

Experiences of lung cancer patients regarding their nursing care

A literature Review

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<p>Abstract</p> <p>In healthcare, patient experiences has become an important factor to indicate the quality of care all around the world .The aim of this literature review was to exploring lung cancer patients' experience regarding nursing care they received or expected. The purpose was to help to identify what lung cancer patients really wanted, felt and expected regarding their care, and help to develop strategies to improve quality of nursing care guided by patient experience.</p> <p>Articles used in this study were obtained from health and social science databases CINAHL and ProQuest. Articles were selected based upon predetermined inclusion and exclusion criteria, relevance by title, abstract and full text. Content analysis was the analysis method to synthesize data for selected.</p> <p>This study identified 3 major categories on content regarding lung patients' experience of nursing care: more and new approaches of social support, communication of care among organizations and patient empowerment. This study revealed in-</p>		
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Miscellaneous		

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1. Introduction

In healthcare, patient experiences has become an important factor to indicate the quality of care all around the world (Wolf, Niederhauser, Marshburn, Vela, 2014), patient experiences are essential, because patients play a central part in healthcare and their experiences act as a mean of evaluating healthcare services provided. Furthermore, adjusting treatment and care based on experience has shown positive impact on patients, healthcare staff as well as organization. For healthcare professionals, designing treatment and care plan guided by experience produced accountability and responsibility and therefore further encouraged them to work closely with patient to improve experience; for patients, experience guided treatment and care helped patient to gain real insight and understanding of the staff which modified their original expectations and values and encouraged them to participate more actively in the care; for the organization, experience guided care created a trend of equal partnership way of working, improved clinical outcomes for patients.(Donetto, Tsianakas, Robert, 2014.)

Different from other common types of cancer, the survival rate of lung cancer has gained little improvement during the past decades (Eustache, Jibb, Grossman, 2014). This is due to the short survival after diagnose, lung cancer patients' voices were not frequently heard, that was why listening to lung cancer patients, realizing their needs, understanding what really mattered to them is crucial to provide patient centered care during the full range of treatment and care. (Tsianakas, Donetto, , Robert, 2014.)

Previous researches have shown that lung cancer patients experience difficulties regarding their care after diagnosed (Eustache et al, 2014; Pollack et al. 2015 ; Rowland et al. 2016). The aim of this study was to exploring lung cancer patients' experience regarding nursing care they received or expected. The purpose was to help to identify what lung cancer patients really wanted, felt and expected regarding their care, and help to improve quality of nursing care guided by patient experience.

2. Care and treatment of lung cancer patients

2.1 About Lung Cancer

Lung cancer occurs when the cells lining the lungs become inflamed and losses it cells that clear secretion from airways, this result in change in cell types, from columnar to flattened squamous cells. (Gately ,2013). Though, majority of lung cancer arises from epithelial cells of the bronchi and bronchioles some occurs as a result of metastases. Lung cancer is capable of spreading to the lung from other cancer areas (Argiris, 2012, 97). Lung is a common passage of many fluids and gases, therefore cancer metastases are common (Romaki, Hong, and Roth, 2014). Lung cancer can either be squamous lung cancer, adenocarcinoma, large lung cancer, or small lung cancer, and adenocarcinoma is the most common type of lung cancer, followed by squamous, small cell and large cell cancer. (Gately ,2013).

The diagnose of lung cancer is becoming more complex, with new techniques for obtaining tissue specimens and imaging. The National Institute for Health and Care Excellence (NICE) recommends that the most appropriate investigation is one that provides the most information to enable diagnosis and staging of the cancer, and carries the least risk of harm to the patient. It is also recommend that during diagnose, adequate tissue samples should be taken to enable a complete pathological diagnosis to be made, including the type and subtype of the tumor (NICE, 2011). Again, Falk and Chris (2010, 43-44) added that Patients experiencing increased breathlessness, a new cough or one that has changed in nature, haemoptysis, weight loss or fatigue should be referred to the lung cancer team to have a more detailed examination. Furthermore, the first investigation for lung cancer should be chest X-ray is strongly recommended , followed by computed tomography (CT) scan of the thorax. (Illoinen, Räsänen , Knuuttila, SaO, Sihvo, 2011). This is because it shows organs abnormalities more clearly. Patients suspected of lung cancer should undergo further investigation such as lymph node biopsy which involves removal of all or small portion of lymph node to look for cancer cells, bronchoscopy to look inside the trachea for abnormality, PET positron emission, endobronchial ultrasound-guided or trans bronchial needle aspiration to look for to look for tumor cells in body.

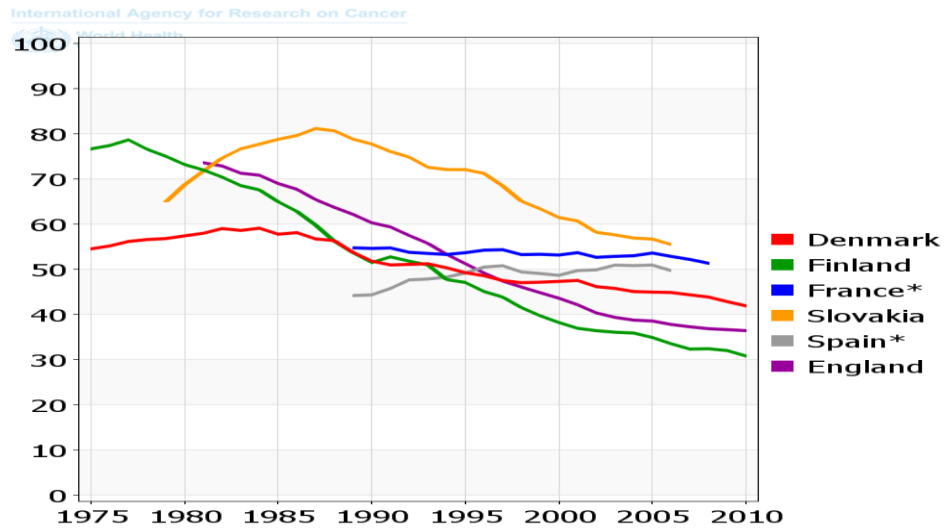
Surgical treatment offers best chance of survival, however, it only applies to patient with stage I/II NSCLC, as most lung cancer are confirmed with diagnose at advanced stage, the treatment option left is usually chemotherapy together with surgery or radiation to shrink tumor to remove tumor completely. Chemotherapy is the most widely applied and less expensive means of managing lung cancer. Cytotoxic drugs of chemotherapy kill both cancer cells and healthy cells (Barber, Blundell and Parkes , 2012, 50). Chemotherapy combined with radiation may cure lung cancer, though mostly it is administrated as one part of palliative treatment which aim to prolong life expectancy and improve quality of life.

