Autoimmune Arthritis Deobfuscated

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Abstract—People suffering with an Autoimmune Arthritis disease carry two burdens: first, they must deal with the chronic illness itself and second, they must often do so while receiving little or no support from friends, family and the general public. This lack of meaningful support stems from a general lack of understanding about what an Autoimmune Arthritis disease is and how it differs from Osteoarthritis. Compounding the issue is that Autoimmune Arthritis diseases are somewhat invisible disabilities. Though often incapacitating, unless the disease has progressed to a point where the person is practically incapacitated, people often do not even notice the limitations and suffering of the person dealing with the disease. In addition, since unlike an Autoimmune Arthritis disease, Osteoarthritis is relatively common and not life threatening, this misunderstanding and general confusion regarding the differences between Osteoarthritis and Autoimmune Arthritis often results in their experience being trivialized. In order to educate the friends and family of those suffering with the disease, visualizations regarding what to say to someone suffering with an AA disease and the differences between OA and AA were created. This paper shows a series of data visualizations that address these issues, discusses the methodology for choosing and creating these visualizations and showcases and addresses the results.

Index Terms—Adult Onset Still’s Disease, Ankylosing Spondylitis, Autoimmune Arthritis, Early symptoms, Juvenile Arthritis, Psoriatic Arthritis, Rheumatoid Arthritis, Sjogren’s Syndrome, Systemic Lupus Erythematosus and Undifferentiated Connective Tissue Disease/Spondyloarthropathy.

1 INTRODUCTION AND MOTIVATION

Though used previously in research to differentiate types of arthritis, it wasn’t until the International Foundation for Autoimmune Arthritis (IFAA) started using the term Autoimmune Arthritis that it became associated with a definition or disease list. Autoimmune Arthritis as used and promoted by IFAA [1] is an umbrella term that “refers to autoimmune, inflammatory diseases that heavily involve the joints but also affect tissues and organs.” Eight of the most common diseases encompassed by this term are: Rheumatoid Arthritis, Psoriatic Arthritis, Systemic Lupus Erythematosus, Ankylosing Spondylitis, Adult Onset Still’s Disease, Juvenile Arthritis, Sjogren’s Syndrome and Undifferentiated Connective Tissue Disease/Spondyloarthropathy. Though the list of autoimmune diseases whose symptoms include arthritis is longer than this, IFAA chose to concentrate on diseases that share similar symptoms, progression, prognosis and treatment.

According to IFAA’s [1] website, as the result of a study that they conducted, they discovered that the group of diseases referred to as Autoimmune Arthritis diseases “typically present with the following symptoms, regardless of diagnosis, within the first 0 to 12 months after initial onset:

- Joint pain in at least one joint that lasts for longer than 6 weeks and cannot be explained due to injury, other condition, or medication
- Tissue (connective tissue and/or soft tissue) pain, spondylitis diseases may have enthesitis (at ligaments)
- Fatigue
- Fever (typically low grade with the exception of Juvenile Arthritis or Adult Onset Still’s Disease, which tend to present with higher spiking fevers)
- Mild confusion, or “brain fog”, or feeling mentally out of sorts for no reason
- Severe stiffness in various parts of the body, which is worse after rest or inactivity
- Flu-like symptoms, including nausea, muscle weakness, and general malaise

Due to the monumental misinformation surrounding the Autoimmune Arthritis (AIA) diseases, the average person thinks that they and Osteoarthritis (OA) are one in the same. While both contain the word arthritis in their name and involve major joint involvement, that is where the similarity between the two ends. OA as defined by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) [2], a part of the National Institute of Health (NIH), is “a joint disease that mostly affects cartilage.” The typical onset of OA is over the age of 65 while there is no typical onset of AIA as disease onset can occur at any age.
and even occurs in children. OA is easily diagnosed degeneration of the joint caused by age, overuse, injury or weight which contrasts sharply with AIA. While the cause of AIA has yet to be proven, there is believed to be both an environmental and genetic component. Though painful and sometimes physically limiting, OA is never life-threatening and does not have other diseases associated with its onset. Conversely, because AIA diseases are diseases in which the body’s autoimmune system is literally attacking itself, it is not uncommon, after initial diagnosis with an AIA disease, to later develop another as well. This tendency for AIA patients to present with multiple AIA diseases complicates diagnosis and treatment. Further, AIA can be life threatening once the internal organs are affected.

