

RESPIRATORY-RELATED QUALITY OF LIFE AMONG PEOPLE EXPOSED TO
LIBBY ASBESTOS

by

Ginger Parrish Warren

A thesis submitted in partial fulfillment
of the requirements for the degree

of

Master

of

Nursing

MONTANA STATE UNIVERSITY
Bozeman, Montana

April, 2011

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Dr. Wade Hill

Approved for the College of Nursing

Dean Helen Melland, PhD

Approved for The Graduate School

Dr. Carl A. Fox

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ACKNOWLEDGMENTS

This author would like to thank the thesis committee: Wade Hill, PhD, PHCNS-BC, Chair; Charlene Winters, PhD, APRN; and Elizabeth Kinion, EdD, APN-BC, for their support and knowledge during the creation of this thesis. This author would also like to thank her children, Laura (the future nurse) and TJ (the future doctor) for allowing their mother to complete this task. This author would like to thank her husband, Frank, for his continued support and encouragement for his wife to achieve her educational and career goals. As always, this author would like to thank her parents, John and Kay Litaker, her sister Beth, her brother Randy, her beloved Aunt June, Aunt Gloria, Uncle Rick, Aunt Barbara, Aunt Ellan, and the rest of the family for their love and support throughout all of the years. This thesis is also dedicated to all of the longsuffering Libby residents with asbestos-related diseases whom this author encountered while working at St. John's Lutheran Hospital and Libby Care Center.

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ABSTRACT

The purpose of this descriptive study was to explore respiratory-related quality of life among people that have been exposed to Libby amphibole asbestos. This thesis analyzed data from a descriptive research study conducted by a team from Montana State University College of Nursing in collaboration with the Center for Asbestos-Related Diseases (CARD) clinic in Libby from September 1, 2006 through August 31, 2007. The main goal of the parent study was to examine the bio-psychosocial health status of persons exposed to Libby amphibole asbestos. This thesis augments that work by examining respiratory-related quality of life from a Libby sample and comparing with other groups reported in the scientific literature. Findings show that overall respiratory-related quality of life for persons exposed to Libby asbestos was similar to other respiratory-related disease cohorts. Implications to nursing practice and limitations of the study are discussed.

CHAPTER ONE

INTRODUCTION

Respiratory disease is a significant chronic health problem in our society and it is the third leading cause of death in the United States (US) (Center for Disease Control, 2008). Over 35 million people in the United States are living with lung disease and one in seven people die from it each year. For example, chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death in the United States and Medicare expenditures for this disease are in the billions of dollars annually (American Lung Association, 2007). Overall, respiratory disease accounts for 14% of total expenditures for health care in the United States (Healthy People, 2010).

A variety of chronic pulmonary diseases impact population health in the U.S. including: asbestos-related diseases, coal worker's pneumoconiosis, silicosis, byssinosis, pneumoconioses, mesothelioma, hypersensitivity pneumonitis, asthma, respiratory tuberculosis, and lung cancer (National Institute for Occupational Safety and Health, WoRLD Surveillance Report, 2002). Increasing concern for occupationally related pulmonary disease is warranted based on social justice and the potential for prevention. Specifically, asbestosis is one of several diseases resulting from occupational exposures. It is caused by breathing in asbestos fibers which results in "scar-like tissue in the lungs and in the pleural membrane (lining) that surrounds the lung..." (Agency for Toxic Substances and Disease Registry, September, 2001).

Montana Burden of Respiratory Disease

In 2008, Montana residents with pulmonary illnesses such as; pediatric and adult asthma, chronic bronchitis, emphysema, and lung cancer numbered 127,109 (American Lung Association, 2008). Montana trends mirror national trends suggesting chronic respiratory illness is a major public health concern. However, not all populations in Montana experience equal risks with respect to pulmonary disease, especially those that are occupationally caused.

On November 22, 1999, the *Seattle Post-Intelligencer* published an article entitled “Uncivil Action: A Town Left to Die” reporting on the devastating effects of the deaths in Libby, Montana resulting from amphibole asbestos exposure (Schneider & McCumber, 2004). According to the article, there were at least 192 deaths and 375 people diagnosed with asbestos-related diseases resulting from occupational or community-based asbestos exposures from nearby vermiculite mining operations (Schneider & McCumber, 2004)..

In December, 2000, the Agency for Toxic Substances and Disease Registry (ATSDR) in conjunction with the Montana Department of Public Health and Human Services (MDPHHS) conducted a mortality review of Libby, Montana residents who died between 1979 and 1998 and presented the following conclusions:

- For the 20-year period examined, mortality in Libby resulting from malignant and nonmalignant respiratory diseases was significantly elevated.
- When compared to Montana and U.S. mortality, there was a 20 percent to 40 percent increase in malignant and nonmalignant respiratory deaths in Libby from 1979 to 1998.

- Asbestosis mortality in Libby was 40 to 80 times higher than expected and lung cancer mortality was 1.2 to 1.3 times higher than expected when compared to Montana and the United States.
- Mesothelioma mortality was elevated but because statistics on this extremely rare cancer are not routinely collected, it was difficult to quantify the increase. Other non-malignant, noninfectious respiratory deaths also were significantly elevated.
- Most of the increase in respiratory mortality noted in the revised report likely can be associated with occupational exposures.
- Asbestosis and mesothelioma mortality were found almost exclusively in former [vermiculite] workers. Some of the lung cancer [mesothelioma and other lung cancers] mortality occurred in former employees of the vermiculite facility.

(ATSDR, Mortality in Libby, MT, 1979-1998).

Purpose

Since 1999, an inconsistent network of medical services has been established for those affected by exposures to amphibole asbestos in Libby, Montana. Increasing focus is being given to treatment resources for individuals as well as continued documentation of morbidity and mortality trends. However, too little is being done to examine the quality of life issues with populations affected by Libby amphibole asbestos. The purpose of this thesis is to examine respiratory-related quality of life among a population exposed to Libby amphibole asbestos.

CHAPTER TWO

LITERATURE REVIEW

Introduction

Libby, Montana has a long history of mining. Many prospectors, including two gentlemen, John S. Fisher and Stephen Allen, came through the Libby area in the early 1860s looking for gold (<http://www.libbymt.com/community/history.htm>, retrieved 6/8/2008). The Snowshoe mine was discovered in 1889, where lead, silver, and gold deposits were found and by the end of the 1890s, mining operations contributed over a million dollars to the local economy. (<http://www.libbymt.com/community/history.htm>, retrieved 6/8/2008).

