Quality of Life in adults with Rheumatoid Arthritis: A closer Look at potential predictive factors

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Abstract

The aim of this study was to consider gender, age, social support, coping and duration of disease as potential predictive factors on quality of life in adults with rheumatoid arthritis. This was a cross sectional study of mixed design, 190 participants completed an online survey which included, demographic information, Quality of Life Index, Brief COPE and Social Support Questionnaire. Two open ended questions were also posed and were analysed using thematic analysis. Results indicated no significant correlation between age or duration of disease and quality of life. Social support and satisfaction with social support significantly correlated with quality of life, as did seeking emotional support. A significant positive correlation between acceptance and duration of disease and negative correlation between denial and duration of disease was revealed. Several insightful themes emerged regarding difficulties experienced and factors that contribute to participants’ quality of life.
Introduction

A Brief History

The word arthritis derives from the Greek "Arthro" meaning joint and "itis" meaning inflammation. It is a form of joint disorder involving inflammation of one or more joints (Sinclair, Fox, Bullon & Manning, 1995). With over one hundred different types of arthritis, rheumatoid arthritis is the second most common form (Arthritis Ireland, 2012). Researchers have attempted to obtain clues to the etiology of the disease by examining it historically and considering its evolution during the development of civilisation.

Palaeopathological studies appear to support the theory that rheumatoid arthritis existed as far back as medieval times (Bridges, 1922; Rothschild, Turner & DeLuca, 1988). Specimens demonstrated patterns of damage indicative of the disease. The term, rheumatoid arthritis was coined by Archibald Garrod in 1880 and replaced all previous terms (Landre-Beauvais, 2001).

What is Rheumatoid Arthritis?

Rheumatoid arthritis (RA) is a chronic, systemic autoimmune disease affecting approximately 40,000 people in Ireland (Arthritis Ireland, 2012). Three quarters of those diagnosed are female and although RA can occur at any age, the average age for diagnosis is between 30 and 50 (Arthritis Ireland, 2012). The immune system plays a vital role in protecting the body against infection and disease, however, in RA, the immune system malfunctions and attacks the bodies own tissue (Arthritis Ireland, 2012). Scientists continue to investigate the exact cause of this malfunction; it is believed that both genetic and environmental elements play a role, however, the exact cause has yet to be established. Three widely accepted risk factors exist; being female, family history of RA and smoking
Psychological stress also appears to be a significant risk factor (Korpilahde et al., 2004). Psychological stress also appears to be a significant risk factor (Walker, Littlejohn, McMurray & Cutolo, 1999) with stressful life events preceding the onset of RA in 86% of cases (Cutolo & Straub, 2006).

There is currently no known cure for RA, however, there are several treatment options available, the aim of treatment is to slow progression, relieve symptoms and improve quality of life for those living with the disease.

In RA, the immune response attacks the synovial joints leading to inflammation of the synovial membrane, tendon sheaths and bursae causing swelling in the joint capsule and stiffness, pain and inflammation of the joint (Arthritis Ireland, 2012). Continued attacks of this nature can lead to permanent damage, immobility and destruction of the joint (Arthritis Ireland, 2012). RA not only affects joints, it can potentially involve every organ in the body, including the lungs, blood vessels, eyes and heart (Davis & Matteson, 2012).

**Gender Differences**

Research indicates gender differences in both the physical and psychological wellbeing of persons with this disease. RA affects females differently to males with a faster rate of progression of disability and lower remission rate reported in women with early onset disease (Tengstrand, Ahlem & Hafstrom, 2004). Additional studies indicate higher disease activity scores, increased pain and greater loss of function in early and established disease in females (Forslind, 2007). In addition, young women with RA have an increased risk of bone fractures compared to young men (Amin, Gabriel, Achenbach, Atkinson & Melton, 2013). Arne et al. (2009) report significantly higher prevalence of anxiety, depression and sleep disturbances in females with RA compared to males.

As RA is more prevalent in females, research generally focuses on females and gender issues are often not considered. Lack, Noddings and Hewlett (2011) conducted a
study on men’s experiences of RA. They highlighted the lack of research in the area and the fact that many studies assume no gender differences. Results indicated emotional and practical issues with difficulties in relation to loss of control, feelings of worthlessness and humiliation. Due to the limited available literature in this area, difficulties exist in gender comparison, further research is necessary to address this deficiency.

*Rheumatoid Arthritis Symptoms*

The most common symptoms include pain, inflammation, fatigue and muscle stiffness (Sinclair, Fox, Bullon & Manning, 1995). Weiner (1975) states “Rheumatoid arthritis provides an insight into the demands placed upon living when uncertainty is exaggerated beyond the usual level of toleration.” RA is characterised by periods of activity (flares) and inactivity (remissions) and is exceptionally unpredictable in nature. The level and frequency of activity differs from individual to individual with some experiencing little remission. During periods of activity, pain and inflammation can become severe and substantially limit functional ability. A low-grade fever, flu like symptoms and chronic fatigue are common characteristics of RA (Arthritis Ireland, 2012).

The course of the disease, its potential physical impact and unpredictable nature can lead to further distress for individuals coping with the daily uncertainty. Unpredictability disrupts life plans, roles and relationships suffer and an increase in emotional distress and helplessness become apparent (Newman, 1996; Ryan, 1996). Planning can be impossible for those living with RA, entering into the unknown on a daily basis can have severe consequences on a person’s quality of life.
The Impact of Rheumatoid Arthritis

RA is a life changing disease with physical, social and psychological consequences; it can potentially affect every aspect of a person’s existence. Simple everyday tasks commonly presupposed such as washing, dressing and cooking may become unmanageable (Arthritis Ireland, 2012). Family members frequently assume additional responsibility and relationship imbalances along with increased pressure often result in relationship difficulties. For a person living with RA feelings of guilt and frustration are common. Increased dependency has been reported to cause significant stress in people living with this disease (Feltz & Yelin, 1989; Hermann Scholmerich & Straub, 2000; Taal, Rasker, Seydel & Wiegman, 1993). Usually, hobbies are no longer attainable and the much-loved daily activity becomes a thing of the past. The opportunity for social engagement can become minimal and social relationships suffer often resulting in further isolation.

RA is a common cause of disability with more than a third of individuals eventually experiencing employment related disability (Allaire, Wolfe, Niu & Lavalley, 2008) which in turn can impinge on financial stability, independence, social status and emotional wellbeing. Newman, Fitzpatrick, Lamb and Shipley (1989) found that disability was the single most significant predictor of depression in people with RA. In a survey conducted by Felts and Yelin (1989) 31% of people with RA reported varying degrees of limitation with activities of daily life with almost 60% discontinuing employment within 10 years of diagnosis.