Most lung cancers are undetected until symptoms develop, therefore the main objective of treatment focus on maintenance of physiological function; enhance pain control, improved communication and nursing care (Roth et al., 2014). Tobacco use, is considered the leading cause of disease and smoking the primary risk factor for the development of lung cancer (Roth et al., 2014). Lung cancer has been conceived to be the most common cancer for decades. According to the date of WHO, 1.8 million new cases of lung cancer were diagnosed in 2012, among which 1.2 million cases estimated to have occurred in men. The disease remains the most common cancer in men, with high prevalence in central, Eastern Europe and eastern Asia and low incident in central and western Africa (WHO, 2012). In women, the incidence rate is generally lower; the highest estimated incidence rate in women was in North America and northern Europe (WHO, 2012).

In Finland, the incidence of lung cancer has developed two different trends for male and female. A decreased from 0,075% at 1980s to 0,029% at 2010; for female, however, it increased from 0,0071% at 1980s to 0,0126% (THL, 2015), the trend could be explained by the fact that more women started to smoke. Each year in Finland, lung cancer claims precious life of around 1459 men and 716 women (Finnish Cancer Registry, 2017), under half of the patients diagnosed of lung cancer can survive one year, and 5-year survival rate is under 16% (Finnish Cancer Registry, 2017), making it the most deadly cancer. The prevalence of lung cancer in Finland's male population is among the highest in the world (GLOBOCAN 2012), which may be well explained by the smoking habits of Finnish Male. (Pukkala and Rautalahti, 2013). In Finland like in other countries, results of lung cancer treatments are still unsatisfactory, despite the

different treatment options available. Fig. 1 indicates the trend of lung cancer in men and women in some selected countries.

Men



Women

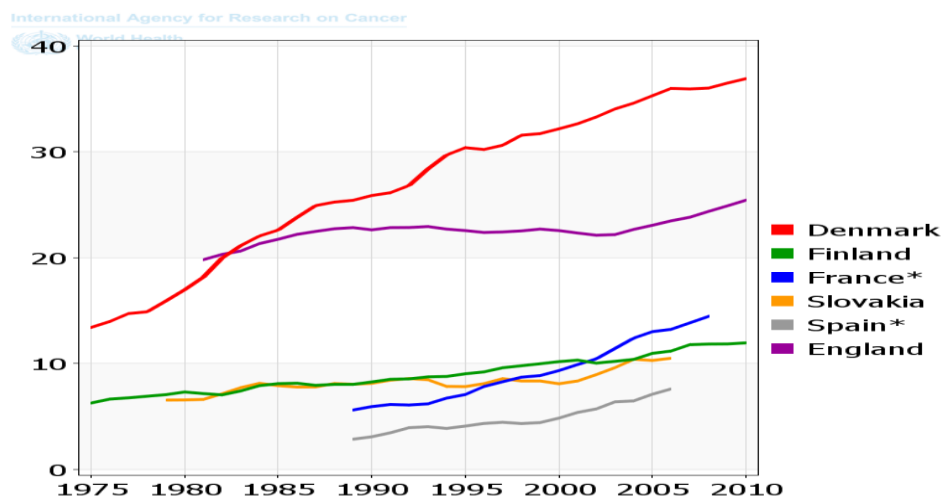


Figure 1: Trends in incident of lung cancer in selected countries for men and

Data source (WHO: GLOBOCAN 2012)

2.2 Patient Experience

The term experience has so many meanings; different individuals look at it differently. Philosopher Dewey (1916) defined experience "feeling, conceiving and enlivening" through an event. Sherry (2016) defines experience as the "the sum total of the conscious events which compose an individual life". The most frequently used definition of 'experience' is "what actually happened to an individual, meaning cumulative life experience". LeSeure and Chongkham-an (2015) assert that "experience' means "how a patient perceived a particular phenomenon. Experience is neither self-evident nor straightforward while it is always contested, it is part of daily activity, serving a way of how to talk about what has happened, and establish similarity and difference. (Scott, 1991). Experience is objective, each person may experience different feelings, attitudes, conceiving towards same event; however, certain groups of people are likely to have collective common feelings, conceiving towards certain events.

Despite the common recognition of the importance of patient experience, there is no clear and shared definition of experience yet. Patient experience shares common themes of emotional and physical lived experience, spanning across the continuum, and importance of partnership/patient involvement, and it is shaped by the organization/culture. (Wolf, Neiderhauser, Marshburn and Vela, 2014). Based on the findings, it is suggested that patient experiences are reflections upon collections of independent events during the continuum of care and patient experience was closely related with patients' expectations beyond clinical outcomes and whether these expectations were realized. In healthcare, patient experiences have become an important factor to indicate the quality of care globally (Wolf, Niederhauser, Marshburn, Vela, 2014).

Nowadays, patient experience is considered as a common part of measuring the quality of patient care and substantial effort is being devoted to designing patient-centered care, which may require certain changes of the traditional healthcare system (Cleary, 2016). The change in healthcare delivery systems requires designing and providing healthcare

services from patients perspective, and accompanied by nurses' practice principles. Following patient-experience guided nursing interventions enables nurses to gain insight into patients' experiences and provide more efficient, effective and patient-centered care. (Provan & Rennie, 2017). Understanding patient experience, barriers and enabling good patient experience are likely to help nurses to adopt new strategies effectively and implement new practices efficiently to improve quality of cancer care, as well as enhance health system performance, which will result to better cancer outcome (Daly, 2012). Patient experience also contribute to motivating stakeholders to initiate changes to service offer and delivery of care (Belanger, Rainville, Coulombe, Tremblay, 2015) so as to better meet to needs of patients.

2.3 Nursing Care

Nursing care was defined as "the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations" (American Nurse Association, 2017) . Understanding this concept was important to design care path for any disease as the concept is wide, and consists not only tasks in clinical settings, but also providing continuous interventions over the whole patients' journey through illness.