Vermiculite deposits were discovered by Ed Alley and other prospectors in the early 1900s on Rainy Creek, which is northeast of Libby (<http://www.libbymt.com/community/history.htm>, retrieved 6/8/2008).

“While exploring the old tunnels in the large mountain north of Libby he stuck his miner’s candle into the wall to chip away some ore samples. When he got his candle, he noticed that the material around the candle had swollen and turned golden in color. He had discovered a unique material that expanded when heated. (page 3).

In 1919, Ed Alley started the Zonolite Company. The vermiculite mined at this site quickly became used in insulation, plaster, and gardening supplies. In 1963, the W. R. Grace Company purchased the mine from Ed Alley and operated it until it closed in 1990. At that time, W. R. Grace Company sold the mine to the Kootenai Development

Company. During the mine's heyday, it produced 80% of the world's vermiculite supply and was a major income source for Libby.

In 1999, accusations were levied towards the operators of the mine concerning worker safety and the rise in asbestos-related diseases and deaths among Libby residents and former mine workers. The Environmental Protection Agency (EPA) has been actively involved in Libby since November, 1999 (<http://www.epa.gov/libby>), removing the asbestos-tainted soil and conducting air, soil, dust, and insulation sampling to determine the percentage of amphibole asbestos in the Libby environment. The EPA initially became involved due to "local concerns and news articles about asbestos-contaminated vermiculite" (<http://www.epa.gov/libby>). Similarly, the U. S. Agency for Toxic Substances and Disease Registry (ATSDR) conducted tests that discovered "lung abnormalities in higher percentages than expected for people who didn't work at the mine and had no known exposure to the vermiculite dust" (<http://www.libbymt.com/community/history.htm>, retrieved 6/8/2008). These lung abnormalities have been found to include asbestosis, pneumoconiosis, and mesothelioma.

Asbestos-Related Disease and Etiology

Exposure to microscopic asbestos fibers is linked to several malignant and nonmalignant illnesses including mesothelioma, cancer of the lung, other cancers, asbestosis, and pleural abnormalities (ATSDR, 2008).

The etiology of asbestos-related diseases is directly related to exposure to asbestos fibers. Castleman (1986) wrote: "...The recognition of asbestos as a cancer hazard took place a remarkable short time after the first case reports were published...Most of the reports published came from England, Germany, and the United

States...In the late 1930s these mainly consisted of case reports...In the 1940s, asbestos carcinogenicity was also noted in reviews in the fields of industrial medicine, cancer research, and pneumoconiosis...” (p. 39). He also reported that, “...The average time from onset of exposure to development of cancer was 25 years for lung cancer with asbestosis, and 30 years for peritoneal cancer...” (p. 97). These statements are consistent with the literature that states asbestos-related diseases can take several decades for their pathogenicity to be detected, and unfortunately the decline in one’s health when detected happens rapidly.

Physical Assessment of Asbestos-Related Disease

Assessment of trends in pulmonary diseases generally and asbestos-related disease specifically is related to the efficiency of current diagnostic process. For the individual, pulmonary disease assessment generally includes auscultation with a stethoscope, chest x-rays, and various pulmonary function tests, such as spirometry, ventilation/perfusion (V/Q) scans, vital capacity (VC), peak expiratory flow rate (PEFR), thoracic computerized tomography (CT) scans, and magnetic resonance imagery (MRI) (Seidel, Ball, Dains, & Benedict, 2006, pp.360 – 413). These and other diagnostic tests are widely used in definitive diagnosis of pulmonary disease, but there has been little done to assess the psychological and emotional impacts that pulmonary disease has on the individual. It is very important to assess the quality of life for individuals with pulmonary disease in order to address not only the individual’s physical needs, but also their mental, emotional, and spiritual needs that coincide with the individual’s quality of life.

Risk Factors for Asbestos-Related Diseases

The two main factors that contribute to asbestos-related diseases include tobacco use and occupational exposure. Cigarette smoking causes profound damage to the cardiopulmonary system, which includes but is not limited to: alveolar damage, weakening of the arterial and venous vessel walls, ciliary cell damage, cellular damage due to metaplasia (chronic injury or irritation), and dysplasia (persistent severe injury or irritation) (McCance and Huether, 2006, p. 49). Irritation of the airways as a result of smoking increases mucus production, blocks the passage of air, and decreases removal of asbestos fibers from the lungs (ATSDR, 2006).

With this damage already in place from tobacco use, occupational exposure to asbestos causes further damage to the pulmonary tissue. The asbestos fibers act like microscopic needles to cause pleural plaques and scar tissue. Dr. Alan C. Whitehouse (2004), a pulmonologist in Spokane, WA, described the following: "...the progressive loss of pulmonary function in 76% of the 123 individuals with pleural changes followed in this group of individuals with Libby tremolite exposure is excessive compared to other published reports...Progression of asbestos disease in patients with exposure to chrysotile asbestos is well documented...Progressive loss of lung function is continuing 40 years after last exposure in 76% of this group who are representative of the population of Libby, Montana..." (pp.223-224).

There are differences in opinion regarding the increased risks of asbestos-related diseases secondary to smoking. Hodgson and Darnton (2000) concluded that: "...the evidence on the joint effect of smoking and asbestos exposure on lung cancer has been reviewed...the overall evidence indicates an interaction in the multiplicative

region...This implies that the relative risk of lung cancer due to asbestos exposure will be the same for smokers and non-smokers alike...” (pp. 567-568). However, ATSDR reports that when a cigarette smoker is exposed to asbestos, his/her risk of lung cancer increases by 50 to 84 times (ATSDR, 2006).

Global Prevalence for Asbestos-Related Diseases

The United States is not the only country that has been seriously affected by asbestos exposure. Lin and colleagues (2007) reported that “...the possibility of a global epidemic of asbestos-related diseases is a cause for widespread concern...such diseases include asbestosis and many types of mesothelioma...the worldwide burden of diseases associated with asbestos has also been estimated; the yearly number of asbestos-related cancer deaths in workers could be 100 000-140 000...” (p. 844). The World Health Organization reports the following about asbestos-related diseases.