As demonstrated RA can potentially affect every aspect of daily life and the ability to adapt efficiently is important after diagnosis. Individuals depend on the current available treatment options to maintain functionality and limit joint destruction.
Treatment Options

The goal of treatment is to control pain and inflammation, prevent structural damage, and maintain functionality and social participation (Singh, Furst, Bharat et al., 2012).

Treatment takes the form of combination drug therapy, physiotherapy and occupational therapy. Physiotherapy and occupational therapy aim to preserve function and mobility. In recent times, it has become widely recognised that early disease activity negatively affects function and can result in joint destruction (Schoels et al., 2010). Consequently, early aggressive drug treatment is vital, despite this, only one-quarter to one-half of people with RA receive appropriate treatment (Harrold et al., 2012).

Drug treatment incorporates four common classifications of drugs; non-steroidal anti-inflammatory drugs (NSAID), corticosteroids, disease modifying anti-rheumatic drugs (DMARD) and biologic treatments. NSAID and corticosteroids reduce symptoms such as inflammation and pain; however, they are not effective in reducing joint damage. DMARD’s and biologic medications specifically suppress the immune system in an effort to diminish the immune response responsible in RA. However, in doing so, the immune system becomes compromised, leaving the body particularly susceptible to infection. Biologic therapies are among the newest classification of medication designed to target specific areas of the immune system and appear to be the most effective drug therapy to date. However, serious adverse effects have been noted, including, serious infections, cancer, heart failure and multiple sclerosis (Colmegna, Ohata & Menard, 2012).

People desperately attempting to get the disease under control are often willing to try any medication on offer and face a trade-off often suffering serious side effects in an effort to preserve their quality of life.
Quality of Life

When examining quality of life, the overall wellbeing of a person in terms of health and happiness, rather than wealth is considered (Sinclair, Fox, Bullon & Manning, 1995). Quality of life is important in understanding the overall impact of a chronic disease in terms of physical, social and emotional wellbeing.

As discussed, the disease can have a detrimental impact on all aspects of a person’s life. Escalante and Del Rincon (2002) found that the persistent pain, stiffness and joint damage of RA not only produce considerable physical disability but also have significant social and emotional consequences. The physical symptoms and functional limitations have been associated with depressive symptoms and impaired quality of life (Brown, 1990; Dickens, 2003; Hawley & Wolfe, 1988; Moldofsky & Chester, 1970; Persson, Berglund, et al., 1999).

People living with RA experience increased depression and anxiety and decreased quality of life in comparison to the general population (Azad, Gondal & Abbas, 2008; Reiger, Boyd, et al., 1988). Researchers have demonstrated that the disease can be seriously debilitating and distressing; however, rheumatologists often report significant variability in functioning and quality of life in people with similar disease activity levels (Escalante & Del Rincon, 2002; Yelin & Katz, 2002). For this reason, it is important to examine additional potential predictive factors.

Coping with rheumatoid arthritis

People diagnosed with RA face a multitude of stressors, including loss of functional ability, chronic pain, decreased mobility, reduced energy and fatigue, uncertainty and troubled marital relations (Ailinger & Schweitzer, 1993; Burkhardt, 1988). Their ability to cope with these stressors and adjust to a new way of life is of vital significance.
So how do people living with RA cope with life after diagnosis?

According to Lazarus and Folkman (1984) coping is a fundamental aspect in combating stress and involves “Constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p.14). The purpose of coping is to reduce harmful environmental conditions and the emotions they elicit.

Coping has two major functions (Lazarus & Folkman, 1986). Problem focussed coping/ active coping involves dealing with the problem causing distress, examples include, efforts to alter the situation and deliberate efforts to solve the problem. Emotion focussed coping/ passive coping involves regulating emotions such as distancing, seeking social support and avoidance. Active coping strategies such as, information seeking, rational thinking and pain control appear effective in helping people with RA adapt psychologically. Passive coping strategies such as, wish fulfilling fantasy and self blame are related to poorer psychological adjustment (Billings & Moos, 1984; Jensen et al., 1991; Young, 1992) and higher psychiatric morbidity (Carlisle, John, Fife-Schaw & Lloyd, 2005).

Revenson and Felton (1989) conducted a study on 45 people with RA who reported having to cope with a number of health related stressors including; restricted lifestyle (82.2%), limited movement (51.2%), pain (31.1%), fatigue & nausea (16.6%) and interpersonal relationship problems (11.1%). Results indicated that participants relied on emotion focused coping strategies such as cognitive restructuring, wish fulfilling fantasy and threat minimization. Treharne, Lyons, Booth, Mason and Kitas (2004) conducted a longitudinal study on psychological wellbeing with RA. The objective of the study was to determine if specific coping strategies acted as buffers in the relationship between stress and emotional well-being. Results indicated that stress and pessimism were related to poorer
emotional wellbeing and optimism, social support and active behavioural coping were related to improved emotional wellbeing.

RA is a chronic disease with no known cure, it cannot be actively “solved”, however, it appears that several fundamental coping strategies are involved in the adaption process for those living with the disease.

**Gender Differences in Coping**

According to Affleck et al. (1999) women use more emotion-focused strategies to deal with health stressors each day than men, suggesting that gender differences exist in coping. A stereotypical view exists with men perceived as strong and more active problem solvers and women more emotional and passive. Several theories exist in this regard. The socialization theory posits “women are socialised in a way that less adequately equips them with effective coping patterns” (Pearlin & Schooler, 1978, p.15). The theory is based on the assumption that women are more passive and freely express emotions and men are more active and approach situations from a problem focussed manner (Lazarus & Folkman, 1984). In contrast to this is the role constraint theory, which argues that gender differences in coping can be explained by the social roles in which individuals occupy, suggesting that if individuals occupy the same social roles, no gender differences in coping would exist (Rossario et al., 1988).

It is important to highlight that although the traditional roles of men as breadwinners and women as homemakers have altered in recent times, societal expectations remain across many cultures. A study conducted by Stamm, Machold, Smolen and Prodinger (2010) highlighted that societal expectations of women’s occupation and everyday roles differed significantly to that of men. Women reported RA as a new challenge and critically reflected on cultural and societal values. Men were less likely to reflect positively on RA and reported difficulty giving up paid employment and a significant effect on social and economic status,
indicating a profound experience for men. Perhaps further awareness on the overall impact of RA across gender and a shift in societal expectations could transform outcomes for people living with the disease.

**Social Support**

Much research has examined the role of social support in the coping behaviours and overall quality of life in people with RA. People living with the disease report significant difficulties in completing daily tasks and often require assistance and support from others in order to live a reasonably normal life. Several studies have examined the role of partner, spouse or close support provider in the lives of people with RA. Those living with a spouse or partner reported more social support, less anxiety and depression and greater emotional wellbeing than those living without a partner (Kraaimaat, van Dam-Baggen & Bijlsma, 1995).