Nursing care for patients for lung cancer patient revolve around comprehensive supportive care, pain and anxiety alleviation, ensuring effective gas exchange and patient teaching to minimized complications from surgery radiation or chemotherapy. Supportive care is a multi-disciplinary concept and it include other aspect such as symptoms management, psychosocial aspect ,coping strategies, issues regarding quality of life, improving patient-reported outcomes, service delivery and so on. (Molassiotis, Uytterline, Hollen, Sarna, Palmer, Krishnasamy, 2015). During nursing care, nurses need to understand patient's needs and challenges, and identification their supportive care needs. Role of nurses caring for lung cancer patients differ from countries to countries. Nursing role is gradually developing and expanding to more areas over some of these role are patients and family, thoracic/pulmonary nurse navigator, referral-primary care physician-feedback, interventional pul-

monologist services, multidisciplinary team care delivery and survivorship. (McPhillips, Evans, Ryan, Daneshar, Sarkar, Breen, 2015).

Symptom management remains the one of the important needs among lung cancer patients, these symptoms includes dyspnea, nausea, vomiting which are the traditional focus of care; other common symptoms such as cough, fatigue, peripheral neuropathies receive less attention; and certain symptoms such as fatigue are easily neglected.(Molassiotis A., Uytterlinde W., Hollen P., Sarna L., Palmer P., Krishnasamy, 2015.)

Psychosocial aspects of management of lung cancer patients has become an important issue for nurses to cope with for a long time, the stigma against lung cancer patients has attracted attention and nurses should address psychosocial wellbeing of lung cancer patients during the care (McPhillips, Evans, Ryan, Daneshar, Sarkar, Breen, 2015). The role of nurses in caring lung cancer patients differs from countries to countries, and the role of nurses has been developing and expanding to more areas all the time, especially the role of navigator has gained increased support. (McPhillips, Evans, Ryan, Daneshar, Sarkar, Breen, 2015). The role of nurses covers services related with patients and family, thoracic/pulmonary nurse navigator, primary care physician-feedback, interventional pulmonology services, multidisciplinary team care delivery and survivorship. (McPhillips, Evans, Ryan, Daneshar, Sarkar, Breen, 2015.)

3. AIM, PURPOSE AND RESEARCH QUESTIONS

The aim of this study was to exploring lung cancer patients' experience regarding nursing care they received or expected. The purpose was to help to identify what lung cancer patients really wanted, felt and expected regarding their care, and help to improve quality of nursing care guided by patient experience. This study addressed the research question: What are the experiences of lung cancer patients regarding their nursing care?

4. Methodology

4.1 Literature Review

A literature review is the analysis and synthesis of previous research, in an attempt to solve a problem or understand a phenomena. (Schwandt, 2007,266.) In addition Ryan (2010) defines literature review, as the combination of multiple single studies that address identical issues. It is supplemented that a literature review is a scientific approach which begins with specific question, identification of relevant material, appraisal of quality and summarization of findings. (Bettany-saltikov, 2010, 8). Kiteley and Stogdon (2014, 10) added that In addition, literature review help researcher to understand and summarized information available on a particular phenomenon (Kiteley and Stogdon , 2014, 10). To summarize all above mentioned ideas, literature review provide a combination of results from multiple studies which can be used to solve a problem (O,Brien and Guckin (2016).

Literature review is increasing gaining grounds in healthcare and social services research. Literature reviews is at the top of the evidence-based research, because they provide a summary of research finding available on a particular phenomenon. (Holly, Saimbert, and Salmond, 2012,3). Moreover, literature review uses an explicit, rigorous process to comprehensively identify, critically appraise, and systematical identify relevant studies, thus making the findings of the study to have greater validity than a single research study. (Leseure and Chongkham-ang , 2015.) Literature review answers research questions using several primary studies, using strict method to select articles and above all is less bias when compared to single research (O. Brien and Mc Guckin, 2016). Some researches though hold a controversial view, and asset that literature review do not completely eradicate bias in research, it simply reduces it, and if not used correctly, it create a lot of bias. (Bettany -Saltikov, 2012), which causes some researchers to disagree with the way information is retrieved. Although this method of researcher has some lapses, it is of great importance tat the world is present with lot of information.

4.2 Scientific Article Selection Process

Scientific studies utilized were selected through a literature search of Cinahl, and ProQuest database. The search was limited to full text, peer review articles published in English within 2010-2016. Eligible studies were selected independently by two reviewers, the following medical search words were used: lung cancer or lung neoplasm or lung tumor" AND experience* or perspective* or view* or attitude* or satisfaction* or emotion* or feeling* or expectation* or perception* AND "nursing care" or "nurse*" or "care*", or "nursing care or nursing intervention". The researchers used a wide range of different synonyms of experience and lung cancer so as not to miss any important articles. The two researchers compared their search results, then remove duplicates and also discard non-English speaking articles. Then researchers then retained similar articles and a difference in the selection of articles was settled by a third reviewer.

4.3 Inclusion and Exclusion Criteria

Study(s) was eligible for inclusion if interview was carried on patients diagnosed of lung cancer. Research article was included if only researcher(s) present information regarding patients' experiences regarding nursing care and excluded if articles focused only nurses and other care givers. Research article were included if the study adopted qualitative research methods and presents information relevant to patients' experiences regarding nursing care or care. This is because qualitative studies often present only result that the researchers considered to be dominant. Articles excluded if it focuses solely on symptoms and treatment procedure. Articles were excluded if nurses were dealing with over two types of cancer patients. Moreover, research article was included if it was published in English and between 01/01/2010 and 30/12/2016. The inclusion and exclusion criteria is presented in the below table 1.