It is estimated that currently about 125 million people in the world are exposed to asbestos at the workplace. According to WHO estimates, more than 107,000 people die each year from asbestos-related lung cancer, mesothelioma and asbestosis resulting from occupational exposures. One in every three deaths from occupational cancer is estimated to be caused by asbestos. In addition, it is estimated that several thousands of deaths can be attributed annually to exposure to asbestos in the living environment
http://www.who.int/occupational_health/topics/asbestos_documents/en).

Considering the global distribution of asbestos, the prevalence of asbestos-related diseases has continued to climb and the only way to abate this trend is to eradicate the use of asbestos (Lin et al, 2007, p. 848).

United States Prevalence of Asbestos-Related Diseases

The World Trade Center terrorist attack on September 11, 2001 created a massive exposure of Libby amphibole asbestos in lower Manhattan area; the effects and long-term consequences of this exposure are still unknown. In addition to disasters creating asbestos exposure, other long-term exposures occur among miners, shipyard workers, and automobile mechanics that many work with asbestos on a daily basis.

(<http://www.epa.gov/asbestos/pubs/abstrategiesrptgetf.pdf>).

O'Reilly, McLaughlin, Beckett, and Sime (2007) discussed the prevalence of different types of asbestos-related diseases in the U.S. as a result of occupational exposure.

The prevalence of asbestosis in the United States is not known, but in 2000, there were an estimated 20,000 hospital discharges with this diagnosis and 2,000 deaths with asbestosis as the underlying or contributing cause, and these numbers are expected to rise through this decade. The incidence of malignant mesothelioma in the United States was thought to peak at 2,000 cases per year from 2000 to 2004; another study suggested there would be a yearly average of 3,200 deaths from asbestos-related lung cancer from 1985 to 2009 (p. 683).

Assessment of Respiratory-Related Quality of Life

Anderson, Anderson, and Glanze (1994) define quality of life as "...a measure of the optimum energy or force that endows a person with the power to cope successfully with the full range of challenges encountered in the real world..." (p. 1319). Respiratory-related quality of life, or health-related quality of life, as described by Voll-Aanerud, Eagan, Wentzel-Larsen, Gulsvik, and Bakke (2007), is "...measured by standard questionnaires and "... has become an important measure of the well-being of those affected [by chronic diseases]. HRQoL is used to evaluate the magnitude of the impact of disease in observational studies, and increasingly as an outcome measure in clinical trials. Further, HRQoL can be important as a predictor of the use of health-care resources..." (p. 1890). The CDC concluded the following about the importance of measuring health-related quality of life:

In public health and in medicine, the concept of health-related quality of life refers to a person or group's perceived physical and mental health over time. Physicians have often used health-related quality of life (HRQOL) to measure the effects of chronic illness in their patients to better understand how an illness interferes with a person's day-to-day life. Similarly, public health professionals use health-related quality of life to measure the effects of numerous disorders, short- and long-term disabilities, and diseases in different populations. Tracking health-related quality of life in different populations can identify subgroups with poor physical or mental health and can help guide policies or interventions to improve their health (CDC, 2009).

Respiratory diseases adversely affect quality of life in that it compromises an individual's total well-being through a range of limitations resulting from loss of

physiological capacity. Inability to breathe properly affects a person's mood, level of consciousness, general outlook on life, physical activity, and productivity in society.

Dyspnea represents one of the most common complaints from those who suffer from respiratory diseases. The American Thoracic Society (ATS) (1999) defines dyspnea as "...a subjective experience of breathing discomfort consisting of qualitatively distinct sensations that vary in intensity..." (p. 322).

In diffuse malignant pleural mesothelioma (DMPM), which is a cancer usually associated with asbestos exposure, dyspnea is a contributor to the presence of pleural effusions and pleural thickening, which results in a poor prognosis in the patient (Cordes & Brueggen, 2003, p. 545). For those individuals who suffer severe dyspnea, symptoms can be temporarily relieved by a thoracentesis or pleurodesis to drain pleural effusions, but the disease process advances to a point where these treatments are no longer effective, and palliative care needs to be considered.

Another symptom that adversely affects quality of life in DMPM is pain. It is closely correlated with dyspnea, and both pain and dyspnea tend to worsen as the disease progresses (Cordes & Brueggen, 2003, p. 546). The most common cause of pain in patients with DMPM is the invasion of the chest wall by the tumor (Cordes & Brueggen, 2003, p. 546). Treatment for pain varies from pharmacological methods to surgical debulking of the tumor to relieve compression of the nerves, to nonpharmacological methods, such as relaxation, distraction, and guided imagery.

In addition to dyspnea and pain, chronic cough is another common symptom in DMPM. Cordes and Brueggen (2003) reported that "...Infiltration of tumor into the pleura and hypersecretion of mucus may contribute to chronic cough..." (p. 547).

Chronic cough makes pain worse and can cause spontaneous rib fractures, as well as nausea and vomiting. Treatments for chronic cough include pharmacologic therapies and providing warm, humidified air.

Fatigue is considered the most frequently experienced symptom in individuals with DMPM. There are multiple etiologies that lead to fatigue, including anemia, electrolyte imbalance, volume depletion, poor nutritional status, nausea and vomiting, dyspnea, pain, depression, and sedation resulting from analgesics, hypoxia, and infection (Cordes & Brueggen, 2003, p. 547). Treatments for fatigue include reversing the cause, such as anemia and electrolyte imbalance; reviewing medications and discontinuing any unnecessary medications that could contribute to fatigue; and educating individuals about adequate sleep hygiene.

Depression is also a common response in individuals with DMPM. There are many fears associated with a terminal illness such as DMPM, such as fear of death, leaving their loved ones behind, inability to maintain their normal level of functioning, loss of independence, fear of constant pain, and loss of hope. Cordes and Brueggen (2003) state: “Depression in patients with cancer can be managed successfully using a team approach of individual or group psychotherapy, cognitive or behavioral techniques, and antidepressant medications. Psychotherapy assists individuals in identifying past strengths and previous techniques for coping. Cognitive-behavioral techniques assist patients in reframing inaccurate perceptions and assessments that can result in feelings of depression. Pharmacologic therapy has been helpful in reducing stress, increasing quality of life, and, in some cases, increasing survival...” (p. 549). Other symptoms, such as dyspnea, pain, and fatigue can also lead to depression.