Further studies suggest that social support from friends and family can assist those living with RA to actively cope with their disease and adjust well psychologically (Affleck et al., 1999; Treharne, Lyons, Booth & Kitas, 2007).

Doeglas et al. (1994) studied 54 people with RA and found that those who received higher daily emotional support experienced much higher levels of emotional wellbeing and persons with a higher degree of companionship were also less depressed.

Affleck et al. (1988) found that the satisfaction with the level of social support received significantly correlated with physicians’ estimates of psychological adjustment. Manne and Zautra (1989) reported that people who perceived their spouse to be supportive engaged in more adaptive coping and those with more critical spouses reported more maladaptive coping behaviours and poorer emotional adjustment. This was supported by Kraaimat, van Dam-Baggen and Bijlsman (1995) who suggested that anxiety and depression are related to high levels of spouse/partner criticism. People with RA have limited social networks consisting of
a small number of family and friends with few opportunities for new social contacts (Bolwijn et al., 1984). It appears through the literature that social support is of considerable importance in the lives of people with RA and contributes to preserving quality of life.

Age

As previously discussed, RA can potentially strike at any age, with the average age for diagnosis 30-50 (Arthritis Ireland, 2012). Several researchers have considered age as a possible factor in relation to quality of life, however, conflict exists in the literature and further research is required in order to reach a resolution. Wright et al. (1998) found younger persons (age ≤ 45 years) with RA were at higher risk for depressive symptoms than their older counterparts. Similarly, Hawley and Wolfe (1988) reported worse depression in younger than older participants. When considering such results, recall that RA is life changing. Perhaps younger people have not yet had the opportunity to fulfil their dreams, establish meaningful relationships or find a vocation. The prospect of an uncertain future and a different way of life to that of their expectations may be devastating. Plach et al. (2005) reported that older women are most likely to experience the limitations associated with chronic disease as consistent with the ageing process and reported fewer cases of depression than younger women. Additional studies report conflicting findings.

Bendtsen and Hornguist (1992) conducted a study on change and status in quality of life in people with RA and reported that higher age was significantly correlated to reduced quality of life. In trying to understand these issues, consider the possibility that further age related health difficulties may exist for the older population and due to the progressive nature of RA, functional capacity is expected to deteriorate over time (Droassaer-Bakker et al., 1999). Duration of disease might also play a role. In recent times, more advanced medications for the treatment of RA have become available; perhaps such treatments were
not available to older people upon initial diagnosis. Further research is necessary in order to reach a conclusion.

**Duration of Disease**

Several researchers investigating quality of life in people with RA have considered duration of disease. Once again, the literature is inconsistent and conflicting in nature. Bendtsen and Hörnquist (1992) reported longer duration of RA significantly correlated with lower quality of life. Increase duration leads to higher levels of disability and lower levels of psychological wellbeing; this was supported by Revenson and Felton (1989). In contrast, Barlow, Cullen and Rowe (1999) found no relationship between duration of disease and quality of life in people with RA.

A study conducted by Newman et al. (1989) on 158 adults with RA, examined the effects of time independently to level of disability and found that people who had RA for a longer period appeared to be better adjusted to those who had a shorter duration. As demonstrated, the literature remains conflicting and further research is required to reach a conclusion.

**Rationale**

RA is a chronic, debilitating disease affecting a significant number of people in Ireland, the physical impact of the disease is often the focus in clinical settings with little or no attention assigned to the social or emotional aspect and the overall impact on quality of life. Although much research exists on the impact of RA some of which focuses specifically on quality of life and examines potential predictor factors, inconsistencies remain throughout the literature. This current study will add to what is already known whilst also attempting to address the conflicting findings of previous research. It will consider the predictive capacity of gender,
age, coping strategies, duration of disease and social support on quality of life in adults with RA. This study included a qualitative element and posed two open ended questions. 1. What are the most important factors that contribute to your quality of life? 2. What is the most difficult aspect of living with RA? These may add some insightful new avenues for further research.

Hypotheses

1. There will be a significant difference in quality of life reported by the younger age group and the older age group.

2. Duration of disease will significantly affect quality of life.

3. There will be a significant relationship between duration of disease and coping strategies employed.

4. There will be a significant relationship between coping and quality of life.

5. Level of social support received and satisfaction with level of social support will significantly impact quality of life.

6. Gender differences will exist in quality of life.
Method

Participants

A non-opportunity sample was employed for this study. A total of 190 (n=190) adults with a diagnosis of RA participated. Participants where recruited with the assistance of several agencies including Arthritis Ireland, Rheumatoid Arthritis Guy and Living with arthritis in Ireland. All of whom agreed to place a link to the survey on their social media sites. Participants took part to increase awareness on the topic.

The majority of participants were female (96.8%) whist males accounted for 3.2% of the sample. Age was initially categorised from 18-25 (4), 26-35 (35), 36-45 (69), 46-55 (56), 56-65 (23) and 66-75 (3); (Mean = 3.36, SD = 1.03). For the purpose of analysis, age was regrouped into two distinct categories, Younger age group (18-45 years) included 108 participants (56.8%) and older age group (46+) included 82 participants (43.2%).

Duration of disease was defined in six categories, just diagnosed (3.158%), 1-5 years (43.68%), 6-10 years (18.95%), 11-15 years (13.68%), 16-20 years (8.421%) and 20 years and over (12.11%).

Design

This was a cross sectional study of mixed design, incorporating both qualitative and quantitative elements using survey methods. A non-probability sample was employed targeting adults with a diagnosis of RA. All participants completed the same survey.

The quantitative element used established reliable and valid measures. For hypothesis 1, 2, 4, 5, and 6, the outcome variable was quality of life and predictor variables included, age, gender, coping strategies, social support and duration of disease. For hypothesis 3, the outcome variable was duration of disease and the predictor variable was coping strategies.
The qualitative element included two open-ended questions that were analysed using thematic analysis.

**Materials**

An online survey was developed which incorporated demographic information, established measures and open-ended questions.

Demographic information including, gender, age, number of children, employment status, relationship status and duration of disease was requested (See Appendix 1).

For the qualitative component, respondents where asked to answer two open-ended questions:

1. What do you believe are the three most important things that contribute to your quality of life?
2. What would you say is the most difficult aspect of living with RA?

**Measures**

Quality of life was assessed using Ferrans’ and Powers’ (1984) Quality of Life Index (QLI). This measures quality of life in terms of satisfaction with life. The questions relate to several aspects of life including, health and functioning, psychological and spiritual, social and economic and family life. The measure consisted of 66 items, 33 of which measured satisfaction e.g. How satisfied are you with your health? How satisfied are you with your ability to take care of family responsibilities?

