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Comorbidity: a neglected aspect of the burden of RA

by

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B.S., Reinhardt University

A Capstone Submitted to the Graduate Faculty
of Georgia State University in Partial Fulfillment
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APPROVAL PAGE

SCHOOL BOARD PERCEPTIONS OF RESPONSIBILITIES FOR
Comorbidity: a neglected aspect of the burden of RA

by

Andrea L. Cole

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Date

ABSTRACT

Comorbidity: a neglected aspect of the burden of RA

By

Andrea Leanne Cole

April 21, 2016

INTRODUCTION: RA is defined as a systemic inflammatory disease that manifests itself in multiple joints in the body (CDC). This inflammation affects the lining of the joints primarily, but can also affect other organs. The chronic inflammation leads to erosion on the cartilage and can cause joint deformity. The cause of RA is unknown, however many factors such as genetics, environment, and lifestyle are being evaluated. Symptoms can include joint pain, rash, fatigue, stiffness in joints, fever, and swollen joints. There is no cure, but there are a variety of medicines used to reduce inflammation. There are a number of comorbidities associated with the disease complex. The incidence of comorbidities is increasing, however, the data from current studies are not being used towards patient information. The availability of information of patients both online and through the doctor is severely lacking.

AIM: The purpose of this capstone is to identify the types of comorbidities associated with arthritis, focusing specifically on rheumatoid arthritis (RA). I identify and review the non scientific literature that patients are likely to seek after a diagnosis to determine the span of information available to the general public as well as provide statistics and articles for comorbidities in RA. This information will inform a set of recommendations for future research and improvement of patient care.

METHODS: This capstone focuses on statistics of comorbidities present in rheumatoid arthritis (RA) and online resources available to patients. Data were collected via Pubmed articles using the Georgia State University Library database list. Articles were analyzed for relevance and data was compiled into a table for easy reference. The patient resource websites were found using a Google search and evaluated for usefulness and the level of information provided.

RESULTS: My research indicated that the prevalence of comorbidities is high among patients diagnosed with arthritis. Patients are most frequently diagnosed with cardiac events, cancer, and respiratory diseases such as COPD. Nearly every researcher assessed that there was not enough research done and that results were conflicting. Patient online resources are lacking and the availability of information is subpar.

DISCUSSION: There are articles that provided statistics on arthritis patients with comorbidities in almost every article within the discussion section, but it was stated that there was not enough data to make definitive statements and conclusions. The problem is that studies and data are being produced, but there is no movement forward to produce a treatment plan and thus the information available for patients should be reevaluated.

Author's Statement Page

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Andrea Cole
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Introduction

The purpose of this capstone is to identify the types of comorbidities associated with arthritis, focusing on rheumatoid arthritis (RA) specifically. I will identify and review the non scientific literature that patients are likely to seek after a diagnosis to determine the span of information available to the general public as well as provide statistics and articles for comorbidities in RA. This information will inform a set of recommendations for future research and improvement of patient care.

RA is defined as a systemic inflammatory disease that manifests itself in multiple joints in the body (CDC). This inflammation affects the lining of the joints primarily, but can also affect other organs. The chronic inflammation leads to erosion on the cartilage and can cause joint deformity. The cause of RA is unknown, however many factors such as genetics, environment, and lifestyle are being evaluated. Symptoms can include joint pain, rash, fatigue, stiffness in joints, fever, and swollen joints. There is no cure, but there are a variety of medicines used to reduce inflammation. There are also a number of surgical procedures available to help patients maintain their mobility, such as a hip replacement. An estimated nearly 2 million of US adults aged 18 and over have RA (CDC). Data from the CDC indicates that prevalence and incidence for RA is rising.

People diagnosed with RA have a higher chance of developing comorbidities such as chronic respiratory conditions, diabetes, heart disease, and stroke (CDC). Arthritis also can lead to a higher chance of developing fatal infections, however, these are frequently related to the prescribed medications currently used for arthritis symptoms rather than the etiology of the disease itself. While these infections may be more important in long term care, as they are more

often not a direct result of the disease, this capstone will focus on the chronic disease comorbidities of arthritis.

