

POSITIVE PSYCHOLOGICAL CHANGE IN PEOPLE WITH RHEUMATOID ARTHRITIS

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Declaration

I declare that this PhD thesis has been composed by myself and embodies the results of my own course of study and research whilst studying at The University of Salford from April 2013 to November 2016. All sources and material have been acknowledged.

Publication and Conference proceedings

The following paper related to this thesis has been published:

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Presentations at Conferences:

The following conferences were attended at which aspects of the thesis were presented. Work was also presented at the National Rheumatoid Arthritis Society Group in Oldham to individuals with Rheumatoid Arthritis and to health professionals at the University of Salford, including physiotherapists. The following presentations were made at such conferences:

Sani Pour, F. (2016). Positive Psychological Change in people with Rheumatoid Arthritis. Paper presented at the SPARC 2016 Salford Postgraduate Annual Research Conference (pp.73). University of Salford, UK. <http://usir.salford.ac.uk/39314/1/2016SPARCAbstracts.pdf>

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Abstract

Most research on patients with chronic medical conditions, including Rheumatoid Arthritis (RA) have focussed on the negative impact of living with these conditions. More recent research has highlighted that some people experience Positive Psychological Change (PPC) in response to traumatic or adverse events or conditions, but very few studies have looked at PPC in relation to people with RA.

The aim of this study was to investigate if people with RA experience PPC and to explore the psychosocial, physical and demographic factors associated with its occurrence. A survey study was conducted to investigate the likelihood and extent of PPC, and the psychosocial, physical and demographic factors that are associated with and which may influence the development of PPC within this population.

This study is based on a sample of British individuals with RA who were recruited from the University of Salford Rehabilitation Research Group's Arthritis Research Panel and from the National Rheumatoid Arthritis Society. The data was collected using a pack of eight reliable and valid questionnaires that were mailed to the eligible individuals.

Out of 338 invitation packs 228 (67%) questionnaires were returned and completed of which 210 were screened to comprise the final sample. The mean participant age was 62, they were mostly female, (79%) and the majority had the disease for more than 10 years (53.3%). The Silver Lining Questionnaire (SLQ-38) was used as the criterion for PPC and the mean score was 95.09 (SD \pm 26.09). In this sample SLQ scores were distributed normally. The criterion for the occurrence of PPC was set at one SD over the SLQ mean (121). Nearly 34% of the current participants reported PPC, and the higher scores were associated with: age; disease duration; psychological well-being; coping strategy; lower fatigue, social support and sense of coherence and resilience. The findings reveal that distancing was the most favourably used coping strategy however, the PPC positively correlated with the cognitive reframing subscale. Implications of this study for the application of psychological principles in Rheumatology services were examined. Limitations of the research along with further direction for the future studies were discussed.

Chapter One

1. Introduction

Chronic health diseases are multifaceted long-term medical health conditions with extensive aftermaths in various life areas (Dager et al., 2012). Even though medical treatments have enhanced throughout current years, patients are yet to deal with the problem of adapting to life with the outcomes of their disease (Chong, Vaingankar, Abdin, & Subramaniam, 2012).

For the duration of 30 years, there has been a growth in studies considering life events, which have demonstrated the effect of trauma on Post-traumatic Growth theory as recommended by Tedeschi & Calhoun, (1996). Post-traumatic Growth (PTG) refers to the positive changes associated with traumatic events. PTG explains the experience of individuals who not only make a recovery from trauma, but also use it as a chance for additional individual development (Maercker & Zoellner, 2004). Tedeschi & Calhoun, (1996) advised that trauma can be a trigger to PTG. According to Tedeschi & Calhoun, (1996) PTG consists of five main classifications of growth, these being appreciation of life, relating to others, new possibilities, personal strength, and spiritual change (Mapplebeck, Joseph, & Sabin-Farrell, 2015).

However, most previous studies lacked factors such as a clear definition and operationalisation of the concept of positive change, a theoretical framework, adequately validated instruments, and incomprehensible instruments which may not have been specific enough to detect changes in people with chronic health conditions such as RA. Despite these inadequacies in the majority of studies some kind of positive change was reported as being produced in chronic health conditions, such as cancer. Currently there is little known in depth about the psychological changes involved, specifically Positive Psychological Change (PPC), occurring in people with RA. Therefore, this thesis aimed to explore PPC as a key role in understanding how people with RA cope with living with their condition. It is hoped that if the study identifies the existence of PPC in people with RA, the research outcomes may influence future interventions and models of psychological change, as well as health measures. Thus, this PhD was organised around a central theme; that of the potential for PPC in people living with RA. This thesis aimed to investigate the factors that were associated with PPC in individuals with RA in the UK. A survey was therefore performed using participants diagnosed with RA, in order to assess the likelihood and extent of PPC, the psychological factors that are associated with the physical and demographic characteristics that may

influence the development of PPC within this population. The study explored whether the potential associated factors are predictive of future PPC and finally, the thesis looked at the bio-psycho-social model to provide a theoretical base for further analysis.

1.1. Literature review

The definition of Positive Psychological Change (PPC) is based on the positive consequences of illness reported by individuals who have encountered RA as measured by the Silver Lining Questionnaire-38 (SLQ; Sodergren, Hyland, Singh, & Sewell, 2002). The SLQ measures the extent to which individuals believe their illness has had a positive benefit, regardless of the negative consequences of being ill (Sodergren et al., 2002).

A chronic condition can be defined as a human health condition or illness that is constant or otherwise continuing in its effects (World Health Organization, 2005). The term ‘chronic’ is clinically applicable when the course of the illness continues for further than three months. Common chronic diseases include Rheumatoid Arthritis (RA), diabetes, cancer, asthma, HIV/AIDS, chronic obstructive pulmonary disease (COPD) and back pain (World Health Organization, 2012). RA refers to the systemic inflammatory health condition that is characterised by insistent synovitis in various joints and autoantibodies which can be causing pain, swelling, stiffness and disability (Scott, Wolfe, & Huizinga, 2010).

The present research aims to explore the likelihood and the extent of PPC and the potential factors that might be related to PPC when considering RA symptoms. The psychosocial variables assessed include: psychological well-being, coping strategies, self-efficacy for pain, arthritis self-efficacy for other symptoms, sense of coherence and resilience, social support, social activity, quality of life, depression and level of tension. The RA physical variables consist of: mobility, walking, bending, hand and finger function, and arm function. The demographic characteristics of those people with RA concern: age, gender, marital status, education, employment and ethnicity. This is addressed within the following chapter.

1.1.1. The roots of Positive Psychology

There is overwhelming documentation to propose that the primary works of the positive psychological movement date back to an early work in the New Thought movement (O’Connell, 2009); mental health (Jahoda, 1958); psychotherapy (Freud & Breuer, 1895); humanistic approach (Maslow, 1955) and social work (Becker & Marecek, 2008). This topic will be addressed subsequently.

The New Thought movement, initiated in the 19th century believed that individuals focus on agency and reason to create growth in their health and lives through positive thoughts (O'Connell, 2009). However, it was not the sole contribution to the development of the positive aspects of psychology. Other early work in psychotherapy also has a major role in recognising how negative thought might change into positive thought. For instance, Jahoda (1958) wrote '*Current Concepts of Positive Mental Health*', a book in which the author considered positive mental health as a long-term personality characteristic.

Breuer refers to the concept of '*talking cure*' (Freud & Breuer, 1895). The term indicates a common belief held in psychotherapy that talking about negative feelings, such as anxieties and guilt, could create relief and recovery (Farber, 2005). In the theory of psychoanalysis, this process is called '*catharsis*', which could potentially produce calm and reduce stress (Freud, 1957). Freud, (1957), believed this is because a person releases negative feelings in a therapy session, where there is no personal judgment about one's behaviour, enabling the individual to find peace and relief. Nowadays, the concept of a talking cure refers to a generic name for a range of psychotherapies, for example, Cognitive Behavioural Therapy (NICE, 2014). In addition to this idea, positive thinking, has become the subject matter of the positive psychology movement developed by Seligman & Csikszentmihalyi, (2000), in which they argue that being given the chance to recognise and challenge the negative thoughts would systematically lead to approach optimism. This, in the long run, can help prevent the development of depression. The mechanism behind this process is akin to those of cognitive therapies, wherein people changing hopelessness into hope to prevent depression (Wong, 2011). Additional impact on the growth of the positive psychology movement is based on a positive attitude towards theories of psychology in the twentieth century. For example, some of the well-known humanistic clinical psychologists considered a human being as a fully functioning person. They were: Allport, (1955), Maslow, (1955) and Rogers, (1959).

Allport, (1955) explained that a mature personality is a configuration of positive functioning, wherein mature individuals can cope in a healthy fashion and face up to life's problem, to achieve pleasure and to follow sensible goals. He assumed that the mature person has a clear philosophy of life and genuine values. For Allport, (1955), the essence of being human is the process of becoming, a concept often found in the literature of humanistic psychologists.

Maslow's, (1955) concept of self-actualisation, as the ultimate level of psychological development, refers to the concept of 'actualisation' of the full personal potential (Ivtzan, Gardner, Bernard, Sekhon, & Hart, 2013). A simple definition of self-actualisation refers to '*the full realization of one's potential*' and of one's 'true self', Maslow (1954, cited in Ivtzan, Gardner, Bernard, Sekhon, & Hart, 2013). Self-actualisation refers to the basic growth motivation which previously exists in the human being or, more precisely, of what the person is (Maslow, 1955). A self-actualiser is an individual who is living innovatively and completely using his or her potential. Maslow believed "what a man can do, he must do", this refers to the desire for self-fulfilment, specifically, to the aptness for him to actualise his potential (Maslow, 1955).

Rogers (1959) puts emphasis on the idea of a fully functioning person. This refers to persons who can live in full with the entire of their feeling and responses in the optimal development (Rogers, 1959). These people trust their own organism and it's functioning, as they can take responsibility of their own actions and can alter them if they consider them to be unsatisfactory. They can experience their entire feelings and not be frightened of what they are. They are open to evidence and are fully implicated in the process of being themselves. These people live life to the full and are aware of themselves through their own experiences, wherein the human being repetitively aims to achieve its full potential (Rogers, 1959).

Sometime later, in 1987, Antonovsky introduced the term 'Salutogenesis' to refer to the field of stress and coping. He describes the processes of health and optimal functioning by referring to the concept of resilience in which the capacity of an individual to cope during difficulty is central to their resilience (Tugade & Fredrickson, 2004).

To end with, it is worthwhile to note that social work was another predecessor in the development of the positive psychology movement, a discipline that, despite partaking positive psychology's approach to support human being power, has also frequently given support for social change (Becker & Marecek, 2008).

1.1.2. The Context of Positive Psychological Change

It has been acknowledged by Seligman & Csikszentmihalyi, (2000) that there are human strengths which act as buffers opposed to psychopathology: the positive human traits, for example, hope, flow and optimism (Csikszentmihalyi, 2014). Therefore, the message of

positive psychology is to reiterate that the field of psychology is equally about the study of disease; strength and positive quality (Michalos, 2014). In this account, positive psychology refers to the scientific study of the positive human functioning and flourishing on multiple levels (Seligman & Csikszentmihalyi, 2000). The term 'Flourishing' is a comprehensive term for all 'positive change' regardless of it being connected directly to the outcome of psychological trauma; other forms of stress or coupled to purely human development without any form of stress precursor at all (Blore, 2012).

In this respect, psychology is not only the study of human weakness and pathology, but it is also the study of strengths, insight and growth (Seligman & Csikszentmihalyi, 2000). Thereby, positive psychology research aims to discover human strengths that act as buffers opposed to mental illness (Seligman & Csikszentmihalyi, 2000). On those grounds, some of the main psychological theories, such as humanistic psychology and Bandura's cognitive social approach (1986), support a concept of strength and personal growth. Thus, dominant psychology theories do not consider the person as a passive entity reacting to stimuli; instead, individuals are now seen as decision makers who make choices and who have the capacity to become masterful and efficacious, or (in distressing conditions) helpless and hopeless (Csikszentmihalyi, 2014).

1.1.3. The concept of 'eudaimonia'

A very large body of literature, philosophy and religion throughout history have suggested that there is an individual gain to be had in human pain (Guruge, 2002). The idea that distress can aggravate positive changes is also contained in humanistic psychology and existential philosophy. It has also been recognised that constructive changes can come about as a consequence of suffering and stressful conditions (Tedeshi & Calhoun, 1996). Although the focus on positive growth has attracted increased attention within the last few decades, it has a much longer history, dating back to Aristotle's *Nicomachean Ethics* (1947, cited in, Waterman, 1990).

The Greek term 'eudaimonia' was translated as 'happiness' (Ryff, 1989). Happiness was described as the sense of stability between negative and positive affect (Ryff, 1989). However, it is open to debate whether the Greek word 'eudaimonia' is accurately translated as *happiness* (Ryff, 1989). For example, Waterman, (1981, 1990) has argued that such a translation would have been contrary to the important difference made by the Greeks among

the fulfilment of right and wrong desires (Ryff, 1989). Thus, Waterman suggests that the concept of '*eudaimonia*' is more accurately referred to '*one's true potential*' (Ryff, 1989, p. 16). Nevertheless, the concept of '*eudaimonia*' as the realisation of one's true potential has not been the only indicator of positive psychological states in earlier empirical studies (Joseph, 2009; Ryff, 1989).

To expand, the concept of well-being can be considered according to two traditional perspectives: one - the hedonic approach- refers to the state of happiness and mainly defines well-being as the existence of positive affect (i.e., pleasure) and the lack of negative affect (i.e., avoiding pain). Thus it is believed that happiness in terms of hedonic feeling is mostly experienced when life is trouble-free and purpose is gained (Straume & Vittersø, 2012). In the second perspective, the eudaimonic viewpoint, personal growth is equated with living with full, optimal functioning in a profoundly satisfying manner (Deci & Ryan, 2008). This means the eudaimonic approach refers to experiencing challenges and to the achievement of goals; it is believed that personal growth is associated with eudaimonic thought (Straume & Vittersø, 2012). However, not everybody agrees with the separation being made between eudemonic and hedonic forms of well-being, as it is avoidable both from philosophical perspectives and scientific theories (i.e., Biswas-Diener, Kashdan, & King, 2009). Nevertheless, little is known about the mechanisms underlying these approaches and the debate is still in progress (McMahan, Dixon, & King, 2013).

Ryff, (1989) distinguished between the hedonic approach, which speaks of the subjective well-being relating it to happiness, and the concept of eudaimonic approach, which relates the psychological well-being to human potential development. Both Maslow's concept of self-actualization and Roger's term fully functioning person refer to the ways by which a person achieves psychological well-being and personal fulfilment (Ryff, 1989).

In an attempt to merge diverse conceptions of well-being, from the earliest Greek to the contemporary psychological theories, Ryff, (1989) divided the construct within six dimensions: Self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life and personal growth. In order to assess the six dimensions she created the psychological well-being scale (Ryff, 1989). It is worthwhile to note that Seligman & Csikszentmihalyi, (2000) argue that happiness, to some extent, is related to one's ability to perceive unfortunate situations as fortunate. Seligman proposed, that

happiness or subjective well-being is not all we want in life, since at the opposite end of the scale, there is suffering or having a mental illness. However, we can be a happy person while we are suffering, only not in the same moment (Diener & Seligman, 2010).

Although the topic of positive psychology has a long history, nevertheless, the concept of positive change has not been fully combined with clinical psychology and empirical studies (Joseph, 2009). This is due to the fact that past research focused on negative psychological change rather than positive change. However, for the last three decades there has emerged a body of literature which provides evidence to encourage positive changes that could occur following a broad range of stressful events (Hungerbuehler, Vollrath, & Landolt, 2011). The events for which growth endings have been accounted include: transportation accidents, natural disasters, interpersonal experiences and chronic long term medical problems such as cancer, heart attack, brain injury, spinal cord injury, HIV / AIDS, multiple sclerosis and RA (Joseph et al., 2005).

Individuals with RA are often faced with novel circumstances that confront their usual coping strategies. In consequence, they should find novel ways of coping with their changed circumstance (Dures et al., 2013). Hence, some RA people finally might reach a state of recovery and in doing so, experience beneficial psychological adjustment (Dures et al., 2013). There is evidence to support the concept that using effective coping strategies has a significant positive impact on psychological well-being (Englbrecht, Kruckow, Araujo, Rech, & Schett, 2013), health-seeking behaviours (McMahan et al., 2013), and treatment outcome (Nygren et al., 2005).