Participants were asked to choose the answer that best described how satisfied they were with that area of their life. Answers where ranked from one to six, with one being very dissatisfied and six being very satisfied.

The remaining 33 items measured importance e.g. How important to you is your health? How important to you is taking care of family responsibilities?
Participants were asked to choose the answer that best described how important that area of their life was to them. Answers were ranked from one to six, with one being very unimportant and six being very important.

Importance ratings were used to weight satisfaction responses, therefore reflecting satisfaction with aspects of life that are important to the individual (See Appendix 2). For the purpose of this study, overall quality of life scores were used in analysis.

Coping strategies were assessed using Carver’s (1997) Brief COPE scale. This measure consisted of 28 items e.g., I’ve been turning to work or other activities to take my mind off things. I’ve been using alcohol or other drugs to help me get through it. The measure incorporated the following 14 coping styles; self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self blame. Participants were asked to rate each item from one to four, with one being, I haven’t been doing this at all and four, I’ve been doing this a lot.

The Brief COPE scale yields subscale scores for each of the fourteen coping styles and rates the frequency of use of each style (See Appendix 3).

Social Support Questionnaire (Sarason et al., 1982) was used to measure the level of social support available to participants and their level of satisfaction with social support. The measure consisted of six questions with two parts per question. Participants were asked whom they can count on for support in certain circumstances and then rated how satisfied they were with the level of support they received. e.g. A. Whom can you really count on to be dependable when you need help? B. How satisfied?
Participants where asked to provide relationship details of those they could rely on to support them in each scenario, they had the option of providing up to nine possible answers e.g. Who can you count on to console you when you are very upset?

1. _____ 2. _____ 3. _____ 4.______ 5. _____ 6. _____ 7. ____ 8. ____ 9.____

Participants were asked how satisfied they where with the level of support they received in each scenario. They where asked to rank from six – very satisfied to one – very dissatisfied. (See Appendix 4)

Procedure

Prior to commencing the study, ethical approval was granted from Dublin Business School. The researcher contacted several agencies including Arthritis Ireland, Rheumatoid Arthritis Guy and Living with Arthritis in Ireland by email and invited them to assist the researcher in reaching the specified target group (Adults with a diagnosis of RA). All agencies agreed and placed a link to the survey on their social media sites. Participants who decided to take part, clicked on the survey link, which directed them to the survey cover page (See Appendix 5). This page informed participants of the purpose of the study and provided researcher contact details should they have any further questions. Ethical considerations were included and participants were assured that the survey was anonymous and confidential and for this reason they could not withdraw after submitting the completed survey. Consent was assumed once the participant completed and submitted the survey. Once participants were satisfied, they clicked on the next page and began the survey. Upon completion, participants were thanked once again and provided with some contact details for support services.
Results

Quantitative

Hypothesis 1.

There will be a significant difference in quality of life scores reported by the younger age group and the older age group.

Descriptive Statistics

For the purpose of analysis, the original age groups were divided into two distinct categories Younger and Older. The younger category included participants aged 45 and below and the older category included participants 46 years of age and above. The younger age group accounted for 56.84% of participants and the older group accounted for 43.16% of participants.

Of the 190 participants who took part in the study, 50 (n=50) fully completed the quality of life index (Mean = 13.4, SD = 4.75) therefore results are based on 50 participants. The younger age group consisted of 19 participants (Mean = 12.9, SD = 4.44) and the older age group consisted of 31 participants (Mean = 14.15, SD = 5.23) (See Table 1).

Table 1: Descriptive statistics for Quality of Life, Younger and Older age groups

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>QOL Total</td>
<td>13.4</td>
<td>4.75</td>
</tr>
<tr>
<td>Younger Age group</td>
<td>12.9</td>
<td>4.44</td>
</tr>
<tr>
<td>Older age group</td>
<td>14.15</td>
<td>5.23</td>
</tr>
</tbody>
</table>
Inferential Statistics

The older age group (mean = 14.15, SD = 5.23) scored slightly higher than the younger age group (mean = 12.88, SD = 4.44). The 95% confidence limits show that the population mean difference of the variables lies somewhere between -4.05 and 1.52. An independent samples t-test found that there was no significant difference in quality of life scores in the younger and older age groups (t(48) = -.91, p=.365) therefore the null hypothesis was accepted (See Table 2).

Table 2: Independent Sample t-test displaying Quality of Life results

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>t</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>QOL</td>
<td>13.4</td>
<td>4.75</td>
<td>-.91</td>
<td>48</td>
<td>.365</td>
</tr>
</tbody>
</table>

Hypothesis 2.

Duration of disease will significantly impact quality of life.

Descriptive statistics

Duration of disease was described in six categories, just diagnosed (3.158%), 1-5 years (43.68%), 6-10 years (18.95%), 11-15 years (13.68%), 16-20 years (8.421%) and 20 years and over (12.11%). (See Table 3) The majority of participants (43.68%) reported the duration of their disease between 1-5 years with only 3.16% of participants being just diagnosed (See figure 1). The analysis was based on 50 participants who fully completed quality of life index.
Table 3: Descriptive statistics for Quality of Life and Duration of disease

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>QOL Final</td>
<td>13.36</td>
<td>4.74</td>
</tr>
<tr>
<td>Duration</td>
<td>1.74</td>
<td>.78</td>
</tr>
</tbody>
</table>

Figure 1: Duration of Disease reported by participants
A spearman’s rho correlation found that there was no significant association between duration of disease and quality of life ($r_s (50) = -0.22, p = .120$) therefore the null hypothesis was accepted (See Table 4).

Table 4: Spearman’s rho correlation table indicating results of analysis

<table>
<thead>
<tr>
<th>Variable</th>
<th>QOL final</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>QOL final</td>
<td>1.000</td>
<td>-.223</td>
</tr>
<tr>
<td>Duration</td>
<td>-.223</td>
<td>1.000</td>
</tr>
</tbody>
</table>

Hypothesis 3.
There will be a significant relationship between duration of disease and coping strategies employed.