Although there are many studies available with statistics about comorbidities and RA, the data is currently not being explored further beyond reporting. As a result of the data sitting untouched, patients do not have resources available to them to allow for knowledgeable choices regarding healthy habits to decrease comorbidity statistics.

Research Questions

The research questions addressed in this capstone are “What are the statistics of people that have arthritis and develop a comorbidity”? Also, “What is currently being done with the statistics gained from studies on comorbidities and RA?” Regarding patient resources, “What is the quality of resources available to patients online?” and “What improvements can be made so that patients have better access to instructional materials?”

Methods

This capstone focuses on statistics of comorbidities present in rheumatoid arthritis (RA) and online resources available to patients. Data was collected via Pubmed articles using the Georgia State University Library database list. Articles were analyzed for relevance and data was compiled into a table for reference. Articles were chosen for their statistics reported on specific comorbidities as well as articles that reported general statistics. Also articles were analyzed that contained treatment information with regards to comorbidities.

The patient resource websites were found using a Google search and evaluated for informational content and the presence of comorbidities. Websites found included social media groups on Facebook as well as government-run websites and sites from health organizations and hospitals. There were no Twitter accounts used as the point of Twitter is not to provide information to patients; same with Instagram in that the point of the website is not to connect patients with information. I focused on Facebook because it is intended to connect people and provide support groups that patients might use when diagnosed.

Literature Review

Rheumatoid Arthritis

Rheumatoid arthritis (RA), one of the most common types of arthritis, represents the highest rates of comorbidities compared with other types of arthritis. RA is an auto-immune disease in which the body attacks the immune system which results in high levels of inflammation that can lead to pain, organ damage, and joint deformity. RA is characterized by patterns of bone and joint destruction (Tobon *et al.*, 2010). The incidence and prevalence of RA vary across populations. In North America and Northern Europe, the incidence of RA is estimated at 20-50 cases per 100,000 people, and the prevalence at 0.5-1.1% . Lower results have been found for Southern Europe, and little to no data is available for developing countries. Tobon indicates that mortality rates are higher among RA patients than the general population; life expectancy decreases by about 3 to 10 years (Tobon *et al.*, 2010). The main causes of death are comorbidities such as cardiovascular disease, infections, gastrointestinal disease, and pulmonary complications.

The diagnosis of RA is through blood tests for rheumatoid factor and associated inflammatory markers such as sedimentation rate. Unfortunately, the symptoms vary widely from person to person, and not everyone tests positive for the rheumatoid factor, which makes a concrete diagnosis difficult. Patients with rheumatoid factor positive RA tend to have increased severity than those with rheumatoid factor negative RA. Due to the complicated and unspecific nature of clinical signs and symptoms of the disease, many of which can implicate other diseases and conditions, many people spend up to 10 years undiagnosed before finally receiving a diagnosis.

RA is more prevalent among women than men. Tobon *et al.* (2010) suggests that the ratio of RA female-to-male is 3:1. Tobon infers that the peak age of onset in RA is around 50 years old, which is the average age in which a hormonal change in women occurs. This suggests there could be a link. The exact cause of RA is unknown. There are several factors including genetic, environmental, dietary, and lifestyle that are currently being explored through research.

Carmona *et al.* (2010) report that there are many challenges with the epidemiology of the disease with regards to descriptive epidemiology. It is unclear when the disease actually starts; there is no standard on how early to call the disease RA versus a more common term of inflammatory arthritis. Further, many patients may be in remission at the time studies take place, which would make the actual data count difficult. The authors also indicate that the prevalence is higher among women than men, and higher among developed countries.