Inclusion Criteria	Exclusion Criteria
peer reviewed full text published in English lung cancer qualitative 2010-2016 experiences, (perception or views or feeling or attitude or satisfaction or emotional) nursing care	review other language other types of cancer quantitative grounded theory focus on symptoms and treatment other care givers early than 2010, later than 2016

Table 1. Inclusion and exclusion criteria

4.4 Articles selection and Critical appraisal

A total of 2051 articles were obtained from the search, 752 from CINAHL and 1298 from ProQuest Central. A total of 2034 were obtained after duplicate were removed. 1443 articles, were excluded for the following reasons; not being peer reviewed, not being full text, and timeline not being suitable. 590 full text articles were further assessed for eligibility and an additional 527 were excluded for the following reasons not being qualitative study, not being the target clinical population and not published in English. After this phase of screening a total of 63 articles were then screened for: title and abstract, focused on symptoms only, medical treatment and others care givers. When all these parameters were examined 54 articles were further excluded leaving us with 9 articles. The researchers, then independently conducted a critical appraisal on the nine articles using JBI critical appraisal checklist. This checklist comprised of ten questions, each question has a *Yes*, *No* or *unclear* response. A *yes* means it fulfills all the inclusive criteria and possessed relevant information for the study. A *no* means it fulfills some of the inclusive criteria but possessed irrelevant material for example the study population comprised of both patients and general practitioners experiences. *Unclear* means the result and information presented was not clearly understood, with each yes, the article received 1 point. The range of points were discussed and agreed that an article receiving more than 7 points would be retained, and the mean average scores articles received was 8.5. The two researchers then conducted the critical appraisal check independently and the result were checked. The results were compared and discussed to reach agreement. After

assessing the quality using JBI Critical appraisal checklist, 1 article was further excluded because it received less than 7 and the study method and population was unclear, for example the two researchers did not understand the meaning of qualitative longitudinal feasibility study and also the study population included physicians, nurses and patients, so finally 8 articles were analyzed in our study.

Critical appraisal is an essential part of a literature review. Critical appraisal of articles helped to assess; the quality of study, the strength and weakness of articles. It also determines whether the study is most relevant to our own review, and how valid is the finding of the study to support the claims (Primary Health Care Research & Information Service, 2017). After critical appraisal, the researchers then proceed to content analysis using the five step analysis applied by Mayring (2000). The process was illustrate in below figure.

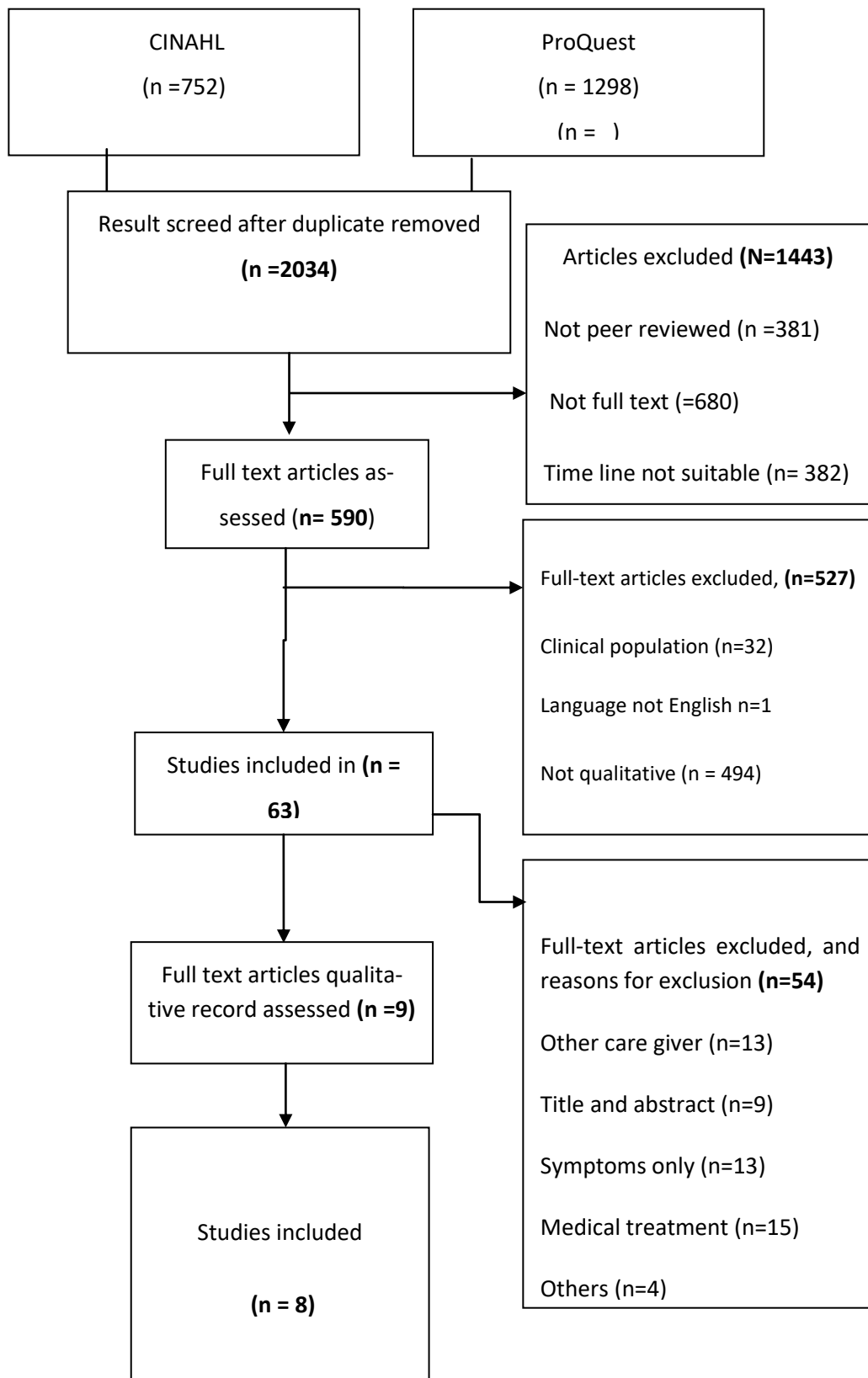


Figure 2: Article selection process

4.5 Data Analysis and Synthesis

The 8 articles used in this study were published in the years 2011(2), 2012(1), 2014(1), 2015(1), 2016(2). The countries where the articles were published are: United Kingdom (5), United States of America (2), and Australia (1). All the appraised articles were qualitative studies, the research methods were either semi-structured interview or in-depth interview. The main finding of each article was attached to this work as appendix 2. Results from the selected studies were analyzed using content analysis. Vaismoradi, Turunen and Bondas (2013) defined content analysis as the “systematic coding and categorization of large amount of text, to determine the trend of relationships”. Tracy (2013, 189) added that a code identify data that represent a phenomenon Gering (2015) added that during the process of content analysis, the researchers identify articles, sort out relevant information into categories and make a link between them.

