THE ABCs of QOLs

Quality of Life is a general term used to described aspects of an individual or group that pertain to standard of health and living and overall well-being that may be either positive or negative. The Corrona® RA Registry patient questionnaires use measures called health-related Quality of Life (HRQOL) to determine an individual’s perception of their physical and mental health while living with RA. These questions can be found on every Corrona Enrollment and Follow-up Subject Questionnaire. Corrona researchers collect these measurements at routine clinic visits to better understand how patients are performing long term and the possible relationship between taking certain medications to treat your disease and managing your RA. The HRQOL questions are divided into sections which address specific categories that are important to RA patients like walking, self-care, anxiety/depression, etc.

Example of HRQOL questions from the RA Subject Follow-Up Questionnaire

More broadly, QOL questions and surveys are used in a variety of settings, such as part of an intake for a new provider or to capture how specific populations, i.e. children, may respond to a type of program or treatment. Academic, civic, and/or health researchers can determine how QOLs are defined depending on what groups the questions target. In any case, QOLs can be used to evaluate how well or how poorly individuals and communities are responding to policies and practices that shape overall health and life quality outcomes.

HRQOL Outcomes in Recent Corrona RA Research

Patients who have RA can experience low or poor quality of life because of the burden of pain or fatigue and may also deal with other diseases and impairments. Corrona has published two recent findings that looked at certain medications and their impact on HRQOL measures.

Continued on page 2
The impact of monoclonal antibodies as RA therapy

Monoclonal antibodies are sometimes used as an infuson therapy. These therapies are prescribed along with methotrexate to treat active RA symptoms when other types of medications called tumor necrosis factor inhibitors (TNFi) have failed to work well. The purpose of this study was to look at HRQOLs, along with other patient related outcomes (PROs), one year after patients started monoclonal antibody therapy. Data from 667 patients were included in the study whose first-time starting the therapy occurred from March 2006 to September 2015. All patients showed improvement in reported HRQOLS and PROS from the time of initiation of the monoclonal antibody therapy to the study end, and 30% of patients achieved low-disease activity or remission (Harrold, John, Best, et al 2017).

Biologies and Clinical Outcomes

Another study looked at an injectable biologic drug that suppresses the immune system. A biologic drug is a product that is produced from living organisms or contain components of living organisms. Biologies include recombinant proteins, tissues, genes, allergens, cells, blood components, blood, and vaccines (see Table 1 for a list of FDA-approved biologics).

Like the monoclonal antibody drug, this biologic is a type of therapy that is prescribed after patients have not responded well to other types of drugs. It can be given alone or in combination with methotrexate, or other DMARDs (Disease-Modifying Antirheumatic Drugs). The biologic study examined several clinical outcomes for patients and measured changes from baseline to the one-year end of the study period. Of the 255 patients that participated, about 49% had taken at least one other biologic medication. Because biologies are typically prescribed when patients have longer standing disease, patients on these drugs tend to be older and have more disability and functional impairment than those who are beginning to take other types of biologics.

By the end of the study, patients reported improvement in many areas. For example, over half (54%) of the patients reported improvement in morning stiffness. The Clinical Disease Activity Index or CDAI is a score used by researchers that includes joint assessments and an overall rating to determine the level of disease activity for a patient at a visit. At the end of the study, 31% had low disease activity and over 11% of patients achieved remission. Patients also had improvement in all five HRQOL sections, including 33% improvement in anxiety/depression (Harrold, John, Reed, et al 2017).

Both studies suggest that the use of advanced therapies can improve quality of life for RA patients. The use of HRQOL questions continues to provide Corrona Investigators with invaluable insights into how patients are doing when they are seen by their providers during routine clinical encounters. Data from these types of questions, along with other patient-reported outcomes, help advance Corrona’s mission to improve patient care.

