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## **Chapter One**

### **Introduction and Background**

#### **1.0 The background to the critical review**

The topic discussed in this critical review is the investigation into the differing health information needs of patients with Chronic Obstructive Pulmonary Disease (COPD). The method of critical review was chosen because it allowed the topic to be viewed within its particular context and set amid other similar information and research, to enable its impact to be evaluated systematically. As Averyard (2010) states, due to the recently modern paradigm of evidence based practice the amount of information available to health care professionals is vast; a critical review fits into this evidence based model by drawing together evidence from various sources to provide stronger evidence for practitioners to apply to their professional practice. Sackett (1997) suggests that health professionals should use both individual clinical expertise and the best available external evidence to support care delivery, and neither alone is enough to provide optimum care to patients. Both Averyard (2010) and Sackett (1997) emphasise the fact that the practice of evidence-based medicine is a process of life-long, self-directed learning and the importance of sharing these lessons with the wider health care community. My dissertation echoes this aim by exploring the differing health information needs of patients with COPD and the impact on nursing practise.

My interest for this particular topic arose from my own nursing practice whilst at an elective placement with the COPD specialist nurses at Eastwood in Nottingham. The time that the nurses took educating patients to meet their information needs

highlighted the obvious need for this to occur in practice. The question of whether meeting the health information needs of patients could be linked to lower hospital admission emerged. Examining the literary evidence confirmed the importance of the COPD management team and its positive effects on hospital admission demonstrated by Annadale's (2009) research study. Although this study only showed the sustained reduction of admission over a year and the longer effects of the COPD team management were not studied, a positive effect on the quality of life of patients within the community is evident. This critical review focuses on the differing health information needs of patients with COPD with the aim to support specialist nurses in the care that they implement, creating a better understanding into why information needs differ between patients and what nurses can do to insure these needs are being met.

### **1.1 Defining terminology**

Chronic Obstructive Pulmonary Disease is the internationally accepted term embracing lung conditions and diseases characterised by chronic obstruction of lung airflow, which interferes with normal breathing and is not fully reversible (World Health Organisation, 2013). COPD is associated with co-morbidity such as that highlighted by Sin (2009) who explains that on average, patients with COPD have two to three times the risk of hospitalisation for cardiovascular conditions, which includes heart disease, stroke, and heart failure compared to those patients without COPD.

Defining 'health information need' is ambiguous due to its broad and inclusive nature; however it is easier to define when looked at from first the patient then the health care professional's perspective. From the patients perspective as identified by Gann and Needham (1992), health information need relates to the information needed to establish self-management and informed choice. The health care

professional's perspective however as highlighted by Eysenbach (2000) is more centred on reducing anxiety by providing the information needed for a patient. The patient's definition does in some ways incorporate the health care professionals, because self-management has been shown to reduce anxiety and thus the patient's stance on the definition of health information will be taken.

The literature on information needs is vast due to its recognised importance to patient care and involvement in tackling chronic conditions such as COPD.

Bourbeau, Nault and Dang-Tan (2004), state that information needs can be defined by patients expressing a desire for more information, or if a clinician believes that a patient's response to a question indicates the patient's self-management is compromised and thus could cause anxiety, and then this may also indicate that the patient has a need for information. Stoller (2002) on the other hand identifies patient education as integral to the care of patients with COPD, and a 'cornerstone' of self-management in chronic illness. This is argued to be due to the fact that patients who do not understand health intervention are subsequently less likely to apply or value them, resulting in health behaviour which could be detrimental to their health. This definition is preferable because it clearly identifies the fact that if patients are unable to understand information then they cannot implement the changes suggested by the health care professional. This idea is investigated in detail in relation to different barriers to patient's education, such as culture and access to sources of relevant information, using a theoretical framework to help explain these barriers.

The theoretical framework in this critical review, through which information needs will be examined is, is the stress – coping model outlined by Miller & Mangan (1983). This model will be used to analyse the reasons why patients with COPD have differing health information needs and if fully explored in the methodology chapter (2) below.

## **1.2 Relevance of the critical review question to nursing practice**

The relevance for nursing research in relation to this disease is clear from the literature with the Department of Health (2011) stating COPD as the fifth largest killing disease in England, causing 30,000 adult deaths annually in England. COPD causes more deaths than breast and prostate cancer combined and it is estimated that around 3.5 million people in England are currently living with COPD (Idriss, in press). Murray and Lopez (1999) predict that this will increase to be the fifth cause of disability and the third largest cause of death worldwide by 2020; as smoking increases world-wide. This shows that COPD is a highly prevalent chronic health condition and this critical review is therefore required and will have an impact on significant numbers of both patients and health care professionals.

The economic burden of COPD is also vast, involving both long-term medical management and disability-related care. COPD is estimated to cost the health service up to £805m a year (unpublished data from Department of Health, 2011) and these costs are likely to have escalated since 2011. Chronic Obstructive Pulmonary Disease is rare in people who have not smoked, and the prevalence of COPD reflects the prevalence of smoking in the population, with a strong social class gradient (Van Schayk, Loozen, Wagena, Akkermans and Wesseling, 2002) with higher diagnosis rates in areas of higher social economic deprivation (East Midlands Strategic Health Authority, 2013). In 2011 the Department of Health, published 'An Outcomes Strategy for COPD and Asthma' highlighting the need for all social groups to receive safe and effective care. With COPD in adults a major contributor to sickness absence, premature retirement, disability and mortality in old age, it is therefore essential that it remains a high priority for nursing research (Littlejohns, Ebrahim, Anderson, 1989). The fact that COPD is such a prevalent health condition means that it has been a heavily researched health condition in areas such as its management, for example the importance of pulmonary

rehabilitation highlighted in the literature review by Lan et al. (2013) and the benefit of early diagnosis stated by Mirsadraee, Boskabady and Attaran (2013) in their quantitative systematic review. However research into the health information needs of COPD patients is scantier and thus increases the relevance for this dissertation to investigate if there are differing health information of patients with COPD.

### **1.3 Aims and review questions**

The aim of this critical review is to analyse the literature and studies surrounding the following critical review question:

- Are there differing health information needs of patients who have COPD?

Whereas this link is well investigated in other chronic illness, such as cancer, it has not been so heavily researched despite its prevalence and thus its relevance for patients and future research is paramount. The reasons for the fact it may not be so heavily researched could stem from the fact that illnesses such as cancer receive more publication due to the wider spectrum of the population affected by this chronic condition; as stated in the study which investigated the health information needs of cancer patients by Leydon, Boulton, Moynihan, Jones, Mossman, Boudioni and McPherson (2000). The review question arose from nursing practice as although the importance of information distribution was obvious, the amount and the reasons why information needs between patients can differ needed further investigation. Once this is understood then the patients' needs can be met more accurately and help contribute to the holistic nursing care model (Dossey and Keegan 2008).

The holistic nursing care model was first established by Florence Nightingale states Dossey and Keegan (2008) and is now widely accepted in the literature as the optimum means of delivering nursing care. The Royal College of Nursing (2009)

identifies six key elements to explain this care models purpose, to promote and maintain health, to care for people when their health is compromised, to assist recovery, to facilitate independence, to meet needs and improve patients quality of life. This clearly shows that by meeting the health information need of patients this can facilitate almost all of the key elements identified by the Royal College of Nursing (2009), with particular emphasis on facilitating independence through self-management. Therefore this model will be help explain how important educating COPD patients on their information needs is in achieving the clinical practise expected by the Royal College of Nursing policy.

The literature will be analysed using a theoretical framework of information needs, stress – coping model outlined by Miller & Mangan (1983). This model will be used as a lens to examine the reasons why patients with COPD have differing health needs and explore health behaviour in relation to this. The sociological research underpinning patients' health behaviour patterns will also be discussed in parallel to the holistic nursing care model (Dossey and Keegan, 2009), such as Henwood et al. (2003) research entitled 'Ignorance is bliss sometimes' which focuses on the emergence of the 'informed patient' in the changing landscapes of health information, this provides insight into factors facilitating and inhibiting the emergence of the 'informed patient'. This empirical study and other sociological research behind the health behaviours of patients in terms of their health behaviour patterns will be examined in detail in the themed chapter (3) on the impact of the internet on health information need.

The first theme will examine if, when met, these health information needs of COPD patients could ultimately improve the quality of care that these patients achieve and reduce admission into hospitals. Through the use of effective health information to promote self-management for patients, with the emphasis on controlling exacerbations through patient information to reduce anxiety will be the

focus of this chapter. The inter-relation between reduced hospital admissions and self- management for patients leading to reduced anxiety will be discussed as a theme, because of the body of literature supporting the argument that they are linked, such as the research by O'Reilly, Williams and Rice's (2007), Maurer et al. (2008) and Guest (1999). As well as my experience of working alongside nurses who implement this health information in the community on placement.