Inductive qualitative content analysis was used in the analysis and synthesis of data to code categories for research results, the procedure followed the model of Mayring (2000). The procedure was illustrated as in the below figure2.

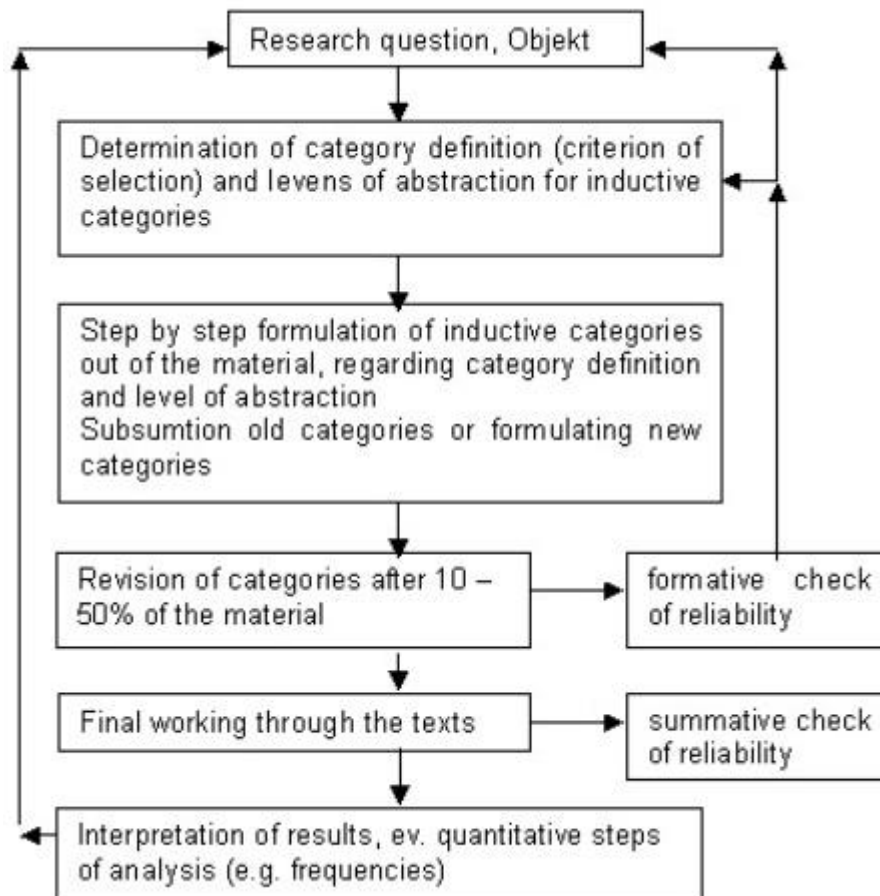


Figure 3: Step model of inductive category development (Mayring 2000)

The researchers independently commenced their analysis by sorting out relevant information such as date, place of publication and main findings as shown on (Figure 3). First, the researchers examined articles' research question and their theoretical background, then selection criterion was established: that only parts of finding about nursing's care that directly affected the quality of care or life of lung cancer patients were considered, which included emotional and physical well beings, managing daily routines, positive experience and challenges. After this, the researchers went through the selected texts line by line, attached post, written note that contained the notions about a particular sentence or quotation, and materials that fitting selection criteria were formulated to fix to new categories, which are terms or sentences that characterized the material as close as possible. After new categories of contents established, researcher went through them and examined whether the category definition had overlapping or fell under the coverage of previous category, which would

be subsumed under the previous category. The process was continued until no new categories were formalized by two researchers. Then, the whole category system was checked to make sure the category had a clear logic, and level of abstraction adequate to the aim of analysis. Quinn et al (2015) supplemented that to code data researchers must re-read the data several times to become familiar with the ideas. In our case, both authors, coded and checked the categories independently, compared results and disagreements were discussed and final categories agreed. This was done to avoid bias and also to ensure content validity.

5. Results

This study focused on lung cancer patients' experience regarding nursing care, the experience included widely their anticipations, their disappointment, how they were treated, issues they thought important, things they wanted address, and ideas they had and so on. The articles used in this study were published in the years 2011(3), 2012(1), 2014(1), 2015(1), 2016(2). The countries where the articles were published are: United Kingdom (5), United States of America (2), and Australia (1). All the appraised articles were qualitative studies, the research methods were either semi-structured interview or in-depth interview. By analyzing and synthesizing data from the selected articles for use in this study, 3 major categories of content were coded: more and new approaches of social support; communication of care among organizations; patient empowerment. The result was illustrated in below table 2.

Research Question	Category of Content	Sub-content
Lung cancer patients' experience regarding nursing care	More and new approach of social support	<ul style="list-style-type: none"> more social support new approach of social support Stigma against lung cancer patients Continuous support from nurse to quit smoking
	Communication of care among organizations	<ul style="list-style-type: none"> After treatment follow up led by nurse Easy understanding and verbal information
	Patient Empowerment	<ul style="list-style-type: none"> Live to the full Normal daily activities Maintain independency

Table 2: Main findings of content analysis

5.1 More and new approaches of social support

Social support has been conceptualized in a variety of ways, although humans hold different views about social support, there are considerable evidences attesting the benefits of social support to patients emotional, physical and psychological well-being. (Pollack et al., 2015 , Rowland et al. 2016, Boyle, 2015, Failey et al.,2016). This finding is in the line with other earlier literature review that suggesting social support should be wide, including four types of different support: emotional support (involve empathy, love and trust), instructional support (services and physical assistance), informational support (advice, suggestions and information) and appraisal support (information for self-evaluation). (Luszczynska, Pawlowska, Cieslak, Knoll, Scholz, 2013). Healthcare professionals should be familiar with the different types and always refer patients to a range of supportive groups.

Patients expressed increased need for social support including lung cancer support group and complementary lung cancer services (Rowland et al., Calman et al), as in this statement, “Lack of support from partners, increases stress and anxiety” (Rowland et al., 2016). Patients told that their diagnosed of lung cancer had substantial impact on their relationships and physical abilities, and expressed desire for more personal contact with friends and nurses. Patient felt that connecting with other lung cancer patients makes them feel that they are not alone. Some found it relieving having face to face discussion with other lung cancer patient (Boyle et al., 2015). Patient recounted that they feel reluctant to come up with their concern because of poor relationships with ward nurses (Sandeman et a., 2011, Lehto et al., 2014). Patients also highlighted the lack of empathy from general nurses but good working relationships from oncology nurses (Rowland et al., 2016). Meanwhile some patients require social groups; some did not in fear of hearing words like cancer and death which they considered heart breaking and distressing (Rowlandt et al, 2016; Boyle et al., 2015; Farley at al, 2016; Dale & Johnston, 2011).

