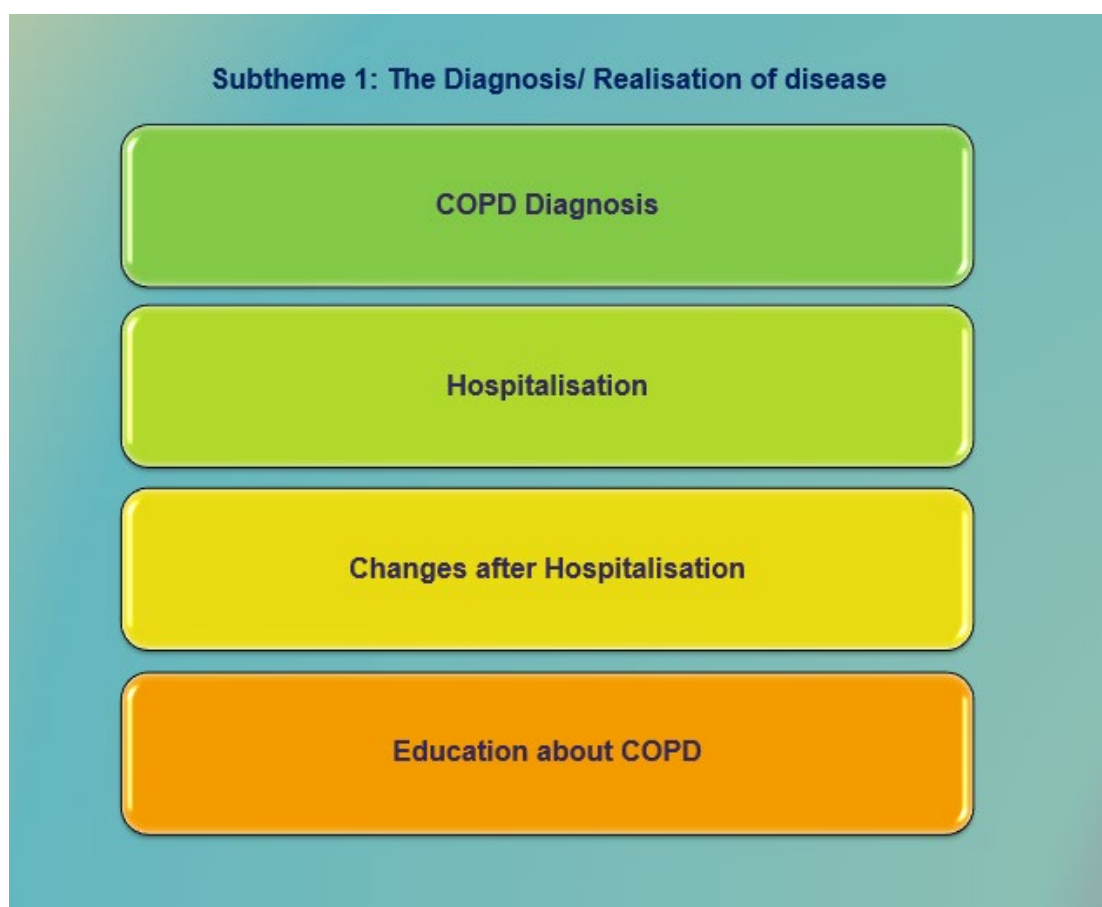
Sub-themes of Theme 1 – Realisation and Reaction



4.3.1.1 Sub-theme 1: The Diagnosis/ Realisation of Disease. The sub-theme details the diagnosis of COPD and how participants realised that they had COPD. This sub-theme also reflects the subsequent hospitalisations for treating the symptoms, changes that were made in their lives after hospitalisation, and any education they received regarding COPD, either during hospitalisation or later. The subsets incorporated in this sub-theme are illustrated in Figure 4.3 and described in the subsequent sections.

Figure 4.3

Subsets of Sub-theme 1: The Diagnosis/ Realisation of disease



4.3.1.1.1 COPD Diagnosis. ‘COPD diagnosis’ refers to how the diagnosis of COPD was made. The method of diagnosis varied for participants. For some participants, COPD diagnosis was an incidental finding during hospitalisation or for an occupational purpose, while others were diagnosed by their general practitioners because of ongoing symptoms. The following quotes reflect the mode of diagnosis.

“Well, it all seemed to come in at once that that [sic]. When I was diagnosed with cancer in 2019, they said I had COPD”. (P1)

“I had an operation that went terribly wrong. So I was...in intensive care for a fair while and on life support for a fair while. And I don’t know if it’s. I think it was. I’m sure it was the smoking and...maybe the operation had something to do with it, I ended up with a bad lung infection. And so I would, I would say, I’ve know I’ve had COPD for about 5 years”. (P2)

Some participants stated that they were diagnosed by their general practitioners after noticing symptoms like difficulty breathing or a cough.

"I think it was my comorbidities... ahh... because I was up to aa..155 kilos after my husband died and I walked in, and my doctor noticed my breathing and he put me on to the stress test and you know how they do your breathing ... and he said you got COPD". (P3)

"Through the doctors, one of the nurses did, did a breathing test and she said Ohh, you've got COPD". (P6)

For one of the participants, the diagnosis of COPD was an incidental finding while undergoing a pre-employment medical assessment.

"I was diagnosed with COPD for a while before that. You know. uumm..I had to go have a full medical done. For the job that I was doing. And the... when they did the... breathing tests all only call it made it, yes, I didn't pass. I failed miserably. And then they'd check me once. And they said, you know what you got probs. And my doctor found out that, she had x-rays done and of course you have two of them together, you have COPD and you probably getting a bit of emphysema". (P4)

4.3.1.1.2 Hospitalisation. The subset 'hospitalisation' details the hospitalisation of participants for treating COPD or related symptoms. Most of the participants had minimal episodes of admission for treating COPD or related symptoms. Mainly, they were admitted for treating respiratory infections, and that was at the beginning of the disease's diagnosis. The following quotes validate the details of hospitalisations.

"Yes and.. umm. the last month I've been good, but the two months before that I ended up in hospital twice and hospital to your home once. I got a. Pneumonia twice... And... will actually pneumonia three times. Once I had Corona ahh, COVID as well. So yeah, which has affected the breathing, yeah. It's just. Yeah". (P2)

"I've had two trips to hospital with shortness of breath". (P6)

In the latent phase, they realised and learned how to manage their symptoms and prevent hospitalisations, as is evident from the following quote.

"No, no. I'm not. I'll make sure that I nip it in the bud before it gets to that stage". (P3)

4.3.1.1.3 Changes after Hospitalisation. The subset 'changes after hospitalisation' reflects any changes that were made by participants after hospitalisation, which helped them to manage their symptoms and avoid readmissions. It is obvious from the excerpts that changes in medications assisted in managing their symptoms.

"Yes, but now they've got me on an antibiotic pill every day for the rest of my life". (P2)

"No, no. I think medication changed". (P5)

Apart from medications, other measures were taken by participants. They tried to slow down and use assistive devices.

" No, no. I, as I said, I'd just take it a bit easier in doing chores". (P6)

"Like we've got a stool in the shower, I've got a thing over the toilet. So, if I if I...I'm having one of the weak days, I can put my hands on the side and push myself up off the toilet". (P9)

4.3.1.1.4 Education about COPD. The subset 'education about COPD' portrays the education received by the participants about COPD or other educational activities they were involved in. Most of the participants denied having any formal education at the time of diagnosis; one participant was told to stop smoking, and this is evident from the following quotes.

"Nothing. Nothing. No. Just stop smoking. That was it".(P3)

"Ohh, I don't think so. No". (P4)

One participant mentioned that they received some information later from their general practitioners, while another participant was referred to the regional community facilities to take part in educational activities.

"I've got some later from my own GP And.. that's what I last had it, but I don't think I read it properly. You know... Yeah". (P4)

"I have gone to the so-called chest clinic at Kirwan. Now recently. ...a doctor suggested that I go to James Cook University health, and I started there". (P5)

One of the participants felt indifferent at the time of diagnosis but attended activities later, while another participant continued attending activities and meetings to improve their knowledge.

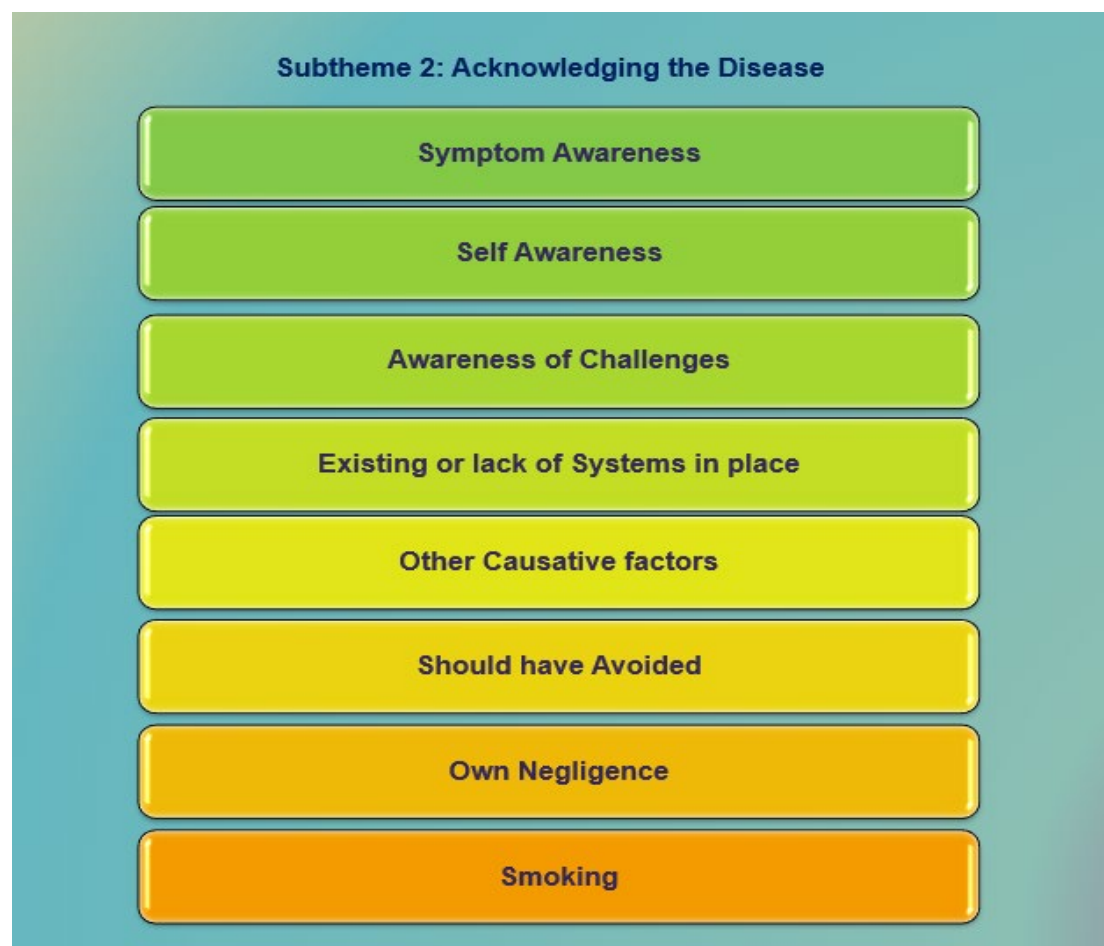
"I was a bit blasé of it all you know, don't know whether was through my gov or something, I went to the Kirwan Place. Yeah... We did we did an exercise programme for so many. You're only allowed to go so many weeks. And then". (P6)

"Aaaa ...I've always gone to whatever...meetings or like before this group even ...aaa...that there might be we we have an asthma foundation (pause) and then any guest speakers that I called, I always would attend and and I think I sort of learned a little bit by little bit".(P7)

4.3.1.2 Sub-theme 2: Acknowledging the Disease. The sub-theme 'acknowledging the disease' incorporates participants' awareness of the symptoms along with self-awareness and perception of challenges. This also led to the recognition of the causative factors for the disease, including smoking and their negligence, which participants felt they could have avoided. The importance of systems in place also played a part in this sub-theme. The subsets embodied in this sub-theme are illustrated in Figure 4.4 and are elaborated in the succeeding sections.

Figure 4.4

Subsets of Sub-theme 2: Acknowledging the Disease



4.3.1.2.1 Symptom Awareness. This subset details participants' awareness of the symptoms. Most of the participants did not notice any symptoms and used to do all activities without any difficulties at the beginning of their disease. They even recollected having no symptoms when they were smoking, but observed the symptoms when they stopped smoking.

"Well, I don't. I I don't know. I probably did but didn't take any notice. I didn't cough. I didn't cough with a smoke when I was smoking. I never coughed or I never had problems breathing. I used to walk the Strand. And I mean, the whole Townsville Strand every day, except Thursday I went to a gym". (P1)

"It's gonna sound stupid, but when I was smoking, I was fine. It's only when I gave up that I felt like I was getting short of breath". (P2)

Even though two of the participants had lung problems since childhood, all the participants perceived of their symptoms getting worse and the effects of these symptoms. They also found ways to manage these symptoms.

"Yeah, I've always...uumm.. had lung problems. And ...aaa.. as a child, I used to get a lot of bronchitis and I was taken into hospital when I was about...eight, I think it was Aaahhh..I was coughing a lot, wheezing. Yeah, and it it, you know, when I was walking, it was difficult. I had to stop and yeah..."(P10)

"I've had it all my life so. Sometimes it gets really bad, you know, and other times like now it's not so bad". (P11)

"So yes. I've gotta have my fans going. I don't bother about the air, but I've gotta have that movement".(P1)

"Aaaa... I've always had allergies. Ahh.. If if I don't, if I get a a bug, I go immediately to the doctor. And if I don't, I go down with a really bad bug and end up with pneumonia". (P5)

"Oh, yes, all the time. what positions to sleep in to get to sleep and if I find I'm I've moved in my sleep, I wake up coughing and have my ventolin aaa...it's all about breathing". (P7)

4.3.1.2.2 Self-Awareness. This sub-theme reflects the realisation of one's own feelings, emotions, strengths, challenges, weaknesses and mindsets which helped them to acknowledge the disease. It is evident that participants had awareness of their own strengths, weaknesses and emotions from the following quotes.

"I am very strong. OK. And I in my mind, you know". (P1)

"Yes, aahhh... I needed to talk to someone about, well, I think would be good. How to breathe again. you know, to teach you how to breathe again. What to do

if you're. Yeah. Umm. Well, as I said, I think it brings in anxiety and depression".(P2)

"Ohh I can get a bit stressed, and a bit upset at times". (P8)

Participants also understood how the disease affected their lives and the restrictions caused by the symptoms. They were aware of how to manage these symptoms and took measures to continue living normally.

"And aaa, Yeah then. I noticed this is COPD getting worse and it was getting worse and it..aa...really stopped me from.umm.. doing any sort of.aahh..anything I like to like, I used to like ride motorcycle, so I've still got the motorcycle, but I can't go riding. I don't play golf anymore. It's just little things. Every time you try to do something, you sort of run and short of breath and stuff. I used to be able to do a a lot walking around but Umm.. limited now I run out of steam sometimes. It's very hard.,,to push your wheeli walker and a trolley at the same time, yeah. And trying to get some fitness happening and happening and see if I can't expand this lungs, from carrying a bit of weight, which means I'm probably pushing on my diaphragm a bit, which is not helping it.we go the slower and we, we easily accomplish it". (P4)

"But because probably because of my age. I...aa..I have to act very quickly and if I, as I say, can't get into my own doctor. There was sometimes sometime just to be with somebody somehow and away from the environment. It helps yeah, just take you. That's why I go to the craft group. Because, It takes me away from everything else.You know, I I know that there's things that can do and things I can't do. there are things I can eat and drink and I can't happen. That's OK. I don't take don't eat things that I shouldn't eat and I don't drink things I can't drink. and I can cope and do what I have to do, I live with it. So that was when I realised just how bad it was. I think that was my realisation. That nothing was going to get any better and I'd better pull up my socks and live with it".(P5)

"I am more aware, and I don't exert myself as much as I would have, you know running around as much and as I say, when I'm doing a chore that keep gets me short of breath, I stop what positions to sleep in to get to sleep and if I find I'm I've moved in my sleep, I wake up coughing and have my ventolin aaa...it's all about breathing. is around my lungs, but I know how to manage it. Because I because I

can't do much active work. There is a lot,, because you need to know your limitations. I'm very aware of.. there..umm... There's some chairs. I can't sit in. It tends to get me around the bottom of the lungs and I cough". (P7)

"If I get puffed through the day, if I hurry anywhere, or lift anything heavy I get breathless. I keep saying to people give me a new set of lungs and you'll never catch me.uumm.. Yeah. So I there's a lot of things like that that I can't do anymore because it's just not safe. uumm..So there's not a problem with the oxygen going into the system. It's when it gets to my lungs. My lungs are so badly damaged that it can't be dispersed properly". (P9)

4.3.1.2.3 Awareness of Challenges. This subset portrays the challenges encountered by the participants in their daily lives. Household chores like cooking, cleaning, and hanging clothes were like a long-haul requiring them to slow down or to pause what they were doing. The feeling of 'every day is a challenge' is evident in their quotes.

"Pretty much all challenges. Yeah, pretty much most days..there will be... there will be challenges somewhere, yeah. And doing something in the garden or wanting to do something to garden and finding us a little bit dark..... I try and try to overcome take it slowly. We go a bit slower. We go the slower and we, we easily accomplish it...but yeah, it wouldn't be done in 10 minutes. We will be done in an hour. But then I still get the job done".(P4)

"I think there's challenges every day, yeah.... You just learn to live with what you have to. that's that's all there is to it. I found it very challenging walking to the clothesline some days". (P5)

The challenges were not only restricted to the household chores. Sometimes, participants found that walking, climbing steps, gardening, and even having intimate relationships were exacting. The symptoms also affected their concentration and often resulted in a tired feeling.

"The only or not the main thing, I still mow the yard and whipper snip, but I have to stop And uu.mm....making the bed I puff, a bit, hanging clothes on the line. I'll

puff a bit, but I'll just... Well, the basics as I say, you do something exertive, and yeah, that's a challenge". (P6)

"but I can garden. And because you just might garden for half an hour have half hour break. I get breathless bending over and weeding. I get breathless doing a lot of things. Ohh..well yes, you know you couldn't join the walking group. Yeah. So the challenges are not being able to do everything And the challenges are travelling aahhh... Yeah, I would. I would love. And and I been very personal. I couldn't have sex. because I just get breathless. It's hard to walk up to the dam". (P7)

"If I've had a busy day, I find it very tired and it's hard to concentrate and sometimes I stuff up when I'm cooking you know, but once I got the the mould and stuff in my lungs...I couldn't lift. I couldn't. I couldn't hurry. I couldn't walk any distance without assistance. Well, like I said, I can't lift anymore. I can't...I used to restore furniture and build furniture. I can't do that anymore because of the dust factor. Challenge to be able to get back, more to normal, do the things I used to be able to do and enjoy doing".(P9)

4.3.1.2.4 Existing or Lack of Systems in Place. Existing or lack of systems in place denotes the lack of enhanced medical care which participants felt could have affected their understanding and management of their disease.

"And I've never had an enhanced medical care like you do now. You know the care plans and things like that. I've never had a care plan for COPD done. But then you've seen my personality, and I tend to joke a lot of stuff off, and I think that GPs don't take me seriously half the time". (P3)

4.3.1.2.5 Other Causative Factors. The subset 'other causative factors' indicates the causes that participants believe could have led to their disease apart from smoking. This was mainly due to their occupation, leading to exposure to silica, dust, mould, and chemicals. They recalled not using any personal protective equipment during those times.

"And it was coming out of a quarry and going to a concrete bashing plant. So I was getting a good dose of silica dust on one side of it. And concrete paddle around the other side of it".(P4)

" I was a commercial cleaner. you never wore a mask, so you were inhaling all these chemicals. And when I moved into that unit, I kept getting chest infections all the time...and I could not understand why I was getting them all the time. the toilet, the bathroom and the kitchen, all the walls were black that had mould in there and that was the first anyone knew about it".(P9)

4.3.1.2 .6 Should Have Avoided. The subset 'should have avoided' portrays the practices or habits that participants thought they should have avoided. Smoking was a common habit, and they all regretted smoking in their life, but one had a different view.

Thinking back, is there anything that you could have done differently?

"Ohh yeah. I could have, when I saw the doctor first when he said you gotta stop smoking or you gotta get emphysema. That's when I should have taken the message and done something about it, and so said I will be alright". (P4)

"I honestly think I've done a good job". (P7)

It was also mentioned that the lack of protective equipment at work was another factor in instigating their symptoms and that their disease would have been avoided if they were informed appropriately. Interestingly, one person mentioned that leaving her husband should have avoided exposure to passive smoking and thus, COPD.

"Yeah. No one said it's an issue when I was working. In the quarry, and then..ahh... then going to the concrete plant. You never think of these things,

yeah very recently, the masks and hearing aids, and all that have come into...aahh..pollution with these queries and that and this time it should be done ages ago, but think about it". (P4)

" To prevent it, yeah, left my husband". (P8)

"Yeah, not being a commercial cleaner and not smoked. And not lived in a house that was full of mould and mildew, but until...until that house was vacant for those six weeks, nobody knew about the mould and mildew. Even the owner didn't know".(P9)

4.3.1.2.7 Own Negligence. Own negligence refers to one's own carelessness, which they felt could have contributed to their disease. This consisted of not being attentive to the health practitioners' advice.

"Ohh yeah. I could have, when I saw the doctor first when he said you gotta stop smoking or you gotta get emphysema. That's when I should have taken the message and done something about it, and so said I will be alright". (P4)

"Chris put me on that[medication] quite a while ago and I am very neglectful and didn't use it for a long time. And like I said, I neglected it for a long time". (P8)

4.3.1.2.8 Smoking. The subset 'smoking' refers to the smoking habits of the participants. Out of 11 participants, six were smokers and gave up smoking eventually after the diagnosis of their disease. It was never explored why participants did not stop smoking soon after the diagnosis. The researcher was collecting data on self-care interventions, not smoking habits, and this was an incidental revelation made by participants. Another two participants were affected by passive smoking, and the other three never smoked in their lives.

" I was a smoker. I gave up, about 5 1/2 years ago". (P2)

"Easy thing you can do is smoke cigarettes. Yeah, even though I was a smoker, I used to continuously smoke".(P4)

“So, say you know, it's 40...40 to 45 years. I've lived in cigarette smoke and thick cigarette...thick cigarette smoke”. (P11)

4.3.1.3 Sub-theme 3: Reaction to Disease. The sub-theme ‘reaction to the disease’ includes the responses of participants to the disease and varied among the participants. Even though most of the participants were apprehensive at the beginning and had negative thoughts, they were able to overcome those emotions and became optimistic later in their lives. The subsets include fear of breathlessness, the effect of disease, negativity, frustration, being active, and a positive outlook, and are laid out in Figure 4.5 and narrated in the sections below.

Figure 4.5

Subsets of Sub-theme 3: Reaction to Disease



4.3.1.3.1 Fear from Breathlessness. This subset reflects the fear of participants caused by breathlessness. A few of the participants expressed the “thought of death “or “falling down or collapsing” because of breathlessness, and the following quotes affirm this.

“I thought I was going to die. I could not breathe, right. I could not breathe. I had to ring my girlfriend”.(P1)

“I do have fear. Umm. At times, it's not always. But at times I worry. When I can't breathe, I will fall down and just collapse. That scares me a bit. Umm.. Yeah, I think, yeah. I think that's my, that's my big fear”.(P2)

“umm.. It is always concerning, not being able to function properly, like my breathing gets really bad. and I really feel the fact is I'm gonna die, but I do feel it like that and sometimes it kills me. I am gonna die, natural bothers than old age”.(P4)

“Scary, scary times and I've even been told to go where different climate. Yess, just sort your lungs closing up and not having help at hand, but I have this. You know, it's scary when you can't breathe”.(P7)

4.3.1.3.2 Effect of Disease. The effects caused by the disease are reflected by this subset. The effects varied for participants, from cough to shortness of breath, and were sequential for some.

“Umm.. So yae shortness of breath. The coughing. Ahh..which causes anxiety, which doesn't help with the breathing either. It's a vicious circle.Umm. Well, as I said, I think it brings in anxiety and depression. It used to. It used to. I had to get help. I went to...umm. I spent six weeks at the Townsville Private Hospital, yeah. I wasn't didn't want to get out of bed. I wasn't leaving the house. I was staying at home, and I was sleeping all lot. Umm. yeah, up to 16 hours a day I would have said I slept”.(P2)

The effects of the disease affected their activities, and the participants had to stop all those activities they used to enjoy.

"anything I like to like, I used to like ride motorcycle, so. I've still got the motorcycle, but I can't go riding. I don't play golf anymore. It's just little things. Every time you try to do something; you sort of run and short of breath and stuff. And I got, where I used to be able to do a a lot walking around... Umm... limited now and I find that I managed to do my shopping in Woolworths. but the time is coming now, so I'm gonna need...uumm..umm.. helper you know. Ohh then I'm happy now and then. because I I do have a lot of depression from it. and...uumm...consumed a lot of alcohol...uumm..smoked, smoked lot of cigarettes, smoking marijuana and yeah, really sort of sent me pleasantly, unpleasantly I should say, depressed. And I ended up in the Townsville private clinics. And there is my life has changed a bit, because I used to go out a lot... and so at night going to local and having a beer and yeah. making a meal in there. uuhh..Now I'm more inclined to want to...to stay home and...uummm. just live quietly". (P4)

"What changes mygoodness me.... .aahhh...Well, I used to play tennis. and I had to stop I can't. I couldn't do that. Aahh... I tried to keep very fit but it's very hard. You can't walk upstairs. You can't walk up hills. Some exercises you cannot do. You know, it's not, I I do exercise, but it's not... They're things that I find very difficult if I have to go somewhere and I have to walk more than one short, or the stairs, that's the end of it. And I I can't even remember how I got over it. I I remember being on my own, not being able to breathe. And now I recognise that and have for quite a lot of years.It's one thing that I I get a bit upset about, yeah".(P5)

"Oh, yes. Aaa..Well... I I can't do anything active".(P7)

4.3.1.3.3 Negativity. This subset incorporates the negative thoughts or adversity generated by the disease. Participants not only felt anxious and depressed but also felt worried and debilitated. The following quotes reflect the adversity that was experienced by participants.