The second theme will explore the idea proposed by the Department of Health, who suggested in the 'Information Strategy for the Modern NHS' in 1998 that the greater availability of health information via the Internet will lead to the emergence of more informed patients who are better able to assess the risks and benefits of different treatments for themselves. The now widely used notion of 'informed choice' within the person centred care was promoted initially by the Modern NHS (1998) which is indicative of the greater agency and sense of empowerment said to be experienced by such patients. This idea was further developed by the 'Patient and public involvement in the new NHS' (2005) and the document 'Equity and excellence: Liberating the NHS' (2010) which is centred around health choices being placed on the patient, with the key phrase being 'no decision about me without me', emphasising the fact that patients must be central to the care delivered to them by health care professionals. This theme will analyse the effect that such initiatives have on both mirroring and fuelling the demand patients have for more and better health information. The focus of the chapter will be on the impact of the internet as a source of health information, and its appropriateness analysed. The argument taken by Hardey (2001) is that the overall expansion in medical knowledge via new media technologies such as the internet will empower patients to become the informed patient desired by the initiatives listed above. This idea is investigated in the final themed chapter, concluding the discussion section of this critical review.

## **1.4 Background literature review**

### **1.4.1 Context of the National Health System (NHS)**

#### Implications of financial context

Establishing the context in which this critical review is placed is important in justifying its relevance and the drive to create an understanding of health information needs. The NHS financial context is one of cuts right across government spending, although the government has frozen cuts to the National Health Services budget, social care expenditure has not been protected from spending cuts (Buck and Gregorys, 2013). Buck and Gregorys (2013) research into improving the public's health, has identified the fact that cuts to the social care budget of a £6.2 billion in-year savings, which includes a £1.165 billion cut in grants will impact dramatically on the NHS. Specifically an increased demand and pressure on health care professionals and the restricting of local care services, which potentially will lead to significant increases in unmet need and additional burdens on carers.

The social care budget is relevant to COPD patients because although the full impact that this will have on the NHS has not yet been seen, as Majeed and Malcolm (1999) identify in their research, it is the elderly patients with chronic health conditions such as COPD who are cared for primarily in their own homes in the community that will suffer most due to the social care cuts. Budget saving will directly impact on COPD patient's health information needs due to pressures on fewer nurses to deliver this information and publish their research findings (Buck and Gregorys, 2013) (Majeed and Malcolm, 1999). It is therefore important that nursing care includes effective education to patients; to ensure health information distribution is achieved as the NHS has less control over the social care that these

patients are receiving. Defining the contractual obligations of providers commissioned to provide care, information and education is even more important in the current climate of the NHS.

#### **1.4.2 Structure of the NHS**

The structure of the NHS of which this critical review is set, is as identified by Holder and Thorlby (2013), implemented by 'The Health and Social Care Act' (2012) which led to reforms of how patient care in the English NHS is organised, managed and delivered. For example, General Practice commissioning as identified by Smith et al. (2000) in the national evaluation of general practitioner commissioning pilots: lessons for primary care groups, highlighted the reported key achievements of improved collaboration between GPs, the establishment of organisational arrangements, and work towards managing the group prescribing 13budget.

The effect that these changes have on the implementation of nursing care for COPD patients is that the bill sets out a new statutory framework that would abolish the duty of primary care trusts to secure health services for everyone living in a defined geographical area. Clinical commissioning groups (CCGs) are now responsible for the provision of fewer government funded health services and determine the scope of these services independently of the Secretary of State for Health. The CCGs have been delegating health services to commercial companies, which Pollock, Price and Roderick (2012) believe will lead to the provision of new charging powers for services currently provided free through the NHS. Which if occurred would affect COPD patients who are primarily elderly patients from lower social economic classes (Van Schayk et al., 2002) (East Midlands Strategic Health Authority, 2013).

The structure of the NHS is coming under criticism by some researchers such as Timmins (2012), whose study evaluating the 'Health and Social Care Act' of 2012

questions the political motives of the reforms and whether the patients were actually at the centre of the changes. It must be highlighted however that the NHS had also come under criticism before the reforms took place, as shown by Eaton (2002) and Smith et al. (2000), who like Timmins (2012) questioned the motives of the proposed reforms and whether they would benefit the patients. This highlights the fact that the NHS will always come under criticism, due to many reasons such as its institutional size, its political influence and the fact taxes pay for its running. The majority of studies (Holder and Thorlby, 2013) however show that the reforms to the NHS structure are being made to mainly improve communication between the multi-disciplinary teams (MDT). This will ultimately benefit patients with COPD because to receive optimum care they need the corporation of the whole MDT.

The context of this critical literature review is important in relation to the health information needs of COPD patients, as it shows that there are strains on health care professionals time and everything the NHS does with its finite budget implies an opportunity cost. Expressed colloquially 'if you do one thing you can't do another', nurses must ensure that what they have the time to do is the most efficient and appropriate delivery of care. Therefore this dissertation aims to investigate the impact of differing health information needs of COPD patients and the reasons why health education must not be compromised whatever the structure of the NHS is in, if the holistic nursing delivery care model is to be achieved. The practise of holistic nursing is evidenced based as being the most effective style of nursing, with Dossey and Keegan (2008) emphasising the importance of delivery nursing care to develop the physical, mental, emotional and spiritual well-being of a patient. The Royal College of Nursing identifies the particular importance of holistic care in the community RCN publication, Pillars of the community (2010), and Pelzang (2010) states that it is through developing patient carer relationships that this care can be ensured. This argument is proven in

the literature evidence, as Wooten (2013) states effective patient communication skills ensures that patients are getting the care that they deserve, including meeting their health information needs.

### **1.4.3 Information needs tools**

There are currently two main health information need tools being used within the health service for COPD patients, varying in purpose and recommendation. The Lung Information Needs Questionnaire' (LINQ) (Sauro et al., 2008) (appendix one) is used to help clinicians identify which patients would be helped by information and the type of information an individual would require to meet their health information needs. The research performed by Sauro et al. (2008) identifies that COPD patients who have been inpatients within the last year have different health information needs to those cared for in the community. The Lung Information Needs Questionnaire (LINQ) assesses, from the patient's perspective, their need for education. The questionnaire yields a total score and scores in six domains: disease knowledge, medicine, self-management, smoking, exercise and diet. Subsequent studies have used the LINQ to show the educational impact of interventions, for example Jones et al. (2008) study on the impact of pulmonary rehabilitation.

The content of the LINQ (2008) can be contrasted with the currently most comprehensive COPD knowledge questionnaire, the Bristol COPD Knowledge Questionnaire (White et al., 2006) which focuses more on what the patient knows already rather than whether an information need is absent. Sauro et al. (2008) highlight the LINQ as being more relevant to health information need identification because of its emphasis on what areas of information the patient is lacking. The Bristol COPD Knowledge Questionnaire was judged by White et al. (2006) to have good content and face validity for investigating areas of health information which COPD patients are familiar with. The time taken to complete a questionnaire needs

to be noted, the Bristol Knowledge Questionnaire takes twenty minutes which is double the completion time of the LINQ. This is important to compare because of practical use in clinical practise, this may contribute to the decision to use the LINQ over the Bristol Knowledge Questionnaire, to ease the patient's involvement in the assessment. The Bristol COPD knowledge Questionnaire is, however, another additional tool to enable the effectiveness of education to be assessed and will be of value in developing and comparing different educational interventions.

After looking at the findings from the LINQ (2008) the information needs vary between patients, however the majority of patients report greater need for non-drug related aspects of self-management of COPD. This impacts on clinical practise, because these areas of health information can be focused on in greater detail by health care professionals, providing the information which has been identified as being the most needed to patients with COPD. This study conducted by Sauro et al. (2008) will be looked at in greater detail in the theme chapter below on the impact that met information needs would have on hospital admission rates.

#### **1.4.4 Information needs in other health conditions**

Research into the health information needs of other chronic health conditions, specifically cancer, have been well established in the literature as essential to ensuring quality care. For example the study by Leydon et al. (2000) who saw an increase in patient involvement in decision-making and greater satisfaction with treatment choices when health information was met. Whereas Velikova, Selby, Snaith and Kirby (1995) and Rutten (2005) saw the effects that information seeking had on demonstrating a critical role in individuals' efforts to cope with the disruption of quality of life associated with cancer and greatly reduced the psychological impact that this health condition caused. Although Rutten's (2005) study was conducted with specific reference to Puerto Rico, the fact that it validates

similar points in Velikova et al. (1995) increases its critical relevance. A critical review therefore into the differing health information needs of patients with COPD and the impact of this on health care professional's implementation of optimum nursing care.

This critical review into COPD patient's health information needs is essential because it will highlight the importance of health education and the reasons that these information needs differ. This will allow health care professionals to create patient centred care surrounding their specific health information needs.