Descriptive Statistics

Analysis was based on 190 participants. The majority of participants (43.68%) reported the duration of disease (Mean = 1.73, SD = .78) between 1-5 years with only 3.16% of participants being just diagnosed. Fourteen coping strategies were examined (See Table 5)
Table 5: *Descriptive statistics for Duration of Disease and 14 coping categories*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration</td>
<td>1.73</td>
<td>.78</td>
</tr>
<tr>
<td>Self distraction</td>
<td>5.45</td>
<td>1.70</td>
</tr>
<tr>
<td>Active coping</td>
<td>5.31</td>
<td>1.61</td>
</tr>
<tr>
<td>Denial</td>
<td>3.18</td>
<td>1.72</td>
</tr>
<tr>
<td>Substance use</td>
<td>3.08</td>
<td>1.68</td>
</tr>
<tr>
<td>Emotional support</td>
<td>4.80</td>
<td>1.72</td>
</tr>
<tr>
<td>Instrumental support</td>
<td>4.45</td>
<td>1.64</td>
</tr>
<tr>
<td>Behaviour disengagement</td>
<td>3.60</td>
<td>1.72</td>
</tr>
<tr>
<td>Venting</td>
<td>4.33</td>
<td>1.63</td>
</tr>
<tr>
<td>Positive reframing</td>
<td>4.85</td>
<td>1.86</td>
</tr>
<tr>
<td>Planning</td>
<td>5.55</td>
<td>1.64</td>
</tr>
<tr>
<td>Humour</td>
<td>4.32</td>
<td>1.93</td>
</tr>
<tr>
<td>Acceptance</td>
<td>6.08</td>
<td>1.52</td>
</tr>
<tr>
<td>Religion</td>
<td>4.18</td>
<td>2.20</td>
</tr>
<tr>
<td>Self blame</td>
<td>4.29</td>
<td>1.87</td>
</tr>
</tbody>
</table>

---

*Inferential Statistics*

A Spearman’s rho correlation found that there was a significant negative relationship between denial and duration of disease ($r_s (190) = -0.18, p = .014$) and a significant positive relationship between acceptance and duration of disease ($r_s (190) = 0.18, p = .015$). Therefore the null hypothesis was rejected (See Table 6).
Table 6: *Spearman’s rho correlation displaying the correlation between Duration of Disease, Denial and Acceptance*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Duration</th>
<th>Denial</th>
<th>Acceptance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration</td>
<td>1.000</td>
<td>-.178*</td>
<td>.176*</td>
</tr>
<tr>
<td>Denial</td>
<td>-.178*</td>
<td>1.000</td>
<td>-.282**</td>
</tr>
<tr>
<td>Acceptance</td>
<td>.176*</td>
<td>-.282**</td>
<td>1.000</td>
</tr>
</tbody>
</table>

Hypothesis 4.

There will be a significant relationship between coping and quality of life.

*Descriptive statistics*

Analysis was based on 50 participants. Quality of life (mean=13.36, SD, 4.74) and 14 coping styles were examined in analysis (See Table 7).

Table 7: *Descriptive statistics for Quality of Life and 14 Coping Styles*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>QOL Final</td>
<td>13.36</td>
<td>4.74</td>
</tr>
<tr>
<td>Emotional support</td>
<td>4.76</td>
<td>1.84</td>
</tr>
<tr>
<td>Self blame</td>
<td>4.36</td>
<td>1.79</td>
</tr>
<tr>
<td>Religion</td>
<td>4.44</td>
<td>2.32</td>
</tr>
<tr>
<td>Acceptance</td>
<td>6.16</td>
<td>1.48</td>
</tr>
<tr>
<td>Self distraction</td>
<td>5.44</td>
<td>1.47</td>
</tr>
<tr>
<td>Active coping</td>
<td>5.34</td>
<td>1.59</td>
</tr>
<tr>
<td>Denial</td>
<td>3.34</td>
<td>1.73</td>
</tr>
<tr>
<td>Substance use</td>
<td>3.24</td>
<td>1.69</td>
</tr>
<tr>
<td>Instrumental support</td>
<td>4.80</td>
<td>1.60</td>
</tr>
<tr>
<td>Behavioural disengagement</td>
<td>3.72</td>
<td>1.76</td>
</tr>
</tbody>
</table>
Inferential Statistics

The mean score for quality of life was 13.36 (SD = 4.74) and for emotional support 4.76 (SD = 1.84) A Pearson’s correlation coefficient found that there was a strong relationship between the two variables (r (49) = 0.56, p < .01) therefore the null hypothesis was rejected.

\[ r = 0.56, (0.56)^2 = 0.3136 = 31.36\% \text{ variance explained.} \]

Hypothesis 5.

Level of social support received and satisfaction with level of social support will significantly impact quality of life.

Descriptive Statistics

Analysis was based on 50 participants, Quality of life (Mean = 13.36, SD = 4.74), Social support (Mean = 16.57, SD = 10.38) and satisfaction with social support (Mean = 28.35, SD = 8.07) were examined (See Table 8).
Table 8: *Descriptive statistics for Quality of Life, Social Support and Satisfaction with Social Support*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life</td>
<td>13.36</td>
<td>4.74</td>
</tr>
<tr>
<td>Social support</td>
<td>16.57</td>
<td>10.38</td>
</tr>
<tr>
<td>Social support satisfaction</td>
<td>28.35</td>
<td>8.07</td>
</tr>
</tbody>
</table>

---

*Inferential Statistics*

Multiple regression was used to test whether level of social support received and satisfaction with level of social support were related to quality of life. The result of the regression indicated that two predictors explained 25% of the variance ($R^2 = .25, F (2, 47) = 8.96, p < .001$) It was found that social support was a significant predictor on quality of life ($B = .222, p = .139, 95\% CI = -.035 - .245$) with satisfaction with level of social support even more significant as a predictor in quality of life. ($B = .372, p = .015, 95\% CI = .38 - .334$)

Therefore, the null hypothesis was rejected (See figure 2 & 3).
Figure 2: Scatter plot indicating weak positive correlation between Quality of Life and Social Support
Figure 3: Scatter plot indicating positive correlation between Quality of Life and Satisfaction with Social Support

Hypothesis 6.
Gender differences will exist in quality of life

Descriptive Statistics

Of the 190 participants who took part in the study, females (n=184) accounted for 96.8% of the sample, while males (n=6) accounted for the remaining 3.2%. For this reason, it was not possible to complete any analysis using gender as a variable. (See Figure 4)
Figure 4: Bar chart indicating the percentage of male and female participants
Results

Qualitative

Participants where asked to answer two open ended questions. Responses were analysed using thematic analysis (Braun & Clarke 2006). Some overlap was evident in the analysis across categories.

Q.1 – What do you believe are the three most important factors that contribute to your quality of life?

Several themes emerged and were categorised for the purpose of analysis. These included family and friends, health, employment /financial stability, acceptance/positivity, functional ability, and faith (See Figure 5). There were aspects of the data that overlapped across these categories.

The most common category was family and friends, this related to love, support and spending quality time with family members and close friends. Sixty percent of participants cited family and friends as an important factor in terms of quality of life.

“My husband and his emotional and physical support. He has taken on almost all my household duties. The fact that my husband has the financial ability and willingness to support me”.

The second most common category was health, this related to controlling various symptoms of RA with medication and accessing specialist services in order to maintain functional ability. Forty percent of participants indicated health as an important factor in terms of quality of life. “Energy Level, Pain Management and Access to healthcare & medications”.