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NEW INSIGHTS INTO RHEUMATOID ARTHRITIS

What a diagnosis really means and how advances in treatment, research, and support are changing the outlook for RA for the better

By MIA JAMES and CHARLES WEAVER, MD
The results of a recent survey conducted with rheumatoid arthritis (RA) patients in theRAconnection, a leading social community and resource for RA patients, one of the biggest challenges for individuals diagnosed with the disease has been inadequate access to accurate information. It is also apparent in the lack of awareness encountered in the general public, which creates unique challenges for those impacted by the disease. Thankfully, several resources and social communities have emerged over the past several years that offer both access to current information and provide support. As a result, these organizations, which advocate for awareness and research, combined with a dedicated research community committed to improving treatment for people with RA, the outlook for battling this disease is changing for the better.

AN OVERVIEW OF RHEUMATOID ARTHRITIS

To begin to understand RA, it’s important to see beyond the name arthritis. Rheumatoid arthritis is a different disease from the osteoarthritis that people are likely to think of, a disorder marked by wear and tear on the joints. Although RA also affects the joints, causing inflammation, Kelly stresses that it’s much more than a joint disorder. RA is in fact an autoimmune disease that causes several types of health issues in addition to joint complications.

The biggest misconception is that it’s not a disease. Many people tend to think that RA is arthritis, but the term is misleading because RA is not limited to joint symptoms. In point of fact, arthritis is only one symptom of the disease, and other organs—including the eyes, heart, skin, and lungs—are also affected by RA.

Eric Matteson, MD, chair of the Rheumatology Department at the Mayo Clinic in Rochester, Minnesota, further explains that RA is a “systemic autoimmune disease”: systemic meaning that it affects a number of organs, and autoimmune meaning that the immune system mistakenly attacks and destroys healthy body tissue. In the case of RA, the joints are just one type of tissue that the immune system attacks; and RA is a chronic disease, which means that it persists for a long time. The disease can result in disability, compromised quality of life, and even early death.

RISK FACTORS

According to Dr. Matteson, one known risk factor for RA is smoking. In addition, he says, “There is a genetic component,” meaning that an individual with a family history of the disease may be at greater risk. And though RA affects women and men, it’s more common in women.

Despite what’s known about risk factors for RA, there is still no reliable way to predict onset of the disease. “It’s very complicated,” Dr. Matteson explains. “There are intrinsic (or genetic) components as well as environmental risk factors.” He likens the combination of genetic and environmental risk to a forest’s susceptibility to fire. “A dry forest is more susceptible to catching fire,” he says, whereas a damp forest is less likely to burn. With RA an environmental risk factor, namely smoking, will more likely trigger the disease in an individual who has a genetic risk than in someone who does not.

SIGNS AND SYMPTOMS

Rheumatoid arthritis causes symptoms that include tender, warm, and swollen joints; morning stiffness that may last for hours; firm bumps of tissue under the skin on the arms; as well as fatigue, fever, and weight loss. The disease often first affects smaller joints (such as in the fingers and wrists), but it can also cause joint damage in larger joints, such as the knees and shoulders. It can also affect other parts of the body, including the eyes, heart, skin, and lungs.

WOMEN Winter 2018 53 the war room | arthritis

awomanshealth.com
fingers and the toes) and then spreads to larger joints (such as the knees, ankles, elbows, hips, and shoulders). It’s common for symptoms to occur in the same joints on both sides of the body. Symptoms may also vary in severity and consistency—meaning that they may come and go.¹

And, as explained previously, the effects of RA are not limited to the joints. The disease can cause complications in organs such as the eyes, heart, and lungs.

**EARLY DETECTION**

As is often the case with chronic diseases, early detection is the first step in effective treatment of RA because it allows for early treatment, before the disease has progressed significantly. And, Dr. Matteson explains, early detection is one area of progress in the management of RA.