This general confusion regarding the true nature of AIA diseases is often fed by medical shows on television with famous hosts. There is a general tendency to believe what is presented in the mass media, this adds to the propensity that the general public has to invalidate the suffering that AIA disease patients experience. When a talk show host states that the patient was even partly responsible for their situation by neglecting their health in some way that was a contributing factor to their getting the disease, compassion for the patient diminishes and criticism increases. For instance, on one show in particular, Dr. McGraw [3], the host of the Dr. Phil show, stated that if a mother didn’t get her child to lose weight, that her child would grow up to have Rheumatoid Arthritis. Though not a medical doctor, Dr. McGraw is perceived as one by the general public and therefore, what he says in relation to AIA diseases is given credence. As a result of this, though he did state a retraction on a future show, anyone who missed the retraction now thinks that Rheumatoid Arthritis sufferers are in essence complaining about something that they did to themselves. One of the many comments that are often made to people with an AIA disease is that they would feel better if they exercised and/or lost weight. This type of comment is not only false, it is potentially damaging to patients. It places the blame for the disease and lack of recovery squarely on the patient. The prevalence of these types of comments is due in part at least to media spread misinformation.

Another factor that adds to the general trivialization of AIA diseases is that many of these diseases show few external symptoms so the people who suffer with them don’t always present themselves as being afflicted with a disabling disease. The disease has to have progressed to the point that the person suffering is experiencing significant physical limitations before it is obvious to the casual bystander and even then, the outward signs of the diseases appear to be symptoms of fatigue, injury and/or the flu.

As a result of these factors and the general confusion between AIA (Autoimmune Arthritis) and Osteoarthritis (OA), people with one of these Autoimmune Arthritis diseases often complain of a lack of support from what is traditionally referred to as a person’s support network: their family and friends. Consequently, they suffer not only the physical burden of living with a debilitating disease which is sometimes fatal but also the emotional and psychological burden of having their experience trivialized by their family, friends and coworkers. At a time when they need moral and often physical support, they find themselves the object of criticism and doubt by the people around them. People are often at a loss for what to say when a friend or loved one is going through a painful, incapacitating or life threatening illness so even when friends, family and strangers are trying to be supportive, they often say things unwittingly that are hurtful to people struggling with an AIA disease.

In an effort to educate the general public and in particular, the loved ones of those suffering with the disease, an easy to understand yet impactful visual presentation of information regarding these diseases and how they differ from Osteoarthritis is needed. With this visualization, AIA disease patients can educate those closest to them by pointing them in the direction of the visualization rather than trying to explain their disease, the seriousness of it and how it differs from OA. In addition, a generally accessible visualization regarding what to say and more importantly, what not to say is needed to teach friends and family how best to verbally support an AIA disease sufferer. This visualization is crucially important because feedback from the AIA community is that they are receiving little emotional/psychological support from their support networks. Patients have a general feeling of being misunderstood. They feel as if everyone thinks that they are whining about something trivial. That emotional/psychological strain makes it even harder to deal with the multitude of physical challenges that occur as a result of the disease. Sometimes knowing that you are not alone to face the disease progression or that someone understands your struggle provides the patient with renewed strength to face their future of living with the disease. Providing a visualization that will teach family and friends what to say to provide comfort to a person with an AIA disease will not only reduce the awkwardness and uncertainty that the family and friends feel about talking about the subject but will also provide immeasurable support for the patient.

2 RELATED WORK

One of IFAA’s primary missions is to raise awareness regarding the symptoms and progression of the AIA diseases, how they differ from OA and the limitations that occur as a result of them. In line with that, IFAA has made several attempts to inform the general public regarding the serious nature of the AIA diseases.