#### **1.4.5 Behaviour change**

The need to educate patients about their health condition is a well-established practise in nursing, with Jones (2007) stating in his research that behaviour change is central to the outcome in people with COPD. Jones (2007) goes on to explain that these behaviour changes such as the stopping of smoking can drastically improve outcomes in terms of lung function and the adoption of exercise can add to these improvements. This is heavily documented in empirical studies such as that undergone by Anthonisen, Connett and Kiley (1994) which highlights the fact that if these health behaviour changes were made the health of patients would improve. However as Jones (2007) points out, the problem is that education programmes alone do not produce much by way of behaviour change and improved quality of life. The argument is that they need to do more than just inform and must address the patients' perception that a change in behaviour is both necessary and beneficial. This argument is researched by Horne, Clatworthy, Polmear and Weinman (2001) and remains valid in terms of Miller & Mangan's (1983) stress and copying model. It is only when patients understand the reasons why they must make changes in their behaviour, do they really adapt and change to ensure a better quality of life is established.

#### **1.4.6 Cultural issues surrounding health information needs**

As health care professionals it is essential that health information is delivered in a way that facilitates understanding, as this creates a balance which is specific to each individual, which could otherwise be a barrier to health information distribution. Miller and Mangan's (1983) model notes a stressor, or barrier, to an individual is creating an obstacle that health care professionals need to overcome to allow effective health information distribution. This understanding is identified in the literature, for example by Quesada (1967) who researched the language and communication barriers for health delivery to Mexican-Americans who are a minority group. This study although set in America where the health care system is different from the NHS, with public and private arrangements being made to provide the poor with the same quality of medical care, relevance can be drawn. As the health information communication barriers are parallel in the United Kingdom, due to the strong social class gradient (Van Schayk et al., 2002) for COPD prevalence, in areas with high proportions of patients where English is not primarily patients' first language (East Midlands Strategic Health Authority, 2013).

A study chaired by Marmot (2010) was a report commissioned by the government which showed health inequalities since 2010. The severely marked disparities in health that exists within the United Kingdom, show similar results to the American study by Quesada (1967), based on social class and literacy. This must be taken into account when health care professionals are distributing information, that the patient can understand and implement the advice being given to them. The Marmot review (2010) clearly showed that there are differences in health due to social situations, with the implication that lower literacy and class could affect the health information needs of COPD patients, and as health care professionals it is a duty to

act as advocates to reduce this disparity. One way of doing this is by using information to educate COPD patients on the best ways to self-manage to accomplish better health outcomes in terms of their health information needs.

Quesada (1967) establishes the importance of understanding cultural differences and how they will affect how patients interact with health care professionals. For example, Quesada investigated how social conditioning in terms of the individual's perceptions of their disease is affected by family relations, social structure and cultural norms and how these factors interact with the attempted delivery of health information. The Mexican-Americans were described in the study as passive patients, who saw doctors and nurses as experts and thus not to ask questions but listen. The study also showed that cultural issues produced inhibitions when expressing health information need to a professional of the opposite sex, because males are not supposed to show weaknesses as family providers and the seeking of health information may be seen as such. This shows that there is a clear gender difference created by cultural differences, this can be compared to similar issues raised by health information delivery to Muslim minority group in the United Kingdom. Chevannes (2002) highlights the issues in educating health professionals to meet the diverse needs of patients and other service users from ethnic minority groups, this study is similar to Quesada's (1967) in relation to how ethnic minorities have cultural difference which can affect how health information should be distributed. However unlike Quesada's research study Chevannes (2002) states that with effective training and education health care professionals could overcome these cultural communication barriers and deliver health information effectively. Although Chevannes (2002) study focuses almost entirely on communicational barriers created by cultural differences and the literacy of these patients is not investigated, it does show that these patients would struggle to receive the health information provided by verbal communication. Whereas they might benefit from

leaflets written in their native tongue or the use of an interpreter, the study by Chevannes (2002) is not specifically on COPD patients, so a future research study into analysing whether such implementation would reduce these communicational barriers would be beneficial.

The aim of this critical review is to establish why health information needs of patients with COPD differ and this will be discussed with a focus on cultural differences also alongside the theoretical framework of the information needs, stress – coping model outlined by Miller & Mangan (1983). When the reasons why these needs are different are established, nurses can then begin to mould their information distribution to focus on the needs of each individual patient specifically.

#### **1.4.7 Processing information for patients with COPD**

Health care professionals need to act as advocates for patients needing information who are unable to remember health information. This is especially important in the community setting, states the Royal College of Nursing (2010) policy entitled the 'Pillars of Community' because patients are more likely to act from the values expected by them in hospital. However when they are in their own home the health information that was taught to them in relation to their health behaviour can be more difficult to implement. As nurses it is essential to remember that health information needs must be delivered in such a way that it maximises recall by patients.

The study conducted by Houts et al. (2006) investigated the fact that pictures closely linked to written or spoken text can, when compared to text alone, markedly increase attention to and recall of health education information. This study looked at various researches in health education, psychology, education, and marketing journals and although looked at not specifically COPD, did evaluate the role of pictures in improving health communication. The review researched the

effect that using pictures had on attention, comprehension, recall, and adherence and found that pictures can improve comprehension when they show relationships among ideas or when they show spatial relationships. This is particularly important for patients with COPD because patients with low literacy skills are especially likely to benefit. There is a strong social class gradient (Van Schayk et al., 2002) with higher diagnosis rates in areas of higher social economic deprivation (East Midlands Strategic Health Authority, 2013) which is coupled with lower literacy skills. These patients with low literacy skills can be helped by spoken directions plus pictures to take home as reminders or by pictures plus very simply worded captions. This is important to consider as health care professionals and the study by Doak et al. (2008) also shows improving comprehension for cancer patients with low literacy skills that pictures can help patients retain information about their condition. Although this study is based in America, its relevance to England is high due to the similar western society, the study conducted by Weiss and Coyne (1997) on communicating with patients who cannot read reflects this similarity between studies. Many patients with COPD are older; others are immigrants who speak English only as a second language and a disproportionate number of those with low literacy skills are members of minority groups states Doak et al. (2005). Even though they may not be aware of it, clinicians probably encounter patients with limited literacy on a daily basis; the literacy limitations of such patients are rarely obvious and therefore effective training needs to be ensured so that health care professionals know what the best means of health education is for the patients.

#### **1.4.8 Education and training for health care professionals**

The strategy for educating health care professionals on health information delivery for patients with COPD is varied and depends on the particular role of the clinician. The utilisation of specialist nurses provides direct patient care and can play a vital role in educating patients on how best to manage their symptoms, as well as

offering support following diagnosis. In many cases the involvement of a specialist nurse can prevent patients being re-hospitalised and thus are essential in the primary care of patients with COPD, states the Royal College of Nursing (2010) in the document called 'Specialist nurses: Changing lives, saving money'. The fact that these nurses are specialists in their fields on chronic diseases, such as COPD, means that they have been trained to a higher standard on delivery health information to this group of patients. These specialist nurses in a national survey of health advocacy groups (Royal College of Nursing, National Voices, 2009) were rated by patients consistently higher than any other health and social care professionals in understanding patient need and delivery health information.

### **1.5 Theoretical framework**

Theories are important in nursing research because as Glanz, Rimer and Viswanath (2008) state they help explain behaviour patterns and suggest ways to achieve behaviour changes. Health behaviour models draw upon a selection of these theories to help identify and understand issues within a specific problems context, Earp and Ennett (1991) hence identify health behaviour models as being superior tools to theories to base patterns of behaviour on due to this selection of ideas. The understanding of patterns in health behaviour is fundamental because the behaviour of patients can only be changed by a health care professional if it is understood as to why a patient acts in a certain way. This understanding has been proven to improve patient care especially with chronic health conditions such as COPD; this is argued strongly by McLercy et al. (1987) and Horn (1976). Although there is an argument to say that some people will continue to behave in ways that are detrimental to their health, despite having the understanding and knowledge as to why they should change. This argument is researched by Gochman (1997) and identified by Glanz et al. (2008) but should not prevent the health professionals aim

of change, as although some people will not change, it is the job of the health care professional to offer impartial advice despite this outcome.

The theoretical framework for this review which will be applied to the literature is the information needs, stress – coping model outlined by Miller & Mangan (1983). This theory identified that purely cognitive drives established by Wilson (1994) earlier information needs model did not explain the fact that, even in critical health circumstances such as diagnosis of COPD, people do not always seek medical health information even when the gaps in their knowledge are evident (Van Zuuren and Wolfs, 1991). Miller and Mangan (1983) identified two cognitive states being central to understanding an individual's response to an adverse situation. These are 1) sensitisation, meaning orientation towards the threat; and 2) repression, turning attention away from the threat. Miller and Mangan (1983) have also used the terms monitoring and blunting to signify the cognitive terms and these definitions have also been used in many studies such as the research by Steptoe & O'Sullivan (1986), Van Zuuren & Wolfs (1991), and Baker (1995). This research study on the health information needs of COPD patients draws on the Miller and Mangan's stress and copying model to identify a possible reason for the difference in the health information needs of patients with COPD.