"As I said, I think it brings in anxiety and depression, But at times I worry. When I can't breathe, I will fall down and just collapse". (P2)

" Ohh then I'm happy now and then. because I I do have a lot of depression from it. Now I'm more inclined to want to...to stay home and...uummm.. just live quietly uhhaa.. Not very good. It does limit you..."(P4)

"That's very debilitating for me".(P5)

"That's horrible.Yeah".(P11)

4.3.1.3.4 Frustration. Participants felt annoyed or irritable from shortness of breath or cough. This was mainly because they were not able to do what they wanted to do, and is evident from the following quotes.

"Hated it, of course. Aaahhh... I was very house proud. And now, my house is still clean to anyone else, but not to me. So I get my brain wants to do things, and my eyes want to do things, but my body won't let me do it. So I get a bit very frustrated, you know". (P2)

"Frustrated. Because you can't do what you wanna do, you you know. You have to pace yourself. Ahh..But it is frustrating at home. It frustrates me". (P3)

"I get very frustrated when I can't,can't do the things I want to do that I you know, I find I'm. I'm getting more and more shortness of breath".(P5)

"Finding that much of a problem it it's it's the cough that causes my, you know, my ... most of my frustration, yeah".(P10)

4.3.1.3.5 Positive outlook. All the participants eventually managed to conquer their negative thoughts and emotions and acknowledged their disease. The subset 'positive outlook' reveals the optimism of the participants, which evolved throughout their disease and is apparent from the following quotes.

"I think you've got to accept it. Yeah. And if you have to adjust life, just adjust life to suit. There's there's only one person in the world that knows you, and that's you. You've got to do things for yourself first". (P1)

"Oh.. just... I have an attitude of, well, you know what? You've got to just get on with it and where there's a will, there's a way to. Get around.I'll just wake up every morning and.... Put on a happy face and let's go.Oh..I found out my father, birth father... before I was adopted died from lung cancer and I went great.. and I got COPD. And then I got out of that negative mindset and went. You're not him. OK. You've got his 10 eggs, but you're not him. You're good.Oh, hell yeah. Yeah, positive mindset. And I mean that's what got me through the cancer. That's what gets me through every day with my osteoarthritis. Umm.. A lot of things. Yeah.I don't like labels.Yeah. Yeah. Where there's will, there's a way,You'll always. You always want a way to do something if you really want to do it". (P3)

" It's no good sitting down and you know, saying I can't do this and I can't do that. Who's gonna do it if you don't. No, no, I think it's just part of it and. You just have to live with it". (P5)

"After that, and I must stay strong, you just learn to cope with whatever you've got. I don't think about it. And it's a reason for getting out of bed and something to look forward. Yeah. But medications getting better and better. And because I'm so active. aaa I think that helps cause and how it's so So don't stop and then my neighbour, one of my neighbours, says. Uh-huh. Oh, you know .. Lot of 81-year-olds won't be walking the block with their dog. That I'm going to school and, you know,aa.. gives me hope to think". (P7)

4.3.1.3.6 Being active. This subset denotes the measures that participants used to overcome the effects of the disease. Being active helped them to overcome or tackle the disease efficiently. Participants involved themselves in various activities.

"There was sometimes sometime just to be with somebody somehow and away from the environment. Yeah, just take you. That's why I go to the craft group, a different group of people all together. And this it was my craft". (P5)

"I attend a school every week with the dog. I have a story dog. ,And I mean, I'm giving back what I can't do...as volunteering and lots of things I can do. That because I can still drive, I can take a dog on a lead and I can take it to school. And there's a lot of preparation goes into that. Yeah, And I knit. Because(P7)

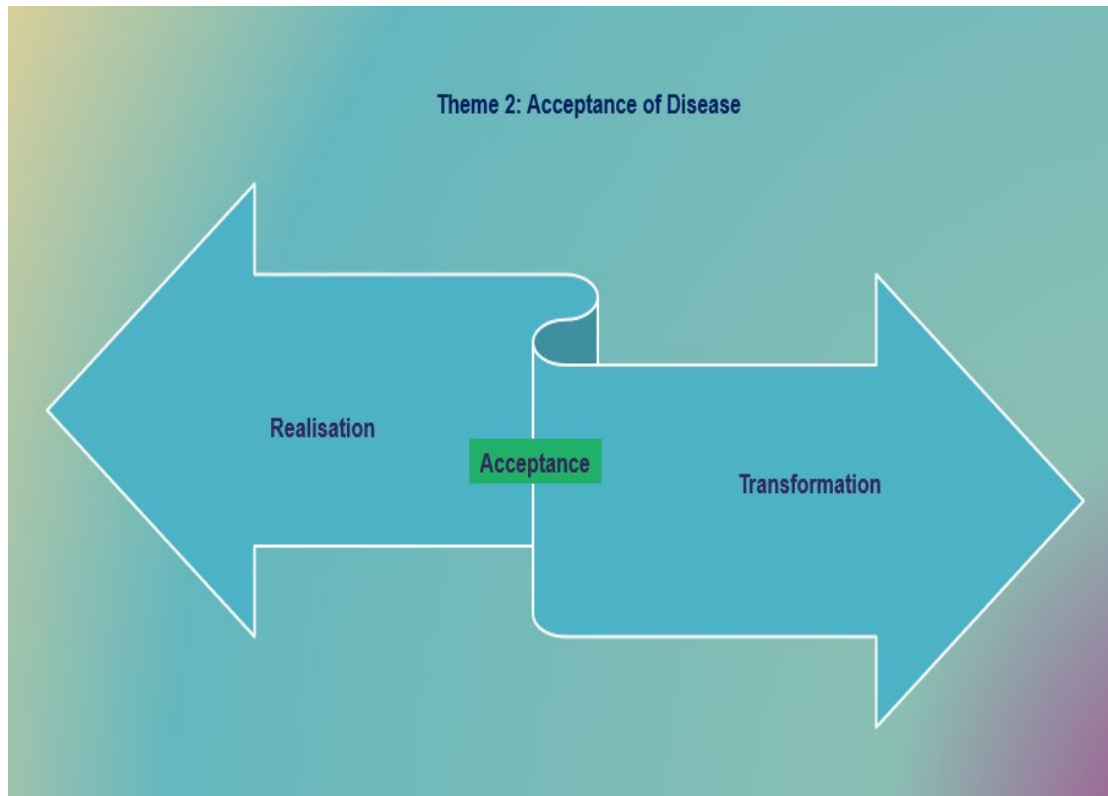
"I've got chooks so I I have to go down and feed the chooks and I do up chook food from fruit and vegetables. I cut up and I I walk unaided down to the chook pen... to feed them. And I've got 4 burkes parrots. And I feed them and clean their cage out. I was getting podiatry done but I do it myself now. I do all sorts of those. I go shopping for this girlfriend of mine who's worse off than I am. I called today. I was the first time I called boy here. I called bingo. FRF is four old fats. It's four of us...umm... Two of us are in our eighties and two in their late 70s... And we go out for lunch once a fortnight... Yeah. That's a good day out. And then on Tuesdays I go out with some friends and the six of us play poker. And we take it in turns to cater for lunch. Yeah. I keep out of mischiefs, keeps me off the streets". (P9)

4.3.2. Theme 2: Acceptance of disease

The theme 'acceptance of disease' portrays a phase of transition from the participants' awareness to their transformation. This transitional phase enabled participants to accept the disease, leading to an alteration in their concept and being realistic about the disease. The realisation that nothing is going to get any better gave them a purpose to move forward in life.

Figure 4.6

Theme 2: Acceptance of Disease



It is evident that participants realised that they could not do anything about the disease. They were aware of their illness and the limitations that came with it. It was also noted that they considered their disease as part of life. The following quotes reflect the acceptance of the disease by participants.

"There's nothing I can do about it, so I carry on living. I just carry on".(P1)

"That nothing was going to get any better and I'd better pull up my socks and live with it".(P5)

"It's just a part of my life now". (P8)

"Got no choice". (P9)

"You know I cope with it. Yeah, I just put up with it. You know". (P10)

They also welcomed the disease and planned their life accordingly. Participants also realised that they must make some lifestyle changes to manage the disease.

"I might need to make a few lifestyle changes and a few adjustments, but I can do this. I can manage this. Is that what I mean by don't and some people are diagnosed with an illness, and they sit in it. Don't do that...accept it and move forward". (P3)

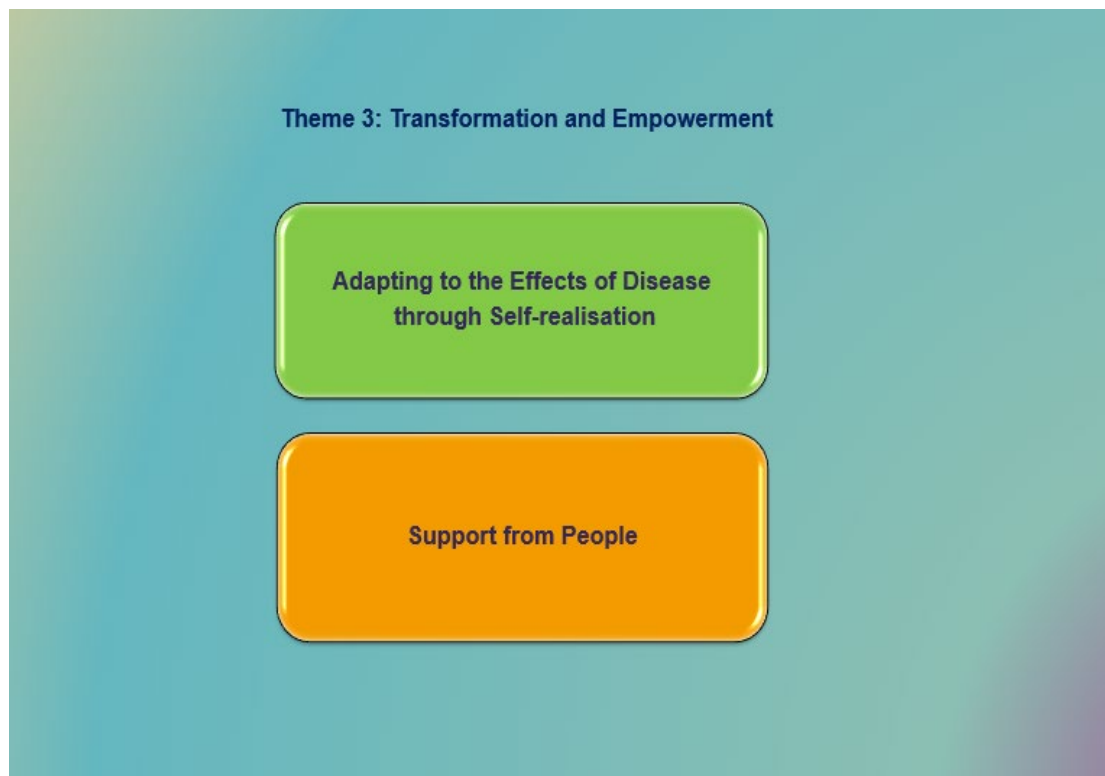
"No, I just planned my day. It's actually a reason for getting about ...if you plan your day". (P7)

4.3.3. Theme 3: Transformation and Empowerment

The theme 'transformation and empowerment' represents all the alterations made by the participants to master the effects of disease in their lives. The realisation of their strengths and weaknesses, along with the challenges in their life, led them to adjust to the disease. An important facet of this transformation and empowerment is evident in the goal of participants. These goals also encouraged them to become better versions of themselves and enabled them to provide advice to others. The impact of the support system was also seen as crucial and gave them the endurance to prevail over the disease. The sub-themes embodied in the theme are illustrated in Figure 4.7 and explained in detail in the following sections.

Figure 4.7

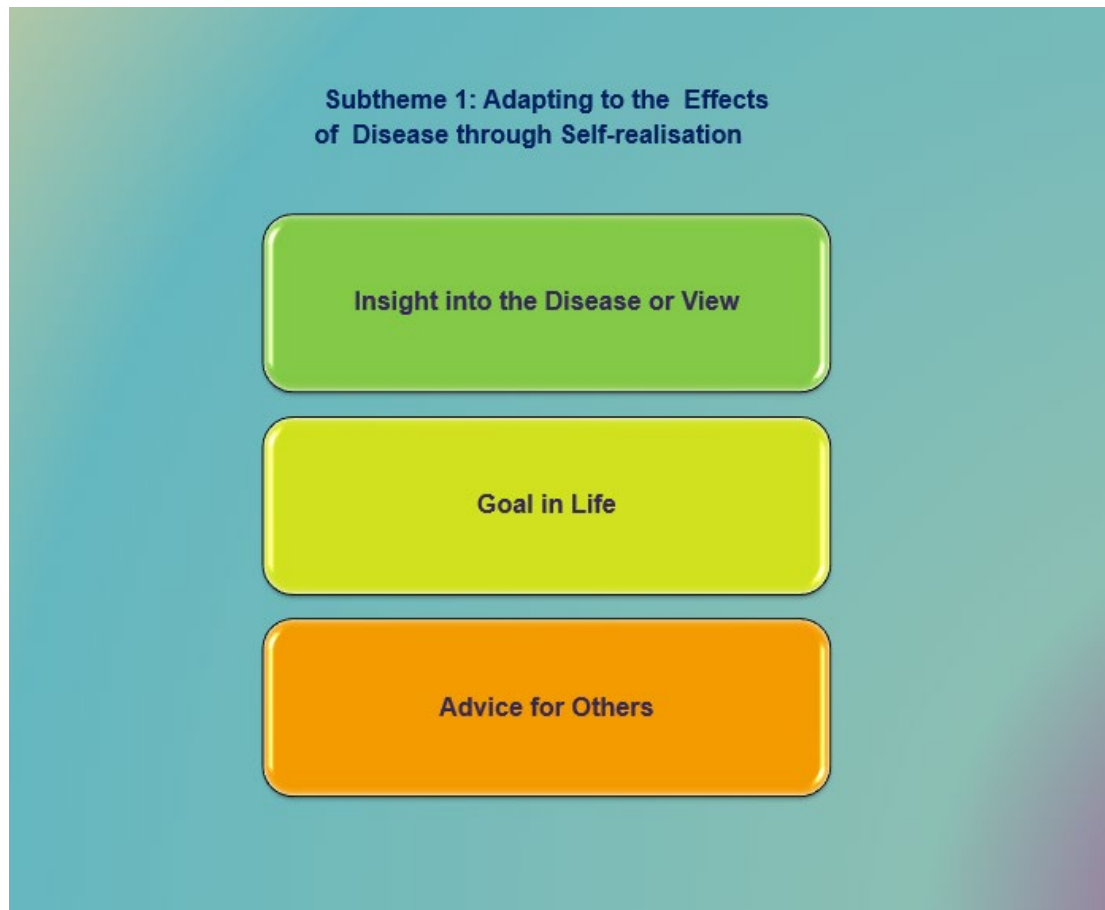
Theme 3: Transformation and Empowerment



4.3.3.1 Sub-theme 1: Adapting to the Effects of Disease through Self-realisation. The understanding of the disease process and self-awareness guided them in accepting that the disease is permanent and eventually lead to adjusting to life to overcome the effects. This understanding motivated them to change their disease view and to formulate goals in life. The subsets embodied in this sub-theme are illustrated in Figure 4.8 and are elaborated in the subsequent parts.

Figure 4.8

Subsets of Sub-theme 1: Adapting to the Effects of Disease through Self-realisation



4.3.3.1.1 Insight into Disease or View. It is evident that the perception about the disease changed as the participants accepted the disease into their lives. Their view about life also changed, and this is evident from the following quotes. They understood that there was nothing they could do about it and appeared grateful for being alive.

"That's life. There's nothing I can do about it, so I carry on living. I don't have any feelings. No, no. Yes, there is actually. I think it's good to wake up in the morning because at least, I'm still alive. I think you've got to accept it. Yeah. And if you have to adjust life, just adjust life to suit. There's there's only one person in the world that knows you, and that's you. You've got to do things for yourself first... I think that you've gotta be gotta, you've got to be strong, got to know your own

body. I if every time anybody gives me any medication like if it's a breather, I've felt like it. Then I look it up to see what it's got in it. If it's something that's going to affect another part of my life".(P1)

"And the medications of pain because you have to take be preventative every day and then you gotta have your inhaler next to you all the time, just in case. And so it's very frustrating. It's limiting. But. I don't think you know what you've got. It just deal with it. I've had it. I've had a bad chest since I was a baby. Little I remember missing school because of bad chest as a child. So that's been something that's been with me for 50 years. So, I should have bet that that I wouldn't be here because I'm stubborn and I have that positive concept that's not gonna happen...". (P3)

Participants learned to live with their disease and accepted it as a part of their lives. One participant mentioned feeling happy as long as they can breathe, while another person considered the disease a punishment.

"Being a smoker, that's your punishment, you know? Get on with it. That's punishment for smoking. You're a woman. You have to cope, don't you?" (P6)

"I must stay strong. I forget, I I don't... I don't dwell on it. I don't... I don't feel sorry for myself. No Yeah, as long as I can breathe. And I'm not just fighting about that, so sounds like, ohh you'll keep myself busy. I don't sit at home and cry on it".(P7)

"uummm. And just...just live with it. I've got it. It's not the only thing I've got. So you know, just get on with it, you know". (P10)

" I mean. I've. ..got no option. I've had it all my life virtually, but it since it's got bad, it's it's difficult. Yeah, makes life difficult. But at the moment I'm alright".(P11)

4.3.3.1.2 Goal in Life. Participants accepted the disease as a part of their life, felt motivated and formulated goals. This attitude is seen in the excerpts below.

"I really want to graduate and get back into the workforce. And be able to manage it to a point that. I know because of my mobility issues, it shouldn't be a barrier, but in outreach. Like when I went with the home. With the Red Cross here in downtown. A lot of us walking. In the parks and gardens the boat ramps, I'd get out of breath. So my goal is to be able to work in a place that allows me to be completely mobile".(P3)

"To stay healthy. I only want to live if I can look after myself. I don't want to die but I don't want to be looked after". (P8)

"Important goal. Get a new set of lungs. The thing is, when you get to my age, they'd rather give a new set of lungs to a younger person than someone whose life is really over anyway. So I just, you know, do the best of I can... what I've got". (P9)

4.3.3.1.3 Advice for Others. From their own experiences, participants knew what to avoid in managing the disease appropriately. The subset 'advice for others' displays the lessons that participants learned, and they thought would help others. This included stopping smoking, living in a dust-free area, using assistive devices, and taking medications appropriately. Participants also mentioned having a change in their mindset and being positive, along with doing activities at a reasonable pace to manage the disease.

"Well, first thing will be give up smoking. Make sure your house is clean and dust free. Yeah, and and try and live life normally as much as you can. There's no, no need, no. You sitting down feeling sorry for yourself because it's not gonna work". (P1)

"Don't be your diagnosis. Don't be. Oh, no. I've got COPD now and get all negative mindset and don't allow it to consume your life. Acknowledge you've got it... Is that what I mean by don't and some people are diagnosed with an illness, and they sit in it, but be mindful and be reasonable too. Don't put yourself at risk or anything like that but just don't get that diagnosis and sit in it and go. That's it. My life's over. That's COPD. All my life over that's cancer. No. Don't do it. Keep a positive mental outlook and nip everything in the bud before it gets too severe. Don't be a hero and go. I can ride this out. Because you want to I I used to do

that at the start, but I'll be right. It's cold. it's, it's blue. And as I've gotten older, I'm even more mindful to get in there early. Because my body is this like watch this. Acknowledge it and be respectful of it, but like.yeah...as you said, move forward with it and if you can get support. Go for it". (P3)

"To go with your body and then don't push yourself. But just try and do the most that you can and not give in because you know, some people, they just say ohh can't do that cause I've got some such and such. But I am, like go forward all our final alternatives". (P7)

"Well, you've gotta do everything in moderation. Because if if and I've done it a few times, I do it actually a bit over. A week ago, I was feeling really good on the weekend, and I stuck into all these jobs that made it doing and Monday morning I was flat out getting out of bed. You know, even if you're starting to feel good, still do everything in moderation because you know, it just knocks your feet out from under you if you don't. And The thing is, they've gotta. They've gotta listen to their body. And be aware of what medications do work for them and don't work for them". (P8)

4.3.3.2 Sub-theme 2: Support from People. The sub-theme 'support from people' consisted of all the support systems that participants relied on to manage their disease. This included support groups, support people at home and general practitioners. The subsets embodied in this sub-theme are illustrated in Figure 4.9 and are elaborated in the subsequent parts.

Figure 4.9

Subsets of Sub-theme 2: Support from People



4.3.3.2.1 Involvement in Support Groups. This subset denotes participants' awareness of or involvement in support groups for COPD. Only one participant was aware of the local support group for lung disease and did not find it beneficial. It was mentioned that it would be beneficial if there were a support group for COPD.

"I didn't know there was any COPD support groups; there was a a group called Breathe Easy. But I didn't find them any good for me. It would be good if there was a support group out there for COPD". (P2)

4.3.3.2.2 Support at Home /Services. This subset reports the support that participants received at home with household chores, shopping and so on. The support varied for participants and depended on their marital status, cohabitation, and caregiver relationship. Some participants depended on their family or friends, while others had hired services.

"Only my husband. My husband does a lot, like he helps me with the dinner. He helps me to hang out the washing and things like that". (P2)

"I have nurses coming in during the day. I have cleaners coming to do the cleaning. When I swim, my neighbour who is a nurse sister say alright, you are going to hospital and call the ambulance, and they put me in nine times and they then they put me in Med Ward one". (P4)

"Not at home, no, no. For cleaning. Yes, I get help. There's a firm here called hello to you that deliver fresh food. It's not frozen. So I do get some from them. Yes, the other thing that happens is on every second Monday is we have a support person comes".(P5)

"No, but I do have aged care... that comes and helps. uummm. Cleaning. ..gardening...uumm I go to the podiatry. I go to an osteopath. Uummm..And then I have aaa... Social support lady, it's called. She comes in for two hours, twice a week. And she just helps me with whatever I need. You know, if I need anything but onions or veggies cut up, she do that". (P10)

4.3.3.2.2.1 Caregiver. This denotes the caregiving relationship of participants. Five participants mentioned that they still care for their family members, but interestingly, one participant mentioned their experience of being cared for by their dog.

"Problem was that...my husband was ill and I wasn't well. And I found I could not do [attend the training program at JCU] two or three times a week. And keep getting him to his appointment. And I couldn't cope with it". (P5)

"Ohh run, I've gotta disable son that I'm...aa.. I don't have him at home full time.

But he does come home one night a week, which is tonight. And but I'm always over at his, where he lives just making sure he's being looked after". (P6)

"I do all your cleaning and cooking and everything and my daughter's. My daughter suffers from panic attacks. So I teach her all the time". (P8)

"My daughter and I share it, but I because she's working long hours, she leaves at quarter past seven in the morning and gets home at quarter to seven at night. So I do most of the cooking".(P9)

"Sometimes it's worse, you know ...when I'm doing things in the garden, I do get breathless, but then I've got this puppy dog who's 18 months old and he is... So tuned in to me that...uummm.. The other day I was out..aa.. using a blower. And I did get out of breath doing that and I and went back and... so I stood up and went like that [moved to the side] couple of times and then he came and stood in front of me and started, you know, yakking at me. And I said, come on out the way. I've just got this. And every time I moved there; he stood in front of me He stood in front... unbelievable. So I said alright, I'll go and sit down. So I turned around, he followed me. I sat down. He jumped up on me, like, gave me a big lick on the cheek and disappeared. Ohh, so he's very much in tuned when I need to rest. That's good. That's a dog looking after you very well."(P10)

4.3.3.2.3 Role of General Practitioners. The role of general practitioners was crucial in participants' diagnosis, treatment, and management of COPD. It was noted that participants had varying experiences with the general practitioners. The diagnosis was made mainly by the general practitioners, but at times, not much information was provided regarding the disease, or the disease was not managed properly.

"Yeah. And then, ahh when I was in my 30s. And they said Ohh, you've got COPD, and I went, that's nice. What's that? Like something like that, OK, whether the medicine back then, medical back then didn't know too much about COPD or what, I don't know. But I was asthmatic. But then you've seen my personality, and I tend to joke a lot of stuff off, and I think that GPs don't take me seriously half the time".(P3)

"Like I said, the doctor when he wrote the last script out, he put it that I have it every night and that doesn't work because without that, having puffer of a morning. I I'm relying on this too much and taking it too often. If I had waited for the doctors, I would have been dead years ago. So, I changed doctors". (P9)

"Well, one of the problems I've got, and I get angry with the doctors... I know what the problem is and they don't listen to me. That's my nose. It's all those sinuses I want to get something done to my sinuses and you know what they say aaahh..you just gotta live with it. But it's causing all the phlegm on my chest". (P11)

One participant was very confident with her general practitioner but had difficulties when she had to approach other general practitioners. It is evident that her general practitioner was very supportive, and the participant had confidence in managing her disease.