Patients wished to participate in sporting activities as they did before diagnosed e.g. swimming, Patients desire supportive services such as quitting smoking (Farely et al, 2016) and lung cancer survival tips (Dale & Johnson, 2011), from which they can have information on how to manage their disease. Many patients expressed wish to have access to complementary services such as sport and mentioned that nurses should supervise the sporting activities to ensure it is done correctly (Boyle et al., 2015;Lehto, 2011) , some desired strong spiritual and emotional wellbeing(Dale & Johnston, 2011). One study claimed that “lack of support from partners, increases stress and anxiety” (Rowland et al., 2016). Some patients expressed desire for more personal contact with friends and health professionals.

Not only more social support is needed from nurses, but also the approach of providing social support should be innovated. Patients rather turned to their family for help when they feel fatigue and tend to lose independency. (Brown et al., 2015).

With regard to stigma, patients recounted how lung cancer resulted to horrible death and because of this, people tended to stay away from them. Patients also recalled that they had experienced health related stigma, which greatly affected their quality of life. On patient said that “My friends and acquaintances kept a distance causing stress and feeling of isolation” (Rowland et al., 2016). In two other studies carry out by Lehto (2014) and Marlow, Waller & Wardle (2015), they affirmed that lung cancer patients reported experiencing stigma from medical professional and friends, because they thought that their disease was as a result of bad lifestyle and smoking history. It is important to notice that stigma against lung cancer patients has negative impact on their quality of life, community relationships and psychology of patients (Shen, Hamann, Thomas, Ostroff, 2016). On the other hand, good communication between patients and medical professionals would significantly help to reduce lung cancer stigma and psychological distress (Shen et al., 2016).

5.2 Communication of care among organizations

Communication is perceived as key element of good working environment and relationships. A number of participants described their communicative experience with oncology nurses as good, meanwhile, many were dissatisfied with the way their diagnosed was communicated (Sande et al., 2011). They wished to have a clear under-

standing of their disease, and what was likely to happen in future, some patients felt that they were not given the necessary information to manage their daily living alone. (Boyle et al., 2015; Dale & Johnson, 2011.) This was evident in this statement "I was told I had cancer but nobody gave me any information. So it's really weird when you go home and you say this to your husband, and he says, 'Well, what does it mean'?" (Tsianakas et al., 2012.)

Patients commented that they did not understand what the nurse was trying to explain. Meanwhile one patient highlights that information about her disease was given in layman language which makes her understand better as in this sentence "He explained everything to me in layman term" (Dale and Johnston, 2011). Patients reported having only one source of information as in this statement "my doctor was my only source of information" (Boyle et al., 2014). Communication preferences were also highlighted in some studies; some patients described their experiences of containing the shocking news alone, and wish it would have been done in the presence of a relative to console them, (Tsianakas et al., 2012, Sandeman and Wells, 2011, Boyle et al., 2014). Honest communication was also highlighted (Boyle et al., 2015). Although a good number of patients reported unmet information and communication needs, a handful, had positive experiences regarding communication and information as in this comment "Well I like him, I trust him & he's been there since the start I never felt that I wanted to go & seek another opinion. I asked him questions & he just answered them" (Sandeman and Wells, 2011).

Communication of diagnosed should be done in an empathetic and sensible manner. It was concluded that patients diagnosed of lung cancer should be given honest information about their diagnosis and treatment options. Patient complained that communication of diagnosed is often done in busy environment where time and space are limited for example "I would have desire to have more time and personal contact with my nurse specialist" (Tsianakas et al., 2012). Patient described that they were too shocked to know what to ask at that time. Informing patient about their diagnoses should be cautiously plan (Tsianakas et al., 2012). Nurses should also clear misconceptions about a particular disease and ensure that the information communicated is evidence based (Kuirjpers, Groen, Loos, Oldenburg, Wouters, Aaronson, Harten, 2015). It is recommend that ward nurses should ensure effective

information exchange by listening to patients, clarifying and explain information and check patients understanding by asking questions frequently and clearly. (Shen et al., 2015)

Patients reported having more care in hospital than in outpatient clinics and also expressed insufficient coordination of care between secondary and primary healthcare (Brown et al., 2015, Sande et al., 2011). This finds shares similarity with other studies carried out regarding care of lung cancer patients. For example, one systematic review carried out in 2011 suggested that follow-up care of lung cancer patients had demonstrated benefits such as on the quality of life (Calman, Beaver, Hind, Lorigan, Roberts, Liloyd-jones, 2011). As in this comment “Long waiting time in outpatient clinics” (Tsianakas et al. , 2012). “Hearing conflicting information”, patients also described receiving different information from healthcare professionals, which create confusion. Though some patients gave positive comments about their care, other expressed worries of not knowing what to do, or who to contact in case of emergency. One patient said “I feel vulnerable at a certain point of the care path” (Tsianakas et al., 2012). This finding was similar to other earlier studies that expressed the need for improvement of coordination of care, and sometimes patients felt unsatisfied with the support and information they received (Husain, Barbera, Howell, Moineddin, Bezjak, Sussman, 2012). Patients desire for effective administrative procedure for appointment and desire to be introduced to care coordinators as soon as possible.

5.3 Patient Empowerment

Empowerment defines as a “social action process in which individuals gain a mastery over their life to improve on the quality of life”. Empowerment represents a central part in health promotion. Empowerment and decision making are very important aspects in health promotion. A number of patients felt that they were not given the opportunity to choose their treatment options, as they desire to pursue alternative treatment (Lehto, 2014 & Rowland et al., 2016). Many patients preferred managing at their home with some extra cooking and cleaning help as in this comment “I would love to manage myself as long as possible” (Dale and Johnston, 2011).