The next category that emerged was employment and financial stability; participants indicated the importance of maintaining employment or resuming work and the importance
of financial stability. One quarter of participants included this as a factor that contributes to quality of life. “Job that I love and financially sustainable”.

The forth category was acceptance/positivity and was cited as an important factor in quality of life by 19% of participants. Acceptance was related to accepting limitations and positivity related to the importance of maintaining a positive outlook despite health status. “Having a positive outlook on life is the most important. If you sit down and feel sorry for yourself, you will only feel worse. Get up let people know how you feel, don't bottle it in”.

The fifth category was functional ability; this encompassed being able to engage in activities/hobbies and to look after oneself, this was cited by 16% of participants in relation to quality of life. “My ability to at least take care of my own personal needs such as eating, bathing, dressing, etc”

The final category was faith, 11% of participants cited faith as an important factor in relation to quality of life. “A connection with a higher spirit and trust in knowing these difficult days have a purpose”

---

**Figure 5:** Categories pertinent to Quality of Life.
Q.2 – What would you say is the most difficult aspect of living with rheumatoid arthritis?

Five themes emerged during thematic analysis and were subsequently categorised as pain, fatigue, physical limitations, lack of understanding and uncertainty (See Figure 6). Some overlap occurred between the categories.

Pain was reported as the most difficult aspect of living with RA by 43% of participants. Dealing with constant severe pain often limited functional ability. “Living with the pain on a daily basis and getting so angry and frustrated when can't do everyday things (like opening a juice bottle)”

Fatigue was the next category with 33% of participants citing fatigue as one of the most difficult aspects of living with RA. “Fatigue is definitely the worst part to me. Pain is difficult, but the fatigue can literally get me down. It is also hard dealing with people who do not understand. Friends and family that disappear because they don't understand. Honestly, it angers me at times”

The next theme to emerge was limitations, reported by 28% of participants. Limitations included loss of functional mobility, being unable to fulfil family roles or engage in activities or hobbies. “Watching other people in my life suffer because of it. My husband has to do everything, our life has changed completely and our dreams and plans have had to be put aside. It's devastated our finances, personal life and social life”.

Lack of understanding was reported by 19% of participants. They referred to the illness as being “invisible”. “Others not understanding because on the outside, it appears that nothing is wrong”

The final category that emerged from the data was uncertainty, 14% of participants reported uncertainty as the most difficult aspect of living with RA. The unpredictability associated with the disease often left participants feeling frustrated, angry, and unable to plan
ahead. “The most difficult thing about this disease is the unpredictability of symptoms regarding pain & energy levels & the worries & emotions that come with having a bad day & how it impacts me, my family & job. Also, the endless doctor appts., blood draws, RA medications, supplements that are a constant reminder & evil necessity of this disease”

Figure 6: Categories representing the most difficult aspect of living with Rheumatoid Arthritis as reported by participants
Discussion

The aim of this study was to consider gender, age, social support, coping strategies and duration of disease as possible predictive factors on quality of life in adults with a diagnosis of RA. The qualitative aspect of this project aimed to gain a subjective perspective on the most difficult aspect of living with RA and what contributes to quality of life. Gender differences could not be examined, as the requisite power for analysis was not achieved due to insufficient male participants.

For the purpose of analysis, age was recoded into two groups, younger age group incorporating 18-45 years old and older age group incorporating 46 and above. Results indicated no significant differences in quality of life scores between younger and older age groups and therefore the experimental hypothesis was rejected. Previous literature reported differences across age groups that were conflicting in nature with Wright et al. (1998) and Hawley & Wolfe (1988) reporting increased levels of depression in younger persons with RA compared to their older counterparts. Bendtsen and Hornguist (1992) and Erik et al. (2006) reported a significant decrease in quality of life in older people with RA. This current project did not reach a resolution in this regard and therefore further research is required.

There was no significant correlation between duration of disease and quality of life therefore the null hypothesis was accepted. As previously mentioned, inconsistencies exist in the literature. This result supports previous research conducted by Wirnsberger at al. (1999) and Barlow, Cullen and Rowe (1999) who found no relationship between the duration of illness and quality of life in people with RA.
Of the 14 coping strategies examined, analysis revealed a strong significant relationship between emotional support and quality of life therefore the null hypothesis was rejected. This result offers support to a study conducted by Treharne, Lyons, Booth and Kitas (2007) who reported a significant relationship between social support and improved psychological wellbeing. This result is also consistent with social support hypothesis.

Analysis revealed that social support and satisfaction with social support were significantly related to quality of life. With satisfaction with social support being the stronger of the two. Therefore, the null hypothesis was rejected. This supports previous research conducted by Doeglas et al. (1994) and Affleck et al. (1988).

In relation to duration of disease and coping strategies employed, analysis revealed a significant negative relationship between denial and duration of disease and a significant positive relationship between acceptance and duration of disease, therefore the null hypothesis was rejected. It can be hypothesised that when initially diagnosed with a chronic debilitating disease, overwhelming fears and apprehension follow, denial has been defined as a passive coping style with implications on psychological wellbeing (Young, 1992). It appears that denial is replaced with acceptance after coming to terms with the diagnosis.

Analysis of qualitative data revealed several themes which were categorised for the purpose of analysis. The most common categories to emerge in relation to the most important factors that contribute to quality of life were reported consecutively, family and friends, health, employment/financial stability, acceptance/positivity, functional ability and faith. Interestingly, the most common factor was family and friends and included support, love and quality time. This is consistent with hypothesis four and five, which confirm significant correlations between emotional support, social support and satisfaction with social support and quality of life.
Concerning the most difficult aspect of living with RA, the most commonly cited categories were pain, fatigue, physical limitations, lack of understanding and uncertainty. This information provides crucial insight into the difficulties faced by people living with RA and is consistent with previous literature (Ailinger & Schweitzer, 1993; Burkhardt, 1988).

**Strengths & Limitations**

This research project used an online survey and targeted a specific sample (adults with RA). It was anticipated prior to publishing that issues may arise in achieving sufficient power considering the nature of RA and the difficulties faced by people living with the disease (pain, fatigue, functional impairment and disability). The survey was developed with this in mind and allowed participants to save their responses and resume later should they have difficulty completing it in one sitting. Several potential predictive factors were addressed. In addition to the established measures and demographic information, the qualitative component allowed participants a voice and afforded them the opportunity to answer two open-ended questions. This provided profound insight into the difficulties faced by individuals living with RA and also highlighted amazing strength and resiliency.

The study recruited 190 participants; however, only five of these were male, as a result gender comparison was not possible. This has been cited as a limitation in previous literature with some studies assuming no gender difference (Lack, Noddings & Hewlett, 2011) further research is required in this area, perhaps increased efforts to seek male participants is necessary.