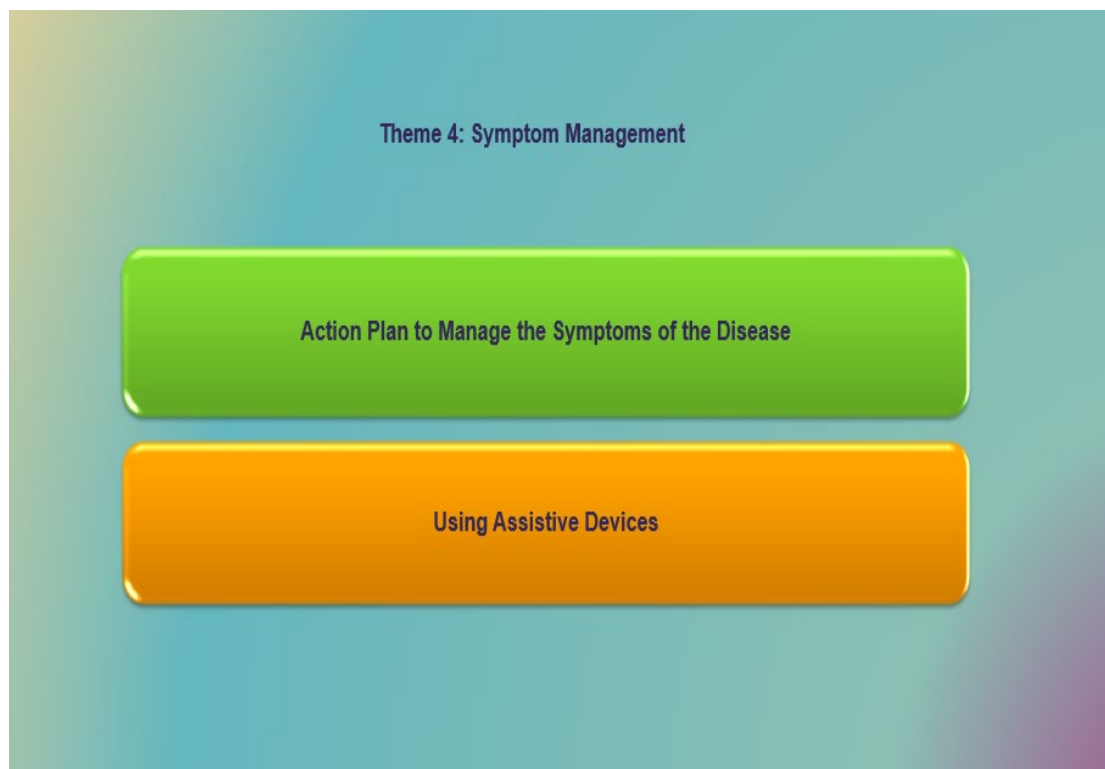
"Uh. That...if a doctor, if I can't get into my own doctor. The doctors are very, very good. I'm not knocking doctors. They're marvellous. They don't understand that they have to give you hard medication, straight up. And while she was such a, she's such such a lovely doctor. My doctor was on leave, and I got this bug. I got to get antibiotics. but you have to have the cortisone to knock it as well. And I didn't get them. And it wasn't till my own doctor came back and she straight away put me on cortisone. But because probably because of my age. I...aa..I have to act very quickly and if I, as I say, can't get into my own doctor. They don't like you're telling them that you must have this and you must have that. Yeah, I do. I know how to manage it. And. And my Doctor Who, you know Uumm.. she knows that I know how to manage it. And and I don't go to the doctor, unless I have to be. I think I was very fortunate. to have the doctor I've got And have her insight You know, I think that the reason I I'm as good or not good or my cope as well as I do is because I've got confidence in that doctor and I know that she supports me And I I know that I can talk to her. And Yeah, that's the thing that actually keeps me going". (P5)

4.3.4. Theme 4: Symptom Management

The theme of symptom management describes the strategies that participants used to manage their disease. These strategies comprised the action plans to manage symptoms of the disease and the use of assistive devices. The sub-themes incorporated in this theme are displayed in Figure 4.10 and explained in subsequent sections.

Figure 4.10

Theme 4: Symptom Management

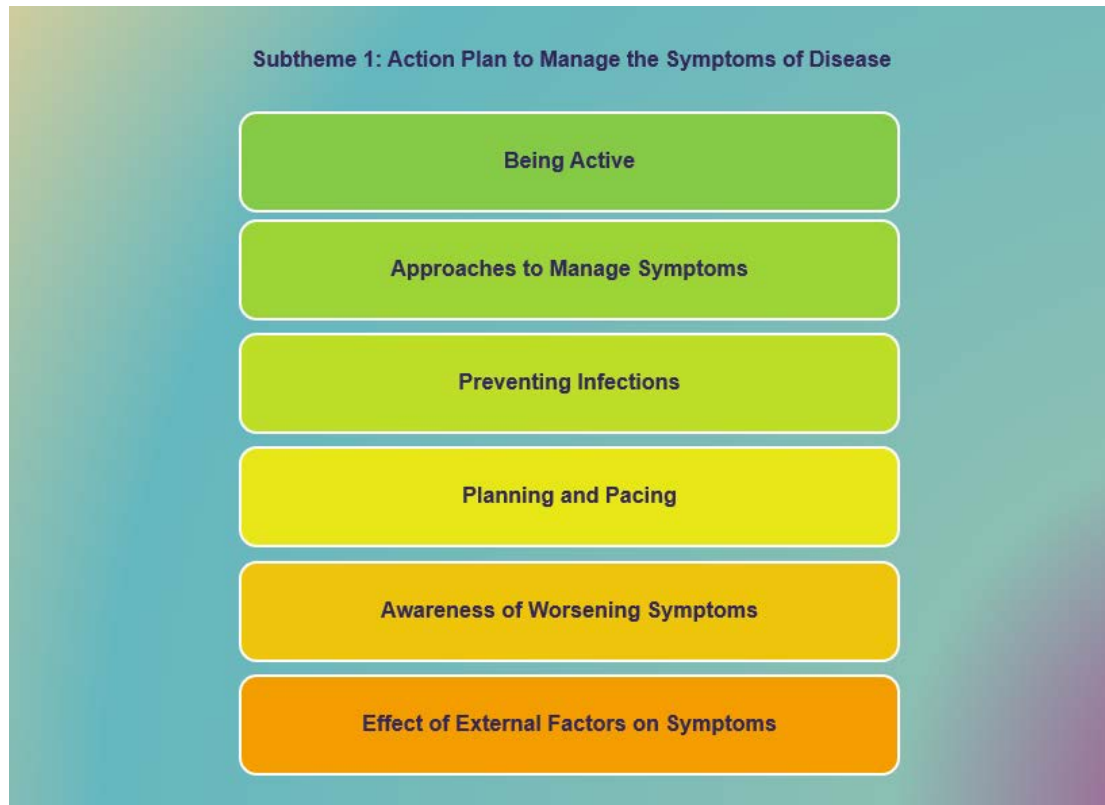


4.3.4.1 Sub-theme 1: Action Plan to Manage the Symptoms of Disease.

The sub-theme Action plan to manage symptoms of the disease comprised various practices that participants thought beneficial in managing their disease. The subsets embodied in this sub-theme are illustrated in Figure 4.11 and are elaborated in the subsequent parts.

Figure 4.11

Subsets of Sub-theme 1: Action Plan to Manage the Symptoms of Disease



4.3.4.1.1 Being Active. Being active was one of the measures participants used to manage their disease. One participant mentioned doing one outside activity per day, while another person felt this helped her to get away from the usual environment.

“No, I don’t think so. Just rest at my supposed. Ummm, I umm.. I try and just do one thing a day. Outside of the house. I just try and do one activity a day outside. I’m going to that exercise Physiology twice a week at the moment”. (P2)

“There was sometimes sometime just to be with somebody somehow and away from the environment. Yeah, just take you. That’s why I go to the craft group. Different group of people all together. And this it was my craft”. (P5)

Participants also found that doing voluntary activities and being involved in different clubs were beneficial to keep them active. They also found joy in helping others. The act of giving back to the community was evident. Volunteering also helped them to connect with others and use their time wisely to help others. Along with keeping them active, giving back to the community was an uplifting experience for them.

"I attend a school every week with the dog. I have a story dog. And I mean, I'm giving back what I can't do...as volunteering and lots of things I can do that because I can still drive. I can take a dog on a lead, and I can take it to school. And there's a lot of preparation goes into that. Yeah, And I knit Because I because I can't do much active work. I knit. And so I thought I'd saw this ad in the paper about volunteering this as needed, and when it inserts for knockers, for the ladies who had mastectomies. Now that's the thing that you can do while you're sitting, you're resting. We're not too hot. I'm gardening. I am in the Garden Club and you go on trips so you can do things. saying ohh I can't get these too many germs".(P7)

"I've got chooks so I I have to go down and feed the chooks and I do up chook food from fruit and vegetables I cut up and I I walk unaided down to the chook pen, to feed them. And I've got 4 birkes parrots. And I feed them and clean their cage out. I was getting Podiatry done but I do it myself now. I do all sorts of those. I go shopping for this girlfriend of mine who's worse off than I am I called today. I was the first time I called boy [bingo at senior citizens club] here. I called bingo. FRF is four old fats.It's four of us...umm..Two of us are in our eighties and two in their late 70s".(P9)

4.3.4.1.2 Approaches to Manage Symptoms. All approaches that were stated by participants that helped to manage their symptoms are explained in this subset. These approaches varied for participants. Breathing exercises, using inhalers, and taking medications regularly were the common measures that participants used most of the time. One participant mentioned that they had to clear their throat every morning, while another person used to go to the beach to make themselves calm and relaxed.

"I I try. I breathe, I breathe. If if I feel myself getting weak. I can't breathe, I suck in as much air as I can into my lungs, hold it for as long as I can, which is not very long and then let it out. In the mornings like as you can probably hear, I have to clear my throat but, probably after about 10:00 I don't even notice that". (P1)

"You know, just know that you have to have your preventative every morning. You know that. You know you're getting cold. You go. Here we go. I need my ventilator. I need to make sure I've go on nebuliser and I need to make sure I've got saline. uumm.. Get to the doctor ASAP. Make sure you've got something in place to help combat it before it gets too bad. Medication and I have learned, aahh.. through the pain management clinic to do breathing exercises. Yes. And just calm myself down because you need to get that panic. you can't get your breath. You can't take a deep breath. So I will do mindfulness. Aahh.. Meditation or I will do box breathing. And I kind of. because I go Yeah. It regulates your breathing and your heart palpitations and all that, so I use that all meditation. It's like. And the other thing I do is go to the beach. Salt air Salt air, I don't know if that's like a sematical And just the rhythm of the ocean, I just". (P3)

"And I'm particular about taking the medication properly. And I don't over medicate, and my doctor's aware that I'm pretty strict with myself. So. I think without the medication I wouldn't go but all". (P5)

One participant mentioned giving up work because of the disease. Planning and pacing were also used to manage symptoms. It is apparent from the below quote about the participant's awareness and the measures they used to control the effects of the disease.

"But now I make myself. I've physically gotta make myself do things and I've gotta plan for them. I gave up work. Yeah, Oh, yes. I couldn't do it without the shower chair. And again, over time I've had a shower. (mumbling.. Who's gonna listen to this?) I'm absolutely exhausted. So I dry myself to a degree. Wrap the towel around me. Go and sit in the lounge room for 1/4 of an hour. Half an hour Then get back and get dressed. I I can't do it all in one". (P2)

Participants were aware that they must do everything step by step. Despite this awareness, participants found it exhausting to prepare food and wash dishes.

Another person mentioned using strategies to counteract the effects along with being aware of positions to manage symptoms.

“Yeah, with everything. Even preparing dinner. You know what I mean? If John's not there and I'm making a start. You know. Like. 2 o'clock I will empty the dishwasher and probably put the the dishes out that I need for preparing dinner. 4 o'clock I might get up and peel the vegetables. And trust me, the meals are simpler now than what they used to be. A lot of things like cold meats and salad. Oh. Shopping. When I mentioned shopping before. I would say. 90 to 95% of my shopping now is done online”. (P2)

“Yes, I'm well monitored, I have a plan on my fridge. And I do things to counteract other things at my own pace. And I know which way I have to lie at night to be able to breathe and know which way. If I move, I will cough. and every I've learned. Well, I've taught myself And I'm not just fighting about that, so sounds like, ohh you'll keep myself busy and happy to be very aware of all the time. You can't let your guard down. I don't stay inside uuhh..More exercises, I guess Ohhh... well, I guess that's where model techniques come into it.Isn't the way I lie. The way I sit propped up Oh, I'm changing things all the time gradually because if I can't, but the the running of it going uphill would be”. (P7)

Gardening, buying a lift, using assistive equipment and keeping windows open for increased circulating air were also other measures mentioned by the participants.

“But she's [daughter] in a high set house, so I've had to buy a lift. I don't use the wheelie Walker at home other than to take my groceries out of the car.....Around to the lift and then the lift takes them upstairs. And I've just gotta sit down and let my breath even out a bit and then take a couple of puffs of that Because I've got a little low office chair and a low a little low stool, the stool's only that square and I find by sitting on that and putting my foot on this stool instead of bringing my my foot up here. Foot down there and hitting the stomach and the stomach blocking the diaphragm off I can put my leg there. There's not a lot I can do, I just very sparingly. I use the puffers Ohh I go. I go to.I go to Physio once a week And I do exercises there and...uumm..like I said I can't carry anything Well, I'm trying to learn more and more all the time”. (P9)

"I find it's easier. I just sit down and... Stop what I'm doing and ..uummm.. sit up straight and breath and... It does..helps..yeah, that's how are you like I say, I used to use the Ventolin, but I didn't think it did much good. and we used to have to do breathing exercises and all this sort of thing. I'm not really. I'll just carry on. Take me, puffer. And... yeah... yeah you know You know there's. I just keep the windows open during the day and fresh air in. But like I say, I'm outside most of the time". (P10)

4.3.4.1.3 Preventing Infections. Participants were aware that they were prone to infections. They kept themselves away from people with colds or flu. Doing online shopping or shopping on days when supermarkets are quiet were other tactics participants adopted to prevent infections.

"So I'm prone to infection, so and with COVID around and and that's yeah. Yeah, yeah, yeah. But it's saying 95% of the time I do my shopping".(P2)

"If anybody's, anybody's got a cold or flu. Umm..umm It's like throwing garlic at them and holy water and like.Umm.. it's not that you're fearful. It's just like you're protecting yourself. It's like, you know, I know you're gonna get really sick. It's just a head cold to you". (P3)

"That was just, when the COVID came, that's where I started to stay at home, I was not going out. I'm staying home. I'm more vulnerable than most other people. I'll go shopping on a Monday. When the supermarkets are normally pretty quiet. And I keep my hands clean with stuff .. that stuffs that I got there".(P4)

4.3.4.1.4 Planning and Pacing. It was noted that participants had to plan in advance. They were aware that there were no spontaneous actions, and they could not overdo things.

"But now I make myself. I've physically gotta make myself do things and I've gotta plan for them. There's no. I'll. I'll get up and do this. You've gotta think about it and kind of plan it out before you can. there's no. There's no

spontaneous. yeah..actions anymore. Ohh, I'll get up and do that, you know. To me, it's all planned in advance".(P2)

"Just trying to get out and get started the day, you know. So just take my breathing and I take it easy. And hope that it's gonna be a good day without any major problems like coughing. Issues that sometimes happen. Then they go quiet and ah..yeah . I plan, plan..what I'm gonna do.....choose to stay or I'll go out, make a cup of coffee and I'll plan. I'm feeling good. I am going visit Kmart, do that go to the butchers. You know, Or... I am not feeling myself. So just go up the bushes[coffee shop near bushes] and request [taxi] home. I try and try to overcome take it slowly. We go a bit slower. but yeah, it wouldn't be done in 10 minutes. We will be done in an hour. But then I still get the job done".(P4)

"Yes always at my own pace. Yes, I can. I can walk the strand, but I can't keep up with the family. I just wouldn't lie in bed.aaa... Wake up, like listen to the news or something, and then I'll just think for now. Today I'm going to do this".(P7)

"umm..But if I do overdo it, which I quite often do, if I feel good, I think, oh, just I'll get into it while I feel alright and the next day I pay for it..uumm..That I I I just try to stick with stuff that I know. I can do. And then I just do a little bit more each time. There's no such thing in my vocabulary as hurry anymore. Because it's something I just can't do It's like...uumm..I can do the laundry. And I can hang the washing on the line. but it will probably take me the best part of the day. To hang the washing on the line because. Up like that and the the pressure of putting the pegs in doesn't seem much, but I can peg a couple of things on the line. And I'm gasping for breath so I've gotta sit down for 10 minutes and get my breath and then I can hang another thing and maybe two on the line get your breath back and then I'll go to".(P9)

4.3.4.1.5 Awareness of Worsening Symptoms. Participants' awareness about worsening of symptoms is reflected in this subset. This awareness led participants to act quickly to manage the symptoms on time.

"Yeah. Ohh shortness of breath. I had more chest infections aahh.. and and every chest infection. I needed something more to help it like steroids or Spiriva or you know, I mean like I just had to keep adding ..So it's getting worse, not like

it's getting better. Yeah, until I stopped smoking two years ago. And it's been so much better, much better I feel. I still cough up stuff. I hate being sick. Yeah. No, I just go in and tell them, listen to my chest. It's a bit wheezy. And like I said, I have phlegm everyday, but as soon as that cough gets worse. And the colour changes. That's it. I'm going to the doctor". (P3)

"I went shopping and when I came back I couldn't breathe properly and found out that one of my,aa.. lower lobe of my lung had collapsed. It's done that. That's first time it's done it again and it's done it again, at the moment I went to see. Aahh..ahh...what they call it, respiratory Dr Yeah, it's got back. It got a little bit worse.umm.. breathlessness umm. coughing.... I get breathless a lot more often now than I did before, yeah".(P4)

4.3.4.1.6 Effect of External Factors on Symptoms: Weather and Conscious of Surroundings. The effect of external factors, like weather or changes in surroundings, is included in this subset. It was noted that weather changes had a negative effect on their symptoms. Participants were also responsive towards smoke and air movement.

4.3.2.4.1.6.1 Weather. The weather changes had adverse effects on participants. Participants mentioned that overcast weather and winter affected them.

"The weather affects my breathing a lot. if it's muggy weather or overcast weather, I find it's harder to breathe...aahh...And when that happens, I just don't have any energy. So that's a...weak day".(P9)

"But like I say in the winter, I'm not as good the summer I'm..pretty good, yeah".(P10)

4.3.4.1.6.2 Conscious of Surroundings. Participants were mindful of their surroundings. They tend to be away from smoke and make sure there is air movement wherever they are. They were cautious of the air temperature as well.

“ Umm..I think it makes you more aware of your surroundings. Like I said, if I'm outside and I smell smoke and I go, oh, here we go. It makes you more mindful yeah. If there's smoke around or I go out and visit friends and family on the Atherton Tablelands and going up in altitude. So, then it's fresh air and it's like, oh, yeah, that's so it's so nice. but then, like I said, I live so close to Mount Stuart and they do those burns. You know the burn reduction and storms up there. You go back inside, turn the aircon on, close the vent so it recirculates”.(P3)

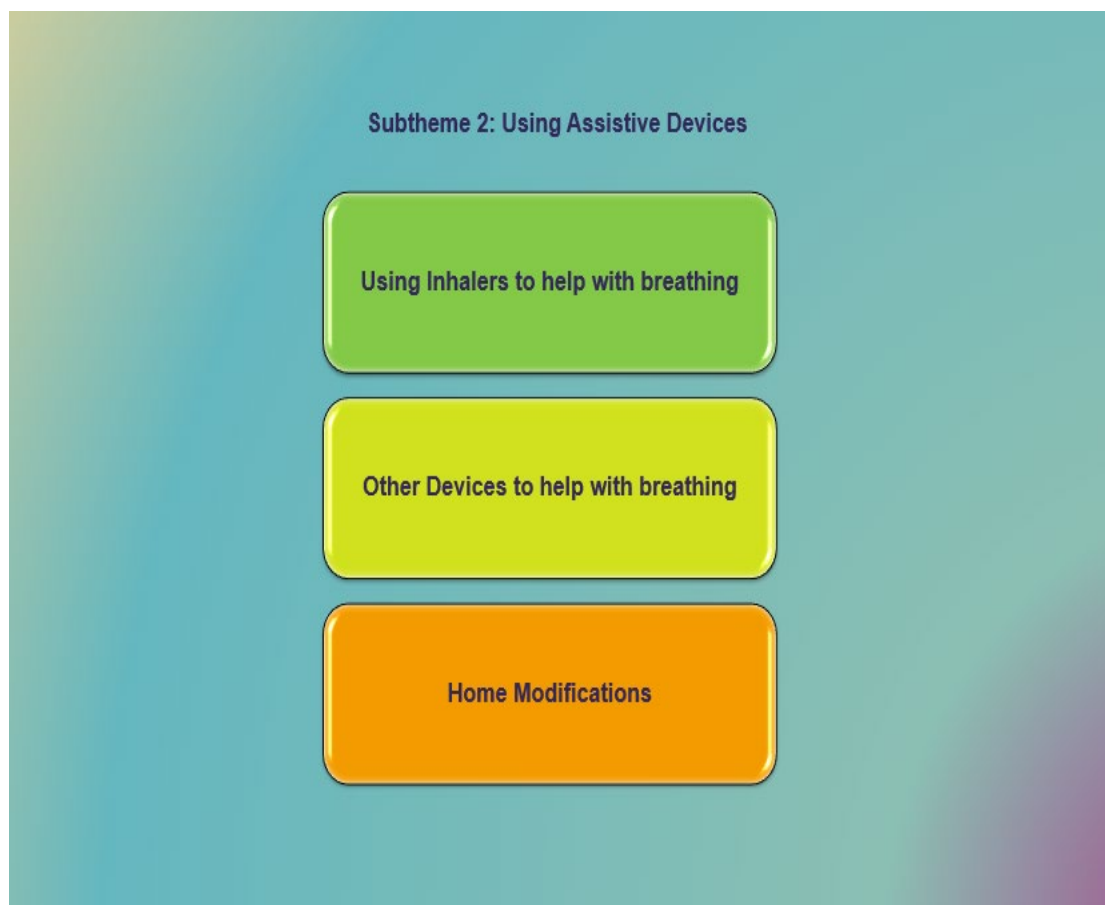
“And I know what affects me so I stay out of the, you know, stay away from because you have medications and you don't know how air temperature like in a plane you don't know in the train. uumm... I stopped travelling by train because of so many cost I'll I'll get it. You know, that's the challenges of sickness around you, not just the COVID. what I could do? The smoke in the air. I shut all the windows and stay inside”.(P7)

"Being outside in the fresh air. Umm. I think it, I don't know if it's improving or not, but you know and and of course being older that makes a difference, doesn't. It, But like I say in the winter, I'm not as good”.(P10)

4.3.4.2 Sub-theme 2: Using Assistive Devices. This sub-theme reflects all supportive devices participants used to manage their disease. This included using inhalers, other devices that helped to manage symptoms, and any modifications done to their home. All the participants used inhalers to manage their symptoms. One participant had a CPAP machine. Home modifications like installing rails and lifts were also used by one or two participants. The subsets contained in this sub-theme are illustrated in Figure 4.12 and are elaborated in the subsequent parts.

Figure 4.12

Subsets of Sub-theme 2: Using Assistive Devices



4.3.4.2.1 Using Inhalers to Help with Breathing. Inhalers were an essential part of the management of the disease. All the participants used inhalers to manage their symptoms.

“Yeah, I am on...aaa.. Trilegy aahhh, one puff of that of a morning. There's not a lot I can do, I just very sparingly. I use the puffers”.(P9)

“No, I got a puffer thing I use first thing in the morning. Eli.. Eclipta..”.(P10)

4.3.4.2.2. Other Devices to Help with Breathing. This subset discusses other devices that were used by participants apart from the inhalers. Only one or two participants were using other devices like CPAP machines or nebuliser machines, which is evident from the quotes below.

"Hmm. I have the ventilator machine. I have the steamer as well, yeah. The ventilator that's only when I get a really bad...ahh.. Chest infection".(P3)

Yes, I do. I've got a...nebulizer... I do have a CPAP machine, but having that I wasn't be able to use it for a while because I had surgery on my head". (P4)

4.3.4.2.3 Home Modifications. Any changes that were made in their homes to assist in living with the disease are discussed in this subset. One participant mentioned using a shower chair, while another person used furniture to counteract the effects of the disease. Grab rails, recliners, and mobile tables were also used by one participant. Interestingly, one person had to install lifts to assist with mobility around stairs.