1.1.4. Proposed definition of Positive Psychological Change

It must be emphasised that the ways in which PPC is conceptualised and operationalised within empirical studies may be critical in determining the ultimate success of the outcomes. Positive change has been described using a variety of terms in the literature. The most common terms which have been used in the previous studies are Post-traumatic Growth (PTG, Tedeschi & Calhoun, 1996) and Benefit finding (BF, Tennen & Affleck, 2002). PTG and BF refers to the positive changes associated with traumatic and stressful life events (Helgeson, Reynolds, & Tomich, 2006; Tedeschi & Calhoun, 1996). In a meta-analysis conducted by Helgeson, Reynolds, & Tomich, (2006, p.797) it was confirmed that previous studies on BF have traditionally associated BF to traumatic events in chronic health

conditions such as cancer (Cruess et al., 2001; McGregor et al., 2004; Penedo et al., 2006) and RA (Dirik & Karanci, 2008). However the mechanisms linking BF and PTG to chronic health conditions are still unclear (Bower, Moskowitz, & Epel, 2009; Helgeson et al., 2006). Moreover, even though both terms, PTG and BF, have conceptual overlap, they refer to dissimilar constructs. For instance, demographic factors showed comparable patterns of relationships across BF and PTG and that higher education is associated with increased BF/PTG (Harding, Sanipour, & Moss, 2014). Conversely, in a study conducted by Sears, Stanton, & Danoff-Burg, (2003) there was no relationship between PTG and the individual's level of education. Thus, it is not yet clear how the two concepts relate to one another (Sears et al., 2003). Therefore, for the purpose of this thesis the aim was to use a term with a clear definition. Hence, the current thesis employed the definition of PPC based on the positive consequences of illness reported by individuals who have been diagnosed with RA, as measured by the Silver Lining Questionnaire-38 (SLQ; Sodergren, Hyland, Singh, & Sewell, 2002). The SLQ measures the extent to which individuals believe their illness has had a positive benefit regardless of the negative consequences of being ill (Sodergren et al., 2002). Therefore, the term PPC has been chosen and the definition of PPC is the extent of positive change that individuals with RA experiences in spite of living with the condition (Sodergren et al., 2002). The SLQ-38 is a generic scale of positivity in which people are questioned about the positive aspects of their illness experience and asked to point out the scope to which they agree or disagree with the 38 statements using a 5-point Likert scale: (1) strongly disagree; (2) disagree; (3) not sure; (4) agree; (5) strongly agree (McBride, Schroevers, & Ranchor, 2009). The scale measures ten aspects of positivity. These are: improved interpersonal relationships, positive influence on others, self-improvement, reappraisal of life, restructuring of life, spiritual changes, sensitivity to emotions, skills and new pursuits, self-knowledge and confrontation of current concerns (Hyland, Sodergren, & Lewith, 2006).

1.1.5. Psychological factors associated with Rheumatoid Arthritis

Chronic conditions are illnesses that remain for an unlimited period and which affect an individual's ability to function (in most cases). Patients with RA require long term pharmacological treatments and so need to cope with the consequences of the medication in order to manage their daily lives. On the other hand, they have to deal adequately with the psychosocial, behavioural and emotional consequences of the illness on a regular basis. For

instance, most often people newly diagnosed with RA are faced with fluctuations in their symptoms; limited mobility and reduced participation in activities (Dures et al., 2013). As a result, a decrease in their level of activity links with a potential reduction in their involvement with their roles and relationships within the community. The combination of these factors may affect the patients' emotions and their impression of themselves (Dures et al., 2013). Therefore, an individual with RA faces a challenge when dealing with the complex combinations of the side effects of their illness.

Even though people with RA vary in the extent to which they are impressed psychologically by their diagnosis, it is believed that some people will experience emotional distress at some point (Dures et al., 2013). For example, in a meta-analysis conducted by Matcham, Rayner, Steer, & Hotopf, (2013), it was found that the prevalence of depression among RA people was between 34.2% - 38.8%, yet the extent might vary depending on the measurement used and the characteristics of the study samples.

Cohen et al., (2012) proposed that chronic psychological stress is related with a higher risk of developing depression and autoimmune diseases. RA is an autoimmune disease, in which the body's immune system stimulates to react against healthy joints instead of fighting infection. Commonly, RA populations have periods of deteriorating disease activity (flares) that encourage them to search for further help or medication change. Individuals with RA describe the depth and the extent of symptom strength and consequences beyond normal symptoms (Hewlett et al., 2012). For instance, a patient with RA commented, '*When it's bad [pain], a lot of joints. I just feel that all my body, my feet, my knees, my hands, even sometimes my hips and my shoulders, in my neck, you know, like everything*' (Hewlett et al., 2012, p. 71). Thus, it is believed that individuals with RA are vulnerable to psychological disorders, mainly as a result of the pain and functional disability that are the characteristics of this disease (Revenson & Felton, 1989). In an another example an individual with RA stated that, '*Whatever pair of shoes I've got on they just don't seem to go on my feet because they're all swollen*' (Hewlett et al., 2012, p. 71). Although, some individuals with RA experience joint symptoms of swelling and heat, these symptoms are not universal among all persons with RA.

Fatigue linked with RA is perhaps induced by a dynamic relationship of clinical elements (for example, pain and inflammation) and psychosocial factors (i.e., mood and illness beliefs), which will fluctuate both between and within individuals and over time (Hewlett et

al., 2011). The acknowledgement of fatigue as a symptom significant to those diagnosed with RA has created global agreements that fatigue should be measured in every RA trial (Dures et al., 2013).

Fatigue is a key common symptom and likely to have complex, multifunctional pathways, including altering combinations of RA clinical and psychosocial factors (Goodchild & Tang, 2011). Some individuals with RA emphasized fatigue as a major concern, just as personally important as pain (Hewlett et al., 2005), as they never recovered even though they had taken plenty of rest. *'You get very tired. It's killer fatigue to the point where breathing is a real . . . it's using energy just to breathe. You can sleep all day and night and never feel refreshed. Yes. Never feel refreshed'* (Hewlett et al., 2012, p. 71).

The present research aims to explore the potential factors that might be related to PPC when considering RA symptoms. It is important to consider psychological factors that might act to alleviate the extent of the symptoms described, the course of the disease, and the RA patient's feelings of psychological well-being. The psychosocial variables comprise of: psychological well-being, coping strategies, self-efficacy for pain, arthritis self-efficacy for other symptoms, sense of coherence and resilience, social support, quality of life, depression and level of tension. One of the potentially valuable psychological concepts to bridge the gap in the current knowledge between disease, disability and adjustment to the illness is psychological well-being. This is addressed in the following sections.

1.1.5.1. Psychological Well-being

Psychological well-being has been conceptualised and measured across studies differently. For instance, some have measured biological markers and some negative and positive affect; others have looked at mental health symptoms, and some have looked at the impact of the illness's presentation in RA. The following few paragraphs address the topic further.

Well-being is a dynamic notion that comprises subjective, social and psychological dimensions along with health-related behaviours. Ryff's *'Psychological Well-Being'* (Ryff & Keyes, 1995), expressly concentrates on measuring manifold facets of this concept. These facets consist of the following: self-acceptance; the establishment of quality ties to another; a sense of autonomy in thought and action; the ability to manage complex environments to

suit personal needs and values; the pursuit of meaningful goals and a sense of purpose in life and finally continued growth and development as a person (Ryff & Keyes, 1995).

Ryff, Singer, & Dienberg Love, (2004) have illustrated how biological markers, such as cardiovascular issues, lower the levels of cortisol and pro-inflammatory cytokines, which are positively associated with eudaimonic well-being (i.e., experiencing optimal functioning), but not hedonic well-being (i.e., happiness) as cited by Ryan & Deci, (2001). Yet the study is limited in its centre of attention, as there was sampling bias due to the small sample size of aging females. Furthermore, the study design is based on a cross-sectional design, so it is unclear whether the well-being influenced the biological markers or the biological markers influenced the state of well-being. However, the findings provide a valuable position to start questioning fundamental associations in relation to well-being and biological elements.

In a study conducted by Coty and Wallston, (2008), the influence of roles taken by RA women compared to healthy participants and their level of well-being were measured. In this study, positive and negative effects have both been considered as an evaluation of well-being. The study findings indicate that females with RA present poorer levels of positive affect compared to healthy individuals. Nevertheless, measuring positive affect and quality of life can be recognised as indicators of hedonic well-being rather than eudaimonic well-being.

Some earlier studies have mainly considered the impact of mental health symptoms, such as anxiety and depression, as indicators of psychological well-being in RA (Covic et al., 2012). Nevertheless, individuals with RA might feel pain from cooperated physical and psychological symptoms, thus psychological well-being does not simply refer to an absence of distress symptoms, such as anxiety and depression (Ryan & Deci, 2001). Alternatively, the impact of quality of life has been examined by Bartlett, Piedmont, Bilderback, Matsumoto, & Bathon, (2003), and this was considered as an assessment of well-being. Treharne and colleagues examined the influence of people's subjective satisfaction with their quality of life in relation to RA duration and psychosocial factors (i.e., social support). The study showed that those who had higher levels of optimism and social support reported a greater quality of life overall (Treharne, Kitas, Lyons, & Booth, 2005).

Some studies have aimed to explore whether people with RA can be classified into groups with the same illness representations. For instance, the data was collected prospectively from 227 individuals diagnosed with RA attending outpatient clinics on two separate occasions, six months apart, by Norton et al., (2014). The latent profile analysis was used to discover the peak number of illness representation both at the starting position and six months later. The analyses recognised two groups from those dividing comparable illness perception profiles (Norton et al., 2014). The first group with a larger number of participants (n=130, 57%) stand for positive illness perceptions which indicates by a strong positive representation of their illness. They recognised fewer symptoms from their condition and described their RA as having a lower impact on their well-being. People with positive illness representation reported higher levels of control over their RA symptoms; lower levels of pain, functional disability and distress, and experienced lower disease fluctuation over time according to variations in their symptoms (Norton et al., 2014). Furthermore, Norton et al. cited that the perceptions of high treatment control are related to higher positive illness representations, which were in the contradictory direction to distress.

On the other hand, those who fitted into the negative illness representation group, n= 97, 43%, recognised more symptoms from their condition and described a stronger impact on their well-being, with lower control over the RA symptoms; higher pain levels; functional disability, and distress. They also experienced wide fluctuations in the disease over time, according to the variations in their symptoms (Norton et al., 2014). Besides, those belonging to the negative illness representation group demonstrated higher pain and distress levels even six months later. Yet, the main disadvantage of this study is that it focuses only on recent onset RA. This is important, as the findings for established RA might have had an influence on the outcome.

Equally, in a study performed by Hobro, Weinman, & Hankins, (2004), 130 newly referred people to the clinic with chronic pain were considered. The participants were assessed based on the key measurements, the Illness Perceptions Questionnaire (IPQ; Weinman, et al., 1996). The data was analysed using the cluster analysis method which identified two groups: “adaptors” and “non-adaptors”. The non-adaptors reported a higher negative illness representation, experienced significantly lower control over the illness and felt it had a stronger impact on their overall well-being (Hobro et al., 2004).

To conclude, acknowledgment of psychological adjustment as a process that frequently changes over time might help people with RA to face the changes in their condition. For example, fluctuations in pain and activity limitations will invariably modify the level of positive change. Moreover, little is known about the positive pointers of health, thus, this viewpoint of psychological adjustment might be useful for RA research (Treharne et al., 2005). Moreover, the validity of psychological well-being is grounded in using a well-known scale to clearly capture the overall well-being. This study expected that there is a significant positive correlation between PPC and psychological well-being (one-tailed).

1.1.5.2. Coping strategies

A standard definition of coping is the cognitive, emotional and behavioural efforts individuals employ to deal with specific internal or external demands (Folkman, Lazarus, Gruen, & DeLongis, 1986). How an individual with RA copes with his/her pain and disability is constantly related to psychological adjustment in relation to depression and anxiety (Covic et al., 2012). Researchers have recognised some dissimilar components of the coping process as Walker, Jackson, & Littlejohn, (2004) stated. Predominant between these are appraisals of warning to self-worth caused by the stressor; the level of control the individual has over the outcome and repetition of the stressful condition (Walker et al., 2004). The appraisal process is founded on the assumption that individuals are continuously evaluating their connection to their surroundings (Walker et al., 2004). The stress process commences when the person becomes aware of a change in the status or faces a threat towards present goals and concerns.

Beyond, RA results in pain, loss of independence, physical disability and psychological distress over long periods of time (Walker et al., 2004; Zautra et al., 2007). Certainly, pain has been significantly associated with prevalence rates of depression and anxiety (Margaretten, Julian, Katz, & Yelin, 2011). Therefore, upon being diagnosed with RA, individuals are challenged with new circumstances that cannot be countered with their usual coping behaviour. Thus, they must discover new ways to cope with their current situation (Englbrecht et al., 2012).

The confirmatory principal component done by Englbrecht et al., (2012), derived four components from the total 18 items of the C-RAQ scale (Newth & DeLongis, 2004). These were cognitive reframing, distancing, emotional expression and active problem solving (Newth & DeLongis, 2004). Cognitive reframing refers to the efforts to perceive an

individual's present situation in a more positive manner through constructive reappraisal and downward social comparison, which has been recognised to be related to positive consequences amongst RA people (Holtzman, Newth, & DeLongis, 2004). The theory of downward comparison argues that individuals experiencing negative affect can often improve their well-being by comparing themselves to those who are assumed to be worse off than themselves, in order to feel better about themselves and increase their well-being (Wills, 1981). Moreover, cognitive reframing has been presented as being related to drops in equally functional impairment and depression (Evers, Kraaimaat, Geenen, Jacobs, & Bijlsma, 2003).

The distancing concept refer to the efforts one make to get away of distress through communicating the pain and indeed looking for emotional support which may cause more trouble (Engbrecht et al., 2012). Devastating thinking and discussions about health problems are related to greater functional problems (Hamilton, Kitzman, & Guyotte, 2006). However, ignoring the pain via distraction might have been linked to get the pain even worse and even might trigger physical disability (Bullington, 2014).

Emotional communication prompts pain-related distress in order to gain interpersonal support. In a study conducted by Affleck et al., (1999), emotional support seeking resulted in higher levels of pain on the following day in individuals with RA. Yet some findings highlight the significance of important personal relationships in encouraging effective coping strategies (i.e., Holtzman et al., 2004).

Active problem solving refers to the enhanced efforts to involve behavioural and cognitive techniques in influencing the pain and its effects (Evers, Kraaimaat, Van Riel, & De Jong, 2002). There is some evidence that active problem solving is typically connected to positive health outcomes (i.e., Sharpe, 2016). However, this finding is inconsistency if people with RA are dealing with a durable stressor, such as pain, where there is unpredictable and uncertain consequences (Aldrich, Eccleston, & Crombez, 2000).

By and large, some individuals diagnosed with RA eventually reach a good psychological status (Hewlett et al., 2012). Those who report positive changes could possibly be connected to improved coping with the disease-related demands (Barskova & Oesterreich, 2009). These changes include the subsequent personality associated area: interactions with others, perception of new possibilities, self-understanding and new dimensions of personal strength, spiritual changes and appreciation of life (Barskova & Oesterreich, 2009). Coping

strategies should therefore be considered an important factor in determining overall well-being in people with RA (Evers et al., 2001) since RA forces a massive burden on the individual's ability to cope (Bartlett et al., 2003) and may significantly reduce psychological well-being and quality of life (Cruice, Worrall, & Hickson, 2011). The present research expected that there is a significant positive correlation between PPC and coping strategies (one-tailed).

1.1.5.3. Self-efficacy

Self-efficacy is the perception of a person's own ability to reach a goal (Zulkosky, 2009). Perceived self-efficacy indicates belief in one's ability to attain given levels of achievement (Zulkosky, 2009). Self-efficacy as a belief, therefore, contains equal confirmation of a capability level and the strength of that belief (Bandura, 1997). Social cognitive theory considers the quality of self-efficacy to be one of the individual resources that balances environmental burdens in the stress appraisal process (Bandura, 1997).

Stress can be cognitively judged as a challenge for those who are living with the symptoms of RA. Thus, beliefs regarding self-efficacy might influence health in two ways. First, self-efficacy impacts the adaptation of healthy behaviours, the termination of damaging behaviours and the upholding of behavioural changes in the face of challenges from stressors. Second, self-efficacy beliefs persuade some biological processes such as the hypothalamic-pituitary-adrenal axis that, in turn, effect health and illness (Bandura, 1997). In addition, self-efficacy beliefs take part in a critical role in psychological adaptation, psychological troubles and physical health, in addition to professionally directed and self-guided behavioural modifications (Moran & Brady, 2010).

Previous studies have widely identified the impact of certain elements of RA in relation to self-efficacy capacity, for instance disease activity (Brekke, Hjortdahl, & Kvien, 2003); daily pain (Turk & Okifuji, 2002); mood (Irwin et al., 2012), and coping with pain (Strahl, Kleinknecht, & Dinnel, 2000). However, these studies have mostly used a cross-sectional design.

In a longitudinal study conducted by Brekke, Hjortdahl, & Kvien, (2001), the aim was to explore whether the level of self-efficacy for pain and other symptoms in persons with RA are related to the patients' health status scores over a two year period (Brekke et al., 2001).

The study findings show that there were favourable changes linked to higher self-efficacy scores, even after adapting for demographic factors (Brekke et al., 2001). Nevertheless, the study is limited in its generalisation as it excluded the data for the self-efficacy function scale and therefore it was impossible to compare these findings with other health status measures for physical functioning.

A study conducted by Barlow, Cullen, & Rowe, (2002) reveals that both psychological and physical health status are associated with self-efficacy scores, moreover, physical dysfunction does not necessarily represent deprived psychological wellbeing (Barlow et al., 2002). Furthermore, some clinical trials have considered educational interventions for people with RA and have cited the importance of using information, coping strategies and problem solving strategies for the administration of RA symptoms (Brekke et al., 2001; Ndosu et al., 2015). Besides, Walker et al., (2004), have verified that self-efficacy is robustly linked to intention and action. Therefore, it is believed that self-efficacy appraisals concerning the potential ability and success of coping strategies may play a most important role in determining the level of psychological well-being in people living with RA (Walker et al., 2004). This study predicted that:

- a) There is a significant positive correlation between PPC and self-efficacy pain management (one-tailed)
- b) There is a significant positive correlation between PPC and self-efficacy other symptoms (i.e., fatigue) (one-tailed)

1.1.5.4. Sense of Coherence and Resilience

Dealing with stress is an expected part of life since, at one point or another, every person experiences barriers on some level. Some of these challenges may be quite small, whereas others might be devastating. How individuals deal with these difficulties can play a key role in the long-term psychological consequences. Salutogenic theory (Antonovsky, 1993) explains why people stay healthy, through introducing the concept of Sense of Coherence (SOC). SOC as a personality characteristic describes a life perspective on harms and difficulties in a way which makes coping with stress easier.