Table 1. Prevalence of comorbidities: cardiovascular diseases by country (Dougados *et al.* 2013)

Country	Number of patients	Myocardial Infarction %	Stroke %
Argentina	200	5	2
Austria	204	5	1
Egypt	308	3	2
France	411	3	2
Germany	209	7	3
Hungary	201	17	1
Italy	228	6	2
Japan	207	5	1

Korea	400	4	2
Morocco	227	1	1
Netherlands	139	7	5
Spain	200	5	1
Taiwan	313	2	1
UK	43	2	0
Uruguay	30	7	3
USA	400	5	3
Venezuela	200	2	1

RA Treatment

One of the key issues with RA treatment is that dealing with the symptoms can increase the risk of comorbidity. For example, Carl Tureson (2016) found that long term use of biologics and synthetic DMARDs, such as methotrexate and leflunomide, are associated with increased risk of cardiovascular disease. Biologics are drugs that are used to treat inflammation in RA patients. They are engineered from a living organism in order to trigger the body's natural response to infection and disease. They target proteins, cells, and pathways responsible for RA symptoms. Proteins targeted include tumor necrosis factor (TNF), interleukin-1, and interleukin-6.

Radner *et al.* (2015) conducted a study that examined the treatment profile of patients with multiple comorbidities in contrast to patients with RA only. Using the Comorbidities in Rheumatoid Arthritis (COMORA), a cross-sectional international study assessing morbidities, outcomes, and treatments of patients with RA, the researchers categorized treatment as either

biologic disease-modifying antirheumatic drugs (bDMARD), or synthetic DMARD (sDMARD) use only, or nonsteroidal anti-inflammatory drug (NSAIDs) use, or corticosteroid use. Results indicated that out of 3920 patients, 32.7% received bDMARD, 59.9% sDMARD only, 51.1% used NSAIDs and 54.8% used corticosteroids. The authors concluded that bDMARD use decreases incidence of each chronic disease by 11% (Radner *et al.*, 2015).

RA and Comorbidities

Dougados *et al.* (2013) completed an international cross-sectional comorbidity of RA (COMORA) that analyzed 3920 patients from 17 countries and found that among patients there was an increased prevalence of comorbidities and risk factors. The most common associated diseases were depression (15%), asthma (6.6%), cardiovascular events (6%), malignancies (4.5%), and COPD (3.5%). She also found that although the long-term prognosis of RA improved following the introduction of effective medications, the threat of comorbidities shortening the life span of patients was still present. Her study linked this to the prevalence of cardiovascular disease, a greater incidence of infections, and development of malignancies (Dougados *et al.*, 2013) (Table 1).

Innala *et al.* (2016) in a study of RA patients in Northern Sweden found that 53.2% of patients had one or more comorbidities at the onset of the disease, with the most common being hypertension (27.3%), COPD (13.9%), and diabetes (8.0%). After 5 years, 41% developed at least one or more new comorbidities, with the most common being hypertension (15.1%) followed by malignancy (7.6%), stroke (5.1%), myocardial infarction (4.3%), and osteoporosis (3.7%). Using a multiple logistic regression model, the researchers found that erythrocyte sedimentation rate (ESR) elevation at inclusion in the study was associated with new comorbidity diagnosis after 5 years. The evidence that 41% of patients developed a new

comorbidity so soon after disease onset is alarming. Researchers must place more attention to the long term effects of the treatments that masks RA's symptoms and not its cause. Carmona et al (2010) lists that cardiovascular disease accounts for around 40% of all deaths in RA, cancer (17%), infection (14%), musculoskeletal disease (9%), respiratory disease (9%), and renal disease (6%).

Lu *et al.* (2008) suggest that the most common comorbidities are cardiovascular diseases, infection, malignancy, gastrointestinal issues, and osteoporosis. The authors indicate that early identification and aggressive management of comorbidities is important. Lifestyle changes such as weight reduction in overweight patients and smoking cessation can help reduce or delay the development of comorbidities. They also suggest that little is known about how routinely rheumatologists consider and assess patients for comorbidity and risks. Comorbidities have considerable impact on RA disability and costs, and contribute to the increased mortality rate, which makes care even more difficult. This is why doctors must pay more attention to comorbidities – to achieve the best possible outcomes for patients. Lu *et al.* (2008) also state that research is warranted to understand how frequently rheumatologists consider comorbidities, and that long term studies are needed to determine the effectiveness of management approaches, because comorbidities can take years to occur.