Other frameworks were considered for use such as Humphreys and Revelle (1984) theory on the relationship between individual personality differences and information seeking and processing. This theory unlike Miller and Mangan's (1983) is based more generally in terms of information seeking and less on health information needs. It does however indicate that every individual processes and seeks information differently due to external pressures such as incentive and intelligence, this is important to consider in clinical practice. However Miller and Mangan's stress and copying model was chosen specifically because it places more

emphasis on information needs which is key to the research question of this critical review.

The literature surrounding the information needs stress coping models clearly shows that as Weiner (1996) states individuals tend to show distinctive patterns of information search and need depending on their stance of monitoring or blunting. Meichenbaum (1992) identifies in his research that victims of anxiety disorders typically focus on potential dangers being monitors and thus benefit from stress inoculation techniques, which can teach these patients how to monitor less and distract more. This is important as highlighted by Van Zuuren and Wolfs (1991) if a balance is created between monitoring and blunting, the acknowledgement of real threats and challenges would reduce anxiety for these groups of patients. Although extreme monitoring is associated with higher psychological and physical costs (Miller, 1992), it has in fact been researched that both blunting and monitoring have their benefits and negatives in terms of impacting health under different conditions. The main negative for blunting has been researched by Miller (1995) and identifies that this category of people tend to avoid screening and it would make sense to advise this group of patients to face the facts about their health condition, in the case of health information needs this would mean giving these people more information than they think is necessary. Whereas Weiner (1996) argues that monitors prone to anxiety should be told less about the negative facts and gloss over the details, even when asked about their chronic health condition. In reality however it has been shown by studies such as that undergone by Miller and Mangan (1983), that when facing medical procedures this is in fact not the case and would not benefit the patient. Monitors benefit psychologically from being more informed and blunters need less health information. This is important to establish as health care professionals because using this theoretical framework it becomes

easier to understand how to help patients meet their health information needs as individuals.

To understand the relevance of Miller and Mangan's (1983) stress – coping model to the impact of differing health information needs of COPD patients, it is important to fully understand that the health information needs model was established first by Wilsons (1981). This model emphasised more on the barriers that lead to individual's differing health information needs surrounding environment and social factors. Whereas the theoretical study by Miller and Mangan (1983) explored the interacting effects of personal dispositions and situational conditions on the stress response to a colposcopy. Therefore it is important to note that this research was focusing on a medical procedure and not a lifelong condition such as COPD, however relevance can be draw out of this study and used to help analyse the differing health information needs of patients with COPD. The emphasise on stress of this theoretical model (Miller and Mangan, 1983) makes it a unique model and the evidence showed that patients' level of psychophysiological arousal was lower when the level of preparatory information was consistent with their coping style; that is, blunters were less aroused with low information and monitors were less aroused with high information. This shows that if the health information delivered by a health care professional is tailored to suit the patient's own specific health information need this enables a better quality of care.

There is strong evidence in the literature to prove that patient education leads to better quality care for patients, with the research by Rosenberg (1971) providing reasons why this is the case. Patient education leads to better care and although the research study focuses on patients with chronic heart conditions the evidence can still be used for other conditions such as COPD. The study investigated the fact that when healthcare professionals spent time educating the patient instead of focusing on just curing the disease, the patient's care improved. This might seem

obvious but from my own nursing experience the individual's needs cannot be met if their background and health behaviour has not been understood. Miller and Mangan's (1983) health information needs, stress – coping model helps to explain the differing health information needs of patients and the impact of these differences by ensuring that social boundaries and outside stresses may contribute to their information need.

The relevance to nursing practice identified by Nikoletti, Kristjanson, Tataryn, McPhee and Burt (2003) of understanding the reasons why patients information needs differ, is that nurses should consider assessing informational coping styles to balance the amount of information given to the patients with appropriate strategies for assisting to cope with stressful information. This challenges the traditional stance on health information needs which is to administer the same amount of information to a patient without assessing what coping strategy they utilise. The fact that Nikoletti et al. (2003) take this stance contradicts research such as that of Eysenbach (2001) who thinks that information should be equal to all, although his research does specifically relate to internet sourced information. This stance on health information taken by Nikoletti et al. (2003) is significant to this critical review because it incorporates Miller and Mangan's (1983) understanding of the reasons why people have differing health information needs.

Health behaviour models are useful in going some way into explaining the reasons why patients behave in different ways concerning health information needs. When looked at alongside the other two themes of this critical review, impact that information needs has on hospital admission and the use of the internet, the theoretical framework of the information needs, stress – coping model outlined by Miller & Mangan (1983) becomes a tool to help explain these themes. It is easier as health care professionals to understand and adapt the way that health information is delivered to patients when the reason why their health information

needs differ is explained. This analytical framework will therefore be used to analyse the themes generated by the literature search explained in this methodology chapter.

### **1.6 Summary**

The context of this critical review comes at a time where financially and structurally the NHS is coming under strain; this is clear from both literature and my own practical evidence.

However as established above the need for health information education to meet the needs of patients with COPD is paramount. Due to its potential to improve patient care through emphasising self-management, therefore research into its importance is necessary to investigate its significance.

## **Chapter Two**

### **Methodology**

#### **2.0 Introduction**

The literature of this critical review was analysed by using the theoretical framework of the stress – coping model outlined by Miller & Mangan (1983) to explore and assess the differing health information needs of patients with COPD, the effect that this has on hospital admission and what effect technology, specifically the internet, has on differentiating health information needs. This methodology chapter will give justification for the method choice of a critical review instead of other means of research, before explaining how the literature was searched and analysed to generate the key themes. Finally summarising the main limitations of this critical review study and highlighting areas which could be improved for further research.

#### **2.1 Rationale for choosing a critical review**

This chapter will look at the methodology of how this critical review dissertation was achieved by first understanding what a critical review is and why this method was used instead of other methods. A critical literature review is defined by Anson and Schwegler (2000) as being an investigation study which is analytical of what has been written, identifies areas of controversy, raises questions and identifies areas which need further research.

In the case of this dissertation the impact of differing health information needs of patients with COPD and the relevance to nursing practise because of this is better

answered by collecting evidence from a range of existing literature evidence. A critical literature review differs from empirical studies as stated by Wisker (2007) because its aim is not to prove or disprove ideas using data analysis but rather to challenge ideas and collect evidence for an issue raised, therefore making it a justified method for this dissertation. Whereas an empirical study could follow this review focusing more specifically for example on the differing health information needs of patients with COPD as inpatients and those cared for in the community. An initial critical review as a formative piece would allow such a study to occur however because no such study exists a critical review was chosen. As although Sauro et al. (2008) research using the LINQ is close this area of research, it was based in Italy which has a different health care system and does not compare the significance of specific locations on patients health information needs.

The need for a critical approach to evidence-based health care is now well recognised and as Miles et al. (1997) establishes essential to develop clinical practise. However, a critical review is not classified as qualitative research but as a literature review of existing evidence, which sits on a continuum of reviews with systematic reviews on one side and critical reviews on the other. A critical review is not purely a research method, it is a type of literature review, a critical review was chosen over the other types of review because of its ability to analyse other primary research studies and draw on this information gathered. Averyard (2010) states drawing together evidence from various sources provides a stronger evidence base for practitioners to apply to their professional practice, particularly in an area as broad as health information differences for COPD patients. Primary research, for example a qualitative study or comparative quantitative study, was rejected because a critical review on this area of research interest was limited.

The method of a critical review was also chosen because, as Aveyard (2010) describes, it has an organic nature; one where the process can evolve with the

question. This means that the structure of the dissertation can develop over time and is less rigid than empirical research. Jones (1995) states that qualitative research and especially critical reviews play an important role in answering questions that are not easily addressed exclusively by experimental methods. In the case of this critical review other qualitative methods such as narrative or systematic literature reviews were not conducted because these were felt to restrict the organic process that would best address the issue of differing health information needs. A critical review was chosen lending less emphasis on inclusion and exclusion criteria. There is concern about the use of such criteria causing an element of bias to the research method (Aveyard, 2010). There is, for example a risk of bias if only published research is cited due to the fact that journals tend to publish research that, for example, show the positive effects of an intervention. This is because to get studies published journals tend to select studies which interests the majority of readers, this idea of bias related to exclusion criteria is stated by Easterbrook et al. (1991) who argues that this prevents the literature review from progressing and in fact prevents the reader from gaining information which is relevant to their research area.