Bonanno, Wortman, & Nesse, (2004) explain that some people, when facing stressful conditions, maintain a firm equilibrium without reactive psychopathology, and that has been named resilience. The explanation is possibly that resilient people have a strong internal locus of control so they believe they can affect their situation (Werner, 2004). However, if the stressors increase, the ability to sustain resilience might become weighed down, and in this case people might reach the breakdown stage. Besides, Bonanno's perspective of resilience refers to all human beings possessing the same essential stress-response system; therefore, the majority of people are relatively good at using the system to handle stressful circumstances, while others are not. According to him what makes people respond differently to stressors is their perception of the event, rather than the event itself.

A body of research has aimed to clarify the characteristics of resilient people, for instance, resilience as a type of adaptive capability is related to well-being and independent functioning (Nygren et al., 2005). A study conducted by Wells, Avers, & Brooks, (2012) aimed to examine resilience and sense of coherence in relation to mental and perceived physical health in 125 people aged 85 and over. The study findings revealed that older people have the same level of internal strength and resilience as younger adults. Moreover, Wells and colleagues (2012), reported that there is a gender difference in relation to the dimension of mental health, but not physical health. However, this finding was not duplicated by Moe, Hellzen, Ekker, & Enmarker, (2012). The goal of Moe et al. was to examine internal strength and its connection to mental and physical health in chronically ill individuals, male and female, of an older age group. The cohort was made up of 79 females and 41 males, and the age range was 80-101. The study findings reveal that people with medium and low resilience showed lower internal strength and were more at risk to experiencing mental health problems, however, there were no gender differences in this group. The study concluded that promoting internal strength in very old people can help to build up their experience of independence and encourage them to enjoy life.

A sense of coherence has been shown to correlate positively with physical performance and future disability (Wells et al., 2012); hope (Nygren et al., 2005); pain and fatigue (Nesbitt & Heidrich, 2000; Nygren et al., 2005), and purpose of life (Nygren et al., 2005; Sarvimäki & Stenbock-Hult, 2000). On the other hand, there is some evidence that suggests that positive change might not be a kind of resilience, such as Levine, Laufer, Stein, Hamama-Raz, & Solomon, (2009). However, the literature surrounding SOC and the interactions that might occur in relation to positive change in individuals with RA, with several aspects of bodily

decline and also functional physical health limitations, is not well understood yet. The present study predicted that there is a significant positive correlation between PPC and sense of coherence and resilience (one-tailed).

1.1.5.5. Social support

RA can be life changing as people with RA might need durable treatment to control their symptoms and decrease joint harm. Thus, sometimes it can be helpful to talk to someone else who really understands what it is like to live with RA. Perhaps chatting to another person who has had to face similar challenges and choices would help people living with RA to progress their knowledge of the illness. Having access to social networks to talk about the condition would be helpful for those who live with RA. One of the reasons is that this could be a chance to develop their perception of the illness and its course. Moreover, there might be an opportunity to counter any misconceptions they might have.

The goal of the research conducted by Savelkoul, Post, de Witte, & van den Borne, (2000), was to explore social support in relation to coping strategies and subjective well-being. In a cross-sectional study the data from 628 people with chronic rheumatic disorders was collected. The results of this study confirm that coping adaptations influence subjective well-being through social support. Moreover, avoidance coping would lead to lower social support, which in turn reduces the level of social well-being.

Griffin, Friend, Kaell, & Bennett, (2001) aimed to measure the link between coping styles over the pain periods and perceived responses from close others, such as family members and friends. The cohort incorporated 42 individuals with RA, mostly white, married, middle aged females. The participants' responded to the survey questionnaires and their rheumatologist assessed their clinical status at two intervals over a period of nine months. The study findings showed that there were a few challenging responses from others, such as getting angry or irritated when the person is in pain. This in turn impacted on the patient's coping style and led to negative emotions. Then again, negative emotions contributed towards general negative affects over time. Moreover, those who experienced punishing responses from others around them tended to have more severe RA symptoms when rated by their rheumatologist (Griffin et al., 2001).

On the other hand, some previous studies have shown that social support can have a favourable impact on overall psychological adjustment and coping processes in people with RA. For instance, Holtzman et al., (2004), looked at the influence of social support on coping and the level of pain in 73 adults with RA. The participants filled in a structured record on pain coping, severity of pain, and satisfaction or dissatisfaction with support, twice a day over a one week period. The study findings show that support influenced RA pain through the coping strategy that was used. For instance, more support from those close to them would assist the patients in employing specific coping strategies, and also in using the coping strategy more effectively (Holtzman et al., 2004). Then again, agreement with support was coupled with adaptive uses of coping strategies, whereas disagreement with support was connected with maladaptive coping (Holtzman et al., 2004). For that reason, Holtzman and colleagues (2004) highlight the importance of close relatives in encouraging adaptive coping strategies. In brief, the majority of the research findings in relation to the influence of social support highlight the importance of close family members or friends in dealing with RA symptoms. This study predicted that:

- a) There is a significant positive correlation between PPC and social support (one-tailed)
- b) There is a significant positive correlation between PPC and social activity (one-tailed)

1.1.5.6. Quality of Life

Quality of life (QoL) can be thought of as the overall impact of the illness and the impact of treatments for that illness (Hunt, McKenna, & Doward, 1993). Measuring QoL has become a crucial and often needed part of the health outcomes appraisal. People with a chronic condition, such as RA, perceive the effect of their disease during measurement of QoL which offers a meaningful way to conclude the influence of health care when a cure is not possible. It was widely accepted as a multifaceted concept that has caused a good deal of research for the period of three decades. It has been operationally defined and measured in various ways by different studies. To begin with, measures to evaluate QoL were derived from objective indicators of living conditions such as: education, health and employment. The concept later extended to subjective factors such as productivity, intimacy and emotional well-being. These subjective factors also influenced an individual's judgement of overall QoL. There has been a growing interest in the measurement of quality of life in RA (Borman et al., 2007) which demonstrates that RA has a profound effect on patients functioning, QoL and well-being (Borman et al., 2007). Moreover, QoL in individuals

diagnosed with RA has often been used as a measure of psychological well-being (Gettings, 2010; Treharne et al., 2005).

Baruth, Wilcox, Schoffman, & Becofsky, (2013), aimed to examine the frequent cause of disability in 396 people with RA using a randomised controlled trial study design. The authors used the Health Assessment Questionnaire (HAQ, Fries, Spitz, Kraines, & Holman, 1980) to measure disability. The study findings reveal that 50% of the disability variance scores were explained through psychological factors, while the remaining were attributed to physical health related factors, such as RA symptoms. Considering the demographic factors, Baruth and colleagues demonstrated that older age; longer RA duration; high school education, and greater pain are significantly associated with higher disability levels. Their study concludes that the possibility of the impact of both physical and psychological variables in relation to disability in the target sample should be considered in clinical trial studies.

In a study conducted by Borman et al., (2007), 40 RA people were examined in relation to their quality of life and life satisfaction. The study employed the Nottingham Health Profile to evaluate QoL and the Life Satisfaction Index to measure psychological well-being (Borman et al., 2007). The study findings show that the RA population had trouble with their QoL, and reduced life satisfaction, compared to the same characteristics in their equivalent control group.

The relationship between work and QoL was measured with a large cohort of individuals with RA (n= 1059) through a postal questionnaire by Chorus, Miedema, Boonen, & Van Der Linden, (2003). The study findings suggest that, although physical role functioning was limited in persons with RA, the impact of physical health related QoL was significantly higher; however, there were no significant effects on mental health related factors. In general, measuring QoL refers to several subjective experiences, for instance psychological well-being and daily function, which is emphasised by the past studies on this target sample (i.e., Bartlett et al., 2003; Sivas et al., 2004). The current thesis predicted that there is a significant positive correlation between PPC and quality of life (one-tailed).

1.1.5.7. Depression

By conservative estimates, nearly 400,000 individuals in the UK suffer from RA and the pain and disability it entails and a considerable number of these people (40,000) are subject to depression (Baldwin et al., 2014). People with RA are two times as likely to experience depression compared to other members of the general population (Dickens, Jackson, Tomenson, Hay, & Creed, 2003), and the variation might be more related to the levels of pain experienced rather than socio-demographic factors (Dickens, McGowan, Clark-Carter, & Creed, 2002). This is because in people with RA, depression not only contributes to the RA, but also influences the way the person perceives and copes with the RA's clinical symptoms, such as pain (Dickens et al., 2003).

Some studies have examined that, while the level of depression in RA is higher than in the healthy population, the difference is due to the level of pain experienced, rather than socio-demographic factors (i.e., Peeters, Brown, & Burton, 2014). On the other hand, there is some evidence that depression in individuals with RA is due to the contribution of social and the biological elements (i.e., Margaretten et al., 2011), suggesting that RA symptoms contribute towards the level of depression equally, through clinical and psychosocial factors. Beyond that, demographic factors such as age and gender, along with clinical factors, for instance pain, might lead to greater level of depression; bearing in mind that depression could be related to increases in pain and negative feelings in RA people (Zautra, Smith, Affleck, & Tennen, 2001). This in turn leads to worse health consequences and more RA related hospitalisations. Besides, there is some evidence to suggest that increases in weekly negative feelings are related to higher levels of RA pain in the proceeding weeks (Smith & Zautra, 2008). Thus, depression should be considered as an RA co-morbid symptom and, as such, it should be taken into account in the RA treatment plan to decrease the level of depression (Margaretten et al., 2011).

Besides, there is some evidence that shows that depression in individuals with RA is associated with enhanced levels of pain (Zautra et al., 2007), as well as increased levels of anxiety (Covic et al., 2012). Covic and colleagues (2012), recruited 169 male and female persons with RA, mean age 58.3 years, from various geographical locations including the UK (n= 89) and Australia (n=80). The participants were examined using the Depression Anxiety and Stress Scale (DASS; Lovibond & Lovibond, 1995) and the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The findings confirm that 58.3%

had neither depression nor anxiety, however 21.8% had both anxiety and depression. Moreover, 13.5% reported anxiety only and 6.4% confirmed depression only. This study concluded with further evidence for the high ratio of depression, as well as higher levels of anxiety in the study population. Although the study findings highlight the comorbidity of depression and anxiety in persons with RA it is unclear on which scale, DASS or and HADS, but it may do so with more sensitivity in this study. Thus it seems a crucial requirement for future studies to examine the responsiveness of those scales.

Depression in individuals with RA can be demanding, to some extent, because it changes one's normal way of thinking. Having depression contributes to make the patients consider the world through negative thoughts to the extent that it deforms reality and a person's general viewpoint on life. Abela & D'Allessandro, (2002) argues that persons with depression get caught in a downward spiral, where depression directs to negative thinking, and negative thinking makes the individual even more depressed. Negative thinking can lead to many problems. Among them, given the link between thoughts and emotions, it can bring down or keep down the patient's mood. Moreover, negative thoughts can impact the way individuals take action, which can lead to a variety of challenging behaviours (Abela & D'Allessandro, 2002).

On the other hand, there is some evidence that shows that greater levels of overall positive feelings can predict lower levels of pain in successive weeks (Zautra, Johnson & Davis, 2005). Thus, the way individuals with RA perceive their illness is crucial to understanding the link between depression, pain and disability (Zautra et al., 2007), however, the mechanism is unclear (Astin, Beckner, Soeken, Hochberg, & Berman, 2002). The reason is that the majority of these studies have a correlational design; therefore, no causal inferences can be drawn. On the other hand, there are a few longitudinal studies that have failed to shed light on the causal associations between pain and depression (i.e., Wolfe & Hawley, 1993). Therefore, it is highly important to understand perceptions of positive change as a reaction to highly uncontrollable and uncertain stressful life conditions, such as RA. The thesis predicted that there is a significant negative correlation between PPC and depression (one-tailed).

1.1.5.8. Level of tension

Individuals with RA face several significant challenges to cope with the impact of symptoms and consequences of the condition (Zautra, Smith, Affleck, & Tennen, 2001). However, possibly the most difficult challenge is stabilising their quality of life regardless of chronic pain and distress that are frequently impossible to predict or control (Lin et al., 2006; Zautra et al., 2001). Clearly, one of the consequences of painful conditions, such as RA, is to develop states of tension and irritability over the period of the pain episode which could potentially increase the level of pain experiencing (Zautra et al., 2007). Without a doubt, both pain and being uncertain about the onset of pain are sources of stress that affect a person's coping resource abilities. Matcham et al., (2013), stated that the high level of depression among individuals with RA, suggests that ideal care of individuals with RA would not be possible without management of their depression. The association among negative affect and pain varies equally between individuals and within the same individuals in due course (Zautra et al., 2001).

Stress and anxiety are relatively important factors in psychological adjustment to RA (VanDyke et al., 2004). This is because the RA symptoms might fluctuate extensively over a particular day or even over extended periods of time, which may contribute towards distressing symptoms (i.e., depression, anxiety and stress). Moreover, the nature of RA as a challenging condition with various illness connections, such as reducing functional status and pain, may raise the possibility of distress symptoms (Mendlowicz & Stein, 2000). To add to this, persons with RA who are identified as being depressed might reveal higher levels of depression and anxiety, as cited by Ho, Fu, Chua, Cheak, & Mak, (2011); Matcham et al., (2013) and Zautra et al., (2008), who confirmed that equal measures of anxiety and depression affect overall distress. In addition, depression and anxiety are frequently co-morbid conditions and are usually interrelated (McWilliams, Cox, & Enns, 2003).

The study carried out by VanDyke et al., (2004) illustrated that the levels of anxiety are correlated with both the scores for depression and stress, although these findings are limited in their focus because the non-random sample technique used restricts the generalisability of the study, but it illustrates that persons with RA, particularly if experiencing depression, tend to show levels of anxiety and stress, which might be higher than for the general

population. However, a few previous studies have considered positive emotional states as valuable psychological resources for the duration of stress (Folkman & Moskowitz, 2000; Zautra et al., 2001). As an example, Fredrickson, (2001), stated that positive emotions can play a key role in undoing negative affective states. Thus, decreasing the level of distress symptoms in individuals with RA might help them to cope with the burden of the illness and facilitate increased psychological well-being. The thesis predicted that there is a significant negative correlation between PPC and level of tension (one-tailed).

Living with RA means learning to cope with physical limitations and to change behaviour accordingly in order to deal with the impact of psychological symptoms such as depression and distress. The next section will look in depth at RA as a medical health condition and explain why RA is challenging.

1.2. What is Rheumatoid Arthritis?

RA refers to the systemic inflammatory health condition that is characterised by insistent synovitis in various joints and autoantibodies which can be causing pain, swelling, stiffness and disability (Scott et al., 2010).

There are nearly 400,000 people with RA in the UK however, the RA prevalence is low, with about 1.5 men and 3.6 women increasing RA each year thus, roughly 12,000 individuals develop RA per year in the UK (Anon, 2013) . Taken as a whole the existence of RA is two to four times larger in females and elderly, onset being most likely for individuals in their 70s, however persons of all ages can develop the disease (Scott & Steer, 2007).

RA mainly affects at least one small joint with swelling that might increase or change over time. Moreover, it could be recurrent and vary from one to another, however, the symptoms are not likely to be explained by any other disease (Wasserman, 2011). It can be seen predominantly in small joints for instance toes and fingers yet it might gradually developed to shoulders, knees and muscles (Lee & Weinblatt, 2001). Besides, the lining of the affected joints might become inflamed triggering swelling and pain (Lee & Weinblatt, 2001).

1.2.1. Aetiology

Over the past few decades it has been known that RA is basically an autoimmune disease since the body's immune system activates to act against healthy joints rather than fight infection. Thus, in people with RA the immune system incorrectly directs antibodies to the

lining of a person's joints, where they damage the tissue nearby the joint. This causes the tiny layer of cells covering the patient's joints to become inflamed and sore (NICE, 2009). Due to the inflammation the chemicals released cause solidify the area around joints and damages to the bones; cartilage and tendons (Scott et al., 2010). Although, it has seen substantial advances in these areas recently, the pathogenesis of RA remains to some extent a mystery. For instance, an infection or virus may prompt onset, but none of these ideas have been proven. Moreover, it is not yet known what triggers RA (Lee & Weinblatt, 2001).

1.2.2. Predisposing factors

The results of several studies have shown the increased risk factors of RA include biological factors such as genes and hormones (Lee & Weinblatt, 2001). There is some evidence that genes can explain a small role in the condition for instance, Scott et al., (2010) proposed that 50% of the risk for development of RA is attributable to genetic factors. Even a monozygotic twin of an individual with RA only has a one in five chance of developing it (Jiang, Frisell, et al., 2015). With respect to hormones, RA is more frequent in females than males, which might be due to the special effects of the hormone oestrogen that is present at greater levels in females (Costenbader & Manson, 2008), however, this has not been proven. Apart from this, there is some evidence that smokers tend to develop RA but the evidence is not conclusive (i.e., Wasserman, 2011).