"I furniture surf. Because I live in a tiny unit, this (pointing towards the wheelchair) won't fit inside it. So I have to use my walking stick, and I have the furniture serve.Umm.. And I just try and get as much fresh air as I can because it's a tiny little unit, it's claustrophobic. Unless I'm studying at the computer. Well, I could be outside". (P3)

"There's been a few changes, and I've got rails around the house now. I have got most of my furniture from CTBAE- DVA, which is like automatic recliner chairs...ahh... mobile tables that you can push around on wheels aaahh.. chair for the kitchen, so when I'm doing cooking cause, I will. I just sit there if I get tired". (P4)

"And the only option was to move into my daughter [daughter's place]. But she's in a high-set house, so I've had to buy a lift. Lift it to walk into .uumm..I have a seat over the toilet". (P9)

The data analysis identified four major themes and is summarised under the overarching theme "Being in Charge". This overarching theme narrates participants'

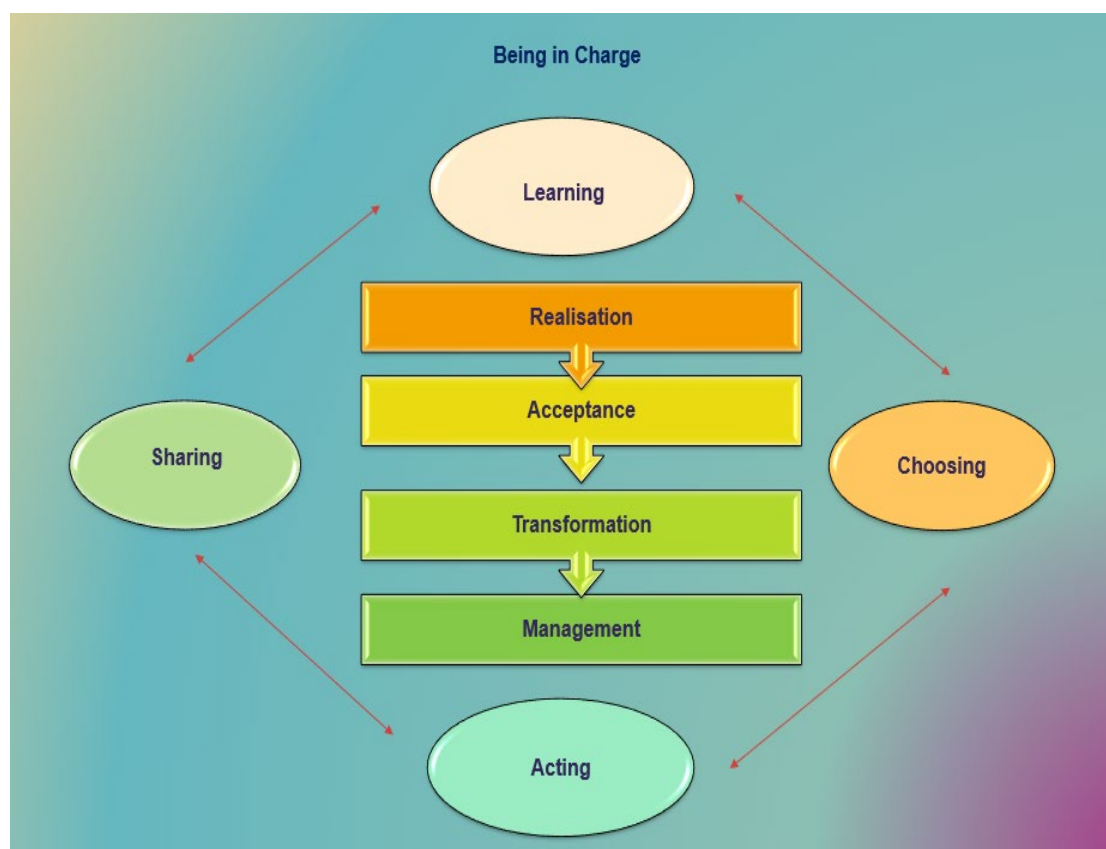
disease journey, indicating the phases and processes that evolved throughout. The recital of this evolution is further explained in the next section, The Story of Being in Charge. In addition, a summary of findings and an accompanying infographic were distributed to study participants via email and have been included as Appendix L and Appendix M, respectively.

4.4 The Story of 'Being in Charge'

The analysis of the data revealed that people with COPD went through different phases in managing their disease effectively. The phases of realisation, acceptance, transformation, and management moulded them to 'Being in Charge' of their disease. Overseeing one's disease also included the processes of learning, choosing, acting, and sharing throughout their life.

Figure 4.13

Being in Charge



The initial phase of realisation and reaction incorporates the awareness of participants about their disease. Participants acquired only limited knowledge at the time of diagnosis, and this knowledge evolved throughout their journey. During this journey, participants discovered themselves, the effects of disease, challenges in day-to-day life, and how their negligence and other factors contributed to their disease. Participants had mixed feelings towards the diagnosis: most of the participants expressed fear and other negative reactions, but eventually had a positive outlook, which was reflected in managing their disease. The 'Realisation' phase commenced with the diagnosis of the disease either via hospitalisation or by their general practitioners. Changes were made after the diagnosis, and the education received also played a part in the realisation of the disease. Self-awareness, awareness of symptoms, and perception of challenges gave a sense of acknowledging the disease. The reaction to the disease varied from negative to positive; participants were able to overcome the negative thoughts and eventually became optimistic in life. The process of 'Learning' is evident in this phase, and it assisted them in changing their reaction towards the disease.

The realisation of their health, strengths, weaknesses, and symptoms of disease enabled participants to accept their disease. The next phase of 'Acceptance' reflects a phase of transition that enables participants to accept the disease, leading to an alteration in their concept and a more realistic view of the disease and life. The process of 'Choosing' is reflected in the phase of acceptance and appears to continue in the next phase. Participants chose to accept the effects of the disease and transform themselves to take appropriate actions to manage the disease.

Adapting to the effects of the disease through self-realisation and the use of support networks empowered the participants. The self-realisation motivated the participants to change their views about the disease and led them to formulate goals in life. The support system played a crucial role in the management of the disease. The support system involved general practitioners, support groups, and other support at home and other services that participants accessed. The process of 'Choosing' continued in this phase as participants chose to adapt and utilise support networks. The process of 'sharing' is apparent in the advice provided to others in managing the disease. This empowerment and support network enabled the participants to enter the phase of 'Transformation' and led to the final phase of 'Symptom management'.

The final phase incorporated the action plan along with using assistive devices, which led to managing the disease effectively. The action plan included the various approaches used by participants to manage the disease effectively. This also portrays the process of 'Acting' in managing diseases. Being active was one of the measures taken by the participants. The approaches to managing symptoms, including preventing infections and avoiding the triggering factors, were some of the actions taken by participants. Using regular inhalers and other assistive devices, along with home modifications, also facilitated symptom management. Participants found to be 'Sharing' their knowledge and trying to assist others were also interesting facets of this phase.

As the participants voyaged through each phase, the process of learning, choosing, acting, and sharing advanced, and participants felt motivated. This motivation prevailed to control their attitudes, behaviours, and perspectives to manage the disease and 'Being in Charge' of themselves and their disease.

4.5 Chapter Summary

This chapter has provided a comprehensive insight into the facets of realisation, acceptance, transformation, empowerment, and symptom management of participants since the diagnosis of COPD, which evolved throughout their lives. The differences in the attitudes and behaviours of participants were reflected through the varying approaches in managing their disease. Thus, this chapter has provided a detailed insight into the *variations in self-care interventions* in coping with COPD. The transcripts of the interviews with 11 participants were analysed thematically, resulting in four major themes and nine sub-themes with multiple subsets. The four themes were realisation and reaction, acceptance of disease, transformation and empowerment, and symptom management. These four themes contained sub-themes of the diagnosis/realisation of disease, acknowledging the disease, reaction to disease, realisation, transformation, adapting to the effect of disease through self-realisation, support from people, action plans to manage symptoms of disease, and using assistive devices. The findings demonstrate that the participants were aware of the disease, accepted the challenges, and transformed and empowered themselves to manage the disease effectively. The next chapter discusses the findings in relation to the literature and identifies the strengths and limitations of the study, along with the implications of these findings and recommendations for future research.

Chapter Five: Discussion

5.1 Chapter Introduction

The previous chapter presented a detailed description of the participants, followed by the findings that emerged from the analysis of their interviews. The experiences of 11 participants with Chronic Obstructive Pulmonary Disease (COPD) were obtained, analysed, and described in the previous chapter. As presented in Chapter Four, analysis of participants' experiences revealed the major phases and processes that helped explain the variations in self-care behaviours in coping with COPD and overseeing health. The chapter also presents the correlation of study findings to other theories and or models as well as to the relevant literature.

5.2 Overview of the Study Findings

The initial portion of this chapter presents an outline of the findings exploring the experience of participants in coping with COPD. This study involved in-depth semi-structured interviews with 11 participants. The participants were recruited from the regional city of Townsville. This study was advanced with concurrent data collection and analysis, followed by a subsequent analytical process of Braun and Clarke's thematic analysis (Braun & Clarke, 2006), which led to the development of multiple codes and categories and later evolved into subsets, sub-themes, and themes. 'Being in Charge' was the overarching theme identified to explain the basic theory of coping with COPD by participants. The overarching theme had four main subcategories, namely 'Realisation', 'Acceptance', 'Transformation', and 'Management', and is respectively discussed to support and further explain nuances, drawing on the literature and existing assumptions.

5.3 Key Findings of the Study

Once the data were obtained, they were analysed through a process called the reflexive TA approach (Braun et al., 2019). The codes and categories had emerged, themes were formed, and an overarching theme was evident after analysis. These emerging themes assisted the researcher in writing an analytical story of the data that was collected (Braun et al., 2019). This analysis showcased that the core of disease management and endurance is the overarching theme of 'Being in Charge'. This overarching theme contained four major categories to show

the phases of how people with COPD managed their disease effectively to minimise frequent hospitalisations.

This study unveiled that people with COPD learned about their diagnosis either from their general practitioners or during hospitalisations for other respiratory ailments. Their reaction to the disease evolved from negativity to positive thoughts. Through involvement in educational activities, through health practitioners and from their own experiences, they understood the causative factors. It is evident from this study that participants formulated plans and strategies to tackle the disease symptoms, which is reflected in their management of the disease. This study reveals the participants' experiences and self-care journey in managing their disease and preventing hospital readmissions. Four key findings arise from this study and are discussed in the context of other relevant literature. These findings comprehensively showcase the concept of 'Being in Charge' in the voyage of participants coping with COPD.

5.3.1 Key Finding One: Realisation of the Disease and Reaction to the Disease

This study revealed that the first phase undertaken by the participants in their disease journey is the realisation of the disease and reaction to the disease. It is noted from this study that the realisation of the disease occurred when the participants received the diagnosis of COPD, and was incidental for study participants. An interview study, which explored the meaning of COPD and people's response to the disease with urban and rural participants in Ireland, states that the awareness of symptoms started before the diagnosis of COPD (Cooney et al., 2013). In this study, most of the participants denied receiving any formal education at the time of diagnosis. This is consistent with the findings of another study that used focus group interviews to find out how moderate to severe COPD patients cope with illness in an outpatient clinic (Jarab et al., 2018). It is evident from this study that most of the participants had minimal hospitalisations for COPD or related symptoms, and the changes made by participants assisted them in managing their disease effectively.

As participants journeyed through their disease, their awareness about the disease increased. This awareness assisted them in understanding the symptoms, their strengths and weaknesses, the habits that contributed to the disease, the difficulties with the existing systems, and the things to avoid in managing the disease

effectively. It was noted that changes were made by the participants after the diagnosis of COPD. They felt that every day was a challenge because of the restrictions caused by the disease on life, and they tried to overcome those restrictions by slowing down and taking small steps. Physical and emotional struggles in daily lives were narrated in other studies that explored the people's experience living with COPD via interviews (Rubio, 2019; Zeb et al., 2021). A study that explored self-management behaviours via semi-structured interviews with 18 men who had COPD for a year indicated that participants opted for behaviour modifications (Chen et al., 2008), while other studies that explored the meanings and experiences of study participants found that participants used different strategies, like planning and slowing down, to manage symptoms (Ansari et al., 2014; Chen et al., 2008; Cooney et al., 2013; Ek & Ternestedt, 2008; Pooler, 2014).

It is demonstrated in this study that the participants' reactions to disease varied throughout their disease journey. The fear of breathlessness, negativity, and frustration was mastered by the participants and is reflected in their positive outlook. The concept of the 'thought of death' in this study has similarities to another qualitative study that explored the meaning of experiences of people with moderate to severe COPD in Colombia (Valencia-Rico & Burbano-Lopez, 2020). It is apparent from the study that participants expressed frustration mainly related to inadequate coping, not because of the dependence on others for daily activities. This finding contrasts with the qualitative research that inspected COPD patients' experiences and management of everyday life activities via interviews with those who participated in a pulmonary rehabilitation program (Kaptain et al., 2022). Most of the study participants were active and energetic, in contrast to a qualitative interview study that explored the symptom burden of COPD in patients with moderate to severe COPD (Johansson et al., 2019). Participants of the latter study chose to stay home as they did not have the energy to participate in activities at the same pace as others (Johansson et al., 2019). No study participants mentioned any concerns about being a trouble to their family members, unlike the other qualitative study that explored the lived experience after hospitalisation with 17 participants in northern Taiwan, which mentioned the participants' concerns about being a trouble to their families (Chang et al., 2016).

5.3.2 Key Finding Two: Acceptance of Disease

The phase of 'Acceptance of Disease' represents a transitional stage from the realisation of the disease to the transformation of participants. Acceptance is the end stage of the grieving process, where patients have given up the stage of denial, the stage of resistance, and the stage of sorrow (Vercoulen, 2012). The stage of denial is characterised by ignoring the condition, the stage of resistance denotes the awareness of the seriousness of the condition, but being frustrated as they cannot continue normal activities, and the stage of sorrow is marked by sadness and passivity (Vercoulen, 2012). Various reactions to the disease, from negative emotions to a positive outlook, are evident in study participants and can be related to the stages of grieving (Vercoulen, 2012).

Once the participants realised or learned their susceptibility to the disease and the severity or seriousness of the disease, that is, the effect of the disease in day-to-day life, they accepted and transformed themselves, which shows similarities to the health belief model (Rosenstock, 1974). In this study, people with COPD who underestimated the severity of their disease were inclined to delay executing their recommended management from the health professionals. It was mentioned by participants that they were advised to stop smoking and use prescribed inhalers, which they neglected and felt should have attended at the time of advice.

The transitional phase of acceptance enabled participants to embrace the disease, leading to altering their concept and being realistic about their disease. The realisation that nothing was going to get any better enabled them to conquer the denial of the symptoms, resistance to adapt, and grief of the loss and gave them a purpose to move forward in life. The study participants accepted the disease and planned their lives, embracing lifestyle changes to manage the disease. This finding is consistent with another study that examined the grieving process using a questionnaire on patients with mild to severe COPD, which also mentioned that participants alter their goals and are inspired to make long-term lifestyle changes (Boer et al., 2014).

The participants in this study realised that they could not do anything to cure the disease. They also accepted the disease as a part of their life and planned their life accordingly. Participants also realised that they must make some lifestyle changes to manage the disease. This acceptance of disease is in line with the

literature, which states that patients are capable of restructuring their goals and beliefs in the 'stage of acceptance' (Post & Collins, 1981).

5.3.3 Key Finding Three: Transformation and Empowerment

This study reports that the phase of transformation and empowerment followed the phase of acceptance. This phase also denotes the adaptation of participants and utilisation of support networks, which assisted in their transformation and empowerment. It is evident from this study that participants' perception of the disease changed as they accepted the disease. This understanding led to a change in their life view, and they appeared thankful for being alive. This finding contrasts with an interview study carried out in Germany with 17 advanced-stage COPD patients, where participants felt that they were 'at the mercy of the disease and denied the threat to life as long as possible' (Marx et al., 2016). This study reveals that participants learned to live with their disease, felt motivated, and formulated goals. These findings relate to another study that examined the grieving process using a questionnaire on patients with mild to severe COPD and identified the adaptation process and restructuring goals after the stage of acceptance (Boer et al., 2014). Participants knew what to avoid in managing their disease, and this is reflected in their advice for others in managing the disease.

The study identified the role and influence of the support system during the phase of transformation and empowerment, and it cannot be ignored in the disease journey. The support system included general practitioners, support persons at home, and other support services. The previous studies that explored patients' experiences, coping, and management via interviews with moderate to severe COPD patients also identified that family support played a crucial role in maintaining the well-being of people (Apps et al., 2014; Chen et al., 2008; Cicutto et al., 2004; Jarab et al., 2018; Johansson et al., 2019; Kaptain et al., 2022; Sigurgeirsdottir et al., 2019; Valencia-Rico & Burbano-Lopez, 2020; Zeb et al., 2021).

An interview study that explored the coping of people in different stages of COPD found that there was over-reliance on family members in managing the disease (Jarab et al., 2018). Another interview study that explored the meaning of experiences with 10 severe COPD patients mentioned that participants relied on caregivers for continuous assistance with basic activities (Valencia-Rico & Burbano-Lopez, 2020). The study participants relied on their families and friends, and some

participants had to hire services. Interestingly, some of the study participants were caring for their family members rather than being cared for by their families. Even though participants were involved in community groups and other social clubs, only one study participant was aware of the support group for lung disease and felt that it would have been beneficial to have a support group for COPD. It was noted in this study that involvement in community groups and other social clubs kept the participants active and assisted in boosting their mental well-being.

The role of the general practitioner in the support of participants cannot be neglected. The study participants mentioned varying experiences with the general practitioners. The diagnosis was made mainly by the general practitioners, but at times, not much information was provided regarding the disease, or the disease was not managed properly. This is in line with the findings of another study that examined the perception of the impact and attempts to manage symptoms of 15 COPD patients via semi-structured interviews (Apps et al., 2014). Another interview study that examined the self-management behaviours of 18 COPD patients of various severities identified that accurate advice from healthcare professionals played an important role in establishing faith in the treatment and prompting adherence to the management strategies, along with ensuring patients' accountability for their behaviours (Chen et al., 2008).

One of the study participants was very confident with her general practitioner but had difficulties when she had to approach other general practitioners. It is evident that her general practitioner was very supportive, and the participant had confidence in managing her disease. Other studies have also found that limited communication and treatment by healthcare professionals (Valencia-Rico & Burbano-Lopez, 2020) along with inadequate information provided by primary care physicians (Ansari et al., 2014; Molin et al., 2020), leading to a lack of confidence in their primary care physician (Halding et al., 2018). Ansari et al. (2014) explored the meaning of experiences with 17 participants in Sydney, Australia, via a semi-structured interview guide. Halding et al. (2018) studied the self-management and transition in the health of 11 COPD patients with significant symptoms in rural Norway, and Molin et al. (2020) examined the impact of new diagnoses of COPD in 14 moderate COPD patients who attended a pulmonary rehabilitation program in Denmark.

5.3.4 Key Finding Four: Symptom Management

The final phase emphasised the action plan participants adopted in managing their symptoms, which assisted them in overseeing their health. This action plan included different strategies and varied among participants. It was noted that all the study participants were active and involved in voluntary activities and social or friend gatherings. This was different to previous studies where participants were found to be socially isolated (Gabriel et al., 2014; Johansson et al., 2019; Marx et al., 2016; Wong et al., 2014; Wortz et al., 2012). Gabriel et al. (2014) explored the impact of chronic phase COPD on families and patients in Portugal, while Johansson et al. (2019) inspected the symptom burden and effects of COPD on daily life in 25 stage three and stage four COPD patients via interviews. The meaning of living with COPD in an advanced stage of the disease was inspected by Marx et al. (2026) in 17 patients. Wong et al. (2014) conducted focus groups with patients and doctors from the chest clinic in Malaysia to explore the unmet needs of patients with COPD that could improve their quality of life, while Wortz et al. (2012) inspected patients' goals and expectations for self-management via interviews in a diverse sample of 47 patients at the University of Texas health centre. All five of these studies identified social isolation as a feature in their participants (Gabriel et al., 2014; Johansson et al., 2019; Marx et al., 2016; Wong et al., 2014; Wortz et al., 2012).

The approaches to managing symptoms also varied among participants. The use of inhalers, medications, and home modifications played an important part in managing disease symptoms. The study participants used breathing exercises, medications, and inhalers to manage symptoms, and the same strategies were mentioned in other interview studies (Apps et al., 2014; Brien et al., 2016). Apps et al. (2014) examined the perception of the impact and attempts to manage symptoms of COPD in 15 patients via semi-structured interviews, while Brien et al. (2016) explored coping strategies across disease severities in 34 COPD patients. As opposed to these studies, the study participants mentioned going to the beach to make themselves calm and relaxed, box breathing, keeping windows open, and buying a lift to assist with mobility. Doing shopping on the days when supermarkets are less busy or doing online shopping was opted for by participants in this study to prevent infections.

Planning and pacing were other measures participants adopted to manage their disease. Participants were aware of the need to slow down, break up tasks,

take more time to do activities, and plan the day. These measures were found in five other qualitative studies as well (Chang et al., 2016; Chen et al., 2008; Cicutto et al., 2004; Williams et al., 2014; Wong et al., 2014). Chang et al. (2016) explored the lived experience of 17 people with COPD following hospitalisation in northern Taiwan, while the self-management behaviours of 18 men who had COPD for a year were explored by Chen et al. (2008). Cicutto et al. (2004) examined the views of people in various urban and rural regions around Ontario, Canada, through focus groups, while Williams et al. (2014) explored 44 patients with various stages of COPD at home. Wong et al. (2014) conducted focus groups with patients and doctors from the chest clinic in Malaysia to explore the unmet needs of patients with COPD that could improve their quality of life. This study highlights that the awareness of participants about worsening symptoms and the time to call for help facilitated the appropriate management of the disease. Participants of this study were aware of weather changes, conscious of their surroundings, and avoided smoking in managing their disease.

5.4 The Core: 'Being in Charge'

The overarching theme of 'Being in Charge' encompasses four components, and each of these components is discussed in comparison to the existing literature in the previous sections. It is revealed from this study that the participants of this study oversaw their disease. The four phases of 'Being in Charge' involved the processes of 'Learning, Acting, Choosing and Sharing'.

In the first phase, participants discovered themselves, the effect of the disease, challenges in their day-to-day lives, and how their negligence and other factors contributed to the disease. This awareness was reflected in the changes they made in their lives to manage the disease. The reaction towards the diseases varied throughout the journey, from fear and other negative reactions to a positive outlook, which enabled participants to accept their disease. The acceptance of the disease led to a change in their concept and being realistic about their disease. The process of 'Learning' is evident and assisted participants to choose and act accordingly.

The realisation that nothing is going to get any better aided in choosing what is right for themselves. This process of 'Choosing' assisted in managing their disease and is evident in the stage of transformation and empowerment. Transformation and empowerment represent all the adaptations made by the

participants to manage the effects of the disease. Participants formulated goals and used their support system as required to become better versions of themselves. The process of 'Acting' continued in managing their symptoms and is evident in the final phase of symptom management. Participants tend to use different strategies to manage the symptoms and prevent infections. The process of 'Sharing' is also evident as participants shared their knowledge and tried to assist others with their disease.

Awareness of self, their diseases, and the time to call for help, along with various strategies used by participants, evolved throughout their disease journey. The participants were prepared to make changes as needed and were motivated to learn. This awareness and motivation persuaded them to manage their diseases effectively, reduce hospitalisations, and oversee their health.

This study has highlighted that participants used measures to be active in overcoming or managing their disease efficiently. They were involved in various activities like volunteering, participating in clubs, and helping others. It was also mentioned by one of the participants that they felt it was beneficial to be away from the usual environment and that giving back to the community was an uplifting experience for them.

The researcher also tried to link the study findings with the processes involved in shaping the metamorphosis. For instance, the phases of evolution of 'Being in Charge' also reflected the process of how people learn, choose, act, and share their experiences. These phases and processes guided the researcher to find any theories related to the concept of self-management and found similarities to the health belief model and the middle-range theory of self-care, which is explained in subsequent sections.

5.4.1 Linkage to Existing Theories

5.4.1.1 Comparison of the Overarching Theme and Health Belief Model.

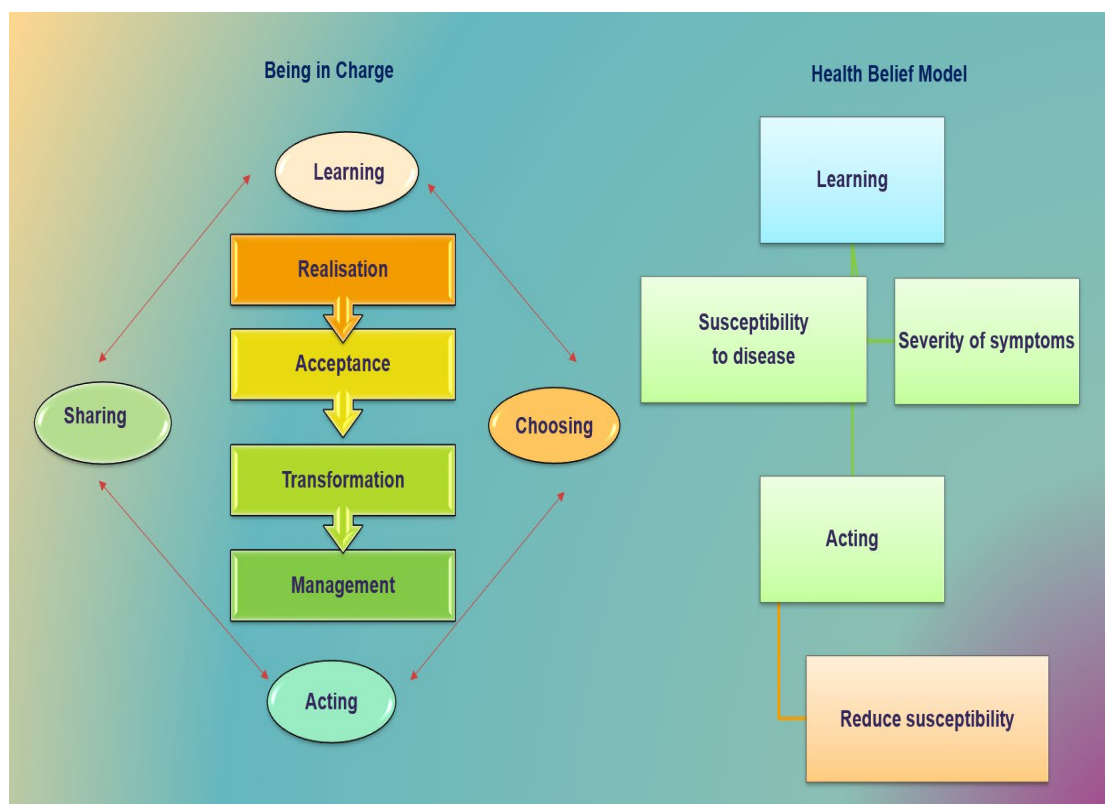
The concept of 'Being in Charge' was found to have a connection to the 'Health Belief Model' (HBM) (Rosenstock, 1974). The HBM identifies the elements that govern people to take measures to avoid disease and promote their health. The HBM states that for persons to promote health, "the person believes that

(1) they are personally susceptible to the disease (health problem)
 (2) the occurrence of the disease (health problem) would have at least moderate severity on some component of their life, and
 (3) taking a particular action would be beneficial by reducing their susceptibility to the condition or, if the disease occurred, by reducing its severity, and that it would not entail overcoming important psychological barriers such as cost, convenience, pain, or embarrassment” (Rosenstock, 1974, p 330).