The National Rheumatoid Society in England (2012) found that there are around 580,000 people in England with RA, around 80% have one or more comorbidities, which means that there are around 464,000 patients with another chronic health condition. The risk of heart attack is doubled for RA patients. Additionally, the risk of atrial fibrillation is 40% higher as well as an increased risk of stroke by 30% for RA patients. Osteoporosis rates can be twice as high, and

interstitial lung disease as well as cancer are significant sources of mortality among RA patients. Accompanying that is an increased rate of depression among patients with RA.

RA and Cardiovascular Disease

Turesson, (2016), also examined cardiovascular disease. He found that it was one of the most common comorbidities resulting in increased mortality among rheumatoid arthritis patients. He estimated the relative risk for cardiovascular events of people with RA between 1.5-2.0 times that of the general population. Turesson's results further showed that the incidence of myocardial infarctions increases within the first few years of diagnosis of RA. He also uncovered evidence that suggests the risk for developing atherosclerosis, or hardening of the arteries, increases within five months after diagnosis. Turesson suggests that explanations for the increased comorbidity from cardiovascular disease is due to the chronic inflammation of the vascular system as well as physical inactivity.

Carmona *et al.* (2010) examined cardiovascular events in RA patients. They present that patients with RA show a higher risk of adverse cardiovascular events than those without RA, but there is an ongoing debate on the confounding effect of adverse cardiovascular risk profiles on the association of disease activity. They also suggest that in addition to inflammation, there may be other factors at work that could be increasing the risk of cardiovascular events. RA is associated with a 60% increased risk of cardiovascular death compared with the general population.

RA and Cancer

Harigai *et al.* (2016) investigated the risk of malignancy in RA patients treated with biologics in Japan and compared to the general population. Data for 14,440 patients from 335 institutions who were given biologics were retrieved from the Safety of biologics in Clinical Use

in Japanese patients with Rheumatoid Arthritis (SECURE) database. The authors found 333 incidents of malignancies in 320 patients during 49,320 patient-years (Harigari *et al.*, 2016). A significant increase for malignant lymphoma was found (6.183, 95% CI 4.809-7.643).

A meta-analysis by Simon *et al.* (2015) found that 6 of 7 studies reported a significant increase in overall risk of malignancy in RA patients. Two studies reported lymphoma rates doubled among RA patients at 2.08, as well as an increased risk of lung cancer among RA patients when compared to the general population (Simon *et al.*, 2015). Interestingly, 7 studies found reported a decreased risk of colon and colorectal cancer among RA patients. Simon *et al.* (2015) report that the results of the meta-analysis of the incidence of malignancy in adult patients with RA are consistent with previously reported data. This shows that the risk of cancer is not declining.

RA and Obesity

Obesity is another common comorbidity associated with RA. Obesity cases linked to RA seem to be associated with the loss of mobility or physically inactive patients, due to the pain or loss of joint mobility as an effect of RA. Evidence shows that people who are overweight or obese report doctor diagnosed arthritis more often than people who are at an ideal body mass index. This is mostly due to the inactivity or lack of mobility caused by joint destruction, inflammation, or pain. Per the CDC, almost 16% of people of normal weight report arthritis, whereas 23% of overweight and 31% of obese people in the U.S. report arthritis. About 66% of adults with doctor-diagnosed arthritis are overweight/obese, compared with 53% of adults that do not have arthritis. Inactivity due to arthritis can be one of the main causes of obesity, with 44% of adults with arthritis reporting no physical activity, compared to 36% of adults without arthritis (CDC).

In recent years, the prevalence and incidence of obesity and RA have risen, according to Crowson *et al.* (2013). Crowson used a cohort of Minnesota residents who fulfilled the 1987 American College of Rheumatology criteria for RA in 1980-2007 and were compared to population-based controls found that the odds in these patients of developing RA while obese was 1.24 times as likely compared to the general population. Although Crowson reports these findings, there are many inconsistencies with findings regarding obesity and RA (Crowson *et al.*, 2013). The difficulty is in defining the direction of causality. People with advanced RA may tend to lose weight because they are hypermetabolic and lose muscle mass. This inconsistency is preventing organizations and doctors from obtaining a set treatment plan that focuses on eliminating comorbidities.