One of their attempts to raise awareness regarding the seriousness of AIA diseases was a poster that was created, shown in figure 1, with pictures of typical treatments, symptoms and experiences of AIA patients. This poster did a good job illustrating the experiences of an AIA patient but the messages of some of the pictures were not clear. For instance, examining the picture in the top right
of the poster it is hard to tell if it is indicating inflammation or a skin rash. The poster can be off-putting to the general with it’s harsh images of the reality of living with the disease.

When this project was started in mid October 2015, on the IFAA website, aside from the abovementioned poster and the following paragraph, shown in figure 3, there were no other attempts at educating the public regarding the differences between AIA and OA. However, after discussing this project with IFAA’s founder and CEO, IFAA added a visualization, shown in figure 4, to their “What is Autoimmune Arthritis” page that specifically addresses the differences. Further, the website now contains a link to a page that further expounds upon the differences between the two.

In an attempt to educate the public regarding the different ages that typical onset occurs for AIA diseases versus OA, IFAA created a poster, shown in figure 2, which graphically portrays the typical age range when onset occurs in the two. While the poster does a good job of illustrating the different age ranges of typical onset of the two, it doesn’t do anything else to clear up the confusion between AIA diseases and OA. It does nothing to indicate the seriousness of AIA versus OA. In fact, due to the cartoonish pictures used, it makes light of what is a can be argued is a serious point.

In a recent survey and report published by the International Foundation of Autoimmune Arthritis [4], the early symptoms of the adult onset Autoimmune Arthritis diseases were analyzed. While much work has been done researching each of the various diseases that make up the Autoimmune Arthritis grouping individually, prior to IFAA’s work [4], no other organization or person has looked into the early symptoms of these diseases as a group. This is due to the fact that IFAA was the first organization to use AIA as an umbrella term to refer to these diseases and as such is the first organization to consider studying them all at the same time. In the study, the early symptoms are examined in great detail, however, the report is written for a trained medical audience and as such is composed of more than a hundred tables detailing the experiences of over 700 AIA patients worldwide. The report states: “The intent of this investigation was not for patients to act as researchers, but rather to collect information from a different perspective which can then be used to determine if there is a need for future research by universities, doctors, and the scientific community. This “pre-research” is one of IFAA’s solutions to include the patient when determining the best use of research dollars for a patient population.
It is also aimed to serve as a potential tool to better understand disease onset progression and which diseases were diagnosed based on those presentations." [4] Since the purpose of the study was to try to unearth information that might stimulate further research into these diseases as a group, the study contains only tables from which conclusions regarding the interrelation of the AIA diseases can be drawn rather than sections in which the authors draw conclusions themselves. With it’s wealth of exact experiential data, it is a good opportunity for researchers to conduct further advances in the field. While it is presented in a way that is understandable to people with a research or medical background, it is not easily understood and absorbed by the average person as intended. An abbreviated version of the report was made to make it more accessible to a larger audience but it was created for a larger medical research audience so even that report can not be used as a tool to inform them about the diseases.

3 Visualization and Design Strategies

I propose to construct several visualizations that address the issues discussed in this paper: one which deals with information regarding the AIA diseases as a group, another that addresses the differences between AIA and OA and a third that educates the public about how to verbally support people suffering with an AIA disease.

In order to educate the general public regarding AIA diseases as a group, the first visualization proposed is of an image of tears running down a face. The tears are wordles in the shape of tears with the first tear containing eight of the most common diseases encompassed by the term AIA, the second containing symptoms typically experienced by those afflicted with an AIA disease, and the third comprised of additional information about the diseases like causes, treatments, prognosis, and demographics of sufferers. A mockup of this visualization is shown in Figure 5. A partial result of this visualization, shown in Figure 6, was presented during a project update and the feedback received on it was, that due to the size of the wordles, it was difficult to read the information in the visualization. As a result of this feedback, I stopped pursuing completion of this visualization.
The second visualization proposed addresses the general lack of knowledge regarding AIA diseases with a wordle containing words and sentence fragments commonly associated with AIA diseases. A completed version of this visualization, shown in Figure 7, was presented during a project update and the feedback was that the black background and dark colored font, in addition to the varying font size, made much of the information difficult to interpret. Due to the feedback received during this update, this visualization was discarded.