1.2.3. The common symptoms

The frequent symptoms of RA are: flare-ups, pain, fatigue, stiffness, warmth and redness. An individual with RA may experience flare-ups at any time over the day or night and when the symptoms are strongest and severe (NICE, 2009). There are various reasons for the cause of the flare, however in RA a flare can be related to stress (Hewlett et al., 2011) and natural fluctuations in the immunological processes that drive inflammation (de Brouwer et al., 2011), though, this has not been adequately understood yet (NICE, 2009). Although, the variety of clinical characteristics of RA is broad, the influence of pain and stiffness mainly is the worst which can last for over an hour (Raza & Filer, 2009). RA is a crippling illness which is mostly linked with hurting and throbbing pain which gets worse when one has been inactive for a while or often felt despite the fact that one is resting (Smith, Smith, & Seidner, 2011). Commonly, RA symptoms are more painful in the morning, when patients with RA

first awaken (Lee & Weinblatt, 2001), nevertheless, the RA symptoms start to decrease as the day progresses and individuals start using and moving the joints (Hewlett et al., 2011). Among RA symptoms fatigue and pain are the most challenging features of the disease that have been considered in previous studies, as discussed in the following sections.

1.2.3.1. Fatigue

Fatigue affects up to 70% of persons with RA and is experienced as devastating and challenging to be managed (Dures et al., 2013; Hewlett et al., 2005). Fatigue in individuals with RA involves unpredictable chronic tiredness that is poorly relieved by breaks, and it seems to be highly linked to psychosocial factors (Mayoux-Benhamou, 2006). For instance, some of the previous research confirms that fatigue, pain and depression are often associated with a complex and dynamic mechanism, considering psychosocial factors and RA illness beliefs (i.e., Dures et al., 2013). Moreover, some studies have revealed that some patients can become detached between the severity of fatigue and their perceived ability to cope with it (Dures et al., 2013; Hewlett et al., 2005; Repping-Wuts, Uitterhoeve, van Riel, & van Achterberg, 2008). In addition, there is various evidence that pain and depression are important predictors of fatigue (Lu, Lin, Lin, & Lin, 2008) and fatigue is an important symptom in RA, which interferes with quality of life (Repping-Wuts et al., 2008).

More recently, Munsterman, Takken, & Wittink, (2013), conducted a cross-sectional study to explore whether physical activity is related to fatigue, when controlling for gender, age, depressive symptoms and pain in persons with RA. The findings show a statistically significant relationship with depressive symptoms, which explained a 33% variance in fatigue. As a result, the authors conclude that depression contributes towards fatigue, and not physical activity. Similarly, in a study conducted by Pollard, Choy, Gonzalez, Khoshaba, & Scott, (2006), they aimed to examine the association between fatigue, disease activity, and pain in persons with RA. The study findings show that fatigue is common, as over half of the study participants demonstrated high levels of fatigue, which is associated with mental health problems in particular, pain and depression, but not disease activity. Aside from that, in a study performed by Franklin & Harrell, (2013), the influence of fatigue, satisfaction with ability and perceived health were examined. The study results confirm that RA related fatigue contributes to reduced psychological well-being in older

persons. In addition, this study reveals that fatigue is a strong independent factor in declining health and psychological well-being in individuals with RA.

Indeed, the past studies' findings indicate that even mild to moderate levels of fatigue can have a significant impact on the psychological outcome. Taking into account that perceived health has been cited as a moderator of the link between well-being and social support, to some extent perceived health is a consequence of the existence or absence of physical health problems (Liang, Krause, & Bennett, 2001). However, little attention has been paid to the multidimensional nature of fatigue and its comprehensive impact on those with RA's psychological well-being. The current research expects that there is a significant negative correlation between PPC and fatigue.

1.2.3. 2. Pain

Pain in response to injury is generally regarded as an adaptive reaction of the body facing heat, while, pain caused by RA can prevent healthy physical activity. This is due to the fact that RA's pain can become problems to psychological adaptation in RA. Chronic pain in RA could initiate pain- avoidance behaviour on the other hand, over involvement in activities can lead individuals with RA toward disability (Vlaeyen & Morley, 2009). Merely a few years ago, the common guidance given to individuals with chronic inflammatory diseases such as RA was to rest (Smith & Polley, 1978) although, activity can be beneficial to those living with RA. Therefore, one of the challenges facing people with RA when adapting to the disease is to engage in those activities that can recover functional ability and emotional status in the face of cytokine- associated symptoms that make activity challenging.

Pain accompanied by other RA symptoms impedes the ability to play a part in normal everyday activities (Katz & Morris, 2007). For instance, Lee, Tsai, Luo and Tsay, (2010) cited that working is a significant predictor of physical health-related quality of life, moreover, being employed positively impacts on perceived quality of life. While pain has been reported as a predictor of losing a job or functional restrictions (Olofsson et al., 2013), self-efficacy ability and social support contributes significantly to predicting commitment to work (Backman, Kennedy, Chalmers, & Singer, 2004). On the other hand, people who are forced to leave their job because of pain engage in fewer activities and are more likely to focus their attention on dealing with pain (Chorus, 2001).

It is also worth noting that, in a longitudinal study of employed individuals with arthritis, lack of support in the work place was significantly related to future depression, maladaptive coping strategies, and also predictors of depression in the future (Li, Gignac, & Anis, 2006). Experiencing pain also interferes with lots of additional social roles such as handling household and upholding close relationships with family members (Hirsh, Waxenberg, Atchison, Gremillion, & Robinson, 2006). For instance, Evans, Shipton, & Keenan, (2005) showed a significant link between parenting difficulties and the level of psychological distress in mothers with arthritis pain compared a control group; moreover, employing emotion-focused coping is connected with greater psychological distress in mothers with pain. As most individuals with RA must cope with pain and other RA symptoms such as (fatigue and physical limitations) the impact of the RA's physical symptoms along with the psychosocial aspects of the illness, should be given serious consideration in RA research. The present study expected that there is a significant negative correlation between PPC and pain.

1.2.4. Physical health function

One of the most important issues with RA is the impact of physical health function in relation to psychosocial activities, such as involvement in close relationships and social functioning, for example employment, spare time activities and socialising. The physical health components are mobility level (i.e., support getting around the house), walking and bending (i.e., stairs climbing), hand and finger function (i.e., handwriting), and arm function (i.e., brushing the hair). Some earlier studies show that people with RA had poorer scores on functional abilities, which is associated with depression and pain (Baykara, Bozgeyik, Akgul, & Ozgocmen, 2013). It has also been revealed, in a cross-sectional study with a cohort of RA people conducted by Munsterman et al. (2013), that there is a significant relationship between fatigue and depression, however, not physical function. In addition, in a study conducted by (Pollard et al., 2006) it was shown that fatigue is connected to pain and depression, but not RA activity. Thus, measuring physical health is of critical importance to RA research because of the impact of the illness on the individual's ability to perform daily tasks. The thesis expected that there is a significant negative correlation between PPC and physical health function. This includes the rate of mobility level; walking & bending; hand & finger function and arm function scores on the AIMS-2 (Meenan, Mason, Andersson, Guccione, & Kazis, 1992).

1.2.5. Physiological features of Rheumatoid Arthritis

RA is a chronic systemic inflammatory illness with unidentified causes so far. An exterior factor, such as an infection or stress, triggers an autoimmune reaction which in turn could lead to the synovial lining become swollen mainly due to increasing the volume of a tissue or organ. Chronic joint inflammation, along with potential genetic and hormonal factors, is theorised to occur in individuals with RA. The physiological aspects of RA are discussed below.

1.2.5.1. Inflammation

Harmful stimuli, or anything that can produce disease, for example a virus or bacterium, damaged cells, or irritants, can cause disease in its host. Inflammation is one of the responses of the person to the unwanted stimuli (Ferrero-Miliani, Nielsen, Andersen, & Girardin, 2007). It is part of the complex biological response which is an attempt to protect the organism by removing the damaging stimuli and thereby initiating the recovery procedure. The typical indicators of acute inflammation are swelling, heat, redness, pain and loss of function (NICE, 2009). Furthermore, inflammatory processes can trigger sickness behaviour which comprise weakness, failure to concentrate, depressed mood, anhedonia, and anorexia (Maes et al., 2012). However, chronic inflammation, might lead to a host of diseases, as an example, RA. It is for that reason that inflammation is usually strongly synchronized by the body through the release of cortisol, produced by the adrenal glands. It is discharged in reaction to stressful situations and has an effect on the immune system to prevent the inflammation (Hassett & Clauw, 2010).

1.2.5.2. The role of cortisol and cytokines

Cortisol affects the immune system significantly by preventing the production of cytokines. Cytokines are the chemical messengers that trigger inflammation (Brouwers et al., 2013). They are released by cells including immune cells and are especially important in health and disease, specifically in host responses to immune responses and inflammation (Cohen et al., 2012). Research indicates that the psychological effects of the pathophysiological processes of the disease are intervened by cytokines since it has been seen in some chronic diseases that proinflammatory cytokines seem to promote the psychological symptoms (Lee & Weinblatt, 2001). They also contributed to the vital tiredness (loss of energy, enlarged irritability, and feelings of depression) seen with severe myocardial infarction (Brouwers et

al., 2013). Besides, research suggests that cytokines mediate distress and disease inactivity (Cohen et al., 2012). For example, in patients with RA, decreased disease activity can be attained by blockade of proinflammatory cytokines. Instantly after blockade of TNF α , a considerable increase of physical functioning, quality of life and decrease in fatigue levels can be seen. The finding that proinflammatory cytokines can encourage – and by blockade reduce – these symptoms illustrates that physiological elements have a real impact on the psychological alteration of RA. Consequently, cytokines are crucial for fighting off infections and in other immune responses, however, they can become deregulated and pathological in RA inflammation (Cohen et al., 2012).

1.2.5.3. The impact of stress and inflammation

Cohen et al., (2012) proposed a model in which chronic stress results in failure to regulate the inflammatory response. A study led by Cohen et al., (2012) shows that inflammation is partially regulated by cortisol, however, chronic stress can change the effectiveness of cortisol to regulate the inflammation and thus a stressed person cannot control the inflammation response. This is due to the fact that immune system becomes insensitive to cortisol which normally regulates inflammation. Thus, the bodies of those people under chronic psychological stress are not only more sensitive to developing any physical health problem such as cold, but also it can produce levels of inflammation that encourage disease such as RA (Cohen et al., 2012). Because inflammation plays an essential role in the arrival and development of a broad range of illnesses, this model may have extensive indications for recognising the role of stress in RA (Cohen et al., 2012). On the other hand, it is suggested that psychological stress might change immune function through stimulating physiological stress pathways (de Brouwer et al., 2010). Accordingly, stress could have an opposing effect on health, mainly in people with immune dysfunction, such as individuals living with RA. Hassett & Clauw, (2010) confirmed that people with RA often report the incidence of a stressor earlier to the onset of their illness and/or find out a link between stress and disease flares. That could be true because scientific research investigating a causal association between stress and autoimmune disease is increasing. Furthermore, Hassett & Clauw, (2010) proposed that stress can also encourage symptoms for example pain, which might be accountable for increased disease activity and/or symptom appearance for the duration of stress.

1.2.6. Common co-morbidities

Nearly 80% of individuals with RA in UK also suffer from another long-term health condition (Parodi, Bensi, Maio, Mela, & Cimmino, 2005). Uncontrolled active RA can trigger joint damage, disability, cardiovascular disease and other co-morbidities such as eye and lung health, along with the psychological influence of living with a long-term health condition (El-Miedany, 2015).

There are some common co-morbidities that are seen as particularly challenging, for example, in people with RA the risk of heart attack (Solomon et al., 2006); the rates of osteoporosis (Michaud & Wolfe, 2007) can be twice as high. The danger of atrial fibrillation is roughly 40% higher (Lindhardsen et al., 2012); stroke is 30% higher (Lindhardsen et al., 2012); interstitial lung disease which may be fatal (Michaud & Wolfe, 2007); cancer such as, leukemia and lung cancer are all more common in people with RA (Turesson & Matteson, 2013). Also, proportions of depression are higher among individuals with RA (Michaud & Wolfe, 2007). Disappointment to handle the RA co-morbidities successfully might enhance the overall levels of disability, or yet the possibility of mortality (Van Doornum, Jennings, & Wicks, 2006).

1.2.7. Treatments

Living with a long-term health condition for which there is no cure can have an overwhelming effect on an individual, their family and their community. The impact can spread out to the various features of a person's life such as, social, economic, psychological, physical, cognitive and cultural features. People with RA not only have to deal with the RA physical symptoms such as pain and fatigue, they also have to challenge themselves to make psychosocial adjustments of having a lifelong illness (Dures et al., 2013). Moreover, they need to change their behaviour to handle the impact of the symptoms on their everyday lives. Pharmacological treatment can considerably improve RA symptoms, for up to 50% of people with early severe RA (Dures et al., 2013). The most common medications that have been used for individuals with RA are shown in Table 1.1.

Table 1.1. Most common medications used for Rheumatoid Arthritis

Name	Description	Type
DMARDs*	These are slow acting drugs that minimize the activity of RA by reducing swelling and stiffness. DMARDs can decrease the effects of the body's immune system. DMARDs also include biological drugs, some of which are called anti-TNFs'.	Methotrexate, Sulfasalazine, Azathioprine, Gold, Cyclophosphamide, Cyclosporine and Anti-malarial drugs.
Biologics	Drugs that are developed through biological processes rather than being chemically synthesized. Biological agents that reduce the effect of the tumour necrosis factor (TNF) protein in triggering inflammation: At present these are eight biologics for rheumatoid arthritis, five of which target the TNF protein (Anti-TNFs).	Etanercept, Adalimumab, Infliximab, Certolizumab Pegol, and Golimumab.
NSAIDs*	These help to reduce inflammation as well as relieve pain.	Aspirin, Ibuprofen and drugs called COX-2 inhibitors and sometimes another pain relief, e.g., Paracetamol.

DMARDs*: Disease-Modifying Anti-Rheumatic Drugs; NSAIDs*: Non-Steroidal Anti-Inflammatory Drugs.

Sources: Arthritis Care factsheets (www.arthritiscare.org.uk); National Rheumatoid Arthritis Society (www.nras.org.uk) and NICE guidelines (CG79, 2009).

Taken as a whole, at present it is not well-known why RA develops, and there is no definite treatment. However, effective action at an early stage of the illness can help relieve some pain and symptoms and also slow down the progress of the disease (Scott et al., 2010). On the other hand, if the condition is not treated, the chemical agents progressively cause the joint to misplace its shape and configuration which ultimately can damage the joint from top to bottom (Klareskog, Catrina, & Paget, 2009). Thus, sometimes RA can be very painful and affect a person's ability to achieve everyday tasks. It is said that pain and disability can be avoided if RA is recognised early and treated promptly and appropriately (NICE, 2009). Therefore, it is vital that treatment is provided early to make light of damage to the joints (Lee & Weinblatt, 2001). However, RA is likely to have complex, multicausal pathways including clinical and psychological factors (Hewlett et al., 2011). Pharmacological treatments reduce but do not resolve RA symptoms. Therefore, treatment involves pharmacologic and multidisciplinary team interventions, including educational support for self-management (Hewlett et al., 2012) and Cognitive Behaviour Therapy (CBT), physiotherapy and occupational therapy are recommended (NICE, 2009). Indeed, it is all about being able to manage the physiological and psychological impact of RA in daily life.

1.3. Demographic characteristics of people with Rheumatoid Arthritis

To explore the characteristics of the illness in people with RA the following demographic features were considered. These are: age, gender, marital status, education, employment and ethnicity. The topic will be addressed below.

1.3.1. Age

Some of the previous studies report the impact age has upon experiencing positive change following chronic health conditions such as for bone marrow transplant patients (Curbow, Legro, Baker, Wingard, & Somerfield, 1993). Concerning those earlier authors who suggest the potential benefit of age, for instance, Watkins, Shifren, Park, & Morrell, (1999), found age to be a significant predictor in controlling pain when using the Coping Strategies Questionnaire (CSQ; Pagoto, 2011; Rosenstiel & Keefe, 1983). Furthermore, age differences for adaptive coping behaviour such as cognitive coping might be apparent because people of an older age reveal a higher ability to use coping strategies to minimise stress related to chronic pain (Dysvik, Natvig, Eikeland, & Lindstrøm, 2005).

In addition, there is some evidence to demonstrate that older people use more positive self-statements in order to reduce the impact of RA pain successfully (Dunn, 2004). This suggests that older people with RA may perhaps better identify, through their own experiences, how to use effective coping responses to be able to control their RA pain (Newman & Revenson, 1993).

Moreover, older people could perhaps show a lower range of psychological and emotional distress, and thus respond more robustly to controlling their pain. On the other hand, there is some evidence shows that age does not impact on illness response. For instance, Sodergren et al., (2002), stated that there is no relationship between age groups and positive change in individuals with respiratory and cardiac rehabilitation issues. Although the clinical course and the RA outcomes in different age groups might vary widely among individuals, it is important to consider the impact of age on RA burden in relation to experiencing positive aspects of the disease. This study predicted that:

- a) There is a significant difference between PPC and different age groups (the age groups are 25-45; 46-66 and 67-87 years old)

b) There is a significant correlation between PPC and the study age groups

1.3.2. Gender

Some studies claim that gender plays a positive significant role in growth experiences, for example, females have been found to score higher on the Stress Related Growth Scale (SRGS; Park, Cohen, & Murch, 1996), in two studies by Park et al., (1996), in which the greater scores indicate higher levels of growth. Then again, Tedeschi & Calhoun (1996) detailed higher scores for females based on the Post-Traumatic Growth Inventory (PTGI). Tedeschi & Calhoun (1996, cited in Joseph et al., 2005), indicates that higher levels of PTG mean positive change results from struggling with the trauma.