These three factors have strong connections to the overarching theme of this study. In this study, it is noted that people realise that they have the disease, accept the condition, transform themselves and manage the symptoms. This involved a process of learning, choosing, acting and sharing. Figure 5.1 reflects the comparison of the overarching theme and the HBM.

Figure 5.1

Comparison of the Overarching Theme and the Health Belief Model



As per HBM (Rosenstock, 1974, p. 330), the acceptance of individuals to a condition varies from denial, admitting the condition and finally accepting it once they understand they are in danger. Once the individual realised or learned of their

susceptibility to the disease and the severity or seriousness of the disease, they acted to reduce the severity of the disease. The study participants were made aware of their disease either via hospitalisation or by their general practitioners. The realisation of the symptoms, the effect of the disease in day-to-day life, and their ignorance, which contributed to the worsening of symptoms, led them to accept the disease. As per HBM (Rosenstock, 1974, p. 330), the degree of perception and acceptance of a disease condition differs among people. It is evident from the interviews that some participants expressed the view that their negligence had contributed to their disease. In this study, people with COPD who underestimated the severity of their disease were seen to hold off their recommended management, which included stopping smoking and using prescribed inhalers. The other causes for disease severity identified by this study were occupation, weather, and smoking habits.

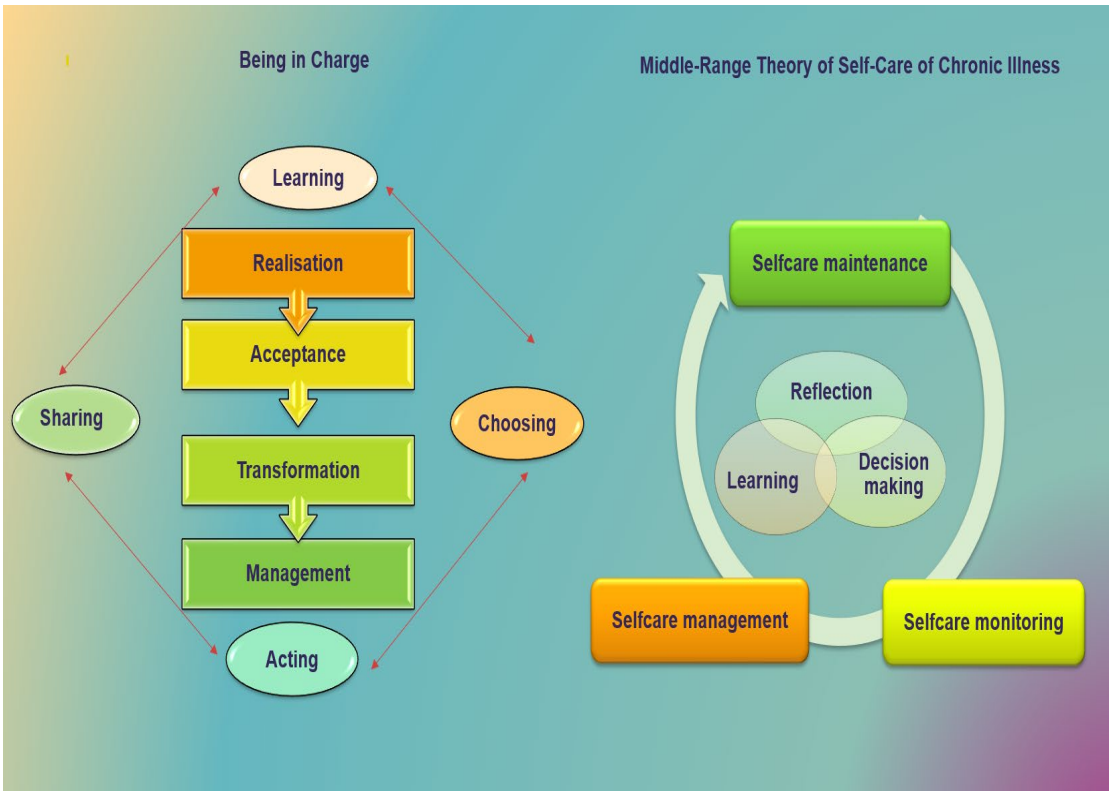
The acceptance of the severity of symptoms enabled them to act to reduce the susceptibility of the disease and transform to better manage the disease. This transformation was achieved by using the support systems and formulating goals. The process of choosing various strategies and acting accordingly was evident in the phase of management. Rosenstock (1974) argues that the acceptance of one's vulnerability to serious disease is a catalyst leading to action and is guided by their perception of the choices they have in diminishing the effects of the disease. It was noted from the results that participants opted for varied approaches to manage their disease. These approaches assisted them in managing their diseases effectively and 'Being in Charge' of their disease.

The overarching theme of 'Being in Charge' encompasses the realisation, acceptance, transformation and management by study participants, which included learning, choosing, acting and sharing. Participants' realisation of symptoms and self-awareness reflect their awareness of susceptibility. Acceptance of the diagnosis reflects the perception of risks, severity of the condition, understanding the effectiveness of interventions to reduce the risk and the barriers to achieving the effectiveness. The transformative phase reflects the triggers for action to achieve self-efficacy, followed by developing action plans, using devices, and drawing on support networks to manage their disease. The HBM helps to explain how beliefs influence individual behaviour. The overarching theme, 'Being in Charge', showcases how individuals evolve towards self-efficacy through a sequential and

developmental phase of realisation, acceptance, transformation, and management in coping with the disease.

5.4.1.1 Comparison of the Overarching Theme and the Middle Range Theory of Self-care of Chronic Illness. Another theory that relates to this current concept is the middle-range theory of self-care for chronic illness, which emphasises self-care maintenance, self-care monitoring, and self-care management (Riegel et al., 2012). Once the participants learned and accepted their disease and symptoms, they moulded themselves to manage the disease to avoid frequent hospitalisations and other complications. Self-care has an important role in disease management. Figure 5.2 reflects the comparison of the overarching theme and the Middle-Range Theory of Self-Care for Chronic Illness.

Figure 5.2
Comparison of the Overarching Theme and Middle-Range Theory of Self-Care of Chronic Illness



Self-care maintenance includes the measures taken to conserve and enhance health and emotional stability, including lifestyle changes and medications (Riegel et al., 2012). The phase of realisation reflects participants' awareness of their own emotions and strengths, along with disease awareness. This awareness aided participants in accepting and transforming themselves to manage their disease effectively. The disease management included adhering to lifestyle changes like smoking cessation and avoiding exposure to chemicals, dust, smoke, and weather changes. The adherence was also extended to taking medications appropriately.

Self-care monitoring is evident in the participants' journey. Participants were aware of their disease and when and how their symptoms worsened. This awareness enabled them to make appropriate decisions, assisted in approaching healthcare professionals for implementation and evaluation of treatment, and aligned with self-care management. Riegel et al. (2012) noted that patients who are adept in self-care monitoring liaise with healthcare professionals to receive effective care, and this self-care monitoring serves as a link between self-care maintenance and self-care management. Self-care is a process that depends on one's learning, decision-making, and reflection of one's actions, which facilitates the relationship with healthcare providers for better outcomes (Riegel et al., 2012). The process of learning, decision making and reflecting advances throughout the self-care journey and can be linked to the overarching theme of 'Being in Charge'. 'Being in Charge' incorporates the processes of learning, choosing, acting and sharing and supports the person to realise, accept, transform, and manage the disease to oversee their health.

5.5 Chapter Summary

The chapter addressed the variations in self-care management of participants coping with COPD and how they managed their disease. This chapter also highlighted the processes and phases involved in disease management. The overarching theme of 'Being in Charge' of one's health and its components was discussed in detail. The next and final chapter presents the implications of these findings and recommendations for future research.

Chapter Six: Reflections, evaluations, recommendations, and conclusion

6.1 Chapter Introduction

The previous chapter presented the findings of this research study and related the findings to existing literature. This final chapter commences with the reflections of the candidate during her candidature. The chapter also reiterates the study findings, and the strengths and limitations of the study are also evaluated. The recommendations from this study regarding practice, education, research, and policy are also narrated.

This study has manifested the overarching theme of 'Being in Charge' in the management of COPD, which represents the processes and phases involved in coping with COPD by the study participants. The variations in self-care interventions of participants in managing their disease appropriately to prevent associated complications were also discussed, supporting the overarching theme of 'Being in Charge'. The key themes of the study were the realisation of disease and reaction to disease, acceptance of disease, transformation and empowerment, and symptom management.

6. 2 Reflections on the Study Process

The candidate has been a registered nurse since 2003 and has worked in a clinical setting, primarily in acute care, until 2023. Since moving to Australia in 2009, the candidate has mainly worked in a medical ward that specialised in providing care for respiratory, renal, and gastroenterology patients. The experience in managing patients with respiratory ailments, particularly chronic obstructive pulmonary disease (COPD) and type one and type two respiratory failure, made the candidate curious about the self-management of patients who avoid frequent hospitalisations. This clinical curiosity was the catalyst for pursuing this research study.

The first year of the candidature was overwhelming, but the candidate was determined to prepare for the literature review and confirmation seminar. The setback with her own health, leading to major surgery and recovery, was utilised wisely by the candidate to complete the literature review and prepare for the confirmation seminar. With close supervision and the support of her advisors, the candidate proceeded through the first year. Preparations to publish the literature

review were despairing, especially with the delayed response from journals. The candidate attended compulsory and several elective professional development workshops, which helped her to some extent in the research study.

At the beginning of the second year, the candidate opted for a change in the work area and no longer worked in the clinical area for the rest of this project. This was a challenge with the research project, as being away from the catalyst, the candidate had to remind herself of the necessity to continue the project. The workload increased dramatically, and the candidate needed to be more strategic and organised. The application for Human Research Ethics Committee (HREC) approval for the project, along with organising and reviewing the literature review, were both daunting tasks. It was delightful when approval from HREC was obtained. Even though approval was obtained in Aug 2023, the candidate only started data collection in February 2024 because the candidate opted to take a break from the project.

The phase of data collection imposed more pressure on the candidate, requiring her to be more organised. Even though the candidate was overstretched with all her commitments, she was even more motivated when she met the participants. The candidate found it was encouraging to talk to the participants to learn about their experiences coping with COPD. Doing the interviews and listening to the stories of study participants was motivating, and the candidate gained insight into how one can cope with any chronic disease. Their stories have inspired the candidate to think and act that nothing is impossible. At the end of data collection, the candidate was delighted. The candidate has learned a lot from her participants, especially how to deal with what you have, rather than getting worried and depressed.

The candidate transcribed the data soon after the interviews, and preliminary analysis commenced at the same time. The candidate was immersed in the data and found the similarities and differences in each study participant during interviews. Another challenge was data analysis. The candidate needed to attend data analysis training, re-read articles, listen to recordings, and learn the data analysis software to master the analysis process. The support and guidance of the advisory panel were exceptional. Data analysis was completed, and key findings emerged.

The candidature involved achieving different milestones, which also included the preparation of a Pre Completion Evaluation (PCE) seminar and submission of the thesis within two months of completion of the PCE. This was a challenging time with work and parental commitments, and the candidate had to be well organised and efficient to use the time wisely to meet the deadlines. Each draft chapter was provided to the advisory panel for review, and prompt feedback was received to assist in updating the draft chapter. The writing skills improved, and so did the confidence as well. Rejections of the literature review from journals did not discourage the candidate from submitting to subsequent journals.

This journey was not easy, but it has taught the candidate the value of self-discipline, the importance of organisation, perseverance, and hard work. The experiences shared by the study participants gave the candidate an in-depth knowledge of how difficult it is to live with COPD, which the candidate had never realised during her clinical work. Apart from learning how to do a research project, reviewing the literature, analysing data, and preparing for publication and presentation, this journey has taught the candidate how to be resilient and move forward in life. The candidate would like to wind up this reflection on the research journey, remembering what one of the study participants said casually after data collection: "Look for what you can do, not what you cannot do".

6. 3 Strengths and Limitations of the Study

This study explored the self-care interventions of the participants, which included data collection via semi-structured interviews followed by data analysis and is characterised by several strengths. However, there were limitations as well. The strengths, limitations, and measures taken to mitigate these limitations are also described in the subsequent paragraphs.

6.3.1 Strengths

The strengths of the study are discussed in detail. The study had a clear, predefined research question, which ensured the research was practical and ethical and assisted in generating quality data. The methodology of the study is clearly stated and provided a framework for establishing the credibility of the data. The predefined inclusion and exclusion criteria ensured that study participants represented the target population. The study was conducted to align with ethical

principles of respect, justice, beneficence, research merit, and integrity. The use of field notes, memos, concurrent data collection and analysis, and coding processes was the method used to contribute to the rigour of this study. The candidate interviewed the participants, performed the transcription, and analysed the data concurrently. The study comprised distinctive findings that were not evident in the previous studies. This study also confirmed the similarities of other findings in other literature related to people coping with COPD.

Another positive feature of the design was the knowledge by the participants that the researcher was not a part of the hospital staff; rather, the researcher was a non-judgmental person with whom they could chat and talk honestly about their difficulties. People were open, and the researcher understood what they were talking about because of the researcher's clinical knowledge and experience caring for patients in acute settings. The study participants were from diverse backgrounds, with ages ranging from 54 to 87 years. Ten out of 11 interviews were conducted face-to-face, so the researcher could observe the participants' nonverbal communication and take field notes. The open-ended questions with semi-structured interviews enabled the participants to fully share their experiences with the researcher.

This study was conducted in a regional area, the city of Townsville. In regional cities, people must manage with the minimal resources they have in comparison to the metropolitan areas with easier access to all services and resources. People living in other regional areas can relate to the experiences of the study participants and incorporate their strategies.

Even though the interviews were conducted outside the usual residence of participants, participants chose the place to be interviewed. They had to travel, but they were relaxed; the interviewer could see them. The main goal of the study was to find out self-care activities that kept people out of hospitals, and by avoiding home interviews, the appropriate cohort of people was obtained, who could provide the data needed to answer the research question.

6.3.2 Limitations

The limitations of the study are detailed as follows. The sample selected for this study was people diagnosed with COPD. This study was qualitative and

exploratory, looking at their experiences in coping with COPD, and did not explore any other facets of COPD management. The results obtained from this study may not apply to different cohorts of samples. The participants were only from the regional city of Townsville, Australia. The findings may not represent the metropolitan population of Australia. There might be possible variations in the study findings of samples from metropolitan locations.

Another limitation of this study is the absence of data on participants' ethnicity and race. The research team was cautious about the possibility of identifying participants from the regional city by revealing their race and ethnicity, which could breach confidentiality and privacy. Additionally, this was not central to the research topic; it is acknowledged that ethnicity and race can influence health experiences and disease perception, and their omission may limit the generalisability of the findings. Future research should consider including these demographic factors to better understand potential cultural or racial differences in COPD management.

The interviews were conducted outside of the study participants' usual residence, requiring them to meet the candidate in a public space. But participants were relaxed as it was not their home, and the interviewer could observe them. To mitigate the inconvenience caused, interviews were conducted at a place suggested by the participants. The researcher had to visit the place before confirming the date of the interviews to ensure the venue of the interviews would be safe. At times, the surroundings where the interview was conducted were noisy and had the presence of others.

The researcher had to schedule interviews as per the existing work commitments. Participants were made aware of the researcher's work commitments and the availability of conducting interviews only on specific days during screening phone calls. All participants were considerate and accommodating. The time constraints affected the data collection and data analysis, but were minimised by spacing out interviews, doing transcription soon after interviews, and taking field notes and memos.

The researcher had to refuse to interview unwell people who were not able to travel. This study only had participants who were well enough to travel; the experiences of people with the latent phase of COPD might vary. Also, there might be people who are not managing COPD effectively, and their experience was not

captured. The interviews with unwell people could have resulted in different results and may not have answered the research question for this study.

All the study participants were well and had a positive attitude. Exploring a sample of patients with different stages of COPD might produce different findings. The main aim of the study was to find out about self-care activities that kept people out of hospitals, and the sample with a positive attitude assisted in answering the research question aptly and was able to identify success strategies that are valuable to teach other patients.

6. 4 Recommendations

An in-depth understanding of the experience of study participants was obtained through data collection. This understanding will be of benefit in designing educational interventions or practice parameters to better support people coping with COPD. Recommendations arising from this study are detailed under four subsections: research, policy, education and research.

6.4.1 Research

This study recommends future research in various areas. This study developed a concept of how people with COPD cope with their disease. Research is required to investigate whether this process is similar to other chronic diseases. This study only identified people with positive outcomes in coping with COPD. Thus, a further study with COPD patients in acute care will be beneficial to understand what other outcomes can be achieved. Future research should include people in different stages of COPD. A research study to explore the experiences of people who are not coping well with COPD can be beneficial to understand the different aspects of self-management and to obtain contrasting results. Repeating a similar study with a different type of population is another area that should be explored.

6.4.4 Policy

Recommendations arising from this study can prompt changes in policies. Providing sources of information about COPD by the Government and healthcare facilities should be mandated by policy. Launching an organisation specifically for COPD would be beneficial for the development and dissemination of information and

the collaboration of activities. Establishing a support group and a credible, professionally updated website that people can approach to gather information would be beneficial to explore more about COPD management. Monitoring the continuity of health education received by patients by clinicians should be made mandatory to improve the outcomes of this chronic disease. The distribution of information through social media groups should be monitored and reviewed by the Government and stakeholders involved in managing COPD. The stakeholders should also inform people to increase awareness about the credibility of information that is being shared on social media.

6.4.2 Education

The recommendations from this study in terms of education are varied. The notion of overseeing one's disease or health can be introduced in the management of COPD and can be included in the curriculum for clinicians, especially in chronic disease management. Clinicians' awareness of the actual experiences of people will assist in appropriately educating and empowering patients with COPD or other chronic diseases. Introducing the overarching theme of 'Being in Charge' to the clinicians will educate them. Clinicians will be able to guide patients to increase their awareness of coping with COPD or other chronic diseases. The overarching theme of 'Being in Charge' can be introduced during workshops or professional development activities for clinicians. Introducing educational sessions and workshops for patients at the earlier stages of diagnosis, mainly at the primary care level in collaboration with the multidisciplinary team, may assist in improving patients' awareness of disease management. These educational sessions not only assist patients in increasing their awareness but also help to identify the obstacles in the effective management of this chronic disease. Early identification and education assist in managing the condition at an earlier stage rather than later and will minimise readmissions and economic burden caused by the disease. As Nelson Mandela once said ~~in his speech~~, "Education is the most powerful weapon which you can use to change the world" (Mandela,1990), and by educating our patients and clinicians, we will be able to change the lives of these patients.

6.4.1 Practice

The impetus of this study was to find out self-care activities that kept people out of hospitals. The success strategies of all the participants are valuable to teach

people how to cope with this disease. In acute clinical practice, our encounters are with only a small subset of people who are sick and dependent. This is a distorted view of the people coping with COPD in the community. The success strategies of participants can be shared with those acute people to engage better in self-care in the future. Clinicians, including general practitioners, need to ensure they have provided education to people with COPD while working with them to align with person-centred care. Clinicians should acquire and enhance their skills in recognising people's difficulties in coping with COPD. People coping with COPD can be non-compliant or have difficulties adhering to their recommended management. By identifying and correcting the reasons behind this noncompliance or difficulties, the patients may have better or more positive outcomes. Creating a plan/ opportunity to engage and empower patients in collaborative decision-making through education and support is beneficial. Introducing educational sessions in collaboration with the multidisciplinary team at the earlier stages of diagnosis will lead to disease awareness and effective management of the disease. Introducing support groups specifically for COPD patients and encouraging patients to be involved in the group will assist them in sharing their experiences among them. The support groups will work as a catalyst for the participants to be active and a venue to discuss their concerns.

6.5 Conclusion

This study reiterated the context and background along with an in-depth exploration of literature-related attitudes, behaviours, and perspectives of people coping with COPD. It was noted from the literature that despite advances in the management of this disease, people still experience high levels of symptom burden and require frequent hospitalisations related to exacerbations. The methodology and methods used to address the study's research question were described. The research elements, the participants, data collection, and data analysis methods were narrated as well.

The variations in self-care management of participants coping with COPD and how they managed their disease were addressed in the study. This study established the overarching theme of 'Being in Charge' in managing COPD. This concept revealed the phases and processes involved in the journey and experiences of people coping with COPD. The phases of Realisation and reaction, Acceptance, Transformation, and Symptom management unfold the process of learning,

choosing, acting, and sharing, which evolves throughout the patient's journey with COPD.

It was noted from the study that people realised what having their disease entailed when they were diagnosed with COPD. Most of the participants denied receiving any formal education at the time of diagnosis and had only limited exposure to educational activities at later stages of the disease. It was also noted that there are no support groups specifically for COPD. Study participants had varied reactions: the negative reactions evolved into a positive attitude. This transitioned to a phase of acceptance where participants embraced their disease as a part of their lives. With this acceptance and the information received along with their own experience, they entered a stage of transformation and empowerment.

In the phase of transformation and empowerment, participants were found to have insight into the disease and formulated goals. The support system played an important role. The role of general practitioners cannot be excluded from the effective management of COPD. The final phase of symptom management included action plans to manage the symptoms and home modifications.

Findings from this study have shown the lack of education, the important role of general practitioners in disease management, and the necessity of support groups for COPD. The in-depth understanding of the experience of study participants will benefit in designing educational interventions and a framework for practice to better support people coping with COPD. Introducing the concept of 'Being in Charge' in one's disease or health for the management of COPD will assist in appropriately educating and empowering patients in collaborative decision-making through advocacy and support.