## **2.2 Searching the literature**

A critical review was conducted using selected keywords generated from a mind mapping exercise. The search terms included COPD, health information needs, internet, hospital admission and hospital admission linked to meet health information. These search terms were applied to electronic literature databases, which focused on a range of health and social care literature to identify appropriate studies that centred on health information needs of patients with chronic health conditions. Terms were provisionally applied to ensure appropriate literature evidence was identified; however these were only provisional because the choice to use a critical review over a systematic review was to ensure that no bias was

created due to these criteria boundaries. To provide context for the findings a literature search on multiple databases was undertaken to identify relevant studies for this clinical review. These databases specifically included:

- The Cumulative Index to Nursing and Allied Health Literature (CINAHL) which although an American based resource for nursing, did allow a broad spectrum of research to be analysed.
- The British Nursing Index, Sage Journals and Medline were other databases which provided the majority of the evidence.
- The PyscINFO database was used specifically for the health behaviour element of the critical review and allowed an insight into other areas of science, which Web of Science also achieved.
- The use of Google Scholar was also used to assess an understanding of some of the ideas generated from these databases; however the reliability of research studies found through this search engine were always investigated on their own merits.

Evidence-based practise requires the continual evaluation of the published literature to identify studies that can assist healthcare professionals in the management of patients (Burns and Grove, 2011). Burns and Grove (2011) identify online subject specific electronic databases as a means of access to a range of different literature, through research studies nurses can develop and refine the best methods for delivering nursing education. The need to identify key words was essential in order to search these databases effectively. The findings from the literature review around the topic of differing health information needs of COPD patient generated two key themes which were identified as the impact that met health information needs has on lowering hospital admission and the use of the internet as a health information source. The psychology of health behaviour in terms of health information needs was also identified as key to the cause of differing health

information needs; all three of these aspects will be discussed in the theme chapters.

### **2.3 Generating themes and analysing the literature**

The S.M.A.R.T criteria outline by Doran (1981) was used to generate the review question as well as the two key themes. Although this criterion was first generated to set goals for management process, it can still be used to ensure that the objectives and themes of a critical review are constructed in such a way as to positively contribute to nursing practise. This S.M.A.R.T criteria is broken down into making sure that the question of the literature review was specific and clear in what it aimed to achieve, 'Are there differing health information needs of patients who have COPD'. With further aims of the study analysing the effect that differing health information needs have on hospital admission and the impact that technology, specifically the internet, has on health information needs. The aims had to be measurable using the specific analytical framework of the Preview, Question, Read, Summarise (Cohen, 1990) and the critical appraisal tool developed by Aveyard (2010) as explained below. The aims needed to be attainable within the University of Nottingham's online and library services, as well as realistic by utilising these services and developing knowledge of the literature through critical appraisal. Finally, the aim had to be achieved within a time limit of finishing this critical review by March 2014, this meant that although there was more literature to analyse a time limit was required.

Whilst analysing the literature a research diary was kept to reflect and to keep a record of ideas and connection whilst reading. Jaspar (2005) identifies that reflective practice using a tool, such as a diary, creates the capacity for reflective writing to develop thinking and analytical abilities, creativity and unique connections to be made between disparate sets of information, and to contribute to

new perspective being taken up on issues, in this case health information needs (appendix two). Thus Jaspar (2005) highlights the features of reflective writing and its use within qualitative research as a method in its own right, as a data source and within the analytical processes of evaluating literature central to writing a research study. It is argued by Jaspar (2005) that, although reflective writing is increasingly becoming visible within qualitative research reports, it needs to be further acknowledged as central to the methodological processes within research studies and recognised as an essential part of their methodology. This argument is also stated by Rolfe, Freshwater and Jasper (2001) and Glaze (2001) but less specifically on research reflection and more about reflection in nursing practise as a whole. However Cise et al. (2004) makes the same link that Jaspar (2005) does about reflective writing using diaries and the development of critical thinking in terms of research studies. Therefore the research diary was used as a tool to generate ideas and keep track of links made within the literature surrounding the health information needs of patients with COPD. Averyard (2010) states that a research diary allows the organic nature of a critical review to develop in order to answer the aims and objectives of the study. On reflection the diary did enable a clear plan to develop and ensured links were fully explored and acknowledgements established where needed.

Critical appraisal tools was used to help guide the evaluation of research in the literature, the first approach taken to analyse the literature was adopted from Cohen (1990) cited in Cronin et al. (2008) which is the preview, question, read and then summarise approach. This technique enables the literature to be viewed with an analytical but broad stance of first previewing the information to find what is relevant to the questions of the critical review. The next stage is to question and read the literature to develop a matrix of what the key findings are in the research, alongside the methodology and bibliography of each source, which was recorded

accurately in the research diary. The purposes of the studies were then noted due to the bias or angle that this might have created when answering the review question. The last part of this analytical approach was to summarise the key findings and arguments of the research studies to enable their incorporation into the review question of the critical review. Although this tool is useful in a general sense the critical appraisal tool developed by Aveyard (2010) is more specific in its criteria of evaluating the value of the literature in answering the research question with its emphasis placed on how they carried out their research. Aveyard (2010) highlights the fact that when the particular research design has been established from the literature, a critical appraisal tool such as that produced by the Critical Appraisal Skills Programme (CASP, 2009) can be used. The advantages of that are the fact that relevant questions will be answered that are specific to the style of research design used by the study being evaluated, which is why both CASP (2009) and Aveyard (2010) were used in this critical review.

## **Chapter Three**

### **Themes**

#### **3.0 Introduction**

There are two themes which will be presented separately below, the first about health information needs linked to hospital admission and the second before the impact of the internet on the health information needs of patients with COPD. This chapter will be concluded with a summary of the key findings of the themes, before moving onto the final discussion chapter.

#### **3.1 Health information needs linked to hospital admission**

This theme will investigate the effect that differing health information needs of patients who have COPD have on hospital admission. This is such an important aspect for both health care professionals and patients because if patients can be nursed in the community and do not have to be admitted into hospitals then this would benefit them, as well as reducing the expense of their care on the NHS. A conservative estimate by the Department of health (2011) is that COPD costs the health service up to £805m a year and nearly half of this money is spent on hospital admissions. Management strategies that reduce either the number of hospital admissions or the length of hospital stay could potentially reduce direct healthcare costs; this was directly shown in Guest's study (1999). One of these management strategies was the use of effective health information to promote self-management for patients. This emphasis on controlling exacerbations through patient information was also emphasised in O'Reilly, Williams and Rice's (2007) study. This shows that there is a need identified in the literature to provide patient

information which is accessible and accurate to patients with COPD to help reduce hospital admissions from this health condition.

The majority of patients with COPD experience at least one exacerbation per year and Osman, Godden and Friend (1997) describe these exacerbations as being an acute deterioration of respiratory symptoms with the most common symptom being breathlessness. Several studies have shown that exacerbations are strongly associated with unscheduled healthcare resource utilisation; these include O'Brien et al. (2003) investigation into the utilisation of health care services by patients. This study showed that although healthcare services were available to patients they were not always fully utilised or understood. This is important to clinical practise because unless the information directed at the patient is being understood it cannot be effectively absorbed and used to manage their COPD.

The economic cost of these exacerbations is calculated as being £44.9 million per year in England and Wales by McGuire, Irwin and Fenn (2001). Although this figure may have increased since then and does not include Scotland which has a high prevalence of COPD, it clearly shows however that COPD hospital admissions cost the NHS millions of pounds a year. The main cost however and one especially key to nursing clinical practise is the cost to the patients on admission, this can be both psychological and physiological, and although harder to measure it is nevertheless important to identify.

The link between anxiety and health information needs of patients has been researched by Maurer (2010) and showed significantly that anxiety was reduced where health information needs were met. Although the study was based in the United States its relevance can be used globally, however due to the different nature of the health service in America this has to be taken into account when evaluating the validity of the research. Other empirical research studies have investigated this

link between anxiety with Bailey (2004) investigating the relationship between acute exacerbations and a patient's physical and emotional functioning. The level of anxiety patients feel about their disease has been shown to increase admissions into hospitals by Bailey (2004); therefore if this anxiety can be reduced it could be assumed that hospital admissions would also decrease. Bailey's (2004) study is a qualitative study focusing on ten patients; the interviews were carried out during an acute episode of the patient's lung disease. They described their understanding of acute exacerbations as an experience inextricably related to anxiety and emotional functioning. Their narratives suggest that given the absence of clear objective measures of illness severity which could be established via health information, the patients reported that anxiety was the most major contributor to an acute exacerbation causing a hospital admission. Health care providers therefore need to recognise the importance of anxiety as a contributing factor in unnecessary hospital admissions. It is important to establish however that this study only followed ten patient's experiences and a much larger research study would have to be conducted to generate stronger evidence, however it is still relevant in exploring the effect that differing health information needs of patients has on hospital admission because from nursing practise this has also been proven to be true. Whilst working with the specialist COPD nurses in the community they emphasised the negative effect that anxiety has on the breathing of patients. As a major symptom of COPD is shortness of breath this is exaggerated when a patient is anxious causing hyperventilation. The tackling of a patient's anxiety could prevent this from occurring and could be reduced by effective delivery of information relating to their health information needs. It may be perceived that what works in terms of information delivery for one patient does not necessary mean that the same method would work for another patient, the key being person centred care. Krohne and Hock (2011) emphasise this point and states in their research that anxiety is central to how much information is retained by an individual. This is especially

important to note in terms of patients with COPD whose anxiety is closely linked to symptoms of the condition. Therefore if anxiety was reduced via more health information, this would consequently reduce hospital admissions and raise patient wellbeing.