Feng *et al.* (2016) states that although many epidemiological studies have investigated the association between body mass index (BMI) and risk of RA, the results are inconsistent. Based on this, the research team performed a meta-analysis to quantify the association between BMI and RA. The risk of RA increased by 13% for every 5kg/m² increase in BMI. A subgroup analysis found that there was a positive association between obesity and increased risk of RA. The positive association between RA and BMI may be stronger in women than men.

In general, RA is not a well-understood disease, which results in the comorbidity risks being overlooked by the public, medical professionals, and policymakers. It is important to raise awareness of the comorbidities linked to RA so that patients have the understanding to report and manage risk factors accordingly. As an example, if a patient does not know about cardiovascular risks, they are less likely to address factors such as smoking, weight, and diet. The challenge now is to identify how best to treat someone with two or more conditions that while also ensuring that they are receiving the best care possible. There have been a number of significant

policy announcements relating to the treatment and management of RA and comorbidities, including the introduction of new indicators within the Quality and Outcomes Framework that will encourage general practitioners to undertake annual cardiovascular and osteoporotic assessments.

Recommendations for Care

The British Society of Rheumatoid Arthritis published that failure to study and manage these comorbidities may result in delays to the care pathway, increased risk of disability, and increased levels of mortality. Although current guidelines recommend some checks for comorbidities among RA patients, a report issued by the society states that it finds that it is patchy and the range of conditions checked is too limited. Key recommendations by the society include: providers should fully implement the guideline that states that all RA patients should be offered annual checks for co-morbidities and have access to a consultant-led multidisciplinary team. Providers should fully implement the recommendations listed in the report by Lord Darzi, the Director of the Institute of Global Health Innovation at Imperial College of London, which states that all people with long-term conditions should be given an annual personalized care plan and the information prescription for RA should be overhauled to include further information about the range of comorbidities that affect people with RA. Additionally, the national clinical audit should make data available about the proportion of rheumatology teams that are offering care plans and comorbidity assessments. Long term condition outcomes strategies should include a section on effective management of comorbidities which promotes investment in self-management programs and annual care plans. This would lead to additional outcome strategies including sections on effective management of comorbidities and identify specific at-risk populations, the quality standard for the management of RA should include a care plan for every

patient, the commissioning board should establish a strategic clinical network for musculoskeletal conditions which would advise groups on the need to prioritize checks on comorbidities, general practitioners should conduct holistic annual reviews with RA patients, and the early inflammatory arthritis best practice tariff for providers should be introduced as soon as possible and should include an annual review.

Online Resources for Patients

The Arthritis Foundation website (www.arthritis.org) has a Better Living Toolkit which provides people diagnosed with arthritis ways to help them track and manage their disease as well as suggestions on how best to communicate with a healthcare provider. This appears to be an excellent tool, since they have many resources that allow patients to learn about the disease and accompanying comorbidities and planning for arthritis management. It also breaks arthritis into subcategories including RA. The information on RA is easy to read with accompanying journal articles and disease information. Patients are able to receive a free toolkit in the mail with brochures and information printed out. The website contains the best types of exercise for RA, how to manage gastrointestinal problems, and also information on the possible comorbidities that a person with RA is at a higher risk of developing. While the website is designed to be accessible for all patients, it is informative and offers a variety of resources and a knowledge portal for patients. This would be a good starting place for newly diagnosed and previously diagnosed patients as a resource. This is more reliable than a public domain website like Wikipedia.