A lot of patients expressed their wish to maintain independence in daily life (Brown et al., 2015), some patients even considered it as the priority of care "stand on your own two feet as long as you can", "I do it all on the one day, on the off chance that I'm going to be well for a couple of days" (Brown et al., 2015), in fact, lung cancer patients employed a number of strategies to achieve the goal and consider managing daily tasks independently a way to keep their pride and a way of fighting the disease. Regardless of the diagnose, lung cancer patients shared the same goal of continue life interests, family roles, and maintain functional independence and dignity (Lehto, 2014).

Discussion

6.1 Implication for nursing care

This study suggested that being one of the most common and deadly cancer, the care of lung cancer patient needs adjustment to improve lung cancer patients experience regarding nursing care. Considering the poor prognosis of lung cancer, the stigma associated with lung cancer, and the fact that little is known regarding lung cancer patients' need, and requirements of continuity of care. It is necessary to have specially trained nurses to look after lung cancer patients.

In fact, some countries such as UK and USA already have lung cancer specialist nurses, who led the care path. Lung cancer nurse specialist was already introduced in year 1995 in UK, where the nurse specialist played a vital role in delivering high quality care and treatment and demonstrated the value upon the skills of providing information, holistic assessment, management of symptoms, psychological support, coordination of care and patient advocacy across the patient pathway (Royal Lung Cancer Foundation, 2013.)

As same in all the industries, nursing care also requires innovation to meet the dynamic changing environment, and innovation had demonstrated to have an positive impact on care and increased patients' satisfaction, as well as improved the effectiveness of organization meant for specially treating and caring lung cancer patients. (Husain, Barbera, Howell, Moineddin, Beznak, Sussman, 2012).

In Finland, it may be a good try to have special program to train lung cancer nurse since lung cancer patient care is wide, and lung cancer specialist nurses should differ from oncology nurses, which are only working on oncology wards. It would be ideal that each lung cancer patients have a specialized nurse, to provide possibly best care; social and psychological support, and as much information as possible. Although some studies suggested that the training of nurses specialized for lung cancer care is demanding; as it requires a nurse to have enough knowledge of lung cancer, how it develops, treatment options, social support network and management of psychological and emotional distress. However, once lung cancer specialist nurses' training is

accomplished, it may result to higher level of patient satisfaction, increase survival time and self-rewarding feeling.

This study also indicated that there is a need to establish lung cancer association in Finland. Generally, lung cancer care is not caused by environmental factors in Finland. (Rautalahti and Pukkala , 2013). Our current society blames strongly on the relationship of lung cancer and tobacco, and nurses' role is to tell the public the relationships between smoking and lung cancer as the role of public health promotion, it is not difficult to image why patients do not want to turn to health professionals for help at first. The anticipation that nurses may blame patients, even grounded without any evidence, is already enough drive many lung cancer patients away from seeking social help from nurses. Despite nurses' professional neutral attitude towards all patients, Lung cancer patients anticipate that there is strong stigma against them, which makes them reluctant to seek help. Establishing lung cancer association may help patients to seek help more easily and finally find someone who can understand them.

Being diagnosed of lung cancer does not mean the patients' human rights can be ignored; they still have rights to choose the life style they want and get as much control as possible over their own life. Through lung cancer association, patient can get information other than treatment, network with other patients or family of lung cancer patients to share their experience, and fight against stigma. Lung cancer association would also be a good platform for families to gather together to communicate and release distress emotions.

In the literature patients felt that the way they were told that they had lung cancer would have been done in a more sensitive way and in a more reserved environment. Others reported getting information on some areas, more than others e.g treatment options and social group. Some patients felt that they were not treated with respect and dignity, since they are considered the cause of their disease Shen, Hamann, Thomas and Ostroff (2016). A number of patients experiences less care and support out of hospital, others desire a care plan and booklet that will enable them have complete understanding of their disease. Many patients highlight good experiences with lung cancer nurse and poor treatment from ward nurses. A significant number

of patients desire to have access to range of social groups and lung cancer survival patients.

Researchers have called for increased tobacco control, strong need for clear and empathic communication from healthcare providers, early introduction to social groups for newly diagnosed lung cancer patients, increase coordination of care, clear information about diseases, and reduction of stigma associated with lung cancer, as these might contribute to increase quality of life for cancer patients. (Polanski et al., 2016) suggest that healthcare providers should control fatigue with pharmacological and no pharmacological means such as physical activities, rest, sleep and proper diet. Also social support, such as being close to kind people and praying to God should not be left out, as it gives a sense of security and acceptance. Social and spiritual support helps to reduce disease complication and increase medical compliance.

6.2 Credibility, Dependability and transferability

According to (Graneheim and Lundman, 2004) credibility in research means how well the process of data collection and analysis was done, in order to address the problem at hand. (McLeod & Childs, 2013) added that a good study should possess the following; reliability, authentic and accurate information, integrity and usability. Information said by the person at the time of claimed, Integrity: complete unaltered information free from corruption. Usability: the information should be such that it can be located, and retrieved. The researchers chose a topic that is precise, focus on a small group of people which makes it manageable and easy to search information. The databases used in the study were from Cinahl and ProQuest Central, which are online databases that contain medical science information. These databases belong to the university in which the students are studying and contain high quality information. The articles used in this study were articles published in well recognized scholarly Journals such as Journal of cancer survivorship New York, BMJ Supportive & Palliative Care; London, European Journal of oncology nursing, and Journal of palliative nursing.

The selection of the most suitable search terms and criteria was done with the aid of an experienced University Librarian which enables us to identify top quality literature. Also the websites CINAHL and ProQuest gave the researchers room to apply inclusive

criteria thus increasing the credibility of the research. The articles utilized in our study presented high patients participation in their study, the articles also supported their findings with patients views and credible studies earlier published, thus making the study trustworthy. Most of the articles authors expressed no conflict of interest in their paper therefore eliminating bias and presenting credible information. This was in line with the views of Salmond (2012) and Aveyard (2014, 12) these authors emphasized that a good study should have no conflict of interest, free from corruption and bias. The two researchers independently conducted critical appraisal on articles to be included in the study and then check their result. This again increased the credibility of the study Aveyard (2014, 150) affirm that the purpose of critical appraisal is to ensure credibility and relevancy. The articles utilized in this study come from different geographical locations and they share similar findings on lung cancer care patients' experiences of nursing care marking the study transferable and trustworthy.