Many other symptoms that can adversely affect a patient's quality of life include weight loss, anorexia, and cachexia. Causes of these conditions include nausea and vomiting from chemotherapy treatments, avoidance of food due to dyspnea and chronic cough, and the progression of the disease. It is important to teach individuals to eat small, frequent, protein-rich foods to help maintain a good nutritional status. It is also important to teach the patient's family and friends to assist with grocery shopping and food preparation so the patient can prevent fatigue as much as possible. There are pharmacological methods used to stimulate appetite, such as megestrol acetate and dexamethasone, but many patients prefer not to take these medications due to the side effects of deep vein thrombosis, fluid retention, insomnia, and hyperglycemia (Cordes & Brueggen, 2003, p. 550).

Due to the likelihood of asbestos-related disease patients experiencing this wide variety of debilitating symptoms, a comprehensive approach to care would recognize that assessment of psychosocial health status may be as important as physical health status when planning care for this group. Among the most widely used methods for assessing quality of life and psychosocial health is to utilize a standardized instrument that specifically examines how respiratory disease impacts QOL in a measurable way. The St. George's Respiratory Questionnaire was designed for this specific purpose.

The St. George's Respiratory Questionnaire

The St. George's Respiratory Questionnaire (SGRQ) was developed by P. W. Jones, F. H. Quirk, and C. M. Baveystock at the St. George's Hospital Medical School in London, United Kingdom, in the early 1990's. It consists of a 76 item Likert scale

divided into three subsections: symptoms, activity, and impacts. The developers of this scale described the subsections as follows:

‘Symptoms concerned with the respiratory symptoms, their frequency and severity; ‘Activity’ concerned with activities that cause or are limited by breathlessness; and ‘Impacts’ which covers a range of aspects concerned with social functioning and psychological disturbances resulting from airways disease. A score is calculated for each section and a total score is also calculated. Each item in the questionnaire has an empirically derived weight (Jones, Quirk, & Baveystock, 1991, p. 26).

The Impacts section of the SGRQ contains the questions most closely related to a patient’s quality of life. Jones et al (1991) wrote that “...The SGRQ Impacts sections showed a more balanced distribution of associations, including anxiety, walking distance, dyspnoea, and wheeze...” (p. 26).

The SGRQ has been translated into several different languages from its original British English version, including American English, Spanish, French, and Swedish (Barr, Schumacher, Freeman, LeMoine, Bakst, & Jones, 2000, pp. 1122 – 1123). The instrument has been used extensively to quantitatively measure respiratory-related quality of life in people with asthma and chronic obstructive pulmonary disease.

The SGRQ has also been used in individuals with cystic fibrosis disease. Padilla, Oliveira, Oliveira, Dorado, Plata, Gaspar, and Perez-Frias (2007) concluded that:

Self-perceived quality of life is worse among adults with CF than in the general population or among patients with chronic obstructive pulmonary disease. The SGRQ is a valid instrument for analyzing health-related quality of life in adults with CF as it discriminates very well between different degrees of severity of pulmonary impairment and has acceptable internal consistency (p. 205).

In the studies reporting on asbestos-related diseases reviewed for this study, none reported using the SGRQ.

The revised SGRQ was developed specifically for individuals diagnosed with COPD and was translated from British English to American English. A review of the literature revealed that the revised SGRQ questionnaire was commonly administered at the beginning of the studies, then four weeks later, and then one year later. The original British version was designed to be used on individuals annually, although Jones et al (1991) wrote that, "...The repeatability of the questionnaire was found to be good when administered to stable asthmatic patients twice, 2 weeks apart..." (p. 26).

Application in Nursing/Roy's Adaptation Model

The nursing theory that was chosen for this study is Sister Callista Roy's Adaptation, which includes the four theory components of physiologic, self-concept, role function, and interdependence modes. Respiratory diseases such as COPD, lung cancer, mesothelioma, asthma, and other asbestos-related diseases significantly impact a person's life. According to Roy and Zahn (2006), the major concepts of the theory are, "...people, both individually and in groups, are viewed as holistic adaptive systems, with coping processes acting to maintain adaptation and to promote person and environment transformations...adaptive responses support health, which is defined as a state and a process of being and becoming integrated and whole..." (p. 270). When a person has a chronic pulmonary disease, they lose control of their life simply because of the inability to breathe adequately. This loss of control can cause a variety of emotions; such as anger, bitterness, depression, extreme anxiety, and total despair. Patients with chronic lung

disease may grieve over a total loss of independence and having to use oxygen constantly.

The Roy Adaptation Model operates on a feedback loop, which, according to Fitzpatrick and Whall (1983), the input includes “external stimuli from the environment” and “internal stimuli from the self” (p. 163). These two inputs make up the “adaptation level (focal, contextual, residual stimuli)” (p. 163). There are “primary, functional subsystems”, which are termed “regulator” and “cognator”, which are “...viewed by Roy as biologic, psychologic, and social in origin, and as methods or ways of coping...” (p. 162). There are “secondary, effector subsystems”, which includes “adaptive modes: physiologic needs, self concept, interdependence, and role function” (p. 163). There are two outcomes of these subsystems, either it “disrupts integrity of person: ineffective responses” or “promotes integrity of person: adaptive responses” (p. 163). The final result is the output.

The treatment modalities for asbestos-related diseases, COPD, and lung cancer are quite extensive, with an adaptation level of comfort measures only. It is important to observe an individual’s adaptation level to determine response to treatment.

CHAPTER THREE

METHODS

For this study, data were collected by researchers from Montana State University College of Nursing in collaboration with health care providers from the Center for Asbestos-Related Diseases (CARD) clinic in Libby Montana from September 1, 2006 through August 31, 2007. The main goal of the parent study was to examine the biopsychosocial health status of persons exposed to Libby amphibole asbestos. This thesis augments that work by examining respiratory-related quality of life from a Libby sample and comparing with other groups reported in the scientific literature. A cross-sectional descriptive design was used to address the aims of both the parent study and this thesis.

Setting and Sample

Participants of this study included any English speaking/writing person with verified exposures to Libby asbestos that was at least 21 years of age and seeking care at the CARD clinic during the time of data collection. Primary data were collected from participants through questionnaires and secondary data were collected from patients' medical records (e.g., diagnostic test results, exposure history, and physician impression of illness).

