

**The Burden of Living and Coping with Rheumatoid Factor positive
Rheumatoid Arthritis in a Developing Country: A Life Experience
Indonesia**

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Objective

To describe the burden of living and coping with Rheumatoid Factor positive Rheumatoid Arthritis.

Medical History

I started to have inflammations on my joints in August, 1999. I went to Rheumatology Clinic in Dallas, USA and was diagnosed with Seropositive Rheumatoid Arthritis (RA+) on January 8, 2000. I was treated with NSAIDS but the disease got worse after 6 months of therapy. My body did not respond well with the medication so I discontinued the medication. I continued with herbal concoction containing prednisone that helped at first. However in August 2000, I was unable to move properly and I had inflammations in most of my joints. Unable to take care of my self in basic daily living activities, I went home to Indonesia to be taken care of by my parents.

On September 21, 2000 I saw Dr. John Darmawan. I had difficulty in walking and moving and in severe pain with a distinct moonface. I had deformity at the interphalangeal joints of my hands due to acute inflammation. Symmetrical acute arthritis was seen in finger joints and wrist joints of the hands, inclusive of both elbows and shoulders, ankle, and knee joints. I was in American College of Rheumatology Functional Class IV with fever, lethargy, anorexia, insomnia (due to pain), gastrointestinal complaints, and cannot made a fist of both hands. I was treated initially with combinations of low dose pulse intravenous (IV) Methotrexate (MTX)+Methylprednisolone+Cyclophosphamide and simultaneous oral Cyclosporine (CyS). After disease was controlled IV therapy was tapered off. I am put on maintenance medication consisting oral MTX+CyS+Myphenolate Mofetil. Currently, I am in American College of Rheumatology Functional Class II. My last X-Ray showed that some of the erosions have reverted.

Life Experience

In 1999, I was at the most productive stage of my life. I love my work and my study. My marriage is a happy one. I know what I want to be and do. Initially, I was not able to

accept that I have this debilitating disease. Having RA+ has changed my life completely. This disease is very costly and has many facets affecting my life and my family's:

The economic side:

- Direct costs:
 1. As someone had told me, “you do not want this disease, unfortunately, this disease falls in love with you. So learn to accept and live with it.” I live and feel better after I accept that I have RA+. Currently, I am trying to redefine and relearn my life to survive this disease. The costs of medical treatment and the medication themselves which are very expensive.
 2. The lost of employment. I had worked as computer consultant in a US Software Company. I haven't worked since September 2000 due to my disability.
 3. The necessity of changing my occupation since I do not have the capability to work with my hands continuously on computer as before.
 4. The inability to continue my education. Until 1999, I had been pursuing my Doctoral Degree in Manufacturing Management and Information System in University of Toledo, USA. I had taken medical leave since I was not well enough to continue working on my dissertation.
 5. The necessity of family support. Currently, I depend on my parents to take care of me. It is a full time job, since they have to take care of me physically and mentally. My father even takes early retirement to be able to accompany me every day.

- Indirect costs:

Loss of a promising carrier and incomes which are unquantifiable

The psychological and the social side:

- The emotional sufferings of being away from my husband since he cannot both be working full time and taking care of me.
- The psychological burdens on my husband, parents, brothers and sisters. I can't imagine my family's emotional burden about my disease.
- The disability and the pain that change my basic life routines. I used to lead an active life. I did aerobic every morning and I jogged every evening. Nowadays, just to take care of my basic needs, I would need help from others. Having to ask for help is very frustrating sometimes.
- The side effects of the disease: skin disorder, moon face, loss of hair, and osteoporosis. These changed my appearance. It made you feel worse about yourself, especially when people started to comment on your appearance.
- People's assumption that I am a recluse and snobby. It gets pretty tedious having to explain about this disease to others that I get tired of it. My tribe culture demands that you made certain body movement to pay respect to others. My limited mobility prevents me from making those movements sometimes. People do not understand and just make harsh judgment.

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