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Appendix A

Search history CINAHL

Firefox	https://web.p.ebscohost.com/ehost/resultsadvanced?sid=2ff68064-55c5-...				
S59	32	Expanders - Apply equivalent subjects	View Results (20,711)		
UK		Search modes - Boolean/Phrase	View Details	Edit	
S58		8 AND S57	Expanders - Apply equivalent subjects	View Results (18,962)	View I
			Search modes - Boolean/Phrase		
	S57	S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56	Expanders - Apply equivalent subjects	View Results (2,034,797)	View I
			Search modes - Boolean/Phrase		
	S56	"health beliefs"	Expanders - Apply equivalent subjects	View Results (42,047)	View I
			Search modes - Boolean/Phrase		
	S55	"emotions"	Expanders - Apply equivalent subjects	View Results (50,104)	View I
			Search modes - Boolean/Phrase		
	S54	"thinking"	Expanders - Apply equivalent subjects	View Results (31,686)	View I
			Search modes - Boolean/Phrase		
	S53	"practice"	Expanders - Apply equivalent subjects	View Results (661,071)	View I
			Search modes - Boolean/Phrase		
	S52	"knowledge"	Expanders - Apply equivalent subjects	View Results (278,120)	View I
			Search modes - Boolean/Phrase		
	S51	"perspectives"	Expanders - Apply equivalent subjects	View Results (63,845)	View I
			Search modes - Boolean/Phrase		
	S50	"behaviors"	Expanders - Apply equivalent subjects	View Results (94,311)	View I
			Search modes - Boolean/Phrase		
	S49	"behaviours"	Expanders - Apply equivalent subjects	Rerun	View Details
			Search modes - Boolean/Phrase	Edit	
	S48	"belief"	Expanders - Apply equivalent subjects	View Results (60,607)	View I
			Search modes - Boolean/Phrase		
	S47	"beliefs"	Expanders - Apply equivalent subjects	View Results (47,932)	View I
			Search modes - Boolean/Phrase		
	S46	"feelings"	Expanders - Apply equivalent subjects	View Results (41,170)	View I
			Search modes - Boolean/Phrase		
	S45	"thoughts"	Expanders - Apply equivalent subjects	View Results (15,622)	View I
			Search modes - Boolean/Phrase		
	S44	"opinions"	Expanders - Apply equivalent subjects	View Results (17,858)	View I
			Search modes - Boolean/Phrase		

☐	S43	perceptions"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (96,268)	View I
☐	S42	attitude to illness"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (11,227)	View I
☐	S41	Attitude to health"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (47,658)	View I
☐	S40	Attitudes"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (249,549)	View
☐	S39	viH "Knowledge+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (77,821)	View I
☐	S38	viH "Health Beliefs")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (14,795)	View I
☐	S37	viH "Emotions+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (159,718)	View
☐	S36	viH "Thinking+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (184,108)	View
☐	S35	viH "Behavior+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (1,093,776)	Vie
☐	S34	viH "Attitude to Illness+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (24,563)	View I
☐	S33	viH "Attitude to Health+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (172,237)	View
☐	S32	8 AND S31	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (3,998)	View D
☐	S31	9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (210,607)	View
☐	S30	Agreeableness"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (8,636)	View D
☐	S29	Selftreatment"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (5)	View Detail
☐	S28	Selfmanagement"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (223)	View Det
☐	S27	Selfcare"	Expanders - Apply equivalent subjects	View Results (285)	View Det

			Search modes - Boolean/Phrase		
☐	S26	Self-nurturance"	Expanders - Apply equivalent subjects	View Results (18)	View Data
			Search modes - Boolean/Phrase		
☐	S25	Self-treatment"	Expanders - Apply equivalent subjects	View Results (583)	View Det
			Search modes - Boolean/Phrase		
☐	S24	Self-management"	Expanders - Apply equivalent subjects	View Results (16,823)	View I
			Search modes - Boolean/Phrase		
☐	S23	Coping ability"	Expanders - Apply equivalent subjects	View Results (316)	View Det
			Search modes - Boolean/Phrase		
☐	S22	Cope"	Expanders - Apply equivalent subjects	View Results (17,766)	View I
			Search modes - Boolean/Phrase		
☐	S21	Resilience"	Expanders - Apply equivalent subjects	View Results (2)	View Detail
			Search modes - Boolean/Phrase		
☐	S20	Adjustment"	Expanders - Apply equivalent subjects	View Results (84,209)	View I
			Search modes - Boolean/Phrase		
☐	S19	Coping measures"	Expanders - Apply equivalent subjects	View Results (108)	View Det
			Search modes - Boolean/Phrase		
☐	S18	Coping mechanisms"	Expanders - Apply equivalent subjects	View Results (16,443)	View I
			Search modes - Boolean/Phrase		
☐	S17	Coping skills"	Expanders - Apply equivalent subjects	View Results (2,376)	View D
			Search modes - Boolean/Phrase		
☐	S16	Coping behaviors"	Expanders - Apply equivalent subjects	View Results (698)	View Det
			Search modes - Boolean/Phrase		
☐	S15	Coping behaviours"	Expanders - Apply equivalent subjects	View Results (188)	View Det
			Search modes - Boolean/Phrase		
☐	S14	Coping strategies"	Expanders - Apply equivalent subjects	View Results (10,507)	View I
			Search modes - Boolean/Phrase		
☐	S13	Coping"	Expanders - Apply equivalent subjects	View Results (64,877)	View I
			Search modes - Boolean/Phrase		
☐	S12	VIH "Self-Management")	Expanders - Apply equivalent subjects	View Results (1,924)	View D
			Search modes - Boolean/Phrase		
☐	S11	VIH "Self Care")	Expanders - Apply equivalent subjects	View Results (43,372)	View I
			Search modes - Boolean/Phrase		
☐	S10	VIH "Symptom Distress")	Expanders - Apply equivalent subjects	View Results (1,861)	View D
			Search modes - Boolean/Phrase		

☐	S9	MH "Coping+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (40,122)	View I
☐	S8	1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (72,775)	View I
☐	S7	Chronic airway limitation"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (1)	View Detail
☐	S6	Chronic obstructive lung disease"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (17,214)	View I
☐	S5	Chronic obstructive airway disease"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (16,900)	View I
☐	S4	Chronic obstructive pulmonary disease"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (24,268)	View I
☐	S3	COPD"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (24,808)	View I
☐	S2	MH "Lung Diseases, Obstructive+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (65,534)	View I
☐	S1	MH "Pulmonary Disease, Chronic Obstructive+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (21,589)	

Appendix B

Search history Emcare

Firefox <https://ovidsp-dc2-ovid-com.elibrary.jcu.edu.au/ovid-b/ovidweb.cgi?&...>

☐	# ▲	Searches	Results	Type	Actions	Annotations
☐	1	exp Pulmonary Disease, Chronic Obstructive/	62414	Advanced	Display Results More	Contract
☐	2	(COPD or Chronic obstructive pulmonary disease or Chronic obstructive airway disease or Chronic obstructive lung disease or Chronic airway limitation).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	75393	Advanced	Display Results More	
☐	3	1 or 2	96605	Advanced	Display Results More	
☐	4	Self Care/	35122	Advanced	Display Results More	
☐	5	exp Self-Management/	4277	Advanced	Display Results More	
☐	6	(Coping or Coping strategies or Coping behaviours or Coping behaviors or Coping skills or Coping mechanisms or Coping measures or Adjustment or Resilience or Cope or Coping ability or Self-management or Self-treatment or Self-nurturance or Selfcare or Selfmanagement or Selftreatment or Agreeableness).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	360725	Advanced	Display Results More	
☐	7	4 or 5 or 6	385986	Advanced	Display Results More	
☐	8	3 and 7	3276	Advanced	Display Results More	
☐	9	Behavior/	30151	Advanced	Display Results More	
☐	10	exp Knowledge/	12967	Advanced	Display Results More	
☐	11	exp Thinking/	307212	Advanced	Display Results More	
☐	12	exp Attitude/	619473	Advanced	Display Results More	
☐	13	exp Attitude to Health/	458168	Advanced	Display Results More	
☐	14	exp Perception/	464837	Advanced	Display Results More	
☐	15	exp Emotions/	375385	Advanced	Display Results More	
☐	16	(Attitudes or Attitude to health or Attitudes to illness or Perceptions or Opinions or Thoughts or Feelings or Beliefs or Belief* or Behaviours or Behaviors or Perspectives or Knowledge or Practice or Thinking or Emotions or Health beliefs).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	2621774	Advanced	Display Results More	
☐	17	9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	3618375	Advanced	Display Results More	
☐	18	3 and 17	12680	Advanced	Display Results More	
☐	19	8 or 18	14792	Advanced	Display Results More ...	

1 of 1 17/03/2022, 1:19 pm

Appendix C

Search history MEDLINE

Firefox

https://ovidsp-dc2-ovid-com.elibrary.jcu.edu.au/ovid-b/ovidweb.cgi?&...

☐	# ▲	Searches	Results	Type	Actions	Annotations
☐	1	exp Pulmonary Disease, Chronic Obstructive/	62414	Advanced	Display Results More	
☐	2	COPD.mp.	53483	Advanced	Display Results More	
☐	3	Chronic obstructive pulmonary disease.mp.	55833	Advanced	Display Results More	
☐	4	Chronic obstructive airway disease.mp.	309	Advanced	Display Results More	
☐	5	Chronic obstructive lung disease.mp.	4426	Advanced	Display Results More	
☐	6	Chronic airway limitation.mp.	6	Advanced	Display Results More	
☐	7	1 or 2 or 3 or 4 or 5 or 6	96605	Advanced	Display Results More	
☐	8	exp Self Care/	59400	Advanced	Display Results More	
☐	9	exp Self-Management/	4277	Advanced	Display Results More	
☐	10	Coping.mp.	64020	Advanced	Display Results More	
☐	11	Coping strategies.mp.	15624	Advanced	Display Results More	
☐	12	Coping behaviours.mp.	261	Advanced	Display Results More	
☐	13	Coping behaviors.mp.	1039	Advanced	Display Results More	
☐	14	Coping skills.mp.	3558	Advanced	Display Results More	
☐	15	Coping mechanisms.mp.	2500	Advanced	Display Results More	
☐	16	Coping measures.mp.	159	Advanced	Display Results More	
☐	17	Cope.mp.	41101	Advanced	Display Results More	
☐	18	Coping ability.mp.	593	Advanced	Display Results More	
☐	19	Self -management.mp.	24168	Advanced	Display Results More	
☐	20	Self -treatment.mp.	1493	Advanced	Display Results More	
☐	21	Self- nurturance.mp.	14	Advanced	Display Results More	
☐	22	Selfcare.mp.	155	Advanced	Display Results More	
☐	23	Selfmanagement.mp.	47	Advanced	Display Results More	
☐	24	Selftreatment.mp.	4	Advanced	Display Results More	
☐	25	Agreeableness.mp.	2821	Advanced	Display Results More	
☐	26	Adjustment.mp.	209143	Advanced	Display Results More	
☐	27	Resilience.mp.	37605	Advanced	Display Results More	
☐	28	8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27	409039	Advanced	Display Results More	
☐	29	7 and 28	3328	Advanced	Display Results More	
☐	30	exp Behavior/	1986696	Advanced	Display Results More	
☐	31	exp Knowledge/	12967	Advanced	Display Results More	
☐	32	exp Thinking/	307212	Advanced	Display Results More	
☐	33	exp Attitude/	619473	Advanced	Display Results More	
☐	34	exp Attitude to Health/	458168	Advanced	Display Results More	
☐	35	exp Perception/	464837	Advanced	Display Results More	
☐	36	exp Emotions/	375385	Advanced	Display Results More	
☐	37	Attitudes.mp.	229165	Advanced	Display Results More	
☐	38	Attitude to health.mp.	207074	Advanced	Display Results More	

☐	39	Attitudes to illness.mp.	103	Advanced	Display Results More	
☐	40	Perceptions.mp.	123414	Advanced	Display Results More	
☐	41	Opinions.mp.	38215	Advanced	Display Results More	
☐	42	Thoughts.mp.	29307	Advanced	Display Results More	
☐	43	Feelings.mp.	38797	Advanced	Display Results More	
☐	44	Beliefs.mp.	65252	Advanced	Display Results More	
☐	45	Belief*.mp.	94972	Advanced	Display Results More	
☐	46	Behaviours.mp.	57012	Advanced	Display Results More	
☐	47	Behaviors.mp.	234384	Advanced	Display Results More	
☐	48	Perspectives.mp.	149732	Advanced	Display Results More	
☐	49	Knowledge.mp.	888754	Advanced	Display Results More	
☐	50	Practice.mp.	1150999	Advanced	Display Results More	
☐	51	Thinking.mp.	56684	Advanced	Display Results More	
☐	52	Emotions.mp.	99849	Advanced	Display Results More	
☐	53	Health beliefs.mp.	3412	Advanced	Display Results More	
☐	54	30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53	4654233	Advanced	Display Results More	
☐	55	7 and 54	21802	Advanced	Display Results More	
☐	56	29 or 55	23624	Advanced	Display Results More	

Appendix D

Search history PsychInfo



Search Strategy from ProQuest

02 March 2022 08:51

SEARCH STRATEGY

Set No.	Searched for	Databases	Results
S1	(MAINSUBJECT.EXACT.EXPL ODE("Chronic Obstructive Pulmonary Disease") AND (MAINSUBJECT.EXACT.EXPL ODE("Perception") OR MAINSUBJECT.EXACT.EXPLO DE("Attitudes") OR MAINSUBJECT.EXACT.EXPLO DE("Behavior") OR MAINSUBJECT.EXACT.EXPLO DE("Thinking") OR MAINSUBJECT.EXACT.EXPLO DE("Emotions")))) OR (MAINSUBJECT.EXACT.EXPL ODE("Chronic Obstructive Pulmonary Disease") AND (MAINSUBJECT.EXACT.EXPL ODE("Coping Behavior") OR MAINSUBJECT.EXACT.EXPLO DE("Coping Style") OR MAINSUBJECT.EXACT.EXPLO DE("Agreeableness") OR MAINSUBJECT.EXACT.EXPLO DE("Resilience (Psychological)") OR MAINSUBJECT.EXACT.EXPLO DE("Self-Management") OR MAINSUBJECT.EXACT.EXPLO DE("Self-Care") OR MAINSUBJECT.EXACT.EXPLO DE("Self-Care Skills"))))	APA PsycInfo® These databases are searched for part of your query.	798

Appendix E
Human Research Ethics Approval

Appendix F

Flyer

Exploring attitudes, behaviours and perspectives of people coping with COPD

Have you had COPD for atleast two years?
Are you above 40 years old?
Can you comfortably speak English?

Researchers from James Cook University, Townsville Campus are exploring how people cope with COPD, so that we can help others in the future.

You are invited to participate in the research project because you have COPD.

What is involved?
Participating in an audio recorded interview for approximately 30-90 minutes conducted at a mutually agreeable time, place and method. If you are interested, please contact us on 0493752321

Theresa Joseph
Dr. Kristin Wicking
Dr. Wendy Smyth
Dr. Peter Hartin

 JAMES COOK UNIVERSITY AUSTRALIA

 COPD Chronic Obstructive Pulmonary Disease

Flyer- Coping with COPD_ Version 2 , 26 Jul 2023

Note: Source: CC BY-NC-ND, 2023

Appendix G
HREC Amendment Approval

Appendix H

Screening Questions



Attitudes, behaviours and perspectives of people coping with Chronic Obstructive Pulmonary Disease (COPD).

Screening Questions

Have you had COPD for at least two years?

Are you above 40 years old?

Are you comfortable talking in English?

Can you understand me?

If the potential participants are eligible, I will ask the following questions to gather more information.

Do you have a COPD action plan/ inhaler to take for panic attacks?

Are you able to meet in person at James Cook University?

If not, what is your preferred method for interviews? It can be via phone or online.

I will require to send information sheet and consent form for you to read before interviews. May I post/email the documents?

Would you like to make a tentative appointment?

Screening questions – Coping with COPD, Version 2, dated 26/07/2023.

Appendix I

Participant Information Sheet



PARTICIPANT INFORMATION SHEET

PROJECT TITLE: "Exploring the attitudes, behaviours and perspectives of people coping with Chronic Pulmonary Obstructive Disease"

You are invited to take part in a research study about Chronic Pulmonary Obstructive Disease (COPD). In this study we are exploring your attitudes, behaviours, and perspectives in coping with this disease. You are encouraged to ask questions about this research project, now or during the project. The study is being conducted by Theresa Joseph, Dr. Kristin Wicking, Dr. Wendy Smyth and Dr. Peter Hartin and will contribute to Theresa's Master of Philosophy (Health) at James Cook University.

Why are you being asked to participate in this project?

You are being asked to participate in the research project because you have COPD. We would like to know more about how you cope with COPD.

What does my participation in the research involve?

If you wish to participate you will be asked to sign a consent form and will be invited for an audio- recorded interview. The interview should take approximately 30-90 minutes of your time including rest breaks or pauses as necessary. You have the right to skip or not answer any questions. The interview will be conducted at a time, method (in person, via phone or online) and place of your choice other than home. A quiet time, alone without any distractions or noises is important for the quality of research.

Do I have to take part in the study?

Taking part in this study is completely voluntary and you can stop taking part in the study at any time without explanation. If you decide not to take part in the study, it does not affect your ongoing healthcare or relationship with healthcare professionals.

What if I withdraw from this research study?

You have the right to withdraw your participation at any time. However, if you decide to withdraw part way through the interview, any information provided up to that point will be included in the data analysis, only if you agree to use the data. If you request not to use the data, it will not be used and will be deleted.

What will happen to the information about me?

Your participation in the study will be confidential. Your contact details will only be known to the researcher and a code name will be used when we analyse the data. The findings from the study will be used in research publications, presentations, and Theresa's thesis. You will not be identified in any way in these publications. The data will be stored in a hard drive, cloud storage and only researchers included in the study will have access to the data. Data will not be used/ shared for any future research to protect and respect your privacy.

What are the possible risks or discomforts involved from being in this project?

The only foreseeable risks from participating in the study is the inconvenience of time. It is unlikely that you will become distressed during the interview. If that happens, we will pause the interview and take direction from you as to whether to continue or not. Similarly, we know that people with COPD

Participant Information Sheet – coping with COPD, Version 2, Date 26/07//2023 Page 1



become breathless at times, so again we will be able to pause the interview until you become more comfortable.

What are the possible benefits from being in this project?

The likely benefit is that you will feel heard and acknowledged. The information we collect may help us to understand more about how to help others manage this disease in future.

Who is organising and funding this research?

This research study is currently undertaken as part of University Degree and is supported by James Cook University staff. This study is being funded by Commonwealth of Australia, Research training program. We value your participation however, there is no payment for your participation.

Further information and who to contact.

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this study or if you have any problems which may be related to your involvement in the study, you can contact Theresa Joseph or Dr. Kristin Wicking. Please find the contact details below.

Theresa Joseph
College of Healthcare Sciences James Cook University
Phone:
Email: theresa.joseph@my.jcu.edu.au

Supervisor: Dr. Kristin Wicking College of Healthcare Sciences James Cook University
Phone:
Email: Kristin.wicking@jcu.edu.au

This study has been reviewed and approved by the James Cook University Human Research Ethics Committee. Should you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information about the conduct of the study or your rights as a participant; or should you wish to make an independent complaint you can contact:

Human Ethics, Research Office, James Cook University, Townsville, Qld, 4811, via telephone (07) 4781 5011 or email at (ethics@jcu.edu.au).

If you would like to know the findings of the study, please provide us your contact details during interview. We can post/email a summary of findings once the project completes in two-three years. Thank you for your time.

Participant Information Sheet – coping with COPD, Version 2, Date 26/07//2023 Page 2

Appendix J
Informed Consent Form

Appendix K

Interview Guide



Attitudes, behaviours and perspectives of people coping with Chronic Obstructive Pulmonary Disease (COPD).

Semi-structured interview guide

Thank you for your time.

Ensure participants' awareness of the study.

The purpose of this interview is to gather your thoughts on your attitudes, behaviours and perspectives in coping with COPD. The interview contains questions and will take approximately 30-90 minutes including any rest/ break. This interview will be recorded with your permission; our conversation will be typed up (and all names and identifying information removed) to assist with analysis. These will be stored securely, with only the research team having access to this recording and the transcript.

There is no right or wrong answer- this is to find out what you think and feel about what you have experienced.

You can skip any questions you wish or stop the interview at any time.

Do you have any questions before you start?

Sign the written consent form.

Verbal check consent for audio recording?

Patient information and demographics

1. Let's start the interview by talking about yourself.

Age

Sex

Marital status

Work

Support person

Assistive devices used

Services etc

Patient journey of diagnosis and awareness of disease

2. Can we talk about your disease and your awareness of the disease.

Details of the illness

How COPD was diagnosed

When COPD was diagnosed
Changes to the symptoms at the time of diagnosis and now
Awareness about the disease
Involvement in educational activities, support group

Effect of symptoms on life

3. How do you feel living with the disease

What changes that has occurred because of the disease

Any distressing symptoms
Changes in life because of these symptoms
Feeling of living with the disease
Thought that comes to mind at the start of a day and throughout.
Challenges in life because of the disease
Any concerns or fear

Strategies used to relieve your symptoms.

4. Have you done anything different in your life after being diagnosed with COPD

Changes to your environment
Adaptations used
What are the barriers, and enablers to relieve symptoms?
Any other support in managing
Important goal of living with COPD.

Hospitalisation

5. Have been to the hospital for treating COPD

Any recent hospital admissions
When was the last time/how many days, frequency?
Changed anything after hospital admission?
Does that help?

Concluding thoughts

6. Thinking back, is there anything that you could have done differently?

7. Is there anything else that you would like to add?

8. What advice would you give to someone who is newly diagnosed about managing COPD based on your experience?

9. Would you like to be notified of the study findings?

Thank you for your time.

Interview guide – Coping with COPD, Version 2, dated 26/07/2023

Appendix L

Summary for Participants

The Story of 'Being in Charge'

The study showed that people with COPD go through four phases to manage their illness. The first is realising the disease and their reaction, which happened when they received their diagnosis. For most, this was incidental, and they only had a few hospitalisations because they managed their condition well. Many did not receive formal education at diagnosis, but their understanding grew as their disease progressed.

As they gained more knowledge about the disease over time, they became better at understanding its symptoms, recognising their strengths and weaknesses, understanding the habits that might contribute to it, the challenges posed by current systems, and what to avoid when managing it. Although each day often felt like a challenge because of the restrictions the disease placed on their lives, they tried to face these obstacles by slowing down and taking small, manageable steps. Many participants initially felt fear and negative reactions, but they gradually changed their thoughts and grew more optimistic about life. The education they received played a significant role in helping them better understand the disease. Their ongoing learning process was encouraging and helped change how they responded to the condition. Most of them stayed active and full of energy, and none of the participants felt they were a burden to their family members.

The next 'Acceptance' phase helped participants acknowledge their illness, shifting their understanding and fostering a realistic view of life. This transition from recognising the illness to transformation allowed them to embrace their situation, changing their perspective and accepting their reality. Recognising no further improvement helped them overcome denial, resistance, and grief, giving them purpose to move forward. Participants accepted their condition, planned futures, and made lifestyle changes to manage it. 'Choosing' begins in acceptance and continues afterwards.

The transformation and empowerment phase followed acceptance, with participants' perceptions shifting to accepting their illness. This changed their outlook, making them grateful to be alive. They learned to live with their condition, felt motivated, and set goals. They also knew what to avoid in managing their illness, which they shared as advice for others. The support system was vital during the transformation, comprising general practitioners (GPs), support personnel, and various services. Participants relied on family, friends, or hired support. Some cared for family members instead of being cared for. Although involved in community groups and social clubs, only one participant was aware of the lung disease support group and believed such a group for COPD would have been

beneficial. These activities kept participants active and boosted mental health. The role of the general practitioner was important, though experiences varied. The GPs mainly diagnosed the condition but often offered limited information or managed the disease poorly. One participant trusted her GP fully but found it hard to approach others. The 'Choosing' process continued as participants adapted and used support networks.

The final 'Symptom management' phase involved following an action plan and using assistive devices, with 'Acting' exemplified. Staying active was key, along with breathing exercises, medications, inhalers, and relaxation techniques like beach visits, box breathing, open windows, and using lifts. To prevent infections, some shopped during quieter times or online. Planning and pacing were vital, with participants slowing down, breaking tasks into smaller parts, allocating more time, and organising their days. Recognising worsening symptoms and when to seek help improved disease management. Participants monitored the weather, stayed mindful of their surroundings, and avoided smoking. Sharing knowledge and supporting others were also key during this phase.

The stages of realisation, acceptance, transformation, and management shaped how participants handled their disease, involving learning, choosing, acting, and sharing throughout their lives. As they progressed, their skills improved, boosting motivation. This motivated them to control their attitudes, behaviours, and outlooks, enabling them to 'Being in Charge' of their health.

Appendix M

Infographics

Being in Charge

Attitudes, behaviours and perspectives in coping with COPD

Realisation

Realisation involved understanding your condition and its impact on daily life. This understanding helped you to overcome your fear and to stay active. The process of learning led to the next stage.



Acceptance

Acceptance means acknowledging your condition and adapting to the changes it brings. The process of choosing began at this stage.

Transformation

Transformation represents the journey of change toward a healthier lifestyle and active coping. The support from family members, friends and general practitioners helped you to continue choosing and share your experiences.



Management

The final stage involved using medications, breathing exercises, relaxation techniques, and shopping on quieter days to stay in control of your disease.

You should:

- Ask for updated information on management
- Be active
- Empower yourself to manage your condition
- Get involved in support groups.

Thank you for your invaluable contributions to our study!



Appendix N

Publication under review

Name of publication

Attitudes, behaviours and perspectives of people coping with Chronic obstructive pulmonary disease: A narrative review

Contribution Roles Taxonomy

Theresa JOSEPH: Conceptualisation (lead); Data curation (lead); Writing – original draft (lead); Formal analysis (lead); Writing – review and editing (equal)

Dr. Kristin WICKING: Conceptualisation (supporting); Data curation (supporting) Methodology (lead); Writing – original draft (supporting); Formal analysis (supporting); Writing – review and editing (equal)

Dr. Wendy SMYTH: Conceptualisation (supporting); Data curation (supporting) Methodology (supporting); Writing – original draft (supporting); Formal analysis (supporting); Writing – review and editing (equal)

Dr. Peter HARTIN: Conceptualisation (supporting); Data curation (supporting); Writing – original draft (supporting); Formal analysis (supporting); Writing – review and editing (equal)

i. Abstract

Aims: To explore the attitudes, behaviours and perspectives of people coping with chronic obstructive pulmonary disease.

Main problem: Chronic Obstructive Pulmonary Disease is a significant cause of dysfunction and a major and increasing cause of disability worldwide, which is identified as the third leading cause of death worldwide and has caused 3.2 million deaths in 2019. The severity of the symptoms varies with disease progression.

Methods: A narrative review was undertaken to gather a complete picture of the literature. Four databases CINAHL, Emcare, MEDLINE and PsycINFO were searched until the 6 March 2022 using combined MESH and keyword searching terms. Full text articles were assessed for eligibility and thematic analysis was performed.

Results: Twenty-five qualitative studies met the inclusion criteria, from eighteen countries. Four themes were identified: awareness; adaptation; assistance and adversity. Most of the studies noted that COPD has significant impact on people's daily life, requiring modification to their behaviours and perspectives. Level of education, family support and socioeconomic status played an important role in the management of disease.

Conclusion: The findings highlighted the importance of people's attitudes and perspectives in ongoing management of this debilitating disease and the multiple contributory factors influencing the ongoing management of the disease.

ii.Keywords: COPD, Chronic obstructive pulmonary disease, Coping strategies, Attitude, Narrative review

iii. Main text

1. Introduction

Chronic obstructive pulmonary disease (COPD) is a lung disease with irreversible, progressive obstruction of airways [1, 2] and is common in nature.[3] It is slowly progressive and has minimal or poor mutability to the bronchodilators.[4] The chronic airflow limitation which is

specific to COPD varies from person to person and progresses at different rates over time.[5] People with COPD experience varying levels of symptoms and activity limitations along with poor health outcomes despite medical management. At times because of the complexities of coping and similarity in symptoms it is difficult to recognise COPD from other respiratory conditions.[4]

2. Background and Significance

According to Robinson and Scullion,[4] COPD causes extensive damage to society both directly and indirectly and is linked to increased health economic costs.[6] The relationship between COPD exacerbations and the cost of care increases as the disease progresses.[7] The GOLD report,[7] noted that in European Union, COPD is attributed to more than half of the annual health care budget for respiratory disease (56%) while in the United States of America, it is expected to be \$40 billion per year. The cost of COPD is estimated \$977 million in 2015-2016 in Australia [8] and does not include the value of care provided to people suffering from COPD by family members.[7]

The World Health Organisation [3] identifies COPD as the third leading cause of death worldwide and caused 3.2 million deaths in 2019. Reports reveal the number of COPD patients was approximately 212 million worldwide.[9] Toelle et al. [10] stated that the pervasiveness of COPD in Australians aged 40 years and 75 years is 7.5% and 29% respectively. Consultation rates for COPD are four times more than for angina and are the second most common cause of emergency admission to hospital with an average length of stay of 7.5 days in the United Kingdom.[4]

Medical management of COPD mainly concentrates on approaches to reducing disease progression and management of symptoms.[11] Ineffective management of COPD leads to the deterioration of symptoms and influences welfare and quality of life.[12] The importance of self-management programs and coaching by health care providers is emphasised in the GOLD: Executive summary.[6] Even though the effects of self-management programs and pulmonary rehabilitation programs are well researched and supported by the healthcare system, the ingress and uptake of these programs are far from ideal.[13]

Prior research has emphasised the importance of adequate coping strategies in dealing with the burden of COPD especially breathlessness, but not the attitudes, behaviours, and perspectives of people coping with the illness. This study aims to explore the attitudes, behaviours, and perspectives of people with COPD coping with their illness in their daily living. Even though attitudes, behaviours and perspectives are interconnected constructs, there are some distinctions between them. Examining these aspects from the people coping with COPD will assist in exploring the strategies people are using or trialing to prevent exacerbations, anxiety attacks and hospitalisation and will give an insight into how people attempt to preserve their quality of life.