Instrumentation

The original British version of the Saint George's Respiratory Questionnaire was used in the CARD clinic to measure patient's perception of the impacts, activity limitations, and symptoms associated with asbestos-related disease. The same version was used during the Montana State University research project to measure

specific symptoms of past and present “chest trouble” and included questions about specific activities of daily living that caused “cough and breathlessness”. It also had questions about how “chest trouble” has affected daily life and prevented the patient from doing what he/she wanted to do.

The SGRQ that was used in the CARD clinic study was the original British version, which is a 76-item questionnaire divided into three sections, symptoms, activity, and impacts. On each subscale and the total, the lowest possible score is 0 and the highest possible score is 100; indicating the higher the score, the worse the patient’s disease perception. Jones et al (1991) wrote: “...the development of the SGRQ has shown that it is possible to produce a standardized measure of impaired health covering a range of disturbances to health and perceived well-being in patients with airways disease which is both sensitive and repeatable...” (p. 30). Ferrer and colleagues (1996) wrote: [“...Cronbach’s alpha reliability coefficient was 0.94 for the overall scale and 0.72 for ‘Symptoms’, 0.89 for ‘Activity’, and 0.89 for ‘Impacts’ subscales...Correlation coefficients between the overall score and dyspnoea and % forced expiratory volume in one second (FEV₁) were 0.59 and -0.45, respectively...”] (p. 1160).

The first part of the questionnaire included questions about the patient’s chest trouble over the past year, specifically about coughing, wheezing, sputum production, and shortness of breath. The second part refers to how much chest trouble that the patient currently has. It includes questions about a description of the quality of the chest condition; how it affects job performance; and how it affects breathlessness with different activities, such as sitting, lying still, walking, and playing sports. There are specific

questions about the patient's cough and breathlessness, regarding pain, fatigue, and insomnia.

The next section of the SGRQ questions the patient about other effects of chest trouble, such as embarrassment about the coughing in public, feeling loss of control of the chest trouble, not expecting to get any better, and fear or panic related to breathlessness. The next section asks the patient about any medications that he or she may be receiving, specifically about if the medication is effective towards the breathlessness, embarrassment about using the medication in public, side effects, and interference with life in general. If the patient is not currently taking any medications, then there are instructions to skip the section.

The next section involves questions about activities of daily living and how the breathing affects the patient's performance of those activities; such as, bathing, dressing, walking briskly, housework, walking up stairs, walking down stairs, carrying things, gardening, dancing, playing golf, bowling, shoveling snow, playing tennis, swimming, or playing competitive sports. The last section of the SGRQ involves true/false questions that evaluates the patient's perception of the breathing problems: including, playing sports or games, going out for entertainment or recreation, housework, going out of the house to do shopping, and a blank line for the patient to write in any other activities that he/she cannot do that is not included on the list provided in the questionnaire. The last question of the SGRQ includes how many activities that the patient's chest trouble affects. Demographic data were also collected from each participant using standard questions addressing factors such as marital status, education, and age.

Procedure

There were two categories of participants in the study: new and established patients of the CARD clinic who resided within the county where Libby is located (local) and long-distance clients who lived outside the county in Montana and elsewhere in the United States (distant). The local patients were approached when they presented to the clinic for usual care, and were given complete study information. Written consent was obtained from patients who were interested in participating in the study. Each consenting patient was provided a computerized kiosk with a touch screen to complete the study questionnaire in the waiting room before their clinic visit. If the patient declined participation in the study, he/she proceeded with usual and customary clinic procedures. Long-distance participants were approached over the telephone with complete information about the study and given an opportunity to verbally consent for participation in the study. These participants were sent paper copies of consent documents, and the study questionnaires to be completed and returned. Consent was also obtained from both categories of participants to access their medical records to obtain exposure history, medical history, diagnostic test results, and demographic data for use in the parent research study. Hard-copy questionnaire data were entered into an electronic file by research team members. Questionnaire data and clinical information from each participant was sent to the researchers for analysis via a secure Internet connection.

Each participant in the parent study and the study reported here was protected by the standards identified by the Montana State University Institutional Review Board (IRB). Written, informed consent was obtained from each participant, and their identity remained confidential. The only data analyzed for the study were the results of the study

questionnaire and the medical record information identified in the study consent. The electronic data analyzed for this study was kept on a password-protected computer.

CHAPTER FOUR

RESULTS

The purpose of this descriptive study was to describe respiratory-related quality of life among a sample of people exposed to Libby asbestos. The data analysis that follows utilized SPSS Version 18.0 to produce frequencies, means, and standard deviations for study variables.

Sample Description

Complete data were available for analysis for 351 people including 192 (55%) males, and 159 (45%) females. Most of the sample were married (n=250). The range of educational years in the sample population was between 0 and 21, with the mean as 12.7 (sd = 2.4). The age in years of the sample population ranged between 28 – 80, with the mean age being 59.91 years (sd = 10.0).

Respiratory-Related Quality of Life Results

Overall and individual subscale QOL results can be seen in Table 1. The mean score for the entire scale (overall QOL) was 37.7 (sd = 23.0) whereas the scores for both the Symptoms and Activity Subscales were considerable higher at 50.6 (sd = 25.4) and 48.3 (sd = 28.5) respectively. The lowest score can be seen with Impacts that resulted in a mean score of 27.0 (sd = 22.3).

Table 1. Summary of SGRQ scores for Asbestos-Related Diseases.

	N	Minimum	Maximum	Mean	Std. Deviation
SGRQ Total	351	.000	92.758	37.67134	23.016081
SGRQ Symptoms	351	.000	100.000	50.63843	25.444250
SGRQ Activity	351	.000	100.617	48.26598	28.540158
SGRQ Impacts	351	.000	91.250	26.98179	22.284541

CHAPTER FIVE

CONCLUSION

The purpose of this thesis is to examine respiratory-related quality of life among a sample of people exposed to Libby asbestos. Findings indicate that the SGRQ scores of the sample selected for this study were not significantly qualitatively different than samples of persons with other respiratory conditions reported in the literature although some distinctions can be made. The following discussion examines the findings from this study in comparison to the others that have used the SGRQ to assess QOL for a range of respiratory conditions including asthma, COPD, interstitial lung disease, and cystic fibrosis.