Because the previous standard for RA diagnosis often led to a late diagnosis—after the disease had progressed considerably—Dr. Matteson says that experts within the RA community have looked for ways to detect the disease in earlier stages. As part of this effort, they have been looking for diagnostic criteria beyond the standard blood test, as not all patients who are eventually diagnosed with RA have a positive blood test (which is marked by an elevated erythrocyte sedimentation rate [ESR, or sed rate] as well as rheumatoid factor and anti-cyclic citrullinated peptide [anti-CCP] antibodies for the disease).

To that end they’ve taken the former standard for diagnosis, which combined blood tests with the number of joints affected, and have lowered the number of involved joints required to make a diagnosis. Now, says Dr. Matteson, a diagnosis of RA is considered when there is “one or more swollen joints, especially if swollen for more than six months and there was no antecedent infection.”

The importance of early detection of RA can’t be overemphasized, as there is currently no method for preventing the disease. “There is no prevention that we know of because we can’t yet predict who will get RA,” Dr. Matteson says, underscoring the need for research into ways to identify individuals likely to get RA—a necessary step for preventive measures to be established.

**TODAY’S RESEARCH**

According to Dr. Matteson, the current outlook for RA research is overwhelmingly positive. “We’re making huge progress,” he says. “There have been important advances in the past 15 years.”
These advances include more-aggressive treatment with drugs such as Rheumatrex® (methotrexate), first developed to treat certain types of cancer and now used at much lower doses to treat RA, as well as drugs known as biologics. Biologics are agents designed to inhibit components of the immune system that play a role in the inflammation associated with RA; Remicade® (infliximab) and Rituxan® (rituximab) are two examples. Also on the research agenda, according to Dr. Matteson, is the search for more-effective therapies for RA, or, as he says, “drugs that really turn off disease.”

Investigation into ways to predict who’s likely to develop RA is also a priority, as this is the first step toward prevention. More understanding of the genetics and the biomarkers associated with the disease will likely hold the key to accurate prediction. Researchers are also looking into ways to determine disease prognosis so that therapy may be appropriately tailored for each patient according to the predicted severity of the disease. This, Dr. Matteson explains, will help doctors avoid prescribing overly aggressive treatment for less severe disease. Along the same lines, he says, is research to further individualize therapy by determining which drugs are likely to work best for which patients.

The most positive news Dr. Matteson cites from the RA research community is that experts are starting to see the possibility of a cure. “We are working toward discovering a cure,” he says, noting the significance of acknowledging this goal when, until recently, a cure was not even considered possible.

LIVING WITH RA NOW
Though it’s exciting to think about research advances on the horizon, the needs of individuals currently living with RA remain a primary concern within this community. Advocate Kelly Young has found that living with RA comes with challenges beyond the pain, complications, and disability that the disease can cause.

One of the noteworthy hurdles faced by RA patients is the widespread misunderstanding about RA among the general public. Because the symptoms aren’t always visible, it can be difficult for others to comprehend the severity of the disease. Individuals with RA can have many symptoms including severe pain and disability that are mostly invisible. This makes living with RA appear less complicated and painful than it actually is. Individuals with RA may experience significant psychological issues and express frustration because RA can be very debilitating—taking away an individual’s ability to do things they need to do on a daily basis—yet people believe there’s nothing wrong with them.

Patients often describe a diagnosis of RA as a huge new life that’s very unwelcome. The combination of medications and symptoms and side-effect management can be so demanding it is essentially, “an additional part-time job,” which can consume an overwhelmingly large part of a patient’s life.

Several websites now exist that provide useful information for coping with RA and a community for those affected by the disease. The online communities are essential in that they provide a safe and secure place where individuals can connect with others to compare treatments, offer support, and share information and solutions to every day problems.

RA OUTLOOK IS IMPROVING
If there’s one message coming from the RA community, from both research and advocacy, it’s that the outlook is ever improving. With the combination of advances in treatment and understanding of RA and improved access to information and support networks, it appears that those affected by the disease have cause to be optimistic.