3. Aims

The aim of this literature review was to identify literature about the attitudes, behaviours or perspectives of people with COPD, with a particular focus on patient-initiated self-care interventions other than pulmonary rehabilitation, education programs, smoking cessation and medication management. The research question guiding this literature review was "What are the attitudes, behaviours and perspectives of people coping with Chronic obstructive pulmonary disease?"

4. Methods/ methodology

4.1 Designs

The narrative literature review was conducted systematically to gather a complete picture of the literature but did not include a quantitative analysis as would be found in a Cochrane systematic review.[14] A thematic analysis approach using literature review matrix method of analysis as per Aveyard,[14] was used to analyse the themes.

4.2 Search Methods

Four databases- CINAHL, Emcare, MEDLINE (Ovid) and PsycINFO were searched. The following combined MESH and keyword searching terms were used to identify a wide range of studies, ("COPD" OR "Chronic obstructive pulmonary disease" OR "Chronic obstructive airway disease" OR "Chronic obstructive lung disease" OR "Chronic airway limitation" OR "Pulmonary disease, chronic obstructive" OR "Lung diseases, obstructive" OR "Obstructive airway disease"

AND "Coping" OR "Coping strategies" OR "Coping behaviours" OR "Coping behaviors" OR "Coping skills" OR "Cope" OR "Coping ability" OR "Self-management" OR "Self-treatment" OR "Self-nurturance" OR "Selfcare" OR "Selfmanagement" OR "Selftreatment" OR "Agreeableness" OR "Adjustment" OR "Coping mechanisms" OR "Coping measures" OR "Self care" OR "Resilience" OR "Coping style" OR "Agreeableness" OR "Self-care skills" OR "Symptom distress") OR ("COPD" OR "Chronic obstructive pulmonary disease" OR "Chronic obstructive airway disease" OR "Chronic obstructive lung disease" OR "Chronic airway limitation" OR "Pulmonary disease, chronic obstructive" OR "Lung diseases, obstructive" OR "Obstructive airway disease") AND ("Attitudes" OR "Attitude to health" OR "Attitudes to illness" OR "Perceptions" OR "Opinions" OR "Thoughts" OR "Feelings" OR "Beliefs" OR "Belief*" OR "Behaviors" OR "Perspectives" OR "Behaviours" OR "Knowledge" OR "Practice" OR "Thinking" OR "Emotions" OR "Health beliefs"). There were no limitations placed on the search. The search was conducted until the 6th of March 2022 using the keywords. The search strategies for the four databases are included as an additional file in the supporting documents.

4.3 Inclusion/ exclusion criteria

The inclusion and exclusion criteria are detailed in Table One.

Table 1. Inclusion/exclusion criteria	
Inclusion criteria	Exclusion criteria
Literature containing attitudes, behaviours and perspectives of people coping with COPD	Literature containing family and clinicians' perspective only
English language only	Languages other than English
Globally found literature	Literature about not for resuscitation
About human only	Other than humans
Age above 18 only	Asthma as primary diagnosis
	Paediatrics and adolescents

4.4 Search Outcome

The search yielded 20455 papers in CINAHL, 14788 papers in Emcare, 23616 papers in MEDLINE and 799 papers in PsycINFO. After removing the duplicates, 37658 distinct articles remained. No additional records were identified from eligible reference lists by manual searching of primary sources. Title screening excluded 37083 papers. The abstracts of the remaining 575 papers were read and 413 papers were removed as they did not meet the

inclusion criteria. From the remaining 162 articles, seven articles were removed as it was not possible to retrieve the full text. One hundred and fifty-five articles were assessed for eligibility and 130 articles were removed, leaving a total of 25 articles to be critiqued and synthesised.

4.5 Quality Appraisal

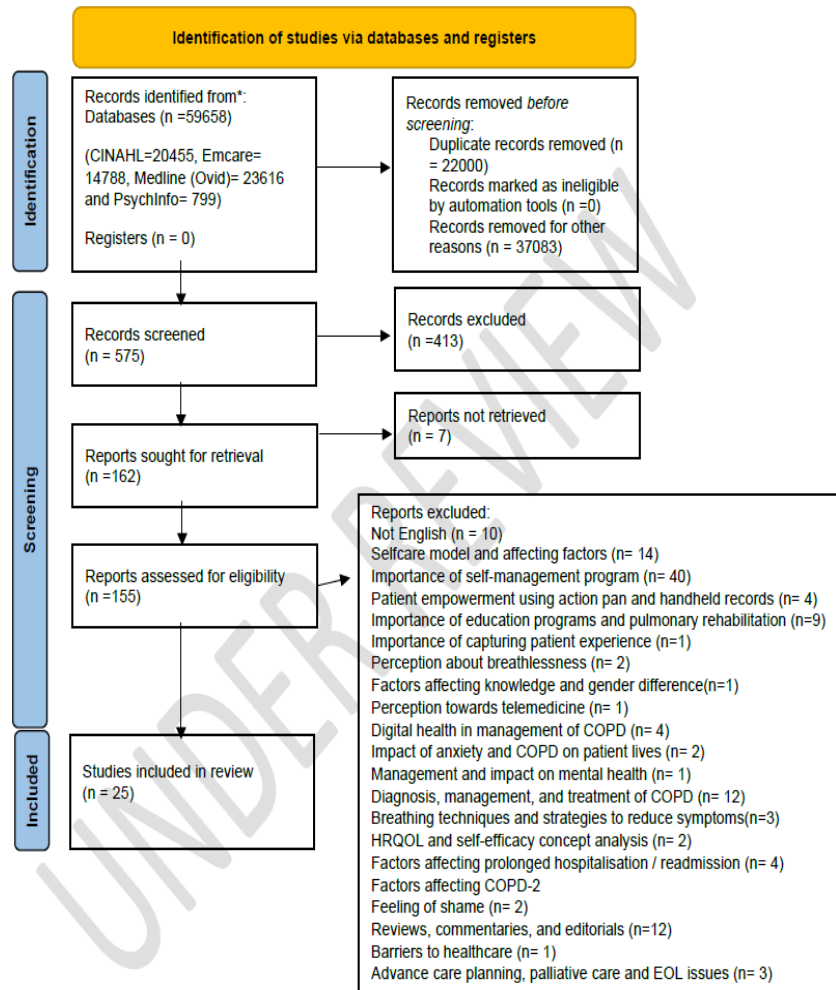
The first author designed the search strategy with the assistance of the co-authors. The key words and search terms were developed by the first author with the guidance of co-authors and were refined as the search progressed. The first author conducted the search and selected the articles that answered the research question. The co-authors assisted in refining the few articles where the first author was unsure about the selection. The first author excluded the articles as per eligibility criteria, read each paper and assessed the quality. The co-authors guided the selection of the quality appraisal tool and assisted in resolving any discrepancies when needed.

The CASP checklist for qualitative studies was downloaded from the CASP website and individual studies were appraised against the ten questions in the CASP checklist. The quality of these 25 articles were evaluated by the Critical Appraisal Skills Program, (15) tool for qualitative research. These studies were identified as valuable with appropriate use of methodology addressing the research issue and demonstrated a clear statement of findings.

4.6 Data Abstraction

Figure 1 PRISMA flow diagram presents the search results.

FIGURE 1 PRISMA flow diagram



4.7 Synthesis

A simplified thematic analysis approach using literature review matrix method of analysis as per Aveyard, (14) was used to analyse the themes by the research team. The lead author created a summary table of the key elements of each of the 25 studies (Table 2 shows a summary of the included studies). Once the studies had been critiqued and summarised in the table, a thematic analysis of key findings was conducted. The research team developed themes and subthemes from the extract of key findings. The PRISMA 2020 checklist was used for preparation and reporting in this review.

UNDER REVIEW

Table 2. Summary of studies

<u>Author /Date</u>	<u>Purpose of study</u>	<u>Study Design</u>	<u>Sample/ Setting/ Country</u>	<u>Method of data collection & analysis</u>	<u>Main Findings</u>	<u>Limitation/ Strength</u>
[16]	Explore the impact of new diagnosis of COPD and the reaction towards the diagnosis in context of multi-morbidity	Qualitative	Sydney, Australia n= 9 males n= 9 females Age: 43 to 84 years	Telephone interviews X 16; in person X 1 Semi-structured interview guide Data collection April to July 2013 Digitally recorded and transcribed verbatim Preliminary thematic analysis and concurrent coding NVivo 10 software	Reaction to diagnosis- shock and denial of the new diagnosis, positive attitude for older participants Impact on function and health behavior- difficulty with daily chores Factors influencing self-management capacity- less knowledge about the disease Healthcare utilisation – lack of communication among health care providers Interplay of comorbidities Low awareness of the disease and its long-term implications leading to suboptimal management Socioeconomic status and level of education had an impact on management of disease	L: Only Caucasian participants L: Newly diagnosed COPD L: Selection bias L: Small scale study S: Samples and themes clearly reported S: In depth analysis was done S: Abstract offered a clear overview S: Sufficient data was included to support findings S
[17]	Describes the perceptions of the impact of the condition and their corresponding attempts to manage symptoms	Qualitative	Primary care COPD registers n=15 (9 female and 6 male) Aged 55-75 years East Midlands, England	Face-to-face, semi structured interviews Digitally recorded and transcribed verbatim Braun & Clarke thematic analysis NVivo software A reflective log was kept	Feeling of frustration – about the condition, lack of knowledge and less information from health professionals Participants independently initiated a range of self-management behaviors such as pacing, adapting activities, distraction, and utilizing social support. Participants were unaware that they were performing self-management behaviors and described a lack of confidence about managing their symptoms because of lack of confidence in the current level of disease knowledge. Importance of family perceptions and involvement in managing COPD.	L: Selection bias L: Small scale study L: Limits generalisability S: Samples and themes clearly reported S: In depth analysis was done S: Abstract offered a clear overview
[18]	To explore and understand	Qualitative	Primary and second-	Face-to-face semi-structured interviews,	Symptoms and impact varied	L: Not much description of the sample

	variations in experiences and coping strategies in COPD patients across different severities of disease and disease impact		ary care sites and a patient volunteer database England n= 34	Dec 2013 to April 2014 Digitally recorded and transcribed verbatim Textual analysis using pseudonyms Reflexive notes Atlas.ti v5.2 for coding and thematic analysis	Varied coping strategies- medication management, PR, activity limitation Support needs Poor QOL is evident in people with maladaptation to disease and has worsened behavioral, psychological and emotional dysfunction.	L: Abstract not offering a clear overview S: In depth analysis was done S: Data saturation reached S: Approaches to minimise bias, a detailed audit trail, negative and deviant case analysis, cross-checking of coding strategies, a multi-disciplinary research team including Patient and Public Involvement input from COPD patients
[19]	To explore the lived experiences of people with COPD following hospitalization for acute exacerbation or pneumonia	Phenomenology	Thoracic and geriatric wards of a medical center Taiwan n=14, 12 men 2 women between 63–86	Semi structured interviews Data collection Jan 2013- 2014 Interview and concurrent data analysis. Data analysis by Giorgi's (1997) method	Impact on daily life Difficulty with tolerance to cold and catching coughs and infections Being a burden to family Striving for wellness- smoking cessation, traditional Chinese medicines Tendency to narrow their activities	L: Single site L: Generalisability L: Participants from one medical centre only L: Small scale study S: Samples and themes clearly reported S: In depth analysis was done S: Abstract offered a clear overview S: Rigor maintained
[20]	To explore the self-management behaviours of patients with COPD to understand how patients	Qualitative, descriptive	Thoracic ward, outpatient department, and the respiratory therapy room in a medical	Semi-structured, face-to-face interviews Data collection November 2006 to April 2007 Transcription by research assistant	Patients chose suitable disease self-management behaviours, based on experience, wisdom and professional guidance. Cultural factors influenced patients' self-management behaviours. Patients integrated environmental control behaviours into their lives.	L: Results can vary in different settings L: Small sample L: Only Chinese L: Only men L: Facility to attend educational programs L: Not able to generalise findings S: Ethical approval was obtained

	manage their disease.		centre, Northern Taiwan n=18, men who had COPD for at least 1 year, Age 55–81 year	and checked by the first author Data collection concurrent analysis Miles and Huberman's (1994) three-step method for analysis	Used a variety of behaviours to manage their disease and to prevent and alleviate symptoms, as well as to maintain quality of life. Participants tended to adopt all five themes of self-management behaviour.	S: Abstract offered a clear overview S: Samples and themes were clearly reported S: Data analysis explained in detail S: Trustworthiness was established
[21]	Understand the day-to-day self-care activities of people living with COPD and the meaning of the activities.	Focus group methodology	Focus group Four in Toronto (n = 25) Three in non-metropolitan areas (n = 17) Canada June to August 2001	Recruitment via posting flyers in doctors' offices and rehabilitation clinics, advertisements in community newspapers and newsletters Interview guide with eight open-ended questions Audio recorded and transcribed Verbatim Transcript coded independently by two team members Constant comparative method of data analysis	Impact of daily activities requiring several lifestyle changes were mentioned Adjusting emotionally was seen as crucial for survival The importance of support from families, peers and health care professionals The importance of family support to accomplish daily tasks and as a crucial enabler of self-care and, ultimately, living life. Peer support was discussed as central to surviving COPD	L: Small scale study L: Purposive sampling L: Not able to generalise findings L: Only participants attended a rehabilitation program was included S: Confidentiality was maintained S: Ethical approval was obtained S: Samples and themes were clearly reported S: Trustworthiness of the data
[22]	To understand the meaning of COPD for people and their response to	Qualitative longitudinal	General practices on the western seaboard, Ireland n= 26	Grounded theory (Corbin & Strass 2008) Data collection - face-to-face semi-structured interviews	Hiding- symptoms were hidden at the beginning. Impact on daily activities Self-initiated steps to reduce symptom burden- participants started to reduce activities to consciously hide symptoms from others Perception of guilt related to smoking	L: Single case study S: Methodological rigor was enhanced S: Abstract offered a clear overview

	this disease.			Data analysis-constant comparative technique NVIVO 9 software	Battling- depends on the severity of disease Daily activities required planning Avoidance of activities at the beginning and eventually stopped doing them when symptoms got worse. Teaching self-management skills improved the burden of hiding and battling Proper education on self-management	S: Purposive sampling
[23]	To describe the essential structure of the lived experience of living with severe COPD during the palliative phase of the disease	Giorgi's phenomenological method based on Husserl's theory of intentionality	Departments of respiratory medicine of two different hospitals Sweden n= 8 (women= 5 men= 3) Age: 48–79 years	Interviews home x 6; hospital x 2 hospital Interviews audiotaped and transcribed verbatim Data analysis method Giorgi and Giorgi (2003a)	Limited living space, changed lifestyle and challenged self-image Lacking physical strength Being socially and existentially alone Increasing dependence causing challenging sense of identity and self-esteem Lack of knowledge about how family interactions are affected when a family member has chronic obstructive pulmonary disease	L: Limits generalisability L: Same geographic location L: Small scale study S: Confidentiality maintained S: Rich in-depth data obtained S: Abstract offered a clear overview
[24]	Explores the perspectives of both patients and family members regarding the impact of chronic obstructive pulmonary disease (COPD) in	Exploratory qualitative study, with a cross-sectional design	Primary care centre, district hospital Portugal October 2011 to February 2012 n=40 (20 patients)	Interviews with open-ended questions and transcribed verbatim Descriptive statistics using Predictive Analytics Software Statistics version 19.0 for Windows Data analysis - thematic analysis (Miles & Huberman, 1994)	Impact of COPD symptoms on personal and family daily life Negative impacts on family activities Participants felt restricted to their home (Over)protective family support Difficulties in couple communication causing an impact on marital relationship Embarrassment to ask their wives to help in activities of daily living Financial strain	L: Selection bias L: Limits generalisability L: Participants were in the chronic phase of the disease L: Single case study S: Confidentiality was maintained S: Abstract offered a clear overview

	their family life		and 20 family members)	Two independent researchers (gerontologists) coded and categorised data into themes in three phases: data reduction; data display; and conclusion drawing/verification	Sense of identity loss Fear of COPD progression Coping resources like positive reappraisal, search for meaning and problem-solving strategies were used by patients	
[25]	Explore how persons living with COPD experience transitions related to health, self-management, and follow-up from the healthcare services	Qualitative	Health unit Rural Norway n= 11 (females= 5, males=6) Age: 62–76 years	Interviews audio recorded Transcribed A qualitative content analysis Perspectives and the transcriptions into NVivo Pro (QSR International).	The struggle to keep going= adaptation to a new way for daily living, the challenges of changing social roles and function. Knowledge of disease helped: self-management courses gained knowledge and received guidance and made contacts that gave possibilities for further follow-up. Interaction with the healthcare services- great variation in what healthcare services the participants had received, from whom, and how satisfied they were with the interaction with the individual healthcare worker. Feeling of guilt – self-inflicted diseases The need for continuity and competent facilitation = rehabilitation and training as a kickoff for the everyday drudgery Competent helpers to contact - COPD is not a topic with the primary physician and the emergency room with no idea of what is going on. If patient learned to live with, and adapt to, the changes that arose, a good life is possible	L: Limits generalisability S: Confidentiality was maintained S: Abstract offered a clear overview

[26]	To explore how patients with COPD cope with their chronic disease, and their needs and perspectives regarding COPD management and its impact on their quality of life.	Qualitative	COPD clinic - Royal Medical Services Hospital, Amman, Jordan n = 28 in five focus groups	Focus groups discussions in Arabic Interviews audio-taped and transcribed Transcriptions translated into English, back to Arabic by two expert and independent translators to guarantee content consistency, and then the English version was utilized. Content analysis-approach described by Lennon et al for data analysis	Poor knowledge about their disease and a lack of information about its etiology and management. Participants suffered from physical inability to perform even simple tasks. Participants described a general feeling of exhaustion, tiredness and slowing down of life. Participants described the psychological impact of the disease from two perspectives: the majority focused on what they had lost, and they spoke in terms of feeling helpless, overwhelmed and reliant on medication and hospital intervention. Others spoke of their coping mechanisms, the changes they had put in place and the need to keep looking on the brighter side of life, despite their severely debilitating disease. Participants expressed their physical reliance on others such as family members or hospital staff at an early stage of the disease. Sufferers often need help to leave their home and to undertake day-to-day activities such as cleaning, cooking and personal care. Improving patients' knowledge about COPD and its management should strongly be considered in future COPD care programs. Education is required to stop the patients from panicking.	L: Purposive sampling L: Influence of prior beliefs on interpretation of the transcripts was acknowledged L: Possibility of increased impact of censoring and conforming because of focus group technique S: Confidentiality maintained S: Samples and themes clearly reported
[27]	Identify and describe the symptom burden and its effect on daily life in people with	Qualitative	Specialist lung or COPD reception at three hospitals	Individual face-to-face interviews with an interview guide Digitally recorded and transcribed verbatim	An altered everyday life which is challenging Prioritising daily activities to cope with energy demands Feeling of being a burden Social isolation	L: Purposive sampling technique S: Every single interview was treated as a unique unit and added to the data corpus without looking for recognition. S: Confidentiality was maintained

	COPD, based on their own lived experiences		Southeast of Sweden March 2015 to June 2016 n=25 (females = 14 males = 11) Age: 58–82	Quotations were originally in Swedish and translated into English Braun and Clarke thematic analysis	Longing for a curative treatment causes the person to experiment with the pharmacological treatment causing overuse of the drugs Fear about the future and knowledge that the disease cannot be cured is both stressful and painful. Feeling of guilt (self-infliction of disease) Adapting to the opportunities in life and taking the day as it comes is a challenge. Need for support from the next of kin as well as society	S: In depth analysis was done S: Abstract offered a clear overview
[28]	To describe how people living with COPD experience and manage everyday life activities	Qualitative	Denmark n= four females four and males Age – 65-87 years	Semi-structured interviews based on an interview guide at participants' home Data collection October-December 2018 Interviews transcribed verbatim alongside data collection Inductive qualitative content analysis (Graneheim and Lundman)	Juggling to manage everyday life activities with COPD Consequences of COPD symptoms Being aware of the body Use of extra time and effort Accepting help while resisting dependence Adjustment of activities	L: Small scale study L: Not able to generalise findings S: Confidentiality was maintained S: Abstract offered a clear overview S: Samples and themes were clearly reported
[29]	To explore patients' perceptions of advanced	Qualitative with grounded theory as	The Canterbury District Health Board	Semi-structured interview QSR NVivo 10 for analysis	Reduced level of activity- loss of recreation Change in home environment caused decline in health, episodes of acute care, oxygen treatment, panic attacks and assistance with self-care.	L: Patients with advanced disease only L: Single case study L: Not able to generalise findings

	COPD and their understanding of a palliative approach to care	methodology	New Zealand n =15	Structural coding Deceptive analysis	All patients with severe COPD see themselves as living with, and not dying of COPD Difficulty with initiating offer of palliative and end-of-life support	L: Data analysis not reported in depth S: Confidentiality was maintained S: In depth analysis was done
[30]	Meaning of living with COPD as an incurable and constantly progressing disease and re-constructed from the patients' perspective	Qualitative longitudinal	n= 18	Qualitative face-to-face interviews at home, hospital or at clinic Interviews were audiotaped, transcribed verbatim but not returned to participants Field notes were made Codes developed using abductive reasoning (Strauss and Corbin) Data analysis using MAXQDA Analysed in German A professional translator translated the passages of the interviews	Difficulty to accept their life-threatening situation and feel at the mercy of the disease. Social isolation Limited knowledge Patients try to maintain daily activities Feeling of guilt Increase of activity limitation and social isolation Benefit of early integration of palliative care and volunteers Provides new insights into patients suffering from progressive COPD and end-of-life care	L: Purposive sampling S: Confidentiality was maintained S: Samples and themes clearly reported S: In depth analysis was done S: Ethical approval

[31]	Explore attitudes to COPD self-management, perceptions of GP commitment to PR, and COPD knowledge	Qualitative	Municipal database 'Sundhed sportalen' (HealthPortal) in Copenhagen Denmark 2012–2015 n= 14 (8 women and 6 men, aged 69–65 yrs) with moderate COPD	Semi structured interviews and audio recorded Data generated February–April 2020 Thematic analysis Investigator triangulation Filed notes NVivo	Self-management involved social gradient and worry about future. Inadequate pulmonary rehabilitation support Inadequate COPD information provided by the GP Lack of patient knowledge of COPD led to disease denial and acknowledgment Feelings of self-contempt and embarrassment Positive relationship between resources (e.g., higher education and stronger social network) and COPD self-management. Importance to act on COPD at an earlier stage of the disease to enable activation of patient resources.	L: Strategic sampling S: Investigator triangulation S: Confidentiality was maintained S: Samples and themes clearly reported S: In depth analysis was done S: Abstract offered a clear overview
[32]	To extend knowledge of the experiences of adults living with chronic pulmonary illness, everyday meanings and activities. connections between, individuals' experience	Phenomenology	Three pulmonary outpatient clinics and programs of a large metropolitan city Western Canada n=16 (6 females and 10	Open-ended, conversational interviews, audiotaped and transcribed Additional text for reflection and analysis with close observation of participants' behaviors, expressions of language, autobiographies, the research literature, and clinical	Impact on daily life Participants found themselves slower than they used to be, slower than others, and out of tempo with others. Limiting activities to conserve energy Reaction to the disease -feeling frustrated Effect of cold weather	L: Data analysis not reported in detail S: Samples and themes were clearly reported S: Sufficient data was included to support findings

	s and health professionals' practices		males, aged 35 to 77 years)	experiences of researcher Lens of Merleau-Ponty for interpretation and approach of van Manen for analysis		
[33]	To describe and contextualise the experience of living with severe COPD; inform health care providers of the potentially unmet needs of this population	Interpretative phenomenological analysis (IPA)	Regenerative medicine clinic in Texas Documented stage IV COPD confirmed by pre-interview spirometry n=6	Open ended in-depth interviews with few leading and probing questions Audiotaped and transcribed Analysis using IPA methodology	Making sense of diagnosis- include change in the way do things, lack of guidance, and coming to an understanding of what may have caused the disease Feelings of guilt for past smoking Being a burden, both on others and of the disease on their own body Feelings of depression and anxiety related to worrying about oxygen and of social isolation related to wearing oxygen The struggle of daily living to manage activities of daily living and the effects of COPD on their bodies Perceived quality of life is heavily influenced by an individual's perception of his or her illness.	L: Limits generalisability L: All the participants were white L: Small scale study S: Rigor was enhanced in this by credibility, member checking, and transferability S: Credibility was achieved by the researcher having prolonged engagement with the cohort being studied S: The conclusions are transferable to other situations and further research studies
[34]	To explore COPD patients' experiences, self-reported needs, and needs-driven strategies to cope with self-	Phenomenology	Rehabilitation center, Iceland N= 10 (3 men and 7 women aged between 59 to 74)	Semi-structured in-depth interviews	Reduced participation in family and social life and loss of ability to perform usual activities Carrying out simple tasks necessitated many breaks and being forced to stay at home Tendency to procrastinate and feel bitter and shameful The participants' knowledge about COPD and its prognosis varied Some felt that education regarding the disease had been provided too late	L: All participants were recruited from a waiting list for PR, indicating a certain population bias, as only a minority of COPD patients is referred to PR L: Not much description about recruitment S: Confidentiality was maintained S: Sufficient data was included to support findings

	manage- ment				COPD negatively affected the participants' physical and psychosocial wellbeing as well as their family relationships and social life Financial worries as not able to work because of the disease	
[35]	The aim of the study was to explore how women with COPD experience their daily life at home	Qualitative explorative and descriptive design	General hospital Norway Data collection January - June 2014 n = 9, women aged 63-79	Semi- structured interviews with open-ended questions Qualitative content analysis, using the interpretative contexts identified by Kvale and Brinkmann (2012) Investigator triangulation	Having a good life with COPD despite the limitations: difficulty with housework, living with a positive look about the illness Predictability and confidence in getting help- aware of who to contact for help, feeling safe at home Trust in hospital and health care professional was important The struggle to achieve a balance between insight and compliance with management of COPD.: sufficient knowledge about COPD, ways to manage, available action plan The women experienced a struggle in daily life to comply with COPD management	L: Only women from urban area L: Single case study L: Results can vary in different settings L: Participants from one medical centre S: Investigator triangulation to enhance credibility S: Data collection and the data analysis were discussed with the other authors, which additionally facilitated discussions of competing interpretation S: Transferability was enhanced by descriptions of the participants, collection of data and the process of data analysis, in addition to enriched descriptions of the results with relevant quotations S: Abstract offered a clear overview
[36]	To ascertain the meaning of the experiences that individuals	Qualitative study based on Martin Heidegger's hermeneutic	Health institute in the city of Manizales (Caldas, Colombia) n=10	In-depth interviews focused by an initial question guideline The data were gathered and analysed simultaneously	Awareness of the disease: All patients knew that their disease was incapacitating and progressing towards a physical and emotional deterioration by a coping mechanism based on problem-solving. The symptoms especially breathlessness made it difficult to carry out daily activities.	L: Small scale study L: Single site study S: Credibility was ensured with continued observation of the phenomenon using various interviews.