However, a study conducted by Sodergren et al., (2002), who explored this concept in regards to respiratory illness, did not show evidence of gender influencing positive change when using the Silver Lining Questionnaire (SLQ-38) scores. There are also some studies that reflect the impact of gender, age and hormonal factors and cite that RA incidence becomes higher in women older than 65 years, which suggests that hormonal factors could play a pathogenic role (Symmons et al., 2002). However, this estimation considers people with clinical and or radiological evidence of having RA and was unsuccessful in capturing some cases, for instance those who had significant deformities (Symmons et al., 2002). Generally, the estimation of gender differences in the literature is varied due to the methods used to estimate the frequency of rheumatoid arthritis, and also differs depending on the methods used to determine its occurrence (Scott et al., 2010). The thesis predicted that there is a significance difference on PPC between males and females.

1.3.3. Marital status

Social relationships, specifically in terms of marital ones, might influence an individual's ability to adjust to RA pain (Hill, Bird, & Thorpe, 2003; Hughes & Waite, 2009). Hill et al. proposed that RA can alter an individual's marital relationship due to the limitations on functional activities, challenging responsibilities and emotional stress. Thus in the case of a person's spouse being incapable of providing appropriate emotional support, an individual with RA might feel more pain and dysfunction (Reese, Somers, Keefe, Mosley-Williams, & Lumley, 2010). Besides, some studies cite that single people with RA show higher illness development and disability in comparison to their married counterparts (Reese et al., 2010).

A study conducted by Reese et al., (2010), aimed to examine 255 people with RA to find out how equally marital status and marital adjustment are associated with pain, physical disability, and psychological disability (Reese et al., 2010). The study findings suggest that marital adjustment is correlated with better health status, with fewer psychological disabilities and a lower amount of pain, after controlling for age, gender and illness severity (Reese et al., 2010). However, those with lower degrees of marital adjustment were more susceptible to psychological disability and experiencing extra pain in to those who had higher degrees of marital adjustment (Reese et al., 2010). This study concludes that being married in itself is not coupled with enhanced RA health; however, being in a happy marriage is associated with better functioning and lower levels of pain. The present study predicted that there is a significant difference between PPC and marital status.

1.3.4. Education

A study conducted by Bergström, Jacobsson, Nilsson, Wirfält, & Turesson, (2013), indicated that low formal education, for instance less than eight years, compared to a university degree, has been linked to a bigger risk of developing RA, and it was also found to be an independent predictor of RA. Similarly, a study conducted by Jiang, Sandberg, et al., (2015), found that individuals with RA with a higher level of education experienced less functional disability and pain (Jiang, Sandberg, et al., 2015). In a study conducted by Bengtsson, Nordmark, Klareskog, Lundberg, & Alfredsson, (2005) it was revealed that people without a university degree had a greater possibility of suffering from RA in comparison to those with a university degrees. There was a negative relationship between the level of formal education and the level of RA in a study conducted by Pedersen, Jacobsen, Klarlund, & Frisch, (2006), which suggests that lower formal education levels might be a contributing factor for people with RA who live in socially disadvantaged areas; therefore, it might be related to reduced access to medical care and thus a poorer RA outcome. However, some studies have found a contrary link, in that a higher level of education is associated with more severe form of the illness, in addition to the earlier start of the illness, as shown by Rodriguez-Rodriguez et al., (2012). In contrast, some did not find a relationship between the risk factor of RA and formal education, for instance, Uhlig, Hagen, & Kvien, (1999). Accordingly, higher and lower education might affect the course of RA differently, and yet the findings are mixed. The thesis predicted that there is a significant difference between PPC and education status.

1.3.5. Employment

There is some evidence that suggests that occupation is not related to the occurrence of RA (Uhlig et al., 1999). However, in a study performed by Bengtsson et al., (2005) it has been confirmed that the risk of developing RA for manual employees was about 20% more in comparison to their non-manual counterparts; moreover, these increased risks were mainly confined to women. Yet the study was limited in its remit due to some methodological issues, such as the study design: a population based case-control study with incident cases. There was a negative association between work activity and the risk of RA in a study conducted by Bergström, Jacobsson, Nilsson, Berglund, & Turesson, (2011). Taken as a whole, the results of earlier studies are to some extent inconsistent, which may reflect a truer picture of RA people according to the current research methodology, and this requires further research. This study predicted that there is a significant difference between PPC and employment status.

1.3.6. Ethnicity

Over 12% of the British population are categorised as ethnic minorities, out of which south Asians form a nearly majority of this population (Office for National Statistics, 2011). However, the findings from some of the past research show that there is not a large variation in prevalence and the clinical features of RA in various ethnic groups in the UK. Even so, there seems to be a higher usage of alternative medication within ethnic minority populations and socio-cultural perceptions of RA influence the use of, or access to, healthcare services (Kumar et al., 2013). The current study predicted that there is a significant difference between PPC and ethnicity.

1.3.7. Duration of RA

In a study conducted by Treharne et al., (2005), the relationship between RA since diagnosis and some psychological factors was explored. The study recruited a total of 154 participants, including: males (n=41) and females (113) with RA. The contributors were classified into three groups for different lengths of time of having experienced RA. The first group, early RA, included 55 people with less than six months since diagnosis. The second group, intermediate RA, included 52 members with one to seven years living with RA, and the final group included 47 people with over seven years established RA. All the group members filled in the same psychosocial questionnaires, for instance, the Illness Perception

Questionnaire (IPQ; Weinman, Petrie, Moss-morris, & Horne, 1996), to measure the perceptions of the RA illness, such as control or cure. The Life Orientation Test (LOT, Scheier & Carver, 1985) was also used to examine the levels of pessimism or optimism. Symptoms of anxiety and depression were assessed by means of the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and social support was explored via the Social Support Survey (SSS; Funch, Marshall, & Gebhardt, 1986). The study identified psychosocial factors as being significant for the well-being of those diagnose with RA at different stages of their RA. For instance, the group with early onset presented more depression and lower life satisfaction. The members in group two, living with RA for one to seven years, showed more morning stiffness, and the third group, over seven years having established RA, illustrated social support in relation to levels of fatigue. However, the authors concluded that the type of social support might be important and require further attention, since emotional support may be beneficial in the early stages of RA, whereas functional support might be more appreciated in the later stages of the disease. Equally, the early RA and intermediate group reported more optimism in relation to experiencing lower levels of pain. While this study highlights the importance of psychosocial factors when exploring the impact of well-being in individuals with RA, the study focus is limited since the partakers were all Caucasian with an uneven gender ratio.

Treharne, Lyons, Booth, & Kitas, (2007) investigated whether using effective coping strategies is related to psychological well-being and perceived stress, in a longitudinal study design which assessed people with RA at the baseline, after six months and one year. It included 134 people with RA, and the majority were female (n=101) and married. The mean age was 55.5 years and they completed questionnaires that considered perceived stress, coping resources and psychological well-being, such as anxiety, depression and life satisfaction (see Treharne et al., 2007). The study findings show that perceived stress had the highest association with psychological well-being at the starting point, and also impacted on anxiety during the next six months (Treharne et al., 2007). Individuals with RA who were more pessimistic described higher levels of anxiety and depression at the baseline and at six months later; they also reported decreased levels of life satisfaction at six months.

The findings from the Treharne et al. (2007) study support the unhelpful impact of negative thinking and the importance of positive thinking, as well as that they might have different effects over time. Furthermore, pessimism and stress were linked to lower psychological

well-being, whereas optimism, cognitive coping and social support were associated with stronger psychological well-being, even after one year, which suggests that pessimism and optimism might have differing effects over time. This study suggests that people with RA with larger levels of perceived stress, who avoid using active coping strategies, are more likely to be exposed to psychological problems. The study cited that people in the early stages of RA are more likely to be in denial about the illness compared to their counterparts who are established patients.

In a study conducted by Revenson, Schiaffino, Deborah Majerovitz, & Gibofsky, (1991) it was confirmed that those with RA with lower perceived support are more depressed in the first four years of the disease compared to those with greater support. Although the findings of these studies enhance the longitudinal evidence more, it is also possible that psychosocial status measured at one point in time does not have much of an impact on psychological well-being as time passes. It is also possible that more complex occurrences might take place that cannot be captured in a study with various time points.

Considering the impact of time post-diagnosis in individuals with RA, Newman & Revenson, (1993), argued that time can have two contradictory effects on RA. On the one hand, in the majority of people, accumulating time with the disease might lead to higher levels of disability; on the other hand, time might have a positive impact in terms of leading to a superior level of adaptation to the illness since people can learn to adjust to the long-term impact of the disease (Newman & Revenson, 1993). Correspondingly, this may confirm that, as people learn to cope with the symptoms, over a long period, they can potentially produce higher levels of RA adaptation, suggesting that people with RA familiarise themselves with the disease when given more time to develop successful strategies to overcome the hassles of RA. Therefore, time possibly will also lead to a greater level of psychological alteration as people with RA learn to adapt to the disease and possibly modify their anticipations and meaning of life and thus long- time sufferers are better adjusted (Newman & Revenson, 1993). Hence, it may be concluded that certain people with RA may display more PPC due to their personal resources, such as age and years post diagnosis. The present thesis predicted that:

- a) There is a significant difference in PPC between RA duration groups (the RA duration groups are: 2-5; 6-10 and over 10 years since diagnosis)

b) That there is a significant positive correlation between PPC and RA duration groups (one-tailed).

Broadly speaking, experiencing RA is usually considered to go hand in hand with experiencing certain changes, for example, changes in bodily function, uncomfortable physical appearance, or changes in social and psychological status. It is also essential to recognise how persons with RA interpret their disease and how it interrupts their behaviour, interactions with others and consequently their adaptive coping strategies. The literature supports the proposal that individuals with RA might experience both positive and negative effects of disease (Tennen & Affleck, 2002). However, usually the negative side of the RA is focused upon neglecting the consideration of the potential benefits (Norekvål et al., 2008). Based upon, the experience of illness reported by people with RA, some previous studies found that people with chronic health conditions report improvement in their skills and confidence and in managing their health problems (Dures et al., 2013; Iversen et al., 2010). In addition, Sodergren et al., (2002) suggested that people with chronic health conditions experience positive consequences of illness more commonly than often realised. Hence, the next section aims to discuss the outcomes of some of the past research in support of PPC in people with RA.

1.4. Investigating Positive Psychological Change in people with Rheumatoid Arthritis

Previous research has recognised various important issues in people living with RA, including conflicts around a person's perception of his/her abilities to deal with RA symptoms (McPherson, Brander, Taylor, & McNaughton, 2001) and the process of adaptation to impairment (de Almeida, Pontes, Matheus, Muniz, & da Mota, 2015). However, there is a small amount of evidence which shows that individuals with RA have reported some kind of positive illness perception/positive change, regardless of experiencing RA symptoms (i.e., Dager et al., 2012; Sato et al., 2008). Therefore, this thesis searched the literature to examine whether there is any evidence of PPC in RA populations. This is addressed in the following sections.

Recently, Brouwers et al., (2013) conducted a Randomized Control Trial (RCT) study with 74 RA patients. The aim was to explore the influences of intervention on stress-induced levels of key cytokines involved in disease progression in people living with RA. The participants were allocated to either a control group or a group that were exposed to brief

stress management training. The study findings showed stress levels were lower in people in the intervention group compared to the control group at the follow-up assessment. In the study, Brouwers et al., (2013), concluded that RA people who received stress management training showed changes in the subjective response to stress and the level of cortisol response to stress (de Brouwer et al., 2011). Furthermore, the authors suggested that the result could also be attributed to an altered immune response to stress (de Brouwer et al., 2011).

Walker, Jackson, & Littlejohn, (2004) specified stress is due to relationship and interrelation between physiological, psychological and environmental factors. Hence, stress comprises various components, for example, an undesirable occurrence such as dealing with the condition of RA; associated changes in Hypothalamic-Pituitary-Adrenal (HPA) functioning, such as, changes in cortisol levels. On the other hand, there is supporting evidence that positive affect triggers the neuroendocrine, autonomic and immune system.

A number of studies have revealed that cortisol inclines are lower when people have a larger positive affect (i.e., Dockray and Steptoe, 2010; Jacobs et al., 2006). An effectual immune system reaction to challenge needs the proper governing of cytokines. Fluctuations in the levels of cytokines serious impacts on the stimulation of the cellular immune system response in people with RA (Dockray & Steptoe, 2010). To date, there are limited studies to examine the impact of positive affect and cytokines. Among them, Brouwers et al., (2013) have confirmed a reverse association of positive affect and Interleukin 6 (IL-6). IL-6 acts as a pro-inflammatory cytokine and stimulates the immune response (Kay & Upchurch, 2012), for example, during infection or after a stressful condition leading to inflammation (Dockray & Steptoe, 2010).

Positive affect has been connected with changes in several immune system cells and also with the function of the system (Dockray & Steptoe, 2010). Enlarged cellular immune ability has been associated with positive affect (Lutgendorf et al., 2001) and positive wellbeing has also been connected with greater numbers of helper T cells (Dockray & Steptoe, 2010). T cells help the activity of other immune cells as well as assist adaptive immune responses. Walker et al., (2004) stated that a list of positive proceedings might occur during perceived pleasurable events. For instance, positive events might trigger positive affect which in turn might cause changes in neuroendocrine function. Thus, the term “eustress” refer to the positive stressors as reported by Walker et al., (2004) and Selye

(1956, cited in Jiménez Ambriz, Izal, & Montorio, 2012). Although the biological elements linked with positive affect are only starting to be described, there is some evidence that positive affect has an impact on biology and that it is associated with health-protective biological responses (i.e., Dockray & Steptoe, 2010; Schubert et al., 2012).

In a systematic review conducted by Sanipour and Harding (2013, unpublished) a broader topic of the intervention studies from 1985-2013, examined whether psychological interventions among those with chronic health conditions facilitate PPC. The concluding outcome revealed that all studies, 15, looked at either BF or PTG in people with other chronic health conditions. However, it is essential to consider that no study examined within this systematic review focused on PPC in people with RA. Furthermore, these findings demonstrate that 14 studies showed a positive effect and one was partially successful in PTG subdomains, new possibilities and personal growth, but had no significant treatment effect on PTG in general. This was a study conducted by Zoellner, Rabe, Karl, & Maercker, (2011). It is worth mentioning that the interventions target a considerably wide range of chronic health illnesses, for instance the majority examined people with cancer and the remainder with multiple sclerosis, complicated grief, motor vehicle accident survivors, and one with stroke but no study examined PPC in persons with RA.

With respect to the intervention studies outcome, the systematic review revealed that, out of 15 studies, five studies were based on a Cognitive Behaviour Stress Management (CBSM) intervention program, (Antoni et al., 2001; Cruess et al., 2000; Cruess et al., 2001; McGregor et al., 2004 and Penedo et al., 2006). In an innovative review reported by a CBSM researcher, the studies explored the link between positive change and physiological functioning. For example, McGregor et al., (2004) suggest that ten weeks of a CBSM intervention programme may increase BF and immune functioning amongst women with early-stage breast cancer. Antoni et al., (2001) reported a reduction in the prevalence of moderate depression, as well as an increased positive lifetime contribution, following a ten week group CBSM intervention programme. Cruess et al., (2000) and Cruess et al., (2001) reported that even a brief psychological intervention programme can influence physiological parameters, such as significant reductions in endogenous levels of serum testosterone, and of cortisol levels, leading to a potential stress reduction and also the effect of CBSM on cortisol was mediated by increases in BF in the study conducted by Penedo et al., (2006). However,

the studies acknowledge that a significant aim of further research will be to examine what component or components may be the main key to beneficial outcomes.

All in all, the findings of the de Brouwer et al., (2013) study and those conducted by Cruess et al., (2000); Cruess et al., (2001); Antoni et al., (2001) and McGregor et al., (2004), provided an initial body of evidence that psychological intervention has an impact on the immune and neuroendocrine systems. It, therefore, might have the potential to decrease the probable damaging effects of stress on health in people with long-term conditions including individuals living with RA (Brouwers et al., 2013). These outcomes may support the action of immunological mediators in stress and disease. Nonetheless, the results of these studies need validation in larger studies (Brouwers et al., 2013).

Within the last two decades, the awareness has come about that offering patients information regarding their illness without help does not lead to changes in behaviour, they need to become more involved in their own care and activated to better manage their symptoms (Lorig & Holman, 2003). The concept of collective responsibility and administration is the key point of self-management, which is discussed to the provision of education and encouraging interventions to enhance a patient's skills in controlling their health trouble (Dures et al., 2013). Self-Management Intervention (SMI) aims to influence the health knowledge, beliefs, attitudes and behaviours in order to encourage autonomy and adaptive life roles (Iversen et al., 2010). This refers to the psychological impact of the disease and considers behavioural, educational and cognitive approaches (Iversen et al., 2010).

A systematic review reported by Iversen et al., (2010) identified four studies using SMI techniques involving people with RA. These were: Giraudet-Le Quintrec et al., (2007); Kirwan, Hewlett, Cockshott, & Barrett, (2005); Riemsma, Taal, & Rasker, (2003) and Van Lankveld, Van Helmond, Näring, De Rooij, & Van Den Hoogen, (2004). Three studies recruited people with established disease (average 12–15 years), and one with early-to-established seven-two years, (Van Lankveld et al., 2004). See Table 1.2.