The third visualization proposed to address the AIA diseases illustrates the disparity between the recommended time from onset to treatment and the average time to treatment from onset. “The American College of Rheumatology (ACR) and European League Against Rheumatism (EULAR) recommend treatments begin within a maximum timeframe of six months of symptom onset to ensure the best chance of limiting disease progression.”[4] The average time experienced by IFAA’s Early Symptoms study participants varies by disease ranging from 2.6 years to 9.5 years.

Fig. 8. Implementation of Barchart showing timeframes from onset to diagnosis and treatment

This disparity was illustrated using a gradient color stacked bar chart. For this visualization, the color blue was used to show the acceptable timeframe from onset to treatment with the red showing the timeframe commonly experienced. Gradient color in the blue area was meant to show that the closer to the end of the 6 month window for diagnosis and treatment, the less optimal. This was illustrated by having the blue more intense at the beginning of that region and less intense at the end. Gradient color in the red area of the chart was meant to show that the farther away from the recommended timeframe treatment occurred the greater the danger. This was illustrated by having a thin white band separating the two color zones with the red color quickly intensifying after that. This completed visualization, shown in Figure 8, was shown during a project update and the feedback received was that the message was not discernible without some kind of written or verbal explanation. Feedback received indicated that it was not clear what the different color zones meant. Further feedback indicated that it was also not clear why the white band of color was separating the two color zones with many thinking that the white indicated a third region located between the red and the blue regions. Since the visualizations presented in this paper are meant to be understood independent of any additional explanation, this visualization was discarded.

A fourth visualization is proposed to address educating family and friends regarding what to say and more importantly, what not to say to best verbally support an AIA disease sufferer. This visualization features a woman trying to deal with the reality of having one of the AIA diseases while getting advice from family, friends and strangers. A mockup of the visualization, as shown in Figure 9, was presented during a project update and while it received the most positive feedback of the four visualizations presented that day for this project, there was not a discernable consensus that its message was clear enough to be understood by the majority of the general public. Consequently, this visualization was put on hold to potentially be revisited at a later date.

Fig. 9. Implementation for Comment Awareness Campaign.

Having learned from the implementation of these four visualizations, two new visualizations will be implemented to address some of the issues mentioned above. The following section will go into detail about this process.

4 METHODOLOGY

Two visualizations are proposed to address some of the issues outlined above. The first visualization is proposed to address the differences between AIA diseases and OA. This visualization animates a wordle to show all the symptoms associated with the two diseases as well as which symptoms are attributable to OA only and which symptoms are attributable to AIA only. The second visualization is proposed to address the lack of appropriate verbal support from friends and family. This visualization utilizes a cartoon animation to illustrate what to say and what not to say to AIA disease patients.
For the first visualization, an animated wordle, the typical symptoms experienced by people with an AIA disease was created using a list, found on the IFAA website [1]. A similar list was created regarding OA symptoms using a mixture of information found on both IFAA’s website [1] and the Arthritis Foundation’s website [5]. Using Wordle.net, a wordle was created from the lists of sentence fragments with Osteoarthritis and Autoimmune Arthritis given double the weight of the symptoms on the two lists. A wordle was created of the two lists together with the symptoms that are attributable solely to Osteoarthritis written in blue, symptoms attributable solely to Autoimmune Arthritis in red and symptoms attributable to both diseases in purple. The wordle image was then altered in GIMP to create five separate images: all of the symptoms together, Osteoarthritis symptoms, solely Osteoarthritis symptoms, Autoimmune Arthritis symptoms, solely Autoimmune Arthritis symptoms. An animated gif was then created that cycles through the five images.

For the second visualization, the cartoon animation, a survey was created based on the results of an informal forum post. The survey asked the question “which of the following one liners have been said to you that you found hurtful”. There were 36 respondents, 32 of whom were female. While every age group was represented among the survey results, the majority of the respondents were between the ages of 25 and 54. All of the adult onset AIA diseases were represented among the survey respondents. The top 5 responses were:
- I have arthritis too in my...
- Have you tried…?
- You’re too young to have arthritis.
- At least it’s not cancer.
- You don’t look sick.