There is a complex and circular relation existing between breathlessness and anxiety established in the above text, in Bailey's study the participants talked of emotional anxiety as being the result of both chronic breathlessness and decreased physical and emotional activity. Emotional vulnerable stories generally concluded with acknowledgement of patients' decreased activity, increased experience of breathlessness, further emotional distress, and often, help seeking behaviour. These help seeking behaviours include admission to hospital and therefore if the anxiety of the patients could be prevented these admissions could be also be prevented. What Bailey's (2004) study clearly showed by the vulnerability stories of patients with acute exacerbations of COPD and their family caregivers revealed an understanding of the dynamic relation between exacerbations and emotional functioning, specifically anxiety. Anxiety was seen not as the underlying cause of distressing exacerbations, but as a sign of longstanding or acute respiratory failure, a relation that could be described as the anxiety breathlessness cycle. Therefore if the anxiety was tackled before it escalated to needing medical attention, these patients could be cared for in their homes rather than having to be admitted to hospital. No author opposes Baileys' observations which could be due to the fact that this area of research is not heavily evidenced and more research needs to be conducted on the link between anxiety and COPD exacerbations.

Michaels and Meek (1999) state that COPD patient's commonly experience anxiety as a sign, and often not the cause, of breathlessness. The presence of anxiety during exacerbations episodes is considered legitimate by patients and adds to the vulnerability experienced. Therefore, nurses should be careful not to assume that

their breathlessness is caused by anxiety, using effective patient management the underlying issues should be addressed as well as the anxiety. From the literature it is clear that anxiety contributes to breathlessness and if reduced could ultimately reduce hospital admissions. The meeting of information needs of COPD patients could help reduce the anxiety that they feel about their disease and how to manage exacerbations when they occur. The distribution of information to patients is therefore essential and should be of high priority to nurses.

There is research to suggest that the sex of patients with COPD alters the information needs required. This is of clinical importance because it could alter the way that nurses deliver their care towards patients, however it is essential that stereotypes are not established and each patient is treated as an individual. This is identified in the Nursing and Midwifery Council (2013) code of conduct but understanding the reasons why individuals behave in different ways is also important. Laurin et al. (2007) identifies the point that psychiatric disorders are at least three times higher in COPD patients compared to the general population, and nearly two times higher in women than in men. Women also have greater anxiety and worse perceived control of symptoms of stress, as well as greater functional impairment as identified by Laurin et al. (2007) in the research. Greater efforts should be made therefore by nurses to identify and treat psychiatric disorders in COPD patients, particularly in women. These issues can be reduced by presenting patients with information about concerns surrounding their health and in clinical practise it is important to establish this. While depressive and anxiety disorders are more prevalent among women than men in the general population, as stated by Kessler, McGonagle and Zhao (1994) there are currently very few studies on the prevalence of psychological distress and psychiatric disorders in women compared to men with COPD. Karajgi, Rifkin and Doddi (1990) research is the only study that directly compares the prevalence of anxiety disorders in patients with chronic

obstructive pulmonary disease comparing gender. This study although conducted in American and on a relatively small spectrum of people, whose cultural background and literacy rates are unknown, it is still relevant to nursing care in the UK. As the UK has a similar western society of which Karajgi, Rifkin and Doddi (1990) states is a factor in creating anxiety disorders for patients with COPD. The fact that this is the only research study that directly investigates this area indicates the needs for more nursing research into the differing health information needs of patients with COPD of opposite sex.

Patients value dialogues with their health care providers and this relationship has been proven to reduce anxiety, this is a well-documented fact highlighted by Toms and Harrison (2002) in their research on living with chronic lung disease and the effect of pulmonary rehabilitation from patients' perspectives. However due to the nature of COPD and the links between smoke inhalation and prevalence of the disease, there can be pressure put on this relationship. As Halting, Heggdal and Wahl (2011) state in their research, on the experiences of self-blame and stigmatisation for self-infliction among individuals living with COPD due to smoking, these emotions of regret and shame can lead patients to steer away from engaging with health care professionals. This study although written for a Scandinavian Journal, therefore not specifically centred on COPD patients within the NHS, is of interest because it highlights the tendency of some patients who adopt health behaviour patterns that are detrimental to their health to choose not to take health information from health care professionals. However there are limitations to this study because of the fact it was based on a relatively small spectrum of people and with no differential between gender or culture was factored into the analysis. The study does show that emotions such as blame, has a detrimental effect on meeting the health information needs of these patients, it is therefore important as nurses to face these emotions with understanding and care. Guilt and shame about having

smoked, and for unsuccessful cessation, is described among patients in the severe stages of COPD by Robinson (2005) focusing on the impact that their disease has had on their families. These emotions are still the same among individuals with newly diagnosed COPD, as Jonsdottir and Jonsdottir (2007) in their research on the experience of women with advanced COPD of repeatedly relapsing to smoking. Although this study focuses on the woman's perspective and is published in a Scandinavian journal, it is relevant to all patients with COPD because it highlights the need to factor in emotions when analysing patients' health behaviour. These experiences that patients have of stigmatisation will affect the well-being and illness experiences of those with COPD. It will also influence how they make sense of their illness and adjust in the society in which they live, because as Radley (1994) acknowledges in Western societies, there is now an increasing awareness of personal responsibility for promoting one's health.

The responsibility outlined by Radley (1994) is that the emphasis in health care is now placed more on individuals making health behaviour choices which will benefit their own health, behaviour such as smoking is seen more and more in a negative light by health care professionals. However it is essential that own personal decisions do not reflect on nursing practise and non-judgemental nursing care is administrated to ensure optimum care for patients, which in turn will allow a relationship to develop that facilitates health information needs being met.

The literature surrounding the differing health information needs of patients with COPD's impact on hospital admission is centred on the positives of self-management; this has been shown to reduce the anxiety felt by COPD patients about their condition. For example, this is seen in the study undertaken by Bourbeau et al. (2006) whose focus is similar to that of Wagner (1988), stating that self-management interventions are an important component of integrated chronic care and the most commonly mentioned in the literature evidence both nationally

and worldwide. Bourbeau et al. (2004) states that the development of self-management for COPD patients could greatly improve their quality of life and reduce hospital admissions. Two recent systematic reviews have shown positive outcomes for patients with COPD in terms of self-management, the first conducted by Adams et al. (2007) showed that self-management programmes reduced the probability of COPD-related hospital admissions. This was further researched by Effing and Monninkhof (2007) who demonstrated a significant reduction in number of hospitalisations and length of hospital stay. This is essential because as health care professionals it should be our main aim to prevent the unnecessary admission of patients into hospital. However it should be highlighted that these studies did not specify which gender or age grouping the self-management programmes benefited. This is important to identify because from the theoretical framework identified in chapter one, Miller and Mangan's (1983), these grouping have very different psychological tendencies and therefore needs.

The research undergone by Pushparajah et al. (2006) clearly show that self-management programmes for patients with COPD, including the delivery of appropriate health information at time of diagnosis, reduces hospital admission. The fact that this study was based in one hospital, the Royal London Hospital, (Barts and the London NHS Trust) means that its relevance to the wider population is reduced. However the fact that data was taken over such a long period from November 2000 to March 2002, means that the results are not affected by seasonal bias for COPD patients, whose exacerbations are predominately worse over the winter period. The results clearly show that these self-management programmes work which include the education of patients to undergo behaviour changes that positively contribute to their quality of life. These behaviour changes can be as simple as following a set of steps, which are taught by the nurse, when a patient is

feeling particularly short of breath. It has been researched by Pushparajah et al. (2006) that health information greatly reduces the anxiety felt by COPD patients.

### **3.1.1 Summary of theme one**

This theme investigated the effect that differing health information needs of patients who have COPD have on hospital admission. Specifically concentrating on the complex anxiety linked to acute exacerbations of these patients, which could be reduced as Maurer et al. (2008) and Bailey (2004) identified if effective health information was received. This theme did however highlight some barriers to meeting these health information needs, establishing as Miller and Mangan's (1983) in their theoretical framework some patients to blunt, move away from information. This maybe because as Holding, Heggdal and Wahl (2011) state due to feelings of blame and guilt due to adopting behaviour habits which are detrimental to their health. The implications for nursing practise which has come out of this theme is that as advocates for these patients, nurses must be sympathetic to these feelings and work towards creating a scenario where the self-management, researched by Pushparajah et al. as being central to these patients receiving optimum care. The value of dialogue was highlighted by Tom and Harrison's (2002) research study as being of great importance to patients in reducing anxiety and from personal experience on practice this is paramount to ensuring patients meet their health information needs.