Table 1.2. Summary of key features of self-management studies in patients with Rheumatoid Arthritis with positive outcomes

Author (year)	Design & sample characteristics	Setting	Intervention duration; comparison group	Delivered by & mode of delivery	Theory	Length of follow up	Significant outcomes: improved
Riemsma et al. (2003)	RCT (n=218); RA, 56 y; 62% women; duration 12 years	Rheumatology out-patient department	(A) SMP 5 × 2 h/week (pain management, relaxation, coping with depression, communication, exercise advice) plus 3 × 2 h booster: 3, 6 & 9 m+ partner. 16h (B) As above without a partner (C) Self-help guide only	2 × RN (Y)	SCT	6 and 12 m	ITT analysis: 6 m : both SMP groups : exercise. 12 m: SMP without partner: self-efficacy, fatigue
Van Lankveld et al. (2004)	RCT (n=59); RA, 50 y; 65% women; duration 7.2 years	Rheumatology out-patient department	(A) Education and Rational Emotive Therapy programme (ED-RET) 8 × 1.5 h/week for 4 weeks (ED × 4: information; 'encourage the practice of active coping skills'; 4=RET) + partner. No booster. 12 h (B) As above without a partner No control group	7 MDT members (not stated) and CP (Y)	CBT and RET	2 w and 6 m	ITT analysis: 6 m: both ED-RET groups : pain, function, mobility, dexterity
Kirwan et al. (2005)	RCT (n=79); RA, 54 y; 79% women; duration 15 years	Rheumatology out-patient department	(A) Education (ED) and CBT 4 × 2.5 h/week + 1 × 2.5 booster at 8 weeks (ED: joint protection, heat and cold; CBT: managing mood, pain, relaxation, sleep communication, coping). 12.5 h (B) Usual care	5 MDT members (not stated)+ CP and RN (Y)	CBT	2 and 6 m	ITT analysis and CC analysis: CC only at 2 m: ED-CBT: self-efficacy and pain, 6 m: no differences
Giraudet-le Quintrec et al. (2007)	RCT (n=208); RA, 55 y; 89% women; duration 13 years	Rheumatology out-patient department	(A) Education and self- management programme (ED-SMP; ED =3sessions (RA, treatment, diet); SMP= five sessions (1=pain and stress management; 4= exercise, relaxation, joint protection, foot care, social advice); 8 × 6 h/week plus 4 h booster at 6 m. 52 h (B) Information booklets	10 MDT members (not stated)	SCT and CBT	6 and 12 m	ITT analysis 12 m: ED-SMP is coping

Sources: Adapted and modified from: Iversen, et al. (2010, p.960).

Intervention: SMP, self- management programme;

Delivered by: RN, register nurse; MDT, Multidisciplinary team (nurse, physiotherapist (PT), occupational therapist (OT) (± rheumatologist, pharmacist).

Theory: CBT, cognitive-behavioural theory; SCT, Social Cognitive Theory.

Analysis: CC, case completers only; ITT, all cases included, imputation of missing values. M, months; RCT, randomised controlled trial; y, years.

All studies measured, function, disease status pain and mood. Self-efficacy was examined in two studies, and fatigue in two (Table 1.3., Iversen et al., 2010). Short-term benefits were found in four studies. Two studies reported longer-term follow-ups of a year; both showed benefits, Giraudet-Le Quintrec et al., (2007) and Riemsma et al., (2003). One used Bandura's SCT or CBT throughout the programme (Giraudet-Le Quintrec et al., 2007), specially trained health professionals and durable booster sessions (Iversen et al., 2010). Two studies recognised enhanced self-efficacy, Kirwan et al., (2005) and Riemsma et al., (2003) and one study reported greater fatigue in persons attending a predominantly cognitive strategy self-management programme, Riemsma et al., (2003).

One study observed related positive changes in cognitions, coping, disease activity, psychological and physical functioning. Furthermore, participants confirmed a reduction in potential support, Van Lankveld et al., (2004). One study noted that, despite improvements in knowledge, satisfaction, patient coping behaviour but the education programme was unsuccessful for the first year of the course, Giraudet-Le Quintrec et al., (2007). Two studies reported an improvement in pain, Van Lankveld et al., (2004) and Kirwan et al., (2005). See Table 1.3.

Table 1.3. Outcome measures assessed in clinical trials of self-management interventions in Rheumatoid Arthritis

Paper	Disease status	Pain	Fatigue	Function/ disability	Self-efficacy	Mood	Perceived control	Coping	Social support	Health behaviours
Riemsma et al., (2003)	√	√	√	√	√	√		√	√	√
Van Lankveld et al., (2004)	√	√		√		√		√		
Kirwan et al.,(2005)	√	√		√	√	√	√	√		
Giraudet-le Quintrec et al., (2007)	√	√	√	√		√	√			√

Sources: Adapted from: Iversen, et al. (2010, p.960).

To broaden that knowledge, a search was extended into the literature to examine if PPC is demonstrated in people with RA. The literature search yielded five articles on positive changes because of living with RA. These are: Danoff-Burg & Revenson, (2005); Danoff-Burg, Agee, Romanoff, Kremer, & Strosberg, (2006); Dirik & Karanci, (2008); Sato, Yamazaki, Sakita, & Bryce, (2008) and Tennen, Affleck, Urrows, Higgins, & Mendola, (1992). Of the five papers, four investigated BF, while only one looked at PTG, and its domains in Turkish individuals with RA (Dirik & Karanci, 2008). It is worth mentioning that BF refers to the constructive personal changes in the wake of a traumatic or stressful event (Moskowitz & Epel, 2006). PTG refers to the positive changes associated with traumatic events. In that PTG articulates the experience of persons who not only recover from trauma, but also use it as a chance for further individual development (Zoellner & Maercker, 2006). Tedeschi & Calhoun, (1996) suggested that trauma can be a trigger to PTG. Full details of the search strategy are laid out in table 1.4.

Table 1.4. Description of quantitative studies investigated positive change (Benefit finding &/Posttraumatic Growth) in Rheumatoid Arthritis

Study	Study title	Sample size and characteristics	Setting	Design	Measure	Main finding
Tennen et al., 1992	Perceiving Control, Construing Benefits, and Daily Processes in Rheumatoid Arthritis	N= 54, 53 y, SD ±12.5, 76% female; 60% married, duration 9 years	Rheumatology practice, university health center and community rheumatology practices in the same locale.	Writing daily dairy	The Perceived Control and Benefits were drawn from an inventory of psychological control appraisals (see Mendola, 1990 for details).	Perceived benefits moderated the relationship between pain severity and activity limitations. That is, with increased levels of daily pain, individuals who had endorsed more benefits from their illness at the start of the study went on to report fewer days on which their activities were limited by their pain.
Danoff-Burg & Revenson, 2005	Benefit-Finding Among Patients with Rheumatoid Arthritis: Positive Effects on Interpersonal Relationships	N=136 (n=111female,n=25 male), 58 y, SD±14:05, %54 married, duration 16 years	Metropolitan hospital that specializes in orthopaedic and rheumatic disorders.	Longitudinal study used mixed methods	Social constraints were measured with eight illness-specific items based on the work of Lepore et al. (1996).	N=71.3% interpersonal benefits; n= 16.2% another type of benefit; n= 12.5% no benefits. The most frequently benefit, 40.3%, has been an appreciation of & support received from loved ones. Interpersonal benefit finding predicted lower levels of disability at a 12-month follow-up.
Danoff-Burg et al., 2006	Benefit finding and expressive writing in adults with lupus (SLE) or rheumatoid arthritis	N= 75 people (28.0% with SLE*), among the 75 (BF: n = 27; EW*: n = 24 & FC*: n = 24), 82.7% female, 51.y, SD±13.25, 68% married, duration 15 years, modal time since diagnosis<10 years.	Rheumatologists' offices, local chapters of the Arthritis Foundation and Lupus Foundation, America	Randomly assigned to one of three: 4-session BF writing/ EW/or a control group.	The Vigor subscale of the Profile of Mood States (POMS; McNair, Lorr, & Droppleman, 1971).	BF appeared effective in reducing pain levels for participants with high trait anxiety, whereas EW appeared effective for participants with low trait anxiety.
Dirik & Karanci, 2008	Variables Related to Posttraumatic Growth in Turkish Rheumatoid Arthritis Patients	N=117,(n= 99 Female;18 male), 48 y, SD±13.17, n= 76.%, widow: n= 2.56 divorced; 7.69 married; duration 9 years	N= 21, rheumatology inpatients; N=26 Physical Medicine & Rehabilitation Clinics inpatients & 70 outpatients, Ankara Numune Education & Research Hospital, Ankara, Turkey	A cross-sectional design	The translated & modified Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) to Turkey.	PTGI has three domains: relationship with others; philosophy of life; and self-perception. Perceived social support appeared as a significant associate for the total PTG levels for all three domains. Age was related only to 'changes in the philosophy of life' factor of the PTGI.
Sato et al., 2008	Benefit-finding among people with rheumatoid arthritis in Japan	N=364 (n= 288,79.15% female; n=76 ,20.9% male,45.5y,SD±8.4, Married: n= 295, 81.3%, married, duration 10.6 years	The commercial health care database services	A web-based questionnaire was conducted	Modified BF based on a review of the relevant literature conducted in the USA (e.g. Mohr et al., 1999; Antoni et al., 2001) plus a focus group, 11 item questionnaire	Majority of the participants, 97.5% experiencing benefit according to one or more items, thus, reported engaging in some type of BF. Developing compassion towards others and an appreciation of things not previously important were the most commonly reported. The patients reporting larger emotional support networks and those performing more self-care activities reported achieving higher levels of BF which was the most significant predictor of mental health.

*SLE, systematic lupus erythematosus; EW, Expressive writing; FC, Fact control

There are also a few qualitative studies investigating the outcomes of intervention studies in people with inflammatory rheumatic disease. This section outlines two qualitative studies which reported positive change. The first study was conducted by Dager, et al., (2012) and the second one performed by McPherson et al., (2001).

In the first study 23 people with inflammatory rheumatic diseases, who had two months previously experienced a four-week hospitalisation period, took part in a semi-structured interview which was conducted by Dager et al., (2012). The study aimed to understand how the participants explored the experience of personal impact of involving in rheumatological rehabilitation programme. These findings showed that during rehabilitation, the patients' primary expresses of uncertainty were replaced with confidence and active coping, which thus reinstalled self-respect and dignity to becoming an active cause in one's personal life (Dager et al., 2012).

Improved awareness regarding their rheumatic disease and the factors activating symptoms was a main finding for several patients to gain insight about new coping strategy skills (Dager et al., 2012). For example, a participant said, *'I understand my disease better. If I walk more than I should, I get severe pain, but I have learned to limit myself. I learned that at the rehabilitation unit. I limit what I do physically; it's a kind of control'* (Dager et al., 2012. P. 912).

The study findings suggested that both dignity and self-respect are associated with confident coping. The confident coping influences a person to become the main basis of gaining insight into illness and symptom demonstration. Therefore, a person has an active role in self-managing the condition. The study concluded that psychological issues play a main role and psychological themes, for example, dignity and self-respect must be taken into account (Dager et al., 2012).

A further example is a study performed by McPherson et al., (2001). The study interviewed ten females with RA to describe the important factors in their life (McPherson et al., 2001). The research findings showed a range of items that were categorised into five themes. These are: personal/intrinsic factors, external/extrinsic factors, future issues, perceptions of normality and taking charge.

With reference to the personal intrinsic factors theme the participants reported challenging their limitations for example:

'You learn to live with pain' (McPherson et al., 2001, p. 709).

*'I was incredibly painful, I don't know how I did it, I forced myself to go to the pool'.
(McPherson et al., 2001, p. 709).*

People even talked about the positive future:

'It's kind of like about trusting myself and just going well' (McPherson et al., 2001, p. 709).

'I think I've accepted now that I'm never going to be able to do what I did before.... I have personally adapted and would just like to find something I can do' (McPherson et al., 2001, p. 709).

With respect to the theme taking charge, one' said; *'You're always having to look at what you can do'. (McPherson et al., 2001, p. 710).*

People accepted the differences and said:

'I enjoy life- Ok, not the way I used to but it has taught me to get on with life' (McPherson et al., 2001, p. 710).

Certainly, these studies have provided valuable evidence, however this literature review has aimed to explore PPC, as described by Sodergren et al., (2002). However, the concept of PPC as described by Sodergren et al., (2002), has not been fully explored in people with RA. The present thesis determined to explore the likelihood and the extent of PPC in people with RA, and the factors that might contribute towards the development of PPC in people with RA in the UK. Thus, it is particularly important for the purpose of this thesis to establish a well-validated questionnaire to assess PPC in people with RA. The selection of reliable and valid questionnaires has been developed following literature review and feedback from the supervisory team that will be explained below.

1.5. Measurement of Positive Psychological Change

The thesis designed a survey study to investigate the experience of PPC in individuals with RA. Thus, the first and most noticeable option was to ask people if they experience such a feeling. Self-report scales are used to look at the difference or the relationship between people on scale items (Shaughnessy, Zechmeister, & Zechmeister, 2012). The self-report scales, which are commonly offered in questionnaire form, are one of the most employed tools in psychology and, as such, it is essential that the measures be structured carefully, whilst also being reliable and valid (Coolican, 2009). The main strong point of self-report methods is that they allow participants to express their own experiences rather than assuming this from observing participants. Thus, using the self-report measurements seems very valuable as people may be asked to disclose feelings and behaviours which have been experienced in actual situations. Moreover, often using self-report solutions seems very economical as it is possible to be able to investigate a majority of variables. However, the use of self-reports implies a series of assumptions. For example, the questions are not always clear and it is unknown to the researcher if the respondent has in fact recognised the question or if the structure of the questions may have an effect on the responses. Therefore, they were informed before taking part in the study that they could have contact with the main investigator or a member of the research team if they had any questions or were concerned about any aspect of the study.

The other issue with the self-report measurements is that participants may not answer honestly, either because they cannot memorise the past events accurately or because they hope to present themselves in a socially acceptable approach. Social desirability bias can be a significant issue with self-report measures, as participants frequently respond in such a way as to describe themselves in a good light. Therefore, it is important to take some precautions to avoid sample bias. Therefore, it is important to take some precautions for instance, for the present thesis the study participants were volunteers in the study and therefore before taking part in the study, they were told why the research was being done and what it would involve for them. They were also told that they were free to terminate their participation at any point of the research. These precautions should limit the possibility that participants would feel uncomfortable in talking about their experiences, as they were aware of the nature of the study.

1.5.1. Choice of the measurements used in the thesis

Past research has used various measurements to examine positive aspects of the illness. The majority utilized the PTGI (Walter & Bates, 2012) and some employed the BF scale (Cruess et al., 2000; Danoff-Burg & Revenson, 2005); the Perceived Benefit Scale: Measuring perceived positive life changes after negative events (McMillen & Fisher, 1998); the modified edition of the benefit finding scale used in Japan (Sato et al., 2008); the Satisfaction with Illness Scale (SIS, Sodergren et al., 2002) and the Silver Lining Questionnaire employed by Bride, Dunwoody, Lowe-Strong, & Kennedy, (2008). From these the current thesis has selected the Silver Lining Questionnaire (SLQ-38; Sodergren et al., 2002) as a key scale with acceptable psychometric properties of reliability and validity to capture PPC in RA populations as discussed below.

1.5.2. The key measurement

The SLQ-38 measures: the extent to which people believe their illness has had a positive benefit despite the negative consequences of being ill (Sodergren et al., 2002). The SLQ-38 incorporates: improved interpersonal relationships, positive influence on others, self-improvement, reappraisal of life, restructuring of life, spiritual changes, sensitivity to emotions, skills and new pursuits, self-knowledge and confrontation of current concerns (Hyland et al., 2006).

Cronbach's alpha has been used to determine to what extent the items on a scale measure the same underlying dimension. The Pearson product correlation between the two assessments was $r=0.90$; $P<0.001$ (Sodergren et al., 2002) showing good retest reliability when the acceptable value for the Cronbach's alpha is 0.7 to 0.8 (Kline, 2000). Therefore, the SLQ-38 looked to have good internal consistency, $\alpha=0.90$, and all items seemed to be correlated with the total scale to a good degree (Field, 2009). Sodergren et al., (2002) found evidence of a one-dimensional factor in the factor structure of the SLQ-38, and showed that the SLQ had a higher score for strongly agree, and agree was equal to frequent positivity; however, this ignored the remaining scores: not sure=3; disagree= 2 and strongly disagree=1. The choice of measurement is discussed in the following section.

1.5.3. The advantage of SLQ-38

The SLQ-38 is preferable for use in the current survey study for several reasons. First of all, the scale was developed in the UK. This is an important factor to avoid cultural concerns. Second, at the development of the questionnaire some of the participants were rheumatoid patients, although the study did not mention the number of arthritis participants, overall participants were chronic health patients. Third, the focus of the scale was to measure positivity following the illness. This is an important point for the purpose of the present thesis because it is aimed at measuring the consequences of living with RA when the long term condition was established. In the case of the present thesis all participants had been diagnosed for over two years. In addition, the scale has acceptable reliability and validity scores. The scale provides the means and standard deviations of positivity consequences across the samples and the most frequently endorsed items by overall sample. The mean was: 10.31, SD= 6.78, however, in this thesis, the total score on SLQ-38 reflected the general PPC following RA.

1.5.4. The limitations of SLQ-38

Although SLQ has several advantageous characteristics, it is worthwhile to note that the measure does not consider the long- term effects of positivity. However, this not relevant for the purpose of this thesis as the survey study does not intend to consider the long-term effects of positivity. Furthermore, the developers did not consider whether other factors such as personality, might relate to larger positivity (Sodergren et al., 2002). The personality factor and in particular optimism is recommended by some other studies to increase positivity, for example Tedeshi & Calhoun (1996) and Linley & Joseph, (2004). However, this is not the case for the purpose of the present thesis because this thesis was not aimed at assessing the impact of the personality factors in the target samples.