The Health Tracker, a tool provided by the Arthritis Foundation (www.arthritis.org) allows patients to track: the ability to easily perform tasks of daily living, pain levels, sleep patterns, and emotional health. The tracker can be used by answering a series of questions on functional status, pain level, and overall feeling of wellbeing. The questions are based on the

RAPID-3 assessment commonly used by rheumatologists. The tracker allows the patient to develop a chart to bring with them to their appointments that helps the doctor assess if the condition is improving or declining, based on patient provided information compared to only bloodwork results. The website strongly encourages communication with the doctor, which is crucial in chronic diseases as the diseases are considered are “invisible”, meaning one cannot look at a patient and know exactly how they are doing, and sometimes bloodwork is not indicative of the patients physical or mental condition. The goal of the health tracker encourages the patient to set low-key goals such as “go on a day trip with your friends” or “take the lead on a new project at work” and provides encouragement at working towards the goal.

Rheumatoidarthritis.net is a website that is centered on other patients’ personal management and living with their disease. This website is intended to be more of a personal resource than a website stacked with scientific articles. It does provide information on what RA is, symptoms, treatment, and provides suggestion on diet and exercise as well as a section called Tools that includes a symptom checker. The website lists brief paragraphs on how RA affects joints, tissues, and bones, as well as a more in-depth page on how arthritis involves each joint, the symptoms, and associated inflammatory-related conditions. It does not refer to these specifically as “comorbidities” however for the average patient which this is geared towards, the information is adequate. The website appears to be a good resource of general information as well as helpful tips and a forum where patients can interact with other patients and share things, which could help to up emotional support.

Unfortunately, while there are good websites as resources for patients, the use of social media is generally unsupported. A search for “rheumatoid arthritis” under Facebook groups only returned 38 results. Of those 38, 8 were support groups, 4 were non-profit groups, and the rest

were informational. The quality of information available on the informational groups was found to be subpar. There were no resources for patients, and the information was a direct link to Wikipedia articles. Most often the “informative” groups had gone inactive and had not been updated since 2014 or earlier. The support groups were actively maintained and recently accessed by Facebook members that had “liked” the page. These support groups also indicated on the Facebook page that they were active in other social media such as Twitter.

A Google search reveals about 20,000,000 results on “rheumatoid arthritis”. Many of the websites on the first few pages are from hospitals or other health organizations. The American College of Rheumatology website on RA (www.rheumatology.org) includes a summary of “fast facts” on RA and a simple introductory paragraph. The website then breaks into small expandable sections that contain information on what causes the disease, how is it diagnosed, how is it treated, a section on what a rheumatologist does, and a section titled “living with rheumatoid arthritis”. The information provided is satisfactory for patients, however there is no mention of comorbidities.

Medline Plus, a website run by the U.S. National Library of Medicine (www.nlm.nih.gov) is an excellent resource for patients. The website provides a basic summary, links under “Start Here” that are informative and easy to read and from trusted governmental sources, not Wikipedia. It includes “Latest News” in which current research updates are posted, and explains many tests that are conducted with RA patients in regards to disease management and drug therapies as well as treatments. There are resources for living with arthritis including links to diet and pain management. The website has a section titled “Related Issues” that has links to articles from reputable websites that deal with headaches, the immune system, ulcerative keratitis, and articles on RA affecting the eyes and lungs as well as osteoporosis. This is the

most mention of comorbidities seen in websites, although the website does not cover the increased risk of cardiovascular disease or obesity, or cancer, which are the major comorbidities that should be addressed.

A similar website, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (www.niams.nih.gov) does not mention comorbidities at all. It addresses the basic information geared towards patients. It does mention research being done, which is more than most other websites for patients. The Mayo Clinic website (www.mayoclinic.org) is similar in that it provides simple information to patients regarding RA, however the Mayo Clinic lists a section titled “Complications” in which there are several comorbidities listed such as osteoporosis, obesity, heart problems, lung disease, and lymphoma.

MedicineNet (www.medicinenet.com) did not have adequate information presented to patients. The article did not even cover one page, and only listed bullet point symptoms. The information was presented in a very poor manner. It lists medication used to treat RA without any explanation. There was no mention of comorbidities or any associated conditions, despite the claim that the page was written and edited by doctors. The website is a poor choice for patient resources; patients would be better off using a Wikipedia article.