### **3.2 The impact of the internet on the health information needs of patients with COPD**

Patients are increasingly expressing their need for more information about their health and as the literature review by Dey (2004) shows this need can be separated into quantity and quality. The internet is fast becoming the first source of patient information need and the dangers of this are heavily investigated in the literature

for example Jones, M.C.R., Hyland, M.E., Hanney, K., & Erwin, J. (2004) and Nettleton, S., Burrows, R. and O'Malley, L. (2005). The differing health information needs of younger patients with COPD and the elderly population of over sixty may cause difficulties for the healthcare professional in determining how much health information to deliver. In the United Kingdom various publications from the Department of Health have emphasised the need to give greater voice and influence to users of NHS services, and patients are expected to assume greater responsibility for their personal health, for example the 'Patient and public involvement in the new NHS' (2005). These initiatives both mirror and fuel a demand for more and better health information. The impact of the internet will be discussed and its appropriateness analysed in terms of COPD health information needs.

As Nettleton, Burrows and O'Malley (2005) state information accessed via the Internet crosses international boundaries and includes access to experiential knowledge from other patients and carers, enabling patients to become more active collaborators in their own health. This is argued in the literature by Ziebland et al. (2004) to mean that as health care professionals the differing health information needs of patients are made more apparent by how much independent research they undergo. The research by Ziebland et al. (2004) was centred on how the internet affected patient's experience of cancer, although not focused on COPD it has relevance for this chronic condition. The study showed that different patients wanted to know different health information dependent on how long they had lived with the condition. It also showed alongside Stevenson, Kerr, Murray and Nazareth's (2007) study that although the literature identifies possible tensions that may be caused by patients' access to information via the internet, generally the internet was perceived as a support, as opposed to a challenge, to medical practice. This means that although technology has changed the source of health information,

in both studies, there was a continuing and strong awareness of the value of medical expertise. The accounts in the research studies did not in any way suggest a desire to disrupt the existing balance of power, or roles, in the consultation with a health care professional.

The study conducted by White and Selwyn (2013) into the 'digital divide' in the United Kingdom over internet access and use raises an important point. Although this study was investigating not only health information access but banking, purchasing and looking for work, it clearly shows that education and age has a huge impact on those groups accessing the internet. This is important to consider in terms of the impact that the internet has on health information because the prevalence of COPD is higher in people over 65 years and in lower social-economic class groupings. Therefore as health care professionals it is essential that health information distribution is not relied upon to be accessed via the internet, because those in most need of being targeted may not be able to access this information.

Demiris et al. (2008) have investigated this relationship between the patient and health care professional, and he states there has been changes that technology has had on the information needs of people who have COPD, he states that patient empowerment has increased due to the shift in need to gain information solely from health care professional. Demiris et al. (2008) states that the patient can now source information about their health condition independently. It should be noted that this does not specifically concern COPD and that the study was based in America, however it is still relevant to the differing health information needs of COPD patients in the United Kingdom. A study that was also set in America but focusing specifically on the resource needs of patients with COPD by Barr et al. (2005) identified the fact that only twenty-five percent of patients considered themselves to be well informed about COPD and treatment, whereas 36% considered themselves to be less than adequately or poorly informed. The study

also found out the sources of patients health information with 77% obtaining information about COPD from physicians (77%). However, the next largest source of information was the Internet (47%), with only 38% from nurses, respiratory therapists (22%), television (13%), and patient organizations (3%). This clearly shows that patients are now using the internet as a major source of information discovery to meet their information needs. Although the US health system is very different to the UK's in particular access to health care, these studies are of interest due to the fact that the access to the World Wide Web is similar in these two western countries. It is therefore essential that health care professionals are able to inform patients of the reliable and accurate sources of information on the internet.

The research undergone by Henwood et al. (2003) discusses the emergence of the 'informed patient' in the changing landscapes of health information. It identifies key arguments relevant to nursing practise regarding the aim to provide patient specific health information. The empirical study highlights the fact that whilst the internet does provide a source of health information for half of the participants in the study, it is just one of many different sources through which they currently access health information, with more traditional sources and media to be just as significant. The results of this study informs this theme on the impact of the internet on the differing health information needs of COPD patients, as it shows that although the internet is an important source of information, health care professionals still have an important role in delivering health information. Particularly to COPD patients who are primarily cared for in the community and are statistically from the elderly population, who Henwood et al. (2003) suggest may value more traditional sources of health information. The study also identified that there was a real problem with information literacy amongst our participants which has implications for the extent to which they are able to become informed about their health condition, this is especially significant in terms of COPD because of the high prevalence of the

condition in low social economic classes which statistically have lower literacy rates. The style of health information delivery must be adapted to the patient's ability to understand and therefore adapt health behaviour through education.

The internet should be seen as a way to reach a vast cross section of society in terms of health information. However it should also be viewed with caution because the literature evidence shows that it has its limitations and problems in relation to accurate health information delivery. Online patients do agree with their doctors on one point: that much of what passes for online health information is not to be trusted. Ferguson (2002) highlights this point about reliable information with his research showing that both patients and health care professionals worry about the source of information that they find on the internet. In his earlier study he found out that of those patients with internet access in his study, 82% said that they are concerned about getting online health information from an unreliable source. Ferguson (2002) went on to identify that where professionals and patients differ is in their views of these patients' ability to tell the good from the unreliable information.

The literature evidence shows as McMullan (2006) states that as patients use the internet to obtain health information this changes the patient-health professional relationship. This relevant to nursing practise because once understood the health care professional can ensure that this change does not mean that the patient is receiving lower quality nursing care. The effect of the availability of health related information on relationships with doctors is a central concern for patients. The sheer quantity and convenience of health information from the internet facilitates people taking an active role in their care. Moreover, in the studies by both Stevenson et al. (2007) and Ziebland et al. (2004) respondents generally reported attempts to manage use of the internet so it caused minimal disruption to existing relationships in consultations with health care professional. This is relevant to

nursing practise because health care professionals should not feel challenged or threatened when patients bring health information from the internet to a consultation, rather they should see it as an attempt on the part of the patient to work with the doctor and respond positively. This shows that there has been a movement away from patients' simply absorbing health information from health care professional instead they are taking proactive steps to sourcing information independently. Both studies show that the attempted need for patients to source information from elsewhere indicates that the need for more information surrounding their condition is needed initially.

A focus group study conducted by Rodgers et al. (2007) emphasises this point regarding the importance of when health care information is delivered to patients. The focus group study evaluated the information needs of patients with COPD following pulmonary rehabilitation. Therefore, its suitability as evidence to the broader COPD patients care is limited; however it can still be used to show that the timing of delivering health information is important in meeting patient's information needs. Since most of the participants said they were diagnosed in primary care, the implication is that they should receive additional information about the condition at the time of diagnosis, rather than further down the line, during the rehabilitation process. At this stage it might be useful for clinicians to identify the specific information needs of individual patients using a validated tool such as the Lung Information Needs Questionnaire conducted by Hyland, Jones and Hanney (2007). Therefore this study is of clinical importance because it clearly shows that health care professionals should be prepared to deliver health information at diagnosis of COPD. This might go against the instincts of health care professionals, who when looking at Miller and Mangan's (1983) stress copying model, would be sensitive to the patients who are blunterners and might not want this information straight away.

The key point identified in Rodgers' et al. (2007) study on the evaluation of health information needs after pulmonary rehabilitation is the fact that this group of patients would rather have written information than that sourced from the internet. This is crucial to health professionals because due to the cost cutting environment, it could be deemed easier to steer patients onto the internet for information. However it is essential that paper copies of all information are also available so that the optimum amount of information is absorbed by the patients.

The study conducted by Rodgers et al. (2007) also showed that although health information needs delivery begins in primary care for COPD patients, it must also extend to the education of the wider public. This improved awareness would prevent any miss representation of the disease from sources on the internet and would also allow carers, who are normally friends and family, to better understand the disease and with this understanding would come high delivery of care. The participants in this study wanted the provision of information to extend to family members and greater encouragement for them to be included in the rehabilitation process, this is an important clinical point because it is easy as nurses to focus on the patient and forget to incorporate the Royal College of Nursing (2010) key points outlined in the 'Pillars of the community' policy. One of the clinical points emphasised in this document is the holistic care of patients and an individual care based on specific needs, this can incorporate the findings from Rodgers et al. (2007) due to the fact that some patients might need their families to understand their condition in order for them to help with their care. This might in turn allow them to come to terms with the condition, which is something that the patients in the study by Rodgers et al. (2007) deemed important if self-management was to be achieved.

### **3.2.1 Summary of theme two**

Theme two analysed the impact of the internet on the health information needs of patients with COPD and the key areas highlighted were the fact that although the internet was recognised as being a tool to access health information, it should not be seen as a substitute. As Rodgers et al. (2002) states patients still value written information and health professional dialogue as means to meet their health information needs. Reading the literature surrounding the impact of the internet on meeting health information needs of patients, access to the internet was an area of concern for many, as highlighted by White and Selwyn (2013). This concern was also backed up by Ferguson (2002) who identified the risk of information not being reliable and up to date. This theme therefore addressed some of the impacts of the internet on meeting patients with information needs; however more research needs to be done on the effects specifically on COPD patients.