Activity

The mean score on the Activity subscale for our study was 48.27 out of a possible 100.62 maximum score with the higher scores on the SGRQ indicate worsening activity tolerance (see Table 2 for a summary of all scores). Scores on the SGRQ subscale for a study investigating individuals with asthma [The Salute Respiratoria nell'Anziano (Sa.R.A.) study] was 50.3 (sd = 25.11) (Incalzi, Bellia, Catalano, Scichilone, Imperiale, Maggi, & Rengo, 2001). This suggests that respiratory-related QOL for this sample was somewhat better when compared to people with asthma. The Sa.R.A. study was conducted on a cohort with a minimum age of 65 years, thus quantitatively the SGRQ scores may tend to be worse than our study sample based on age.

Scores on the SGRQ Activity subscale for studies investigating individuals with COPD range from 49.6 (sd = 22.5) (Llor, Molina, Naberan, Cots, Ros, & Miravittles, 2008) to 61.4 (Alvarez-Gutierrez, Miravittles, Calle, Gobartt, Lopez, & Martin, 2007). The Emotional Intelligence in Marketing Exchanges (EIME) study (Alvarez-Gutierrez et al) gathered information regarding the study group's (n=1124) activity tolerance via the SGRQ. The group's age range was from 40 – 90 years. This suggests that the respiratory-related QOL for our sample was slightly better when compared to people with COPD. The chief complaint of the EIME study group was dyspnea (Alvarez-Gutierrez et al, 2007, p. 66), which is similar to our study group with the chief complaint of breathlessness. It can be concluded that dyspnea or breathlessness is one of the main causes of activity intolerance. The EVOCA (the EVOLution of the quality of life of individuals with COPD) study (Llor et al) concluded that a higher SGRQ score indicated “a worse state of health”, therefore, “...is a predictive factor of frequent exacerbations...” (Llor et al, 2008, p. 589).

Scores on the SGRQ Activity subscale for a study investigating individuals with interstitial lung disease secondary to systemic sclerosis was 50.91 (sd = 18.73) (Beretta, Santaniello, Lemos, Masciocchi, & Scorza, 2007). This suggests that the respiratory-related QOL for our sample was again slightly better when compared to people with interstitial lung disease secondary to systemic sclerosis. Beretta et al (2007) stated that “...Interstitial lung disease (ILD) represents the leading cause of morbidity in SSc [Systemic sclerosis] individuals, profoundly affecting survival rates at 8 and 9 years...Functional lung impairment in SSc patients is likely to be accompanied by a decline in patients' capacity to cope with day-to-day activities...” (p. 296).

Scores on the SGRQ Activity subscale for a study investigating individuals with pulmonary sarcoidosis ranged between 40.17 (sd = 26.46) (Gvozdenovic, Mihailovic-Vucinic, Ilic-Dudvarski, Zugic, & Judson, 2008) and 55.27 (sd = 23.77) (Gvozdenovic et al, 2008). This suggests that the respiratory-related QOL for our sample was about the same when compared to people with pulmonary sarcoidosis. Fatigue, pain, dyspnea, and lack of mobility were the main concerns of the pulmonary sarcoidosis study sample (Gvozdenovic et al, 2008, pp. 1639-1640). Again, dyspnea is a common factor in all of the study cohorts.

Scores on the SGRQ Activity subscale for a study investigating individuals with cystic fibrosis was 28.9 (sd = 25.2) (Padilla et al, 2007). This suggests that the respiratory-related QOL for our sample was worse when compared to people with cystic fibrosis. The cystic fibrosis cohort consisted of young adults, ranging from ages 20 – 30 years, with their diagnosis of cystic fibrosis confirmed between ages 10 – 12 years. Based on the activity score for the cystic fibrosis cohort versus the activity score for our asbestos-related disease cohort, our cohort seems to have higher activity intolerance.

Based on all of these activity scores, each of these individuals with various respiratory conditions, including asbestos-related diseases, are limited with performance of activities of daily living independently, as well as limited ability to continue with employment outside of the home, if at all. Many of these individuals need assistance in various levels with activities of daily living either from family members or outside caregivers. Padilla et al (2007) concluded that, "...In our study, patients with cystic fibrosis scored higher on the SGRQ than a reference population, and these higher scores represent a poorer quality of life despite the fact that the study group was younger..." (p.

210). Alvarez-Gutierrez et al (2007) reported in their study that, "...10.1% of patients were on sick leave, mostly due to COPD (9%)..." (p. 66). Gvozdenovic et al (2008), "...conclude that patients with pulmonary and extrapulmonary sarcoidosis are more fatigued, have more dyspnea, are more limited in their everyday physical activities, and have lower health status in comparison with those with isolated pulmonary involvement..." (p. 1641). Incalzi et al (2001) reported in their study that COPD individuals state "...more severe limitation in taking a bath or shower in the Activity section..." (p. 737).

Symptoms

The mean score on the Symptoms subscale for this study was 50.64 out of a possible 100 maximum score (higher is worse). Scores on the SGRQ symptom subscale for a study investigating individuals with asthma was 40.4 (sd = 20.79) (Incalzi et al, 2001). This suggests that respiratory-related QOL for our sample was somewhat worse when compared to people with asthma. As stated above, the Sa.R.A. cohort is comprised of a geriatric population, so the exacerbations would be more prominent due to natural changes due to age as well as the asthma symptoms.

Scores on the SGRQ symptom subscale for studies investigating individuals with COPD range from 47.8 (sd = 30.9) (Llor et al, 2008) to 53.78 (sd = 23.38) (Incalzi et al, 2001). This suggests that the respiratory-related QOL for our sample was the same when compared to people with COPD. Llor et al (2008) reported for the EVOCA study that "...Exacerbations are associated with a significant worsening in the quality of life of patients with COPD measured with the SGRQ..." (p. 585). They also identified that the

main symptoms of an exacerbation are dyspnea, increased sputum production, and increased purulence of the sputum.

Scores on the SGRQ Symptoms subscale for a study investigating individuals with interstitial lung disease secondary to systemic sclerosis was 27.37 (sd = 17.99) (Beretta et al, 2007). This suggests that the respiratory-related QOL for our sample was better when compared to people with interstitial lung disease secondary to systemic sclerosis. Beretta et al (2007) concluded the following regarding their findings regarding symptoms:

In our study, we did not find significant correlations between the ‘symptoms’ score and the selected lung parameters. This result is not completely unexpected, since the items composing the ‘symptoms’ score specifically address to COPD-related manifestations, such as wheezing, productive cough or lower respiratory tract infections, that are virtually absent or marginally important in ILD patients (p. 300).