Findings/Discussion

My research indicated that the prevalence of comorbidities is high among patients diagnosed with arthritis. Patients are most frequently diagnosed with cardiac events, cancer, and respiratory diseases such as COPD. These comorbidities are the most frequent cause of death among patients with arthritis. It is well-known that patients taking biologics or other DMARDs (disease-modifying anti rheumatic drugs) that suppress the immune system are more likely to die from an infection such as tuberculosis than the general population. Taking the focus from infectious complications and turning to chronic comorbidities, every article I found stated that there is not enough research in this area. I attribute this lack of research to the reason for the lack of information provided to patients and families on comorbidities.

From the websites that I encountered that were intended to be patient resources, it is evident that there is not enough information accessible to patients regarding comorbidities.

A good website that I found for patient information was the Arthritis Foundation at arthritis.org. I was able to find this easily and navigate around the website without difficulty. I am concerned however that older patients or patients who are not as familiar with technology would be able to access the website. Another website that I found to be the most useful was rheumatoidarthritis.net, which is set up more as a blog. It does have information, but it focuses more on articles written by patients themselves, but does not really touch on comorbidities. If patients are looking at in-depth possible symptoms and health concerns, this would not be the best website to visit. It does provide tips for exercising and making healthy decisions and life choices, which is very important when trying to eliminate comorbidities. Patients can also visit this website to ask questions of other patients to discover what works best for others and allow patients to try out some suggestions.

There is no information that patients can take home without being their own doctor, to speak, and researching for themselves. The British Rheumatoid Arthritis Society provided excellent suggestions for increasing the access that patients have to information about comorbidities. They also agreed that there is not enough focus on comorbidities and how to ensure the patient is well-informed in order to possibly reduce the incidence and prevalence of comorbidities. The organization stated that patients should have personalized health plans that allow them to make the best choices that fit their specific health needs.

The focus in healthcare today appears to be solely on treating the symptoms instead of educating patients about the best ways to eliminate the prevalence of comorbidities. With education, it might be possible to reduce the prevalence of rheumatoid arthritis itself. There are many articles available, however there is still a need for follow up with the data. More research needs to be done on why patients are developing comorbidities, instead of just reporting statistics. The statistics are important; however, a direction is still needed to develop how best to address the concerns. There are a variety of websites available to patients from reputable sources, however very few resources shared information about comorbidities with patients. The presence of RA support and facts on social media is severely lacking. There were only 38 resources on Facebook, with the majority of groups neglected over time. Twitter yielded similar results. In order to best reach younger people and create mobility for arthritis resources, this needs to be addressed.

Patients with rheumatologic diseases would greatly benefit from resources provided by the American College of Rheumatology that doctors could hand out at the start of diagnosis. This packet could include possible symptoms of the progression of the disease, as well as information on the possibilities of comorbidities occurring, with information on the most

common types. Each patient should have a general packet, and then an informational packet that suggests specific exercises per the patient's mobility level and helpful resources that the patient could seek out on various websites. Some of this information should start at the general practitioner level so that when patients are referred to a specialist such as a rheumatologist they will know somewhat what they can expect. The pamphlet should focus on laymans terms as to what the disease is, how it affects the body, what the comorbidities are, and how the patient can try to strive for normalcy in their diet and exercise regiments. It is important to stay away from presenting statistics to the patient, as the focus is to remain positive.

I feel that the British Rheumatoid Arthritis Society had the best information with regards to recommendations. It provided a report that not only reported statistics to stress the importance of comorbidities, but they provided suggestions that could improve patient access to information as well as the suggestion that each patient be provided a care plan by multiple specialists. This is a better approach because without information, we cannot study the effects of the disease and the comorbidities, and the reality is that the information is just not out there. The U.S. does not have any such organizations that advocate for any certain rights or care plans for arthritis. I believe that the U.S. and other European countries with higher numbers of RA cases could strongly benefit from organizations such as this.