1.5.5. Comparing SLQ-38 with other measurements

The SLQ-38, (Sodergren et al., 2002) has the larger coverage of positivity compared to the Perceived Benefit Scale (PBS). The SLQ-38 (Sodergren et al., 2002) is a generic scale of positivity compared to the BF scale which has been adapted for the cancer patients (Cruess et al., 2000).The PTGI focused on the event and not illness, while the SLQ-38 is based on the illness. Compared to the modified version of the BF scale used in Japan's study (Sato et al., 2008), the SLQ seems to be ideal, due to the cultural issues. The Satisfaction with Illness

Scale (Hyland & Kenyon, 1992) could be considered as an old version of the SLQ-38 (Sodergren et al., 2002). This was confirmed by one of the authors of the scale, Professor Hyland, when he was contacted by email in 2014 before making a decision about the proper scale. Moreover, SLQ has been recommended by Joseph & Linley, (2012) where they confirmed that *'a wider pool of measures is available for assessing the potential for positive outcomes of negative events that are often more specifically tied to a particular stressor, such as illness, Silver Lining Questionnaire* (Joseph & Linley, 2012, P.22); Finally, most recently some of the investigators have used the SLQ to assess positive change in other chronic health conditions, for example, a sample of 85 patients with Myocardial Infarction (Maqsood, Jabeen, & Khatoon, 2013) and a sample of patients with cancer eight years post-diagnosis (Bride et al., 2008). All in all, SLQ was preferred for use in assessing PPC in people with RA for the purpose of the current thesis.

There is rising agreement that generic, as well as disease-specific tools, must be employed to measure the disease process, its impact and to allow for comparisons between disease conditions and therapeutic findings (Danao, Padilla, & Johnson, 2001). The sub-aims for this thesis were: to explore factors connected with PPC in people living with RA. For example, this thesis was intended to examine the association between clinical variables used, such as pain, and PPC in people living with RA, thus a range of reliable and validated measures was considered which is addressed below.

The Arthritis Impact Measurement Scales-2 (AIMS-2; Meenan, Mason, Andersson, Guccione, & Kazis, 1992) is an arthritis specific questionnaire which assesses physical, emotional and social well-being using 12 domain scales: mobility level, walking and bending, hand and finger function, arm function, self-care, household tasks, social activities, support from family and friends, arthritis pain, work, level of tension, and mood (Szende et al., 2003). Out of 12, this thesis chose some of the AIMS-2 subscales to assess functional state. These were: mobility level (i.e., support getting around the house), walking and bending (i.e., stairs climbing), hand and finger function (i.e., handwriting) and arm function (i.e., brushing). In addition, mental health symptoms were explored via level of tension and mood (depression) sub- scales. Other domains are described in the methods section.

Fatigue in people with RA may be caused by a dynamic relationship between some clinical (i.e., inflammation, pain, disability) and psychosocial factors (i.e., coping, mood, illness beliefs), which may differ within individuals and over a period of disease (Hewlett et al.,

2011). The Bristol Rheumatoid Arthritis Fatigue Scales (BRAFs) are employed to measure fatigue in RA patients. The scale was produced in the Rheumatology Department at Bristol, UK.

Bandura defined self-efficacy as: one's judgement of their capabilities of what a person can do with whatever skill she/he possesses (Bandura, 1986; Brekke et al., 2001). This judgement is based on some major resources of information, for example; modelling, social persuasion, mastery experiences and psychological state (Brekke et al., 2001; Lomi & Nordholm, 1992). There is evidence that examining the level of self-efficacy and health related to the disease may be important in people with RA (Brekke et al., 2001; Aldwin, Levenson, Tedeschi, & Calhoun, 2004). The present thesis chose to include pain and other symptoms on the sub-scale of the Arthritis Self-Efficacy Scale to examine self-efficacy in people with RA (Aldwin et al., 2004).

RA is a chronic, progressive (and in the long run) debilitating health problem worldwide, to be so ignored (Danao, et.al., 2001). Previous studies have found that RA is associated with decreased levels in QoL (Carpenter, Stoner, Schmitz, McGregor, & Doorenbos, 2014). Danao, et.al., (2001) proposed a list of various elements relevant to the QoL: physical ability, pain, interaction with family and friends, support from family and friends, mood, tension, arthritis, and health (Danao, et.al., 2001). This was examined by the Quality of Life-Rheumatoid Arthritis Scale (QoLRA; Danao, et.al., 2001, English version).

Some theories suggested that the emotional responses and coping efforts determine people's explanations of the distress and how they respond to it, in terms of their attempts to relieve, fix or resolve the challenging conditions (Park, 2010). As such, the coping strategies mainly emphasize the importance of the meaning of the stressor and how each individual responds to the stressful events (Park, 2010). Therefore, coping strategies are assessed by the Rheumatoid Arthritis Questionnaire (C-RAQ; Englbrecht et al., 2012). The questionnaire comprises the following coping domains: cognitive reframing, distancing, emotional expression, and active problem solving (Newth & DeLongis, 2004).

Psychological well-being has been conceptualized as incorporating of six dimensions: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, self-acceptance (Ryff & Keyes, 1995). Psychological Well-Being Scales (PWB; Ryff & Keyes, 1995) were used to examine psychological well-being.

Dealing with stress is an inevitable part of life. How individuals cope with these troubles can play a main role in their long-term psychological consequences. Antonovsky, (1993) introduced the concept of Sense of Coherence in reference to a person's viewpoint of life in a way that makes coping with stress easier. The ability to cope with stress has been described as resilience (Luthar & Cicchetti, 2000). The short-form of the Sense of Coherence (SOC; Antonovsky, 1987) was used to inspect a person's ability to manage stressful conditions such as dealing with RA. (See chapter two, method section, for more details).

1.5.6. Psychometric properties of the survey measurements

Reliable measures of self-report are defined by their stability. Hence, a reliable self-report measure generates stable outcomes every time it is performed (Shaughnessy et al., 2012). A test's reliability can be considered in a few ways (Shaughnessy et al., 2012). First, one can calculate test-retest reliability by giving an identical questionnaire to a big cohort at two dissimilar times (Field, 2009). For the questionnaire to be treated as reliable, persons in the sample do not need to score similar for each test, but rather their status in the score allocation should equally be the same for both the test and the retest (Shaughnessy et al., 2012). Self-report scales will usually be more reliable when they have several items measuring a construct (Bowling & Gruys, 2010). Moreover, measurements will be more reliable when the characteristic being measured has greater changeability among the persons in the sample that are being tested (Shaughnessy et al., 2012). Finally, there will be better reliability when directions for the completion of the questionnaire are clear and when there are narrow interruptions in the testing environment (Bowling & Gruys, 2010). Adversely, a questionnaire is valid if what it measures is what it had initially designed to measure (Bowling & Gruys, 2010). Construct validity of a measure is the extent to which it measures the theoretical construct that it was firstly intended to measure (Shaughnessy et al., 2012). Lastly, for the purpose of the research, the data was collected using reliable and validated measures. For more details in respect of the psychometric properties of the study measurements (see App.1.1., table 1.5. &1.6.).

1.6. The key theoretical concepts in building a psychosocial model of understanding Rheumatoid Arthritis

There is some evidence to support that negative Repeated Thought (RT) contributes to equally depression and anxiety (Harvey, Watkins, Mansell, & Shafran, 2004), while, constructive RT could possibly help recovery (Watkins, 2008). Repetitive thought, refers to a “*process of thinking attentively, repetitively or frequently about one’s self and one’s world*” (Segerstrom et al., 2003, p. 909).

A review conducted by Watkins, (2008) illustrates that there is a massive body of studies which suggest that negative RT is involved in vulnerability to depression (Roelofs, Huibers, Peeters, Arntz, & van Os, 2008; Watkins, 2008); anxiety (Harvey et al., 2004) and impaired physical health (Verkuil, Brosschot, Gebhardt, & Thayer, 2010). There is considerable evidence to show that focusing on negative features of the self is strongly associated with amplified levels of negative affect, while attention to positive aspects of the self is connected to lower levels of negative affect (i.e., Mor & Winquist, 2002). Yet, positive rumination has been referred to as “*the tendency to respond to positive affective states with thoughts about positive self-qualities, positive affective experience, and one’s favourable life circumstances that might amplify the positive affect*” (Johnson et al., cited in Watkins., 2008, p. 165). In accordance with this, there is good evidence that supports positive RT following stressful conditions, for example diagnosis or living with RA, in the form of cognitive processing, and this is linked to acceptance and recovery (Ullrich & Lutgendorf, 2002).

Moreover, positive RT contributes towards health promoting behaviour (Dijkstra & Brosschot, 2003); predicts concurrent affect and well-being (Segerstrom, Stanton, Alden, & Shortridge, 2003); further positive affect with improved overall mental health and lower levels of anxiety (Segerstrom et al., 2003), and less physical symptoms following distress (Sloan et al., 2008). These findings indicate that RT has an impact on a person’s cognition, emotion and behaviour through the coping strategies employed (e.g., Watkins & Baracaia, 2002; Watkins & Moulds, 2005).

There is also reliable evidence that beneficial tasks include an emphasis on positive content of thought while continually thinking about the stressful condition or difficult situation takes place (Cryder, Kilmer, Tedeschi, & Calhoun, 2006). Consequently, a positive balance of thought- constructive thinking- during RT appears to be a key point to solve some of the

problems and this can generate better outcomes (Watkins, 2008). Hence, RT may be a common process that bridges several important constructs in the realms of mental health, psychopathology, stress management and self-regulation that has been predicted to have equally constructive and unconstructive consequences (Watkins, 2008).

1.6.1. Psychological Models to explain Positive Change in Chronic Health Conditions

Several models have been suggested for how patients could successfully adjust to chronic illness. For example, the biomedical model which emphasises diseases and their characteristics, for instance, what causes and cures a certain illness. In this regard, the human body is considered to be a machine, which was originally expressed by Descartes (1598-1650 cited in Walker et al., 2004). Psychological models of adaption to illness (Taylor, 1983), draw attention to illness acceptance and perceptions of control over illness (Walker et al., 2004). The stress and coping model highlights the strategies used by patients to handle adaptive tasks forced upon them by the disease, with an aim towards creating or maintaining positive well-being (Dubos, 1959). The bio-psychosocial models bring to light the special effects of change in interactive stress on disease activity through neuroendocrine and immune pathways (Walker et al., 2004). The stress and coping model admits that chronic illness comprises of a number of challenges, but simultaneously, it has an interest in processes of appraisal and coping that describe why some patients effectively recognise and act on opportunities to achieve these tasks, while others might fail to do so. In general, psychological models show the active role that patients have in adapting to the challenges posed by their condition, and they have been utilised for different chronic conditions, for example cancer and RA (Walker et al., 2004). Nevertheless, the main problem with these models is that they explain only one element of a person's response to illness, which is dealing with the negative aspects of the illness. Accordingly, they neglect the role of complicated positive emotional and cognitive responses of a psychological function that are recognised as acting as buffers contrary to stressors, and the effect of coping behaviours on the development of positive change that accompanies chronic illness.

The present research has introduced the Bio-psychosocial model, which considers the positive impact of the illness, RA, based on the present study's data file that has been explained in the discussion section in full.

1.7. The application to study Positive Psychological Change in Rheumatoid Arthritis

Most clinical and health psychology research has examined the influence of disease on negative emotions and cognitive elements. However, there has been limited focus on how psychological responses to stressful conditions might lead to enhanced health, and partial physical recovery from long-term illness conditions such as RA. Under stressful conditions, one would expect to see a psychologically weakened system, but positive responses can often occur in the context of traumatic events (Tedeschi & Calhoun, 1996). The challenging area can be argued considering three aspects, these are: terminology; measurement and the theory.

1.7.1. Terminology

When talking about positive change, it is important to outline a clear definition. The issue becomes more complex when there is no clear definition of the construct of positive change in the past literature. As shown later in this section, there are different options that might be considered when trying to capture PPC, but each one leads to a series of methodological issues that need to be addressed. This section starts by reviewing how past research has measured the topic so far and then focuses on how this thesis thought of measuring the PPC.

Some of the previous research has reported positive change (i.e., Barskova & Oesterreich, 2009), however, in psychology, there are many terms that could be used (14) when the positive aspects of an event are being considered (Blore, 2012). Thus, with reference to the concept PPC has been described using a variety of terms in the literature. There has been no initial study that introduces the concept of PPC rather than focusing on Post-traumatic Growth (PTG) or Benefit-Finding (BF) and some other similar terms. such as, ‘meaning-making’, ‘perceived benefit’, ‘positive adjustment’, ‘thriving’, ‘positive adaptation’ and ‘adversarial growth’ (Joseph & Linley, 2004). However, the most common term that has been used in the psychology literature is the concept of PTG, as proposed by Tedeschi & Calhoun, (1996), and BF, as stated by Tennen & Affleck, (2002). Both terms, BF and PTG, refer to one's perception that positive changes could occur as a result of traumatic life events, such as RA (Rahmani et al., 2012; Dirik & Karanci, 2008), or following psychological trauma caused by a road traffic accident (Blore, 2012).

The focus on PTG and BF within the research has increased, especially over the last three decades, but relatively few studies have examined positive change in RA as an area under

discussion in its own right. For instance, Sato, Yamazaki, Sakita, & Bryce, (2008) focused on BF, as stated by Tennen & Affleck, (2002), and Dirik & Karanci, (2008) have considered the concepts of PTG as proposed by Tedeschi & Calhoun, (1996) to explore positive change in people with RA. However, RA is a medical health condition rather than a traumatic event, as considered by past studies (i.e., Dirik & Karanci, 2008; Sato et al., 2008), even though the diagnosis of RA could be a traumatic event initially.

Due to this complexity and controversy, some of the past researchers choose not to provide a clear definition, preferring instead to use the term in a manner that assumes that all clinicians and researchers have a common understanding of what it corresponds to (Wortman, 2004). Although these concepts have appeared in diverse research, they are usually not paralleled with one another and have various meanings. Moreover, recent research has employed interchangeable terms with a diverse range of measurements to display the study outcomes (Linley & Joseph, 2004). However, an explanation of the conflicting concerns of positive change is critical to understanding the basic mechanisms of personal growth; in addition, it has noticeable clinical value, with regard to enhancing recovery from chronic health conditions and dropping susceptibility to psychological distress.

1.7.2. Measurement

In regards of the measurement to examine positive change, in the absence of clear definitions, a handful of studies have used several psychometric tools to measure positive changes due to the traumatic events, however, the majority of the last studies used the Post-traumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) to examine positive changes. PTGI is a twenty-one-item self-report inventory that measures the individual's perception of positive changes after a traumatic life experience (Tedeschi & Calhoun, 1996). The scale has five subscales that measure growth across the dimensions of relating to others, new possibilities, personal strength, spiritual change and appreciation of life (Tedeschi & Calhoun, 1996). PTGI has mostly been used in the studies to assess the impact of traumatic events in individuals with cancer (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Manne et al., 2004). However, this thesis was not looking at PTG or any other similar terms, so would not use the PTGI scale. The reason is trauma refers to an emotional response to a terrible event such as an accident, rape or natural disaster, right away after the event, shock and denial are usual however, longer term responses incorporate unpredictable emotions,

flashbacks, strained relationships and even physical symptoms like headaches or nausea (American Psychiatric Association, 2013). Thus, the term, trauma, refers to the damage or injury that results from a violent attack and therefore is highlighted as a negative effect and so, based on this definition, RA is not considered as a trauma.

RA is an autoimmune disease and it is difficult to identify the exact stressor that may cause or participate in the processes of the illness. Moreover, while the exact cause of RA is unknown so far, it is a common agreement that RA has an internal nature and genetic basis. The internal nature of the illness, along with environmental factors might play a key role in adaptation to the illness. In addition, in acute trauma the onset and termination of the traumatic events are well established compared with the ongoing progressive presence of the RA in which the patients have no choice of restricting the onset and termination of the illness. Therefore, people with RA have to live with a long-term condition for many years. Thus, although a numbers of studies reflect interest in the positive effects reported by those who have experienced chronic health conditions and they consider the medical long-term condition as a traumatic event, (i.e., Dirik & Karanci, 2008), it should be emphasised that RA is not a traumatic event. Thus, the present thesis acknowledges that PTGI is not an appropriate measurement to assess PPC in people with RA. Therefore, for the purpose of this thesis a clear operationalise definition of PPC by Sodergren et al., (2002) was adopted. Moreover, having identified a clear definition suggests a strong need for an accurate assessment to examine PPC in people with RA. For the current research, the Silver Lining Questionnaire-38 has been chosen to explore PPC as a consequence of illness, that is, RA (SLQ; Sodergren et al., 2002).

Beyond that, despite the growing body of literature on positive change from experiencing stressful life events or traumatic events, the proportion of positive change varies across the literature. The answer to this information is essential as it gives the chance to the researcher to compare their findings with the previous studies. However, the ratio of positive change (i.e., PTG &/ BF) is mixed depending on various factors. These include the illness (i.e., cancer) and or the events (i.e., survived the sinking of a cruise ship, Joseph, Williams, & Yule, 1993); rape, Burt & Katz, 1987). The study design: a single item study (i.e., McMillen, Smith, & Fisher, 1997) and or longitudinal design (i.e., Danoff-Burg et al., 2005). Other factors include measurement for instance; benefit finding scale, (i.e., Mohr et al., 1999) and or Post-traumatic Growth Inventory (PTGI, Tedeschi and Calhoun, 1996).