Scores on the SGRQ Symptoms subscale for a study investigating individuals with pulmonary sarcoidosis ranged between 37.32 (sd = 26.21) (Gvozdenovic et al, 2008) and 42.19 (sd = 20.56) (Gvozdenovic et al, 2008). This suggests that the respiratory-related QOL for our sample was worse when compared to people with pulmonary sarcoidosis. Gvozdenovic et al (2008) state that “...Patients with pulmonary sarcoidosis may have symptoms related directly to the chest such as cough, dyspnea on exertion, chest pain, chest discomfort, and wheeze...” (p. 1637). These symptoms are similar to the asbestos-related disease cohort.

Scores on the SGRQ Symptoms subscale for a study investigating individuals with cystic fibrosis was 35.29 (sd = 19.3) (Padilla et al, 2007). This suggests that the

respiratory-related QOL for our sample was worse when compared to people with cystic fibrosis. Padilla et al (2007) also concluded that the older the patient, the worse the symptoms are, and thus the poorer quality of life (p. 210).

In terms of daily management, the asbestos-related disease cohort would require intervention for their pulmonary needs, such as supplemental oxygen, metered dose inhalers, or nebulizers, similar to those individuals with COPD. Access to health care is critical for these individuals, especially if the patient develops an upper respiratory infection, bronchitis, pneumonia, or a similar insult to their already compromised respiratory system. Incalzi et al (2001) stated study that the COPD patients in their study reported a "...higher frequency of attacks of chest trouble in the last year..." (p. 737).

Impacts

The mean score on the Impacts subscale for this study was 26.99 out of a possible 91.25 maximum score (higher is worse). Scores on the SGRQ Impact subscale for a study investigating individuals with asthma was 14.1 (sd = 11.52) (Incalzi et al, 2001). This suggests that respiratory-related QOL for our sample was worse when compared to people with asthma. Incalzi et al (2001) concluded the following about the impacts result in the Sa.R.A. study:

Paradoxically, a progressive disease could make the patient more confident in the pharmacologic therapy, because a return to baseline in physical capabilities and QoL never occurs nor is expected to occur: accordingly, the expectancy of well-being is lesser than in asthmatic patients, and comparably lesser is the psychological discomfort by experiencing progressively declining HS [health status] despite even optimal pharmacologic therapy (p. 739).

Scores on the SGRQ Impact subscale for studies investigating individuals with COPD range from 17.6 (sd = 11.52) (Incalzi et al, 2001) to 38.7 (Alvarez-Gutierrez et al, 2007). This suggests that the respiratory-related QOL for our sample was very similar when compared to people with COPD. The EIME study focused on the fragility of the individuals, which they concluded that the more fragile the patient is, the more that COPD has an impact on their life (p.70). Our study group also showed a worsening quality of life with increased fragility with a higher SGRQ score on the Impact subscale, as well as the Symptom and Activity subscales.

Scores on the SGRQ Impact subscale for a study investigating individuals with interstitial lung disease secondary to systemic sclerosis was 27.3 (sd = 19.1) (Beretta et al, 2007). This suggests that the respiratory-related QOL for our sample was slightly better when compared to people with interstitial lung disease secondary to systemic sclerosis. Beretta et al (2007) correlated an increase in “functional lung impairment” to a decline in the patients’ ability to “cope with day-to-day activities”, thus a decline in their “emotional well-being” (p. 296).

Scores on the SGRQ Impact subscale for a study investigating individuals with pulmonary sarcoidosis ranged between 27.69 (sd = 23.83) (Gvozdenovic et al, 2008) and 37.55 (sd = 24.39) (Gvozdenovic et al, 2008). This suggests that the respiratory-related QOL for our sample was slightly better when compared to people with pulmonary sarcoidosis. Gvozdenovic et al (2008) concluded in their study that pain and lack of mobility leads to fatigue, which ultimately leads to depression (p. 1640). Depression and feelings of worthlessness are common impacts in our study group.

Scores on the SGRQ Impact subscale for a study investigating individuals with cystic fibrosis was 18.6 (sd = 14.6) (Padilla et al, 2007). This suggests that the respiratory-related QOL for our sample was worse when compared to people with cystic fibrosis. Padilla et al (2007) state the following about their study:

Assessment of health-related quality of life (HRQL) in these patients provides additional information on the impact of the disease that cannot be obtained by means of other purely physical tests such as lung function or nutritional status. It is also a useful tool for describing the situation in a comprehensible way for health professionals, patients, and relatives (p. 206).

The interstitial lung disease secondary to systemic sclerosis and the pulmonary sarcoidosis patients scored worse than the asbestos-related cohort on disease impacts. Incalzi et al (2001) stated the COPD patients in their study reported a “feeling of frailty or invalidity in the Impacts section...” and “...only lack of confidence in the effort of pharmacologic therapy, from the Impacts section, prevailed among asthmatics...” (p. 737).

Results of Total Score

The mean total SGRQ score of this study was 37.67 out of a possible 92.76 maximum score (higher is worse). Scores on the SGRQ subscale for a study investigating individuals with asthma was 36.1 (sd = 20.53) (Incalzi et al, 2001). This suggests that respiratory-related QOL for our sample was worse when compared to people with asthma. Incalzi et al (2001) concluded in the Sa.R.A. study, that “...the approach to the treatment of chronic diseases should aim at improving both survival time and QoL. This implies that physicians should be aware of the effects of most common chronic

conditions on this outcome...” (p. 734). “Chronic airflow limitation” is one of the most important progressive symptoms that will alter the patient’s ability to perform ADL’s and cope with their health condition (pp. 734-735).

Scores on the SGRQ for studies investigating individuals with COPD range from 43.8 (sd = 20.4) (Incalzi et al, 2001) to 47.8 (Alvarez-Gutierrez et al, 2007). This suggests that the respiratory-related QOL for our sample was the better when compared to people with COPD. Alvarez-Gutierrez et al (2007) concluded in their EIME study, that “...we found that we were able to define a social profile for fragile individuals that were characterized by older age, a lower level of education and economic status, and a greater probability of being single, widowed, or living in a nursing or retirement home...” (p. 69).