Of the 190 participants who took part, only 50 fully completed the Quality of Life Index and therefore analysis was based on only 50 participants, results could have differed significantly had all 190 participants responded.
It is important to consider the nature of the design and possible implications regarding results. As RA is characterised by unpredictability and periods of flares and remissions, it is possible that some of the participants were having a particularly good/bad day when responding. A longitudinal study could be beneficial in addressing this potential issue. In addition, the only method used to promote this survey was social media. Social media is generally accessed more by younger and middle aged people; perhaps an additional method could have been included to specifically target the older population.

The most apparent result demonstrated in this study was the importance of social and emotional support in overall quality of life. This has been highlighted in previous studies and is an area that could be further developed in practical application.

**Conclusion**

RA is a chronic, debilitating disease with physical, social and psychological consequences. The physical components of the disease (pain, inflammation) are often the focus in clinical settings. Rheumatologists are experts in this field; however, they often appear to lack understanding on the social and psychological impact of the disease, which receives minimal consideration. Perhaps training on the possible psychological implications of chronic illnesses such as RA could be incorporated into physician education curriculum. This knowledge would provide professionals with the confidence to identify and assist people struggling to cope with the disease.

The most palpable result in this project was the important role of social and emotional support in relation to overall quality of life. This has been indicated throughout the literature with increased social support relating positively to quality of life and decreased psychological distress. Social support can take many forms, from family, friends, doctors, rheumatologists to name a few. This is an area that could be further developed upon and applied in a practical
setting in the form of peer/professional support groups. Another factor to consider is the importance of adapting and coping with life after diagnosis. The ability to understand universal coping strategies that constitute positive outcomes could be further developed upon and used as interventions to assist those who are struggling to cope.

RA generally remains misunderstood and is often confused with osteoarthritis or aches and pains by the general population. As reported in qualitative analysis, lack of understanding from others was considered among the top five categories defining the most difficult aspect of living with RA. Increased public awareness and an appreciation of the daily difficulties faced by a person living with this chronic disease could be worthwhile. RA is more than just a physical disease; therefore a holistic approach to treatment may be beneficial. Scientists continue in their attempts to identify the exact cause of rheumatoid arthritis with the expectation of eventually finding a cure. This provides immense hope for those living with the disease.
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everyday activities, including paid work. *Musculoskeletal Care*, 8(2), 78-86. DOI: 10.1002/msc.168


APPENDICES

Appendix 1

Demographic details

Gender  
O Male  
O Female

Age  
O 18 - 25  
O 26 – 35  
O 36 – 45  
O 46 – 55  
O 56 – 65  
O 66 – 75  
O 75 +

Number of children  
O 0  
O 1-2  
O 3-4  
O 5+

Employment  
O Full time  
O Part time  
O Unemployed

Living with RA  
O Just diagnosed  
O 1-5 Years  
O 6-10 Years  
O11-15 Years  
O16-20 Years  
O20 +

What do you believe are the three most important things that contribute to your quality of life? Please provide details below.

___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

What would you say is the most difficult aspect of living with RA
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
Appendix 2

Quality of Life Index

1 - Very Dissatisfied
2 - Moderately Dissatisfied
3 - Slightly Dissatisfied
4 - Slightly Satisfied
5 - Moderately Satisfied
6 - Very Satisfied

PART 1. For each of the following, please choose the answer that best describes how satisfied you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

**HOW SATISFIED ARE YOU WITH:**

1. Your health? 1 2 3 4 5 6
2. Your health care? 1 2 3 4 5 6
3. The amount of pain that you have? 1 2 3 4 5 6
4. The amount of energy you have for everyday activities? 1 2 3 4 5 6
5. Your ability to take care of yourself without help? 1 2 3 4 5 6
6. The amount of control you have over your life? 1 2 3 4 5 6
7. Your chances of living as long as you would like? 1 2 3 4 5 6
8. Your family’s health? 1 2 3 4 5 6
9. Your children? 1 2 3 4 5 6
10. Your family’s happiness? 1 2 3 4 5 6
11. Your sex life? 1 2 3 4 5 6
12. Your spouse, lover, or partner? 1 2 3 4 5 6
13. Your friends? 1 2 3 4 5 6
14. The emotional support you get from your family? 1 2 3 4 5 6
15. The emotional support you get from people other than your family? 1 2 3 4 5 6
16. Your ability to take care of family responsibilities? 1 2 3 4 5 6
17. How useful you are to others? 1 2 3 4 5 6

18. The amount of worries in your life? 1 2 3 4 5 6

19. Your neighborhood? 1 2 3 4 5 6

20. Your home, apartment, or place where you live? 1 2 3 4 5 6

21. Your job (if employed)? 1 2 3 4 5 6

22. Not having a job (if unemployed, retired, or disabled)? 1 2 3 4 5 6

23. Your education? 1 2 3 4 5 6

24. How well you can take care of your financial needs? 1 2 3 4 5 6

25. The things you do for fun? 1 2 3 4 5 6

26. Your chances for a happy future? 1 2 3 4 5 6

27. Your peace of mind? 1 2 3 4 5 6

28. Your faith in God? 1 2 3 4 5 6

29. Your achievement of personal goals? 1 2 3 4 5 6

30. Your happiness in general? 1 2 3 4 5 6

31. Your life in general? 1 2 3 4 5 6

32. Your personal appearance? 1 2 3 4 5 6

33. Yourself in general? 1 2 3 4 5 6

PART 2.

For each of the following, please choose the answer that best describes how important that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

1- Very Unimportant
2 - Moderately Unimportant
3 - Slightly Unimportant
4 - Slightly Important
5 - Moderately Important
6 - Very Important
**HOW IMPORTANT TO YOU IS:**

1. Your health? 1 2 3 4 5 6
2. Your health care? 1 2 3 4 5 6
3. Having no pain? 1 2 3 4 5 6
4. Having enough energy for everyday activities? 1 2 3 4 5 6
5. Taking care of yourself without help? 1 2 3 4 5 6
6. Having control over your life? 1 2 3 4 5 6
7. Living as long as you would like? 1 2 3 4 5 6
8. Your family’s health? 1 2 3 4 5 6
9. Your children? 1 2 3 4 5 6
10. Your family’s happiness? 1 2 3 4 5 6
11. Your sex life? 1 2 3 4 5 6
12. Your spouse, lover, or partner? 1 2 3 4 5 6
13. Your friends? 1 2 3 4 5 6
14. The emotional support you get from your family? 1 2 3 4 5 6
15. The emotional support you get from people other than your family? 1 2 3 4 5 6
16. Taking care of family responsibilities? 1 2 3 4 5 6
17. Being useful to others? 1 2 3 4 5 6
18. Having no worries? 1 2 3 4 5 6
19. Your neighborhood? 1 2 3 4 5 6
20. Your home, apartment, or place where you live? 1 2 3 4 5 6
21. Your job (if employed)? 1 2 3 4 5 6
22. Having a job (if unemployed, retired, or disabled)? 1 2 3 4 5 6
23. Your education? 1 2 3 4 5 6
24. Being able to take care of your financial needs? 1 2 3 4 5 6
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>25. DOIng things for fun?</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>26. Having a happy future?</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>27. Peace of mind?</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>28. Your faith in God?</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>29. Achieving your personal goals?</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>30. Your happiness in general?</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>31. Being satisfied with life?</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>32. Your personal appearance?</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>33. Are you to yourself?</td>
<td>1 2 3 4 5 6</td>
</tr>
</tbody>
</table>
Appendix 3