### **3.3 Synthesis of both themes**

Both themes have highlighted that the need to educate patients about their health condition is a well-established practise in nursing, with Jones (2007) stating in his research that behaviour change is central to the outcome in people with COPD. This statement was heavily researched in the background literature review and its relevance to nursing practise made apparent due to its positive relationship with reduced hospital admission, evidenced by Guest's study (1999). Other studies such as the one conducted by O'Reilly, Williams and Rice's (2007) highlighted the use of effective health information to promote self-management for patients.

The discovery of the fact that health information needs is stimulated by the personality traits of patients, using the Miller and Mangan's (1983) stress copying model to explain this, has led the critical review to view the themes through this discovery. This has highlighted the fact that nurses must view each patients need

for information in isolation and understand that psychology of the patient will determine how much information they want to receive. The fact that different people need different amounts of information is central to the nursing care of patients, if holistic nursing care is to be achieved as identified by Dossey and Keegan (2008).

In both themes the importance of patient, health care professional dialogue was highlighted. Firstly by Toms and Hansson (2002), as a means of reducing anxiety by COPD patients, then by Rodgers et al. (2007), as being equal to the internet in informing patients. This shows that health care professionals have a pivotal role in addressing the health information needs of patients and must be trained to meet each individual's specific needs. As previously mentioned, there is a higher prevalence of COPD in patients with low socio-economic status and also in those aged 65 and over. These two groups are less likely to have regular access to the internet, further highlighting the importance of the health care professional in delivering health information to patients.

## **Chapter Four**

### **Discussion**

#### **4.0 Summary of the key findings from the themes**

The review question was to assess if there are differing health information needs of patients who have COPD. There is sufficient argument in the dissertation that there are differing health information needs of patients, however not enough detailed analyses across different sub groups of patients, for example those with web and those without, those who are admitted to hospital and those who are not. The key finding however was the identification of how important meeting the health information needs of these patients are despite these differences. These themes highlighted the need to increase research into the benefits of health information focusing on admission rate, anxiety and the impact of the internet. The key finding that has come out of the literature is how important it is that health care professionals can address the differing health information needs of COPD patients, tackling those barriers suggested by Miller and Mangan (1983), to enable optimum care.

#### **4.1 Limitation of a critical review**

The broad nature of the term health information needs which is so specific to each individual makes creating patterns and developing links in the literature difficult. The literature showed that more research had been done surrounding other chronic health conditions such as cancer and health information needs than that of COPD, this shows that there is definitely a gap in the literature into COPD related research.

The fact that this critical review was undergone by a novice researcher did have an effect on how this critical review was undertaken. This should be taken into account when evaluating the relevance of this study on nursing practise, however saying this the review was undertaken in a thorough and analytical way to provide an insight into how nursing practise can develop to ensure health information needs of patients are being met.

The nature of the critical review methodology does in turn ensure some limitations, particularly the fact that no concrete answers can be made. The review can only, as Averyard (2010) states, add to an existing stance taken after evaluating the literature evidence that has been read. Therefore due to this fact, the evaluation of the research (although steps have been taken to reduce bias) may have been viewed through a stance that was predicated before the evaluation was taken place. This must be taken into account when discussing the relevance of the review but reassurance must be noted from the fact that critical appraisal tools were used to reduce this bias. Therefore although a slight limitation remained, its impact was reduced to a minimum in order to increase relevance of the critical review.

The influence that a comprehensive critical review regarding the impact of increasing health information needs of COPD patients could develop optimum nursing practise in this scope of nursing was explored. This work could also lead to an empirical study more specifically on the different health information needs of inpatients with COPD and those cared for in the community. To see whether those who attend self-help groups, such as Breatheasy conducted by the British Lung Foundation, have less health information needs than admitted patients and thus lower hospital admission rates. This could also be used to analyse the influence of the specialist COPD nurses which I worked alongside with on my elective management placement in Eastwood.

Therefore this critical review could provide the evidence needed for more research into this specific area of particular importance to nursing and with major implication to improving the care for patients with COPD.

#### **4.2 Reflection of the dissertation process**

This dissertation process has been a welcomed challenge which has greatly improved my time management and researching skills. As a novice researcher, my approach to the identification, critique and bringing together of information and literature may not of been as thorough as that of a more experienced researcher. However using the Critical Appraisal Skills Programme tool this allowed effective analysis of literature, and using the database searches provided by the University allowed a broad spectrum of literature research to be examined. If I was to conduct this critical review again, more emphasis would have been taken on researching the cultural and gender differences of COPD patient's health information needs. To suggest some more in depth specific reasons as to why health information needs of patients with COPD differ. However these points were touched upon in this dissertation and have been analysed in enough detail to offer critical discussion.

This process has allowed me to develop skills which have been progressively improving since joining University and partaking in this Master of Nursing Science course. My primary research question has only been partially addressed due to the primary evidence surrounding health information needs of patients with COPD being limited. Therefore this critical review has identified an area of further development in research both empirical and qualitative. The clinical relevance to clinical practice, especially to health care professionals responsible for the delivery of health information needs, has been vast and will be discussed in detail below.

This critical review has highlighted the need for more research to be undergone on the impact of the differing health information needs of patients with COPD. This

literature review has provided an in-depth background justification for more empirical and qualitative interview style research studies to take place. The initial idea for this dissertation was to compare the health information needs of patients that were cared for in the community setting by specialist COPD nurses to those that were in hospital and had not had access to this care service. The justification for such an empirical study to occur has been made from this review and would provide valuable evidence that specialist nurses in the community are a vital tool to educating COPD patients.

#### **4.3 Implications for management and clinical practice**

The fact that patients with COPD have different health information needs has highlighted the need to train health care professionals, both pre and post registration, to be able to overcome barriers to these individuals as identified by Miller and Mangan's (1983) in the theoretical framework. These barriers include culture and personality differences which might initially for health care professionals be difficult to distinguish. Therefore the implication for management and clinical practice is to educate health care professionals on effective methods to be able to address these sometimes sensitive issues, to enable health information distribution to be targeted and understood.

The policy within the NHS should remain focused on health information distribution because it is only from this that patients can achieve the self-management status that managements of the system want to accomplish. The Royal College of Nursing (2010) document on specialist nurses shows the benefits for patient care delivery that these teams achieve. Therefore it is essential that the management of community nursing does not cut the resources needed to educate COPD patients effectively in order to achieve better personal self-management.

This critical review has highlighted the importance of effective health information distribution. The health care professionals that are responsible for this distribution must be made aware of the reasons why health information need differs. They can then tailor the information distributed to the patient's specific psychological need. Nurses, as educators, need to inform patients in ways that facilitate their learning by understanding how they best process and implement health behaviour.

After looking at the literature evidence and from witnessing nursing practise in the community, it is clear that personalised delivery and education on health information works. Therefore as health care professionals this must be delivered accurately and the psychological needs of the patients must be taken into account, in terms of how much health information is delivered. The cultural differences and barriers which are made difficult to patients, such as language, must be identified and overcome by effective nursing education. Although it is not the role of the nurse to implement change in terms of these barriers, it becomes the need of the nurse to ensure that the equity health gap between social classes is reduced and this can be partly achieved by optimum health information need delivery.

#### **4.4 Conclusion**

COPD is a health care condition where symptoms can be dramatically reduced by patients implementing key health behaviour changes. Despite this fact, research into the differing health information needs of these patients has not been as heavily investigated as other health conditions such as cancer. This therefore highlights a definite area of growth in terms of research and an area which would benefit from significant further investigation.

The anxiety cycle that has been highlighted in the themed chapter on hospital admissions shows that when a COPD patient feels anxious, the symptom of breathlessness increases and they are more likely to contact emergency services. If

by effective education provided by specialist nurses in the community, this anxiety is reduced, by providing clear instructions on self-management, then the number of patients being admitted into hospital would reduce. This would not only benefit the patient but would reduce the economic cost of treating patients with COPD, which in the NHS' current financial state is an issue worth addressing.

The key argument that has come out of this critical review is that addressing the health information needs of patients with COPD is of critical importance. The fact that the internet is a point of access to some of the UK's population should not be used as a reason to reduce resources to health care professionals implementing health education. The importance of face to face consultation between a health care professional and a patient remains paramount; it is much more likely to reduce anxiety and create a conducive climate of learning for these patients to implement self-management in terms of their health condition.

The NHS is currently in a climate where defining the contractual obligations of providers commissioned to provide care, information and education is more important than ever before. Health information must be at the forefront of management and policy because it is through this that patients can become informed in their condition and work towards greater self-management. This would not only improve the quality of life of the patients but reduce work load and costs for the finite NHS budget. Therefore, as health care professionals, it is essential to promote and become ambassadors of health information distribution to ensure that the patients with COPD are receiving the information that they need and deserve.