Through this entire process of researching organizations, websites, and other available resources, I found articles that provided statistics on arthritis patients with comorbidities in almost every article within the discussion section, BUT it was stated that there was not enough data to make definitive statements and conclusions. The problem is that studies and data are being produced, but there is no movement forward to produce a treatment plan. Unfortunately, there are few studies that focus entirely on the cause of death in patients with doctor-diagnosed

arthritis because these aspects of the disease are largely unknown. Even other studies and reports mention this deficit. This is a huge problem, because the information is not out there, which means that patients do not have access to the reality that people can die from these comorbidities.

Needs and Recommendations

The arthritis community desperately needs a stronger presence in online and additional supporting information available. In addition, there is not enough information being supplied by doctors to patients. Patients are left on their own to delve further into websites for more information, which is a problem. Information should come from the doctor so that patients can trust the information they are receiving.

If I were to create a website for patients and family members for RA I would include: statistics for comorbidities, but angled in such a way that patients can understand and are not alarmed, and information that enables patients to make healthy decisions about their lifestyle such as exercise and diet. I would include forums for people to post questions, as well as blog posts by website staff that might cite upcoming findings or draw attention to current issues with arthritis. In this, it is important to include resources to help family members cope with their relatives diagnosed with arthritis. This can also come in the form of blog posts and forums on a website. Also on the website I would provide a page for resources including books, websites, apps, and organizations.

In addition to online resources I would encourage the development of apps to be used on cell phones and tablets that help patients monitor and log changes in their symptoms, track doctor appointments and emotional feelings, and set goals like the health tracker on arthritis.org, but in portable form so that patients are not always tied to their computers. I would encourage the delivery of information that is not centered on technology for patients that are older or are unable to access a computer; these should be provided by the doctor. There definitely needs to be more information received from doctors in patient care. Each patient should have access to a specific care plan that fits their needs and level of activity. The doctor should be able to either

provide this themselves or point the patient to a doctor-sponsored website that can generate a care plan for the patient. This care plan should focus on exercise, dietary needs, medicine changes, symptoms, and emotional care.

I would encourage epidemiologists to research RA and arthritis because as stated earlier, the incidence of RA is rising as well as the incidence of comorbidities. There are many articles published that provide statistics, however they do not take the data further. It would be helpful if the data were published and then researchers go behind and put the data to use to pinpoint the exact cause of the development of comorbidities. Reporting the incidence and prevalence is useful, however it would be better if there was more research with a cohort of patients that do not have any comorbidities at onset of the study separately with a focus on discovering not only the development of the diseases, but why they are showing. There is such a lack of information available to patients, which can be attributed to the lack of concrete data. Until the data currently published is taken and delved into, there will be no change in the availability of information on arthritis.

Conclusion

My findings indicate that patients are most frequently diagnosed with cardiac events, cancer, and respiratory diseases such as COPD. The websites I encountered for patient resources show that there is not enough information available for patients regarding comorbidities.

The research questions addressed in this capstone are “What are the statistics of people that have arthritis and develop a comorbidity”? Also, “What is currently being done with the statistics gained from studies on comorbidities and RA?” Regarding patient resources, “What is the quality of resources available to patients online?” and “What improvements can be made so that patients have better access to instructional materials?” To accomplish this, data was collected via Pubmed articles using the Georgia State University Library database list. Articles were analyzed for relevance and data was compiled into a table for easy reference. The patient resource websites were found using a Google search.

I would recommend more websites with information geared towards patients, and more information provided by doctors regarding comorbidities. This would allow patients to make decision in their healthcare. In addition, I would recommend the use of social media and apps. I would also recommend patient care plans that include specific suggestions for patients with regards to disease management and lifestyle choices.

Arthritis, especially RA, patients should have access to resources provided by their doctor as well as resources on the web that help patients to determine what they can do to prevent the development of comorbidities. If patients had access to these resources, it is possible that the incidence of comorbidities could decrease over time. In addition to the availability of resources, more research should be done on how and why comorbidities develop, which would aid in

dissemination of information to patients. Without these changes, the incidence of RA and comorbidities will continue to rise.

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