These items deal with ways you've been coping with the stress in your life. There are many ways to try to deal with problems. These items ask what you've been doing in general to cope with stressful events. Obviously, different people deal with things in different ways, but think about what you usually do when you are under a lot of stress. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things. ___
2. I've been concentrating my efforts on doing something about the situation I'm in. ___
3. I've been saying to myself "this isn't real.". ___
4. I've been using alcohol or other drugs to make myself feel better.___
5. I've been getting emotional support from others. ___
6. I've been giving up trying to deal with it. ___
7. I've been taking action to try to make the situation better. ___
8. I've been refusing to believe that it has happened. ___
9. I've been saying things to let my unpleasant feelings escape. ___
10. I've been getting help and advice from other people. ___
11. I've been using alcohol or other drugs to help me get through it. ___
12. I've been trying to see it in a different light, to make it seem more positive. ___
13. I've been criticizing myself. ___
14. I've been trying to come up with a strategy about what to do. ___
15. I've been getting comfort and understanding from someone. ___
16. I've been giving up the attempt to cope. ___
17. I've been looking for something good in what is happening. ___
18. I've been making jokes about it. ___
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. ___
20. I've been accepting the reality of the fact that it has happened. ___
21. I've been expressing my negative feelings. ___
22. I've been trying to find comfort in my religion or spiritual beliefs. 
23. I've been trying to get advice or help from other people about what to do. 
24. I've been learning to live with it. 
25. I've been thinking hard about what steps to take. 
26. I've been blaming myself for things that happened. 
27. I've been praying or meditating. 
28. I've been making fun of the situation.
Appendix 4

Social Support Questionnaire (SSQ)

Instructions:
The following questions ask about people in your life who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the person’s relationship to you (see example). Do not list more than one person next to each of the numbers beneath the question. For the second part, circle how satisfied you are with the overall support you have.
If you have no support for a question, check the words “No one,” but still rate your level of satisfaction. Do not list more than nine persons per question.
Please answer all questions as best you can. All your answers will be kept confidential.

Example:
Who do you know whom you can trust with information that could get you in trouble?

1) No one, 2) brother, 3) father, 4) friend, 5) doctor, 6) employer, 7)____8)____9)____

How Satisfied?

6 – very satisfied, 5 – fairly satisfied, 4 – a little satisfied, 3 – a little dissatisfied

2 – fairly dissatisfied, 1 – very dissatisfied

1. Whom can you really count on to be dependable when you need help?

1) No one, 2) ____3) _____4) ____5) _____6) ____7)____8)____9)____

B. How Satisfied?

6 – very satisfied, 5 – fairly satisfied, 4 – a little satisfied, 3 – a little dissatisfied

2 – fairly dissatisfied, 1 – very dissatisfied

2. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

1) No one, 2) ____3) _____4) ____5) _____6) ____7)____8)____9)____

B. How Satisfied?

6 – very satisfied, 5 – fairly satisfied, 4 – a little satisfied, 3 – a little dissatisfied

2 – fairly dissatisfied, 1 – very dissatisfied
3. Who accepts you totally, including both your worst and your best points?

1) No one, 2) _____ 3) _____ 4) _____ 5) _____ 6) _____ 7) _____ 8) _____ 9) _____

B. How Satisfied?

6 – very satisfied, 5 – fairly satisfied, 4 – a little satisfied, 3 – a little dissatisfied
2 – fairly dissatisfied, 1 – very dissatisfied

4. Whom can you really count on to care about you, regardless of what is happening to you?

1) No one, 2) _____ 3) _____ 4) _____ 5) _____ 6) _____ 7) _____ 8) _____ 9) _____

B. How Satisfied?

6 – very satisfied, 5 – fairly satisfied, 4 – a little satisfied, 3 – a little dissatisfied
2 – fairly dissatisfied, 1 – very dissatisfied

5. Whom can you really count on to help you feel better when you are feeling generally down-in-the dumps?

1) No one, 2) _____ 3) _____ 4) _____ 5) _____ 6) _____ 7) _____ 8) _____ 9) _____

B. How Satisfied?

6 – very satisfied, 5 – fairly satisfied, 4 – a little satisfied, 3 – a little dissatisfied
2 – fairly dissatisfied, 1 – very dissatisfied

6. Whom can you count on to console you when you are very upset?

1) No one, 2) _____ 3) _____ 4) _____ 5) _____ 6) _____ 7) _____ 8) _____ 9) _____

B. How Satisfied?

6 – very satisfied, 5 – fairly satisfied, 4 – a little satisfied, 3 – a little dissatisfied
2 – fairly dissatisfied, 1 – very dissatisfied
Appendix 5

The Psychological Impact of RA

My name is Vicki Fermoyle and I am conducting research in the Department of Psychology regarding the impact of RA on quality of life in adult males and females. This research is being conducted as part of my studies and will be submitted for examination.

You are invited to take part in this study and participation involves completing and returning the attached anonymous survey. While the survey asks some questions that might cause some minor negative feelings, it has been used widely in research. If any of the questions do raise difficult feelings for you, contact information for support services are included on the final page.

Participation is completely voluntary and so you are not obliged to take part.

Participation is anonymous and confidential. Thus responses cannot be attributed to any one participant. For this reason, it will not be possible to withdraw from participation after the questionnaire has been collected.

The questionnaires will be securely stored and data from the questionnaires will be transferred from the paper/online record to electronic format and stored on a password protected computer.

It is important that you understand that by completing and submitting the questionnaire that you are consenting to participate in the study.

Should you require any further information about the research, please contact Vicki Fermoyle at

Thank you for taking the time to complete this survey.

_________________________________________________________

Please find below, details of some available support services.

Samaritans: Ph: 1850 60 90 90
Email: jo@samaritans.org

Arthritis Ireland: Ph: 1890 252 846
Email: www.arthritisireland.ie

Aware: Ph: 1890303302
Email: wecanhelp@aware.ie