Scores on the SGRQ for a study investigating individuals with interstitial lung disease secondary to systemic sclerosis was 34.82 (sd = 16.07) (Beretta et al, 2007). This suggests that the respiratory-related QOL for our sample was worse when compared to people with interstitial lung disease secondary to systemic sclerosis. In this study, the six minute walking distance test influenced all components of the SGRQ scores, by measuring pulse oximetry before, during, and after the test, the patient’s perception of their condition after the test, and the degree of dyspnea was measured (pp. 297-298).

Scores on the SGRQ for a study investigating individuals with pulmonary sarcoidosis ranged between 33.07 (sd = 22.81) (Gvozdenovic et al, 2008) and 43.69 (sd = 21.55) (Gvozdenovic et al, 2008). This suggests that the respiratory-related QOL for our sample was similar when compared to people with pulmonary sarcoidosis. It was identified that fatigue is the most concerning symptom during the study (p. 1637).

Scores on the SGRQ for a study investigating individuals with cystic fibrosis was 24.5 (sd = 16.8) (Padilla et al, 2007). This suggests that the respiratory-related QOL for our sample was worse when compared to people with cystic fibrosis. Padilla et al (2007) made the following conclusions about individuals with cystic fibrosis (CF): "...Self-perceived quality of life is worse among adults with CF than in the general population or among patients with chronic obstructive pulmonary disease. The SGRQ is a valid instrument for analyzing health-related quality of life in adults with CF as it discriminates very well between different degrees of severity of pulmonary impairment and has acceptable internal consistency..." (p. 205).

The COPD cohort overall scored higher than the asbestos-related disease cohort. Although the scores are higher, the asbestos-related disease cohort is just as severely impacted by the disease process as the COPD cohort.

The SGRQ data for the different cohorts is summarized in the table below:

Table 2. Summary of SGRQ scores for various respiratory-related diseases.

	Asbestos-Related Diseases ¹	Asthma ²	COPD ³⁻⁴	Cystic fibrosis ⁵	Interstitial lung diseases ⁶	Pulmonary sarcoidosis ⁷⁻⁸
SGRQ Activity	48.27	50.3 (25.11)	study #3 49.6 (22.5) study #4 61.4 (NR*)	28.9 (25.2)	50.91 (18.73)	study #7 40.17 (26.46) study #8 55.27 (23.77)
SGRQ Symptoms	50.64	40.4 (20.79)	study #3 47.8 (30.9) study #4 53.78 (23.38)	35.29 (19.3)	27.37 (17.99)	study #7 37.32 (26.21) study #8 42.19 (20.56)
SGRQ Impacts	26.99	14.1 (11.52)	study #3 17.6 (11.52) study #4 38.7(NR)	18.6 (14.6)	27.3 (19.1)	study #7 27.69 (23.83) study #8 37.55 (24.39)
SGRQ Total	37.67	36.1 (20.53)	study #3 43.8 (20.4) study #4 47.8(NR)	24.5 (16.8)	34.82 (16.07)	study #7 33.07 (22.81) study #8 43.69 (21.55)

*NR – not reported

¹CARD clinic study

²Incalzi et al. (2001). Sa.R.A. study

³Incalzi et al. (2001). Sa.R.A. study

⁴Alvarez-Gutierrez et al. (2007). EIME study

⁵Padilla et al. (2007)

⁶Beretta et al. (2007)

⁷⁻⁸Gvozdenovic et al. (2008)

Application of the SGRQ and Roy's Adaptation Model

There are three concepts of Roy's Adaptation Model: Person, Goal, and Health (Lutjens, 1991, p. 9). The person is identified as the patient, which has their own unique set of coping mechanisms. It is important for the nurse practitioner to keep in mind that individuals do not always cope with chronic illnesses in the same way. Lutjens (1991) wrote the following about goals: "...The goal of nursing within this model is to promote adaptation in four adaptive modes (physiologic, self-concept, role function, and interdependence) and thereby contribute to health..." (p. 9). Lutjens (1991) also wrote that, "...Health is a process whereby individuals are striving to achieve their maximum potential..." (p. 10).

The patient, according to Roy, adapts to the environment, which is "...all conditions, circumstances, and influences that surround and affect the development and behavior of the person..." (p. 10). Roy's Adaptation Model can be easily integrated into the Impacts section of the SGRQ in that behavior is an excellent indicator for the healthcare provider to gage the patient's level of coping with the illness. The physiologic adaptive mode is similar to the Activities and Symptoms section of the SGRQ in that it focuses on "...five primary needs...oxygen, nutrition, elimination, activity and rest, and protection..." (Lutjens, 1991, p. 22). The self-concept mode is defined as "...the composite of beliefs and feelings that one holds about oneself at a given time, formed from perceptions particularly of others' reactions, and directing one's behavior..." (Lutjens, 1991, p. 23). The role function mode can be integrated into the SGRQ's Activities and Impacts sections because as the respiratory disease progresses, the

patient's role becomes more dependent on others around them, which makes it important for the healthcare provider to involve the patient's support system as much as possible.

Implications for Advanced Practice Nursing

Advanced practice registered nurses (APRNs) can utilize the SGRQ as an assessment tool to gain a better understanding of the patient's perception of the asbestos-related disease and to anticipate the current and future needs of the patient as the disease progresses. The number of cases of asbestos-related diseases has grown in numbers and will not decrease for quite some time, especially in the northeastern and the northwestern parts of the U.S. It is important for the APRN to gain a good understanding of the asbestos-related disease process and the management of this devastating disease.

Study Limitations and Conclusion

This parent study was conducted using a cross-sectional design, which is limited by data-gathering at one point in time. Since asbestos-related diseases are progressive in nature over time, the results from a single data collection point may not clearly describe the changing health condition. Perhaps using a longitudinal design, which involves collecting data from different points over an extended period, would create a more definitive study to describe respiratory-related quality of life among this population.

This study was also conducted with only one exposed population associated with Libby asbestos. It is not known how our results may generalize to other exposed groups, such as automobile workers and shipyard workers. Last, there may have been self-report bias from the sample as they were completing the research questionnaires. It is not known to what extent that recall or other self-report biases may have affected our findings.

In conclusion, asbestos-related diseases and other terminal pulmonary diseases have the potential to dramatically influence quality of life and psychosocial health. Accurate assessment of these qualities is critical to plan care comprehensively. Our findings show that respiratory-related quality of life for our sample was similar to other groups of persons experiencing chronic respiratory disease although some qualitative differences exist.

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