RA COMMUNITIES AND RESOURCES

- theRAconnection.com
- Rheumatology.org

Visit TheRAConnection.com for a Complimentary Subscription to WOMEN Total Health & Wellness
By now, you’ve probably heard the virtues of Omega-3 Fatty Acids praised as the good type of fat essential to a balanced diet. Your body cannot make them, so you need to get them from foods. Certain types of fish and seafood provide an excellent source for these nutrients. There have been several studies demonstrating that consuming fish oil can decrease joint pain and stiffness in folks with RA. But, did you know that anchovies—yes, anchovies—contain 3.4 grams of omega-3 fatty acids in a six ounce serving?

So, forget about holding the anchovies on your next pizza. Try this delicious, comforting, and easy-to-make fish stew steeped in Mediterranean-inspired flavor!

Source: *New York Times Cooking*

**Easy Fish Stew With Mediterranean Flavors**

**YIELD** Serves four  
**TIME** 1 hour 15 minutes

**PREPARATION**

**Step 1**

Place the garlic cloves and 1/4 teaspoon salt in a mortar and pestle, and mash to paste. Add the anchovy fillets and mash with garlic. Set aside.

**Step 2**

Heat the olive oil over medium heat in a large heavy soup pot or Dutch oven, and add the onion, celery and carrot with 1/2 teaspoon salt. Cook, stirring, until the onion is tender, about 5 minutes. Add the pureed garlic and anchovy. Cook, stirring until the mixture is very fragrant, about one minute, and then add the tomatoes. Cook, stirring often, until the tomatoes have cooked down a bit and the mixture smells aromatic, about 10 to 15 minutes. Add the water, potatoes, salt (to taste) and the bouquet garni. Bring to a simmer, turn the heat to low, cover partially and simmer 30 minutes. Taste, adjust salt and add pepper to taste. Remove the bouquet garni.

**Step 3**

Season the fish with salt and pepper, and stir into the soup. The soup should not be boiling. Simmer five to 10 minutes (depending on the thickness of the fillets) or just until it flakes easily when poked. Remove from the heat, stir in the parsley, taste once more, adjust seasonings and serve.

**Tip**

Advance preparation: You can make this through step 2 up to three days ahead. Keep in the refrigerator, bring back to simmer and proceed with the recipe.

**INGREDIENTS**

- 4 large garlic cloves, cut in half, green shoots removed
- 4 anchovy fillets, soaked in water for 4 minutes, drained and rinsed
- 2 tablespoons extra virgin olive oil
- 1 large onion, chopped 1 celery rib, chopped
- 1 medium carrot, chopped
- Salt, preferably kosher salt, to taste
- 1 (28-ounce) can chopped tomatoes, with liquid
- 1 quart water
- 1 pound small new potatoes, scrubbed and quartered or sliced
- A bouquet garni made with a bay leaf, a strip of orange zest, a couple of sprigs each thyme and parsley, and a dried red chili if desired, tied together with a string
- Freshly ground pepper
- 1 to 1 ½ pounds firm white-fleshed fish such as halibut, tilapia, Pacific cod or black cod, cut in 2-inch pieces
Table 1  Drug name (brand name)

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<tr>
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The ABCs of QOLs continued from page 2

List of FDA-approved biologics used to treat RA

Try your hand at this crossword puzzle containing clues straight from this issue of Joint Counts™!

Across:
2. complete this at a registry visit
4. hearty dish of meat and vegetables
5. drug given through the skin
10. take this to treat a disease
11. Omega-3 is a good type
12. pain reliever
13. what opioids are prescribed for
16. risk factor for RA
17. take an excessive amount of a drug
18. severe diarrhea

Down:
1. wake up in the morning with this
3. disorder of joint wear & tear
4. abbrev for qual of life measure
6. some people have pain here
8. registry visit after enrollment
9. region between Europe and N. Africa
14. not male
15. tiny fish (plural)
17. opioid 13: pain 16; modifiable 15; overdose 12. dyspnea
18. medication 6. follow up 9. medication 14; female 12; antibiotics

Answers:

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