A follow up survey was then created asking “what are some things that others have said to you or that you wish others had said to you that you find comforting/supportive?” There were 45 respondents, 41 of whom were female. The majority of the respondents were between the ages of 35 and 64. All of the adult onset AIA diseases were represented among the survey respondents. The top 5 responses were:
- I’m here if you need me.
- I’m sorry that you are going through this.
- How can I help?
- I love you.
- Is there anything that you need?

A storyboard was then developed from which an animated cartoon was then created that incorporated much of the data gathered from these two surveys.

5 Visualization Implementation and Results

In creating the animated wordle, I was mindful of the comments generated by the visualizations presented during the project update. Consequently, I chose to have font styles and colors that were easily readable and a white background rather than having a black one for the wordle. In addition, rather than having variable weights attributable to the pervasiveness or severity of the symptoms of the diseases, I chose not to weigh any of the sentence fragments other than the names of the two diseases. This uniform weight decision caused the fonts of all of the symptoms to be uniform and easily read. I chose to have the animation slowly cycle through the 5 images at a speed that facilitated reading the symptoms. Overall reaction to the animated wordle’s speed and composition was favorable. The 5 images from which the animated wordle were created are shown in figure 10. A wordle is an appropriate type of visualization for this topic in that it covers all of the information that I want to convey without forcing people to read large blocks of texts. It gives a quick summary of the ideas in an easy to digest manner. As Jonathan Feinberg [6], “People often want to preserve and share the Wordles they make; they use Wordles to communicate. A beautiful visualization gives pleasure as it reveals something essential.” That in and of itself, makes a wordle ideal for the purposes of this visualization. This wordle communicates the differences between AIA diseases and OA. It educates people about a serious subject in an accessible way. The animation adds to the visualization by allowing the differences between the two to be focused upon as the symptoms solely attributable to each are displayed alone on the screen.

The animated video “Tea as Consent” [7] served as a motivation for doing an animated cartoon visualization shown in Figure 11. For the animated cartoon, a software package was used to create the animation. Some of the storyline and much of the style decisions for the animation were forced due to a lack of animated characters and actions to choose from in that package. In the video, a friend of the main character’s gets diagnosed with an autoimmune arthritis.
The main character is unsure what to say to her friend and imagines what his reaction would be to several different possible statements. She rejects each choice and is still unsure what to say. Then the video introduces an RTTS (Right thing to say) machine that alters anything that is said to be the right thing to say. Examples of the RTTS machine working its magic on a few inappropriate and unsupportive comments are shown. Afterwards it’s shown that the good news that people are actually born with their own RTTS machines built right in. The RTTS machine is shown as an analogy to a person’s heart. The video finishes with the main character confidently saying only the right thing while speaking from her heart.

Reaction to the animation was overwhelmingly positive, it was decided that the animation should stay as is until such a time as another software package can be utilized to redo the cartoon in its entirety for aesthetic purposes.

6 Conclusion

In conclusion, several visualizations were proposed to address the issues discussed in this paper: information regarding the AIA diseases as a group, the differences between AIA and OA and education concerning how to verbally support people suffering with an AIA disease. Four visualizations were discarded in varying stages of completion after receiving feedback during a project update. Two visualizations were created that effectively communicate to wide audiences: an animated cartoon that educates people on what not to say versus what to say. Cartoon animation was an effective visualization for educating people about what to say versus what not to say. As Ilya Spitalnik [8] states “we naturally let our guards down when watching cartoons and our minds accept the messages that they convey with far less criticism or defensive attitude.” This lowering of a person’s defenses is helpful when trying to alter their behavior by showing them how they have been saying inappropriate things in the past.

Future work will create visualizations that illustrate the early symptoms of the 7 most common adult onset AIA diseases with xray type pictures of the human body. The first image will show all of the symptoms commonly occurring in AIA diseases with a heat map indicating their prevalence and severity among the seven diseases. Then seven other similar images with just the early symptoms of each disease shown independently again with a heat map indicating prevalence and severity. Figure 12 shows a mockup of the proposed visualization.

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8 References