	with serious and very serious COPD encountered, to provide information relevant to nursing care from the subjective perspective of those who had this disease	pheno- menology		Superficial analysis, in depth analysis and triangulation were used The criteria established by Guba and Lincoln	Constant use of inhalers and oxygen to cope with the symptoms. Another coping system described is related to religiousness, which increases as the disease progresses. Feeling of anxiety along with disease burden (involve their family members mistreating them, being abandoned, not being considered, and being embarrassed because of the care that has to be given them by the members of their own family with whom they do not feel close enough) Limited communication between them and the health professionals Different meaning to symptoms and functional changes in daily moments and times of exacerbation Changes in lifestyle and adaptation strategies	S: The mechanism of triangulation was used for auditability or reliability of the information, submitting it to another researcher's analysis S: Transferability was applied, contrasting the findings first with the study question and then with other similar studies S: In depth analysis was done S: Abstract offered a clear overview
[37]	To identify how patients recognise and manage exacerbations at home.	A qualitative, interview-based study	From primary and secondary care settings in Oxford, UK, during 2012–2013 n= 44 (17 women, 27 men; age range	In-depth interviews, at patients' homes Audio-recorded, transcribed verbatim NVIVO 10 to store, organize and analyse data Analysis by grounded theory approach and included constant comparative method; open, axial and selective coding and memo-writing to identify theoretical	Difficulty with daily activities Identifying the symptoms Self-managing with inhalers and medications prior to contacting health professionals Patients particularly notice physical limitations, and found to be an important change to patients than respiratory symptoms Uses experiential knowledge to assess both objective signs and subjective 'invisible' chest sensations, including breathlessness and bodily changes Health-care professionals and clinicians should acknowledge this 'expert patient' knowledge and integrate this into patients' care plans to facilitate early recognition and treatment of exacerbation	L: Purposive sampling L: Results can vary in different setting L: Limits generalisability as recruitment was part of a clinical trial with strict eligibility criteria S: Analytical processes discussed in depth throughout the study among the research team members. S: Interviewer had extensive training in qualitative research methods S: Abstract offered a clear overview

			55–85 years),	links and concepts from the data		S: Two interviews were coded by an experienced qualitative researcher external to the project to ensure rigour of the coding process. S: Research team met regularly to review and discuss the analysis process and interpretation of data to aid transparency and credibility of findings
[38]	To explore the perceived needs and expectations of patients with regards to their lifestyle, management, and adaptation towards the disease.	Qualitative method	Tertiary hospital, urban suburb of Kuala Lumpur, Malaysia in 2012 A total of 8 FGDs (4 with a total of 18 male patients and 4 with a total of 18 doctors)	Focus group discussions (FGDs) using a semi-structured topic guide Thematic analysis Transcripts coded independently by two researchers There were few discrepancies in coding, which were resolved by discussions and consensus was made	Knowledge and awareness of COPD- unfamiliarity with the term COPD Effect on daily activities -psychosocial and physical impact The utility of self-management Experience a loss of intimacy (One patient expressed difficulty in performing sexual intercourse) Loss of social interaction and bonding Only study that has examined patients' experiences of COPD from the doctors' perspective	L: All patient participants were male L: Convenience sampling by research assistant S: The focus group discussion was led by a researcher who was not directly involved in the management of the patients S: Abstract offered a clear overview
[39]	To describe the results to guide development of cognitive-behavioural interventions for self-manage-	Qualitative study	From University of Texas Health Science Center at Tyler n=54	Interviews Coded into non-hierarchical thematic categories in an inductive approach using grounded theory methods	Loss: loss of normal functioning, independence, social contacts, and loss associated with other medical conditions Fear: about disease progression and suffocation Desire for improved care: lack of self-management support and a general lack of understanding of their condition	L: Results can vary in different setting L: Limits generalisability S: Confidentiality was maintained S: Samples and themes clearly reported S: Ethical approval was obtained S: Rich in-depth data obtained

	ment support of patients with COPD					
[40]	To understand the lived self-care experiences of patients with COPD and to explore the role of the family in self-care care	An interpretive phenomenological inquiry	Out patient pulmonary clinic at two public hospitals in Northern Pakistan n= 13 aged above 30 years Data collection from September to December 2019	Semi-structured interview guide The interpretive analysis was based on Ricoeur's interpretation theory (Ricoeur, 1976) The trustworthiness criteria (Guba & Lincoln, 2005) were used to establish rigor	Daily struggles – physical and emotional struggles affecting self-care Fear of putting burden on families for assistance with daily needs Believing in spiritual and traditional healing – spiritual approaches to healing Alternate ways to manage selfcare- hospitals, community workers Role of family in patient selfcare support Reliance on family and emphasis on traditional interventions for disease management	L: Not able to generalize S: One experienced researcher and other attended training S: In depth analysis was done S: Abstract offered a clear overview

LEGEND: PR = pulmonary rehabilitation

5. Results

Twenty-five studies, all of qualitative design, met the inclusion criteria. The studies were published between 2004 and 2021. The sample sizes of these studies ranged from six to 54 participants, with participants aged 40 - 85 years. Semi-structured interviews were the main method of data collection for twenty-three studies, while the remaining two studies used focus groups. Non-participant observation and field notes were used along with interviews for collecting data.

All 25 studies reported about people coping with COPD and the numerous behavioural changes and support system in their day-to-day life. [16-40] Appropriate research design and data collection methods were used, and all 25 studies had human research ethics approval. A summary of the key features of the 25 articles can be found in Table Two.

The generalisability of the results was limited as they were small scale studies.[41] These studies were from varied geographic locations and results may not be applicable to other areas, due to the cultural differences. The studies portrayed varied stages of COPD ranging from new diagnosis, mild, moderate, and severe stages and discussed the perspectives of people after acute exacerbation. The four main themes identified are awareness, adaptation, assistance, and adversity which portrayed the life of people coping with this disease and can be found in Figure 2.

Figure 2 Themes versus disease progression

"[insert Figure 2.]"

1. Awareness

The theme 'awareness' revealed that consciousness of symptoms, socioeconomic status, level of education and communication of healthcare providers played an important part in the timely management of symptoms. The participants had awareness of symptoms as there was something different noted in their bodies. Depending on their socioeconomic status and education, they anchored correct or incorrect meanings to those symptoms. At some point, after the encounter with healthcare providers, they realised the meaning of the symptoms and the

disease process in their body. Those encounters assisted them to understand the disease process and to initiate ongoing communication and follow up with healthcare providers to manage the disease effectively. The subsets of the theme 'awareness' are portrayed in the Figure 3 and elaborated further.

Figure 3 Theme 1 subthemes

"[insert Figure 3.]"

1.1 Awareness of symptoms

It is evident from the studies that the awareness of symptoms started before the proper diagnosis of disease.[22, 25, 26, 28, 36, 37] The participants were not able to recall the actual onset of symptoms.[22] They did not realise the changes in their body were related to a disease process and only became aware of the disease during the hospital stay.[26, 36] and this awareness assisted in identifying exacerbations along with their bodily knowledge.[37] Being proficient in understanding the symptoms associated with the disease gave them a feeling of confidence and security [28] and their awareness grew gradually.[25]

1.2 Socioeconomic status

Three studies found that socioeconomic status played an important part in the awareness and management of disease. [16, 31, 40] The view of participants about health was impacted by the socioeconomic status.[16] Participants with limited or no resources were continuously battling poverty and struggling for better health and did not have sufficient finances for medications, follow-up visits or hospital admissions.[40] Resourceful participants selected choices that reflected the suggestions for COPD treatment, while participants with fewer resources associated their choices for avoiding discomfort rather than disease management.[31]

1.3 Level of education

The relationship between participants' education and the understanding and management of symptoms were evident in the studies. [16, 31] A competent approach for management of symptoms was evident in participants with higher education. [31] Participants' level of education appeared to impact the way they experienced and managed health conditions: especially those with tertiary education perceived the magnitude and intimation of the disease accordingly and prioritised their disease more coherently than others.[16]

1.4 Communication from health providers

Communication from health providers varied and affected the understanding and confidence of participants. [16,17, 20, 21, 25, 31, 34, 35, 36] Advice from healthcare professionals played an important role in establishing faith in the treatment and prompting adherence to the management strategies. [17] Healthcare providers played an important role in persuading participants to take part in educational activities, which helped them to be more accountable for their behaviours. [20] The communication and relationship with healthcare providers not only gave them the latest information and treatment options but also the confidence that everything is alright and a supportive decision-making ability as well. [21] Participants wished for contact with a health professional with a good relationship to meet their needs individually in a caring manner, which reflected the importance of trust and confidence in the system. [35] The continuity in professional healthcare was considered vital by some participants, [34] while a few participants mentioned the limited communication and were displeased with the 'inhuman treatment' by healthcare professionals. [36] The information provided by primary care physicians was inadequate, [16, 31] while participants received a better understanding from the specialists [31] and expressed lack of confidence in their primary care physician. [25]

2. Adaptation

Adaptation to the disease began prior to the diagnosis of the disease but evoked a strong reaction at the point of diagnosis. After being diagnosed with the disease, the existing level of knowledge may change in response to the consciousness about the disease. Once the understanding or perception increased, changes occurred in emotional reactions, and it is reflected in how they managed the activities of daily life. Further in the adaptation process, people living with the disease tried to initiate other activities to improve their quality of living. The factors incorporated in the theme 'adaptation' can be found in Figure 4 and narrated below.

Figure 4 Theme 2 subthemes

"[insert Figure 4.]"

2.1 Reaction to disease/ diagnosis

It is evident from the studies, being diagnosed with COPD led to various reactions. [16,19, 22, 23, 24, 25, 30, 32, 33, 36, 39] Some of the participants were in shock, while some were in denial, but participants aged in seventies and eighties had a cheerful outlook to the disease.

[16] A theme found by Chang et al. [19] was “trapped in an invisible cage”, while Cooney et al. [22] found that participants tried to hide the symptoms from others. While some tried to make sense of their diagnosis, [33] others mentioned a feeling of meaninglessness and wanting to die [23] and still others feared death. [36] Feelings of sadness and loneliness, [24] fear of disease progression and prognosis, [25, 39] a feeling of being at the mercy of the disease [30] and difficulty accepting the diagnosis and disease [32] were also evident in the studies.

2.2 Knowledge of the disease

It is apparent that participants had varying levels of understanding of COPD prognosis and management and it affected their confidence in managing the disease. [16, 17, 20, 25, 26, 28, 30, 31, 34 – 39] Participants' knowledge about COPD and prognosis varied [34] and only a few participants knew what their lung condition was called and were confused about the symptoms. [16] Participants were confused and frustrated because of the lack of understanding of their condition and wanted to learn more about self-management. [39] Participants had poor knowledge about the disease and a lack of information about management prior to the diagnosis of the disease, [26, 30, 38] but people with higher education and good social networks had a greater understanding and good self-management. [31] Some had sufficient knowledge about COPD but experienced a struggle in knowing what they had to change in their lifestyles. [35] The knowledge level impacted their confidence in managing medications and acute events [17] but some used strategies from their previous experience. [20] Participants' knowledge and experience were important in developing self-management skills. [25]

2.3 Adaptation in daily chores

All of the studies support that participants had to adapt their daily chores in response to their disease and symptoms. [16, 20, 21, 22, 23, 25, 27, 28, 30, 32, 33, 35, 36, 38, 40] Participants encountered physical and emotional struggles in their daily lives, [33, 40] and these struggles led to modifications of behaviours. [16, 20, 22, 23, 32] Cooney et al. [22, pp 990] mentions “the tasks became military operations requiring strategic planning”, while Wong et al. [38] mentioned about breaking down the tasks into small steps. Participants became constant observers of symptoms to adjust their behaviours to lessen the intensity, [36] but required planning their daily lives to accommodate the changes. [25, 27, 28] This included planning, pacing and prioritising activities by changing from an active to passive role, [21] where some used a positive outlook by prioritising the current situation and not worrying about the future. [30, 35]

2.4 Self-initiated activities

Experiencing various symptoms in daily lives eventually led participants to self-initiate symptom management activities to overcome or adapt to the disease. [17, 19, 20, 21, 32, 36, 37, 38, 40] It is noted that self-management strategies were initiated without any instructions from health professionals. [17] Participants adopted various strategies like taking a few steps at a time, breaking up tasks, taking more time, reduction in activities, planning and pacing. [19, 20, 21, 37, 38] Participants paid attention to food and used traditional therapies, [19, 40] some took measures to avoid cold weather to reduce the symptoms [19, 20, 32] while constant use of inhalers to control external factors, alteration in food and avoiding strong odours [36] were mentioned.

3. Assistance

The theme 'assistance' revealed the support network that participants relied on in their daily life which either had a positive or negative impact. This included family and peer support, financial stability and spirituality which helped participants in maintaining physical and psychological wellbeing. The subsets of the theme 'assistance' are portrayed in the Figure 5 and elaborated further.

Figure 5 Theme 3 subthemes

"[insert Figure 5.]"

3.1 Family support

Some of the studies found that family support played a crucial role in maintaining wellbeing of participants. [17, 20, 21, 26, 27, 28, 34, 36, 40] Participants acknowledged the support from family and friends, [34] especially with tasks at home, but also noted family can be overprotective. [27, 28] It is evident that there was over reliance on family members in managing the disease, [26] but this reliance was related as a challenge at times when creating conflict, and yet a positive source of support by some participants. [17] Participants relied on caregivers for continuous assistance with basic activities [36] and compassionate family support was evident in physical, psychological, financial, and emotional needs. [40] Some participants mentioned family as the only cause for sustaining the challenges [21] and it is a joy to note that the "family first ideology" encouraged family members to support their family member's health. [20, pp 601]

3.2 Peer support

Peer support was pivotal in surviving COPD [21, 34] and participants were contented to openly talk about the disease and support each other. [34] They mentioned the new insight and knowledge from their peers was inspirational and made solving problems easier. [21]

3.3 Financial status

Having adequate financial resources made a substantial difference in the ability of people with COPD to manage their disease. Financial status played a major role in diagnosis and management of COPD. [16, 40] Financial restrictions led to delayed management of disease due to affordability issues. [16] Zeb et al. [40] mentioned about participants who did not have enough money to buy medications, afford follow up visits and travel to hospitals. Retired participants had better financial stability because of the concession than those employed or people on benefits. [16]

3.4 Spirituality

Spirituality was an efficient survival approach for participants. [36, 40] Spirituality had a positive impact and served to perceive the inner peace and comfort [36] and those beliefs gave the power and courage to manage the negative effects. [40]

4. Adversity

The theme 'adversity' illustrated all the adverse effects of the disease on participants. The emotional changes included a feeling of guilt and frustration, anxiety, worry about being a burden and worry about finances along with social isolation, loss of recreation, and episodes of acute care were portrayed in the theme adversity, which had an ambiguous effect on most of the participants. The subsets of the theme 'adversity' are portrayed in the Figure 6 and elaborated further.

Figure 6 Theme 4 subthemes

"[insert Figure 6.]"

4.1 Emotions

The COPD had psychosocial impact and participants attempted to control emotional

disturbance by changing negative thoughts into positive ones. [20] Participants mentioned the change in emotional state while living with COPD and implemented different strategies like self-talk, acceptance of the condition and laughter for emotional adjustment. [21] Participants encountered a sense of meaningfulness, but at times with challenged self-esteem felt worthless and desired for death. [23] Shortness of breath made the participant frightened, [24] while some felt fearful when left alone at home. [37]

4.1.1 Feeling of guilt and frustration

Participants felt frustrated and confused about their condition and it was worsened by inadequate information from healthcare professionals. [17] Participants expressed guilt and negative emotions about the self-inflicted disease, [22, 25, 27, 33] and experienced psychological burden. [30] Frustration was also caused in relation to inadequate coping [26, 29] and because of the dependence on others for daily activities. [28] Participants mentioned about feeling embarrassed [31] and felt frustrated because they were forced to do less. [32]

4.1.2 Anxiety

Panic and anxiety were common among participants related to breathlessness [26] or worrying about oxygen and social isolation, [33] while some participants became "maddened with fear" [34 pp1036]. Participants reported COPD triggered their anxiety causing panic attacks at times restricting their lives [18] and they felt they might die during panic attacks. [38]

4.1.3 Worry about being a burden

Participants were concerned about being trouble for their families [19] and were reluctant to ask for help because of the uneasiness of being a burden on their family. [40] They also felt being a burden with an inability to participate in social activities and socialise with family because of low energy levels. [27] The support from family and friends led to a feeling of burden on their support system, [29] because of their disease [33] and with loss of independence which strengthened the feelings of uselessness and desperation. [36]

4.1.4 Worry about finances

Financial worry was mentioned in association with the inability to work and earn money. [34] Financial strain was also attributed due to early retirement and the need for costly medications. [24] These affected men losing their leadership qualities and ability to make decisions because of the lack of economic productivity. [36] Participants consulted care providers in their

neighbourhood, built connections with community workers for free advice and requested assistance from community pharmacist for free medications because of lack of funding for renewing medications and follow up visits. [40]

4.2 Social isolation

Participants reported loneliness despite close relationships, [23] while some reported the negative effect on family activities and felt restricted at home. [24, 27, 30, 38, 39] Participants tended to avoid family gatherings and other activities [24, 27, 30, 38, 39] and some were worried about wearing oxygen which led to social isolation. [33]

4.3 Loss of recreation

Loss of recreational activities and devoting time to spend with family were other hardships associated with advancement of COPD. Advancement of COPD affected the depth of relationships with others and participants were woeful. [29]

4.4 Episodes of acute care

The necessity for acute hospital care to manage symptoms was another unpleasant situation but most of the participants expressed confidence in the hospital. [29] Acute hospital was perceived as a “haven or place of security” by the participants. [29 pp 15043]

6. Discussion

This review examined attitudes, behaviours and perspectives of people coping with COPD.

There were areas of agreement and disagreement between the 25 studies included in the review. However, collectively the findings highlight the various approaches implemented and revealed that people with COPD start modifying their attitudes and behaviours before the diagnosis of disease. [22, 25, 26, 28, 36, 37] Awareness of the disease is dependent on the socioeconomic status of people with COPD, [16, 31, 40] level of education [16, 31] and communication with healthcare providers. [16, 17, 20, 21, 25, 31, 34, 35, 36]

Awareness and knowledge are reflected in emotional and behavioural changes and assist to build confidence in initiating and modifying activities to improve quality of life. [16, 20, 21, 22, 23, 25, 27, 28, 30, 32, 33, 35, 36, 38, 40] As participants acquired more knowledge about the

disease and changes, they sought assistance from family and friends [17, 20, 21, 26, 27, 28, 34, 36, 40] and found it inspirational and made problem solving easier. [21]

Financial stability played an important role in supporting the needs of participants, [16, 40] along with spirituality which helped them to adopt a positive outlook towards life. [36, 40] The unpleasant effects of the disease including feelings of guilt and frustration and anxiety along with being a burden, financial worry, social isolation, loss of recreation and episodes of acute care have not only affected participants and family but also the healthcare system. [18, 19, 24, 26, 27, 29, 34, 36, 38, 40]

This review reinforced that the symptoms of the disease along with activity limitations and associated anxiety adversely affected the quality of life leading to increase in COPD exacerbations and COPD-related hospitalisations and correlated to the findings of other studies. [42 – 46] It is apparent from our review that the rate of anxiety and depression among people with COPD is high, which was also found in another study. [47] This review reinforced the correlation between anxiety and impairment in physiological and psychological functioning leading to frequent exacerbations and corresponded with other studies [48, 49] as well. It is evident from this review that the activity limitations, work absenteeism, emergency presentations to hospital, frequent hospitalisations and medical emergencies resulted in extensive demand on healthcare facilities and patients, which has been found in other studies. [46, 50, 51]

This review underlined the importance of having knowledge about the disease for better self-management behaviours and to engage in shared decision making with healthcare providers and is supported by previous studies. [52, 53] This review has highlighted the poor knowledge of participants and the lack of information and support from healthcare professionals about the management of the disease, especially from the primary health care physicians. This review revealed that participants preferred having a contact health professional to discuss their needs in a caring manner and reflected their trust and confidence in the system. Effing et al. [54] stated the importance of coaching and education by health care providers in transforming health behaviours and developing skills. Blackstock et al. [55], which was a randomized controlled trial stated disease specific education will facilitate health related quality of life.

Our review emphasised that information and advice provided by health care providers played an important role in persuading participants to take part in educational activities and to build confidence in supportive decision-making and is slightly different from the GOLD- report [5 pp 97], which disclosed “Physicians and healthcare providers need to go beyond pure education/ advice- giving (didactic) approaches to help patients learn and adopt sustainable self- management skills”.

Recommendations arising from the literature review

The role of healthcare providers especially primary care physicians cannot be replaced in the management of the disease. It is evident from the review that changes in professional practice and empowerment through education at the primary level are necessary for the proper diagnosis, management of the disease and supporting healthcare clients.

The review reinforced the necessity of proper educational activities for participants as the poor knowledge of the participants and lack of information about the management of the disease is evident. [16, 26, 30, 34, 38, 39] Implementation of practice changes to support improved communication, assessment of needs and maintaining continuity of care to achieve a holistic person-centred approach in the management of the disease is crucial. Educational activities and coaching by health care providers should aim to motivate, engage and coach patients to confidently transform their health behaviours [54] and to enhance skills to improve wellbeing. [55] This review has highlighted the need for health providers to be a person of contact to discuss the issues in a caring and friendly manner rather than the traditional role of being a health care provider.

Even though the included studies exposed the influencing factors in coping with COPD, scant research was located that delved further into the variation in attitudes, behaviours, and perspectives in coping with the disease and the strategies besides pulmonary rehabilitation or educational sessions, which participants use to cope with their illness to prevent readmission to hospitals. This lack of research into this facet of the variation in coping indicates the need to explore this topic in further studies. Research should include patients, family and clinicians in future samples and consider their perspectives. In addition, such research might enable future development of a systematic and holistic framework in the management of this disease.

Strengths & Limitations

This is a comprehensive review of the literature about attitudes, behaviours and perspectives of people coping with COPD to inform conclusions about the gaps and future opportunities. A key limitation of the review is that of the total 25 studies directly relating to the research question, all were qualitative in nature and thus ranked lower in all established hierarchies of evidence. [56 - 58] Despite having predefined search criteria tailored to each of the four databases [14, 59] no quantitative studies were retrieved. The measures to maintain rigour of this review were: no limitations on search strategy; a clear predefined research question; and predefined inclusion and exclusion criteria.

7. Conclusion

This literature review included the participants with varying levels of COPD and explored the attitudes, behaviours and perspectives of people coping with COPD. The interrelatedness of numerous factors is evident in the diagnosis and management of this debilitating disease. The awareness of the disease empowered the person to adapt to the symptoms and situations with the assistance from support systems to reduce or overcome the adversities. Despite advances in the management of this disease, people still experience high levels of symptom burden and require frequent hospitalisations related to exacerbations. The symptom burden varies in different patients and underlines the importance of collaborative healthcare based on education, respect, and effective communication to manage this disease and enhance patient wellbeing.

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v. Supplementary material

All the search histories from databases used to generate this literature review (CINAHL, Emcare, MEDLINE and PsycINFO) is included as separate files.

vi. Statements and declarations:

i. Ethical consideration

Ethics approval was not required as this is a literature review

ii. Consent to participate

Not applicable

iii. Declaration of conflicting interest

The authors declare no conflicts of interest to study, authorship, and publication of this article.

iv. Funding statement

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iii. Data availability statement

The authors confirm that data sharing is not applicable for this manuscript - no new data was generated, or the article describes entirely theoretical research.