6.3 Ethical Considerations

A number of things such as research methods, procedure employed to retrieve material for the study were all documented as instructed by Mcleod & Childs(2013) and Aveyard (2014). Research permit was not necessary since the authors conducted a literature review of already published articles. The articles were read thorough by two different authors and notes taken individually and later compared with to make sure ideas of the original authors were maintained as far as possible as recommended by Mayring (2000), Ryan (2010) and Aveyard (2014). The titles, country of origin, authors of selected articles, publications, research method, research sample and original findings were all present for verification (Mcleod & Childs, 2013). The access to database ProQuest and Cinahl were granted to authors as beings students of JAMK University of Applied Science. All statements applied in this research work have been referenced All statements applied in this research work have been referenced clearly.

6.4 Limitations

This research focused on the experience of lung cancer patients whose disease was generally not caused by environmental factors. So the finding of this research work

may not necessary apply to the patients who are suffering from lung cancer that are caused by environmental factors such as pollution. Those patients may not experience stigma as patients who smoke, and the demand for information and social support may be very different. Potential articles were missed due to search strategies such as time frame and articles published in English. Research in this area is rare therefore further research is needed to explore the experience and difference of lung cancer patients with different causing factors.

7 Conclusions

The study findings have revealed increased concern for information, communication, social support and treatment options for lung cancer patients. Patients expressed the need for further improvement of treatment and care and experiencing certain stigma owing to the attribution of lung cancer to cigarette smoking. Public campaigned against smoking, limited treatment options for lung cancer added the feeling of stigma among lung cancer patients and therefore hinder the experience the qualitative nursing care. Patients also expressed wish for better communication with the nurses regarding their diagnose and treatment options as well as coordination of continuous care. Patients were also expressing the need of more social relationship support from nurses, family members and friends. Patients reported difficulties gaining access to lung cancer social groups, which may be attributed to the low survival rate of lung cancer patients. The finding of this study may help to contribute to improve the lung cancer care practice and also help nursing students and nurses to understand the essential factors during the care of lung cancer patients

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Appendices

Appendix 1. JBI Critical appraisal checklists

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and research methodology?				
2. Is there congruity between the research methodology and the research question or objectives?				
3. Is there congruity between the research methodology and the methods used to collect data?				
4. Is there congruity between the research methodology and the representation and analysis of data?				
5. Is there congruity between the research methodology and the interpretation of results?				
6. Is there a statement locating the researcher culturally or theoretically?				
7. Is the influence of the researcher on the research, and vice-versa, addressed?				
8. Are participants, and their voices, adequately represented?				
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?				
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?				

Source: The Joanna Briggs Institute Reviewers' Manual 2014.
https://joannabriggs.org/.../ReviewersManual_2014-The-Systematic-Review-of-Preval

Appendix 2. Data extraction

Author	Journal	Titles	Analysis method	Participants	Findings	Critical Appraisal
Tsiankas. et al. 2012, UK		Implementing patient centered cancer care: experience-based co design to improve patient experience	narrative, unstructured interview participant observation	13	Better information about treatment Patient empowerment Sense of community	9
Rowland, Danson, Rowe, Merrick, Woll, Hatton, Wadsley, Ellis, Crabtree, Horsman, Eiser, Cwland . 2016, UK	Supportive & Palliative Care	Quality of life, support and smoking in advanced lung cancer patients:	qualitative study Semistructure interviews	9	Anxiety, fear, depression, wanted more support from nursing even does not express that, cancer stigma, aware of links between lung cancer and smoking, but some continued to smoke. sensitive to the opinions of medical staff	8
Brown N., Liu, C.W., Robinson, P.C., Boyle, Natasha, lui, robinson & Boyle 2015, Australia	Supportive Care Cancer	Supportive care needs and preferences of lung cancer patients:	Qualitative semistructured qualitative interview study	12	Patients reported low use of supportive care services and resources in medical info, physical symptoms, daily activities, emotional needs. Prefer verbal info than printed or online info, upfront and hones communication highly valued, strong determination to manage daily living independently, prefer to seek	9

					help from family over others Underutilization of support- ive care is complex than simply lack of availability.	
Farley, Amanda; Aveyard, Paul; Kerr, Amy; Nai- du, Babu; Dowswell, George 2016, UK	Journal of Can- cer Surviv- orship .	Surgical lung cancer patients' views about smoking and sup- port to quit after diagno- sis: a qualita- tive study	Qualitative narrative, un- structured interview	22	. Most participants wished they were a non-smoker but, in conflict with this, also felt that smoking was enjoyable, helped with psychological coping or had some health benefits. Some also demon- strated a fatalist attitude towards the potential detri- mental health effects. How- ever, all participants felt that it was important for health professionals to address smoking and some wanted cessation support although it was often not provided. Par- ticipants wanted support to start as early as possible and to continue for the first weeks after discharge.	9
Lehto, 2011, USA	Oncol- ogy Nursing Forum	Identify- ing Pri- mary Concerns in Pa- tients Newly Diag- nosed With Lung Cancer	Qualitative semi structure interviews e	34	Cancer related worry exists all the time, positive health environment perceptions induced positive content. Negative content included concerns related to cancer diagnosis and treatment, the need for information, symp- toms, fears, death-related concerns, being a burden on loved ones, smoking; positive content included identifying active strategies, focusing on recovery, being positive, get- ting positive support from friends and family, and spir- ituality.	8
Lehto, 2014, USA	Euro- pean Journal of on- cology nursing	Patient views on smoking, lung cancer, and stigma:	A focus group interview inter- view	11	Lung cancer patient uniquely experience burden from de- veloping an illness that the public recognizes is directly associated with smoking, stigmatization and smoking related cancers are of high importance.	9

Sande G. Sandeman, M. Wellsman et al, 2011, UK	European Journal of Oncology Nursing	The meaning and significance of routine follow-up in lung cancer – A qualitative study of patients' experiences and interpretations	Interview	10	patients confident in their consultants and important to have a connection with oncology department, desire for follow-up to continue, prefer to have nurse-led follow-up in clinical setting	9
Dale & Johnston 2011, UK	Journal of palliative nursing	An exploration of the concerns of patients with inoperable lung cancer	2 round interview	6	Determine to get on with lives, maintain normal life, independent and integrity, trust in professionals, feel being listened to, concerns being followed up Prefer to receive information in an understandable way, and need info about where to seek psychological help	9