Framing of the topic, for instance, how much benefit is required to indicate the occurrence of positive change? as considered by Nolen-Hoeksema & Davis (2004). In all of these studies the range of positive change varied from 1-100. As a result, it is hard to quantify the proportion of people who showed positive change based on the literature.

In brief, the lack of a standard operational definition used by the previous researchers can confound efforts to develop a well validated, consistent to measure positive change within people with chronic health conditions, such as RA. Therefore, having identified the characteristics that distinguish chronic medical conditions from traumas of an acute nature, the current thesis confirmed that the term PTG/BF or any other interchangeable terms would not be appropriate to analyse the possible PPC in RA populations.

1.7.3. The theory

With respect to the model, based on the literature (Sharpe & Curran, 2006; Walker et al., 2004), it is apparent that the most appropriate model for explaining PPC concepts needs to incorporate neuroendocrine elements in a comprehensive psychosocial model to adjust to chronic health conditions, such as RA. Yet, at present, there is no evidence that a most referred to theory, Post-traumatic Growth (PTG) model (Tedeschi & Calhoun, 1996), has applied an entirely combined approach into the model to deal with the multifaceted interrelationships among psychosocial factors, neuroendocrine and immune function, and disease impact as discussed by Walker et al., (2004). For example, the influence of stress on autoimmunity is mainly complex, since stress often has an impact on initiation, aggravation and improvement of disease activity (Walker et al., 2004); however, it is ignored in most psychology models such as PTG.

In fact, based on earlier research, it might be hypothesised that an individual's response to psychological stressors could eventually influence PPC through neuroendocrine and immune mechanisms (Cohen et al., 2012; Walker et al., 2004). However, the difficulties in the theory and measurement on both the psychological and physiological aspects of stress may lead towards a suspension in an inclusive and testable bio- psychosocial model of adjustment in RA. That is because RA sometimes persists for an extended period, requires long-term pharmacological treatment and impacts a person's ability to take action (Pais-Ribeiro, da Silva, Meneses, & Falco, 2007).

Most often, RA is branded by a developing physical disability which also has the prospective to make deep changes to a person's life, which might result in negative effects and a drop in their constructive overall wellbeing. The absent function of physiological and biological indicators in the past psychological growth model would have an impact on the potential role of the cognitive processes in personal growth. This is because the exact mechanism underling the relationship between the immune system and psychological growth in people with medical conditions remains unknown. Consequently, some questions in the context of clinical research remain to be addressed, such as: how does personal growth in people with chronic medical conditions, such as RA, take place, if it does occur? With respect to people with RA, how might living with pain and disability lead to positive change? What is the mechanism of changing from pain in people with RA to personal growth? What is the impact of negative/positive thinking on handling RA? Does positive thinking lead to more positive feelings about living with RA? If people think positively, does it affect their immune system functioning? What is the possible consequence of more positive thinking in people with RA? Can it foster psychological growth, perhaps through cortisol reductions? Does this possible thinking positively allow one to self-produce benefits through hormonal levels whereas visibly forced suggestion of particular benefits?

A more recent area of research suggests that positive emotions can have an effect on the processes of personal growth (Tugade & Fredrickson, 2007). Subsequently, it is reasonable to conclude that intensifying physical functioning and activity could have an impact on positive emotions and create the potential physiological capacity to create room for psychological growth. However, the most commonly referred theory in the context of positive change, does not consider the physiological and biological roles involved in determinant personal growth or recognise this potential link, with only a small number of exceptions to date (e.g. Sabiston, McDonough, & Crocker, 2007). The possible impact of chronic health conditions leading to personal growth is not complete without considering the physiological and biological elements of such experiences.

1.8. The study rationale

As noted in the opening section of this thesis (and indeed acknowledged in the literature review) there are a number of unanswered questions about the definition and measurements used to examine the positive consequences of illness in RA. There have been some intervention studies that have focused on the relationship between PTG and BF in other clinical populations (Antoni et al., 2001; McGregor et al., 2004; Wagner, Knaevelsrud, &

Maercker, 2007). Having said that, there are a few studies based on a qualitative design, which refer to a patients' experiences of positive outcomes that support their internal personal resources, as having the greatest impact on managing the burden of RA (i.e., Dager, et al., 2012).

Positive psychologists develop the grounds to promote outstanding ability and talent to make normal life more rewarding, instead of just treating mental illness (Compton, 2005). The concepts of positive changes are discussed in this chapter. Some studies have presented support that these positive processes occur in long- term health conditions, including persons living with cancer (Antoni et al., 2001), multiple sclerosis (Hart, Vella, & Mohr, 2008), complicated grief (Wagner et al., 2007), Stroke (Hartke, King, & Denby, 2007) and RA (Dirik & Karanci, 2008; Sato et al., 2008). However, the background literature for the current research illustrates that there are no past studies which have focused on PPC in the target population, people with RA.

In relation to favourable health outcomes, there are several reasonable approaches through which positive affect has been linked to physical health lifestyles (Dockray & Steptoe, 2010). There is likely to be a general underlying genetic substance impact that affects collectively physical health and health behaviour (Brouwers et al., 2013). Positive affect might also be a broad field to measure other psychological factors which might be recognised to impact on health outcome, such as, coping strategies (Brouwers et al., 2013). There is also a growing indication that supports a straight link between health and positive affect, connecting decreased psychobiological activation of neuroendocrine, autonomic, immune and inflammatory pathways (Dockray & Steptoe, 2010) in which positive affect stimulates autonomic, neuroendocrine and immune systems towards reducing the amount of cortisol released (Dockray & Steptoe, 2010). The level of cortisol has constantly been revealed to be lower amongst persons with superior levels of positive affect (Brouwers et al., 2013).

The favourable effects of positive affect on cardiovascular function have been documented, in cooperation with blood pressure, heart rate and the immune system. Kubzansky and Thurston, (2007) applied a prospective epidemiological cohort design, signifying that positive affect might have biological characteristics associated with better health outcomes. In addition, the impact is maintained significantly after considering other identified risk factors. It has also been reported that greater levels of positive affect were linked to a lower

occurrence of stroke even after six years (Dockray & Steptoe, 2010). Therefore, it might in turn influence the original physiological aspects of a chronic illness (Salovey, Rothman, Detweiler, & Steward, 2000). These biological links might be accountable for the shielding impacts of positive affect through positive psychological wellbeing on better health predictions (Diener, 2009). Thus, the focus of the present study is to explore PPC, measured using SLQ, in individuals with RA, as a medical health condition, which has been described in the present thesis.

To end with, the focus on positive change within research has increased, especially over the last three decades, but relatively few studies have examined positive change in RA. As noted earlier in the present thesis (and indeed acknowledged in the literature review) there are several unanswered questions about the definition and measurements used to examine the positive consequences of illness in RA. There have been some intervention studies that have focused on the relationship between PTG and BF in other clinical populations (Pascoe & Edvardsson, 2013). However, no formal study has investigated whether PPC exists among people with RA prior to this thesis. Having said that, there are a few studies based on a qualitative design, which refer to patients' experiences of positive outcomes that support their internal personal resources, as having the greatest impact on managing the burden of RA (e.g. Dager, 2012). Therefore, this PhD was organised around a central theme: The likelihood and the extent of PPC in people living with RA. A survey study was designed to investigate PPC in RA population.

After all, without a foundational exploration of PPC in relation to the well-being of people with RA, it would seem unnecessary to pursue an analysis of the components of PPC, namely classified as positive illness representation, to identify the impact of positive change on illness.

1.8.1. Why Rheumatoid Arthritis has been chosen?

As previously stated individuals with RA are living with pain, fatigue, inflammation and an uncertain future. RA is a serious, progressive, disabling chronic medical condition, and is a source of stress in itself (Walker et al., 2004). Since various joints are implicated in RA, more movement restriction with pain is apparent among these patients as usually RA participants have to live with a long- term condition (Zautra et al., 2001). Thus RA is less

predictable in its course and potentially more distressing to quality of life and social relations.

All these factors might reflect on one's mental health and accordingly on the study outcome as the role of the disease itself. Nearly a third of individuals with RA become work disabled because of the illness within two years of onset and this figure is seen to increase in subsequent years (Barrett, Scott, Wiles, & Symmons, 2000). A survey performed by the British Society for Rheumatology (2008) expected that when a patient discontinues work caused by RA, it signifies an average damage of productivity comparable to £287,544 (Parsons, Ingram, Clarke-Cornwell, & Symmons, 2011). Obviously, this relates to a massive cost to the UK budget and a huge cost to single patients. As with many chronic conditions, RA is economically costly in which the total UK costs, counting unplanned costs and work linked disability, are estimated to be roughly £3.8 - £4.75 billion per year (Home & Carr, 2009).

RA is a painful condition, with at times rapid progress, and can cause swelling and damage to the cartilage and bone around joints. This leads to impairment in movement, which can disturb a person's capacity to perform daily responsibilities. Thus, RA can be considered as the cause of a severe physical disability. Furthermore, unrestrained RA increases the risk of mortality through an increased susceptibility to cardiovascular diseases, such as heart attacks and strokes (Sen, González-Mayda, & Brasington, 2014). Due to these economic, physical and even emotional costs, the requirement for timely treatment is imperative (Kyburz & Finckh, 2013).

To end with, developing health-promoting techniques of living with chronic health conditions is a challenging procedure, including psychological, social, behavioural and existential questions (Dager et al., 2012; Walker et al., 2004). So far, medical treatment of RA delivers symptomatic relief as opposed to overall cure (Dager et al., 2012), and the primary focus of the medical programs has been on physical and functional outcome measures (Dirik & Karanci, 2008). Despite this, for the last three decades, a wealth of research has suggested that chronic health conditions can cause positive change such as PTG and BF. However, the positive psychological impacts on individuals living with RA have thus far been insufficient in many areas (Alamanos & Drosos, 2005). Thus, with reference to the terminology the definition of PPC for the present thesis is based on the

positive consequences of illness reported by individuals who have encountered RA as measured by the Silver Lining Questionnaire-38 (SLQ; Sodergren, Hyland, Singh, & Sewell, 2002). The SLQ measures the extent to which individuals believe their illness has had a positive benefit regardless of the negative consequences of being ill (Sodergren et al., 2002). Besides, the background research for this thesis looked at PPC and this has not been fully investigated in the RA population.

1.9. Survey study

This dissertation determined to fill up the gap in the current literature by exploring the positive aspects, that is PPC, of the RA symptoms in persons with RA in the UK. A survey study was conducted to investigate the likelihood and extent of PPC, the factors that relate to PPC in persons with RA and to examine the psychological and social factors and the physical and the demographic characteristics, that associate with and may influence the development of PPC within this population. The study explored whether the related factors are predictive of PPC.

1.9.1. Aims and objectives

The present thesis aimed to explore the factors that associate to PPC in individuals with RA in the UK. A survey was therefore conducted with RA people to investigate the objective of the study as below:

1. The likelihood and extent of positive psychological change in people living with rheumatoid arthritis in the UK
2. Describe the personal characteristics of those people who have reported PPC from their RA experiences
3. Explore potential psychosocial and physical factors associated with PPC in people with RA
4. Explore whether the associated factors are predictive of future PPC

1.9.2. Research Questions

In this survey, reliable and valid measures were used to investigate the aims of the study in people with RA. The study sought to develop current understanding of the illness experience by concentrating on PPC amongst people living with RA. A key question would

be why some people, when thinking of their problems and feelings of distress are able to engage in adaptive reflection and reduce negative effect? Whereas others fall into brooding, build more negative feelings and might become more susceptible to depression. In addition, there are still certain concerns regarding the factors that differentiate people who engage in PPC and those who demonstrate mental health symptoms. The thesis also questions what are the factors associated with the occurrence of PPC in people living with RA. Specifically, the demographics; clinical and some of the other psychosocial factors considered in the present thesis have been addressed in the methods section.

1.10. Hypotheses

The study hypotheses are as below:

1.10.1. Demographic characteristics

The demographic characteristics of those people who have reported PPC from their RA experiences have been addressed as below.

1.10.1.1. Hypothesis

It is predicted that:

- a) There is a significant difference between PPC and different age groups (the age groups are: 25-45; 46-66 and 67-87 years old)
- b) There is a significant correlation between PPC and the study age groups

1.10.1.2. Hypothesis

It is predicted that there is a significance difference on PPC between males and females

1.10.1.3. Hypothesis

It is predicted that there is a significant difference between PPC and marital status

1.10.1.4. Hypothesis

It is predicted that there is a significant difference between PPC and education status

1.10.1.5. Hypothesis

It is predicted that there is a significant difference between PPC and employment status

1.10.1.6. Hypothesis

It is predicted that there is a significant difference between PPC and ethnicity

1.10.1.7. Hypothesis

It is predicted that:

- a) There is a significant difference in PPC between RA duration groups (the RA duration groups are: 2-5; 6-10 and over 10 years since diagnosis)
- b) There is a significant positive correlation between PPC and RA duration (one-tailed)

1.10.2. RA clinical characteristics

The RA clinical variables have been addressed as below.

1.10.2.1. Hypothesis

It is expected that there is a significant negative correlation between PPC and fatigue (one-tailed)

1.10.2.2. Hypothesis

It is expected that there is a significant negative correlation between PPC and pain (one-tailed)

1.10.2.3. Hypothesis

It is expected that there is a significant negative correlation between PPC and physical health function (one-tailed). This includes the rate of mobility level; walking & bending; hand & finger function and arm function scores on the AIMS-2

1.10.3. RA Psychosocial factors

The RA Psychosocial variables have been addressed as below.

1.10.3.1. Hypothesis

It is expected that there is a significant positive correlation between PPC and psychological well-being (one-tailed)

1.10.3.2. Hypothesis

It is expected that there is a significant positive correlation between PPC and coping strategies (one-tailed)

1.10.3.3. Hypothesis

It is predicted that:

a) There is a significant positive correlation between PPC and self-efficacy pain management (one-tailed)

b) There is a significant positive correlation between PPC and self-efficacy other symptoms (i.e., fatigue) (one-tailed)

1.10.3.4. Hypothesis

It is predicted that there is a significant positive correlation between PPC and sense of coherence and resilience (one-tailed)

1.10.3.5. Hypothesis

It is predicted that:

a) There is a significant positive correlation between PPC and social support (one-tailed)

b) There is a significant positive correlation between PPC and social activity (one-tailed)

1.10.3.6. Hypothesis

It is predicted that there is a significant positive correlation between PPC and quality of life (one-tailed)

1.10.3.7. Hypothesis

It is predicted that there is a significant negative correlation between PPC and depression (one-tailed)

1.10.3.8. Hypothesis

It is predicted that there is a significant negative correlation between PPC and level of tension (one-tailed)

1.11. Chapter summary

To conclude, some of the literature on stress and coping concentrated on the negative consequences of stressful conditions (Park, 2010 & 1996). However, much empirical research has shown that some people reported positive change because of coping with stress or they experienced positive outcomes and growth through their coping experience (Park, 2010 & 1996). In fact, some people who have experienced chronic health conditions confirm their stressor as having a very positive effect (i.e., Joseph & Linley, 2012). Of course, not all people with chronic health conditions report experiencing such a positive change. More importantly, experiencing positive change does not necessarily mean that people do not experience pain and distress. Nor does it mean that they experience positive change in all domains of their lives. The challenge for the progress in stress and coping research is to find out why some people experience a positive change following stressful conditions, while others experience some growth and others none (Park, 2010). Therefore, people with chronic health conditions such as RA may experience positive change effects of illness. However, usually the negative side of the RA was focused upon neglecting the consideration of the potential benefits (Afrasiabifar, Hassani, Fallahi Khoshknab & Yaghmaei, 2011). Although, there are some negative experiences of physical illness reported by people living with RA, there might be more positive consequences of illness than often realised (Sodergren et al., 2002).

The findings of some of the past research (e.g., Iversen et al., 2010 & McPherson et al., 2001) of people with RA show that physical limitations on RA people may become disabling, the disease may challenge RA population emotions, and life may become even tougher due to an inability to keep working. However, there is evidence of enjoying life and facing the challenge of the problematic issues imposed by RA.

Psychological factors are likely to have complex, multi-causal pathways comprising varying combinations of clinical and psychosocial factors. However, the impact of the psychological factors of RA is uncertain. Therefore, there is a strong need to consider whether there is any PPC in people with chronic health conditions, in particular in people living with RA. Despite recent efforts in the development of medical treatments, RA is coupled with a significant degree of stress, caused by severe pain, loss of essential functioning, and the disturbance of daily schedules. People with RA also reveal a greater prevalence of

depression and anxiety in comparison to other patients with chronic illness and healthy individuals (Cohen et al., 2012). Pincus (1996) suggested that depression in the RA population is correlated with pain and work-status. There is also some evidence that pain and depression are important predictors of fatigue (Repping-Wuts et al., 2008; Rupp, Boshuizen, Jacobi, Dinant, & van den Bos, 2004), thus, for a minority, living with their illness can have serious psychological consequences, such as clinical levels of anxiety and depression (Dures & Hewlett, 2013; Cordova et al., 2001 & Cohen et al., 2012). On the other hand, people with RA have to adapt to the physical, psychosocial, behavioural and emotional impacts of RA in order to cope with the influence of the treatments and the illness on their daily lives (Dures & Hewlett, 2013). However, the positive consequence of living with RA is unclear as little research has been undertaken to understand whether PPC is possible in people with RA. Therefore, this thesis concerned with whether there are any positive aspects of living with RA.

Chapter Two: Method

2. Introduction

The aim of the thesis was to examine if people with RA experience PPC and to explore the psychosocial, physical and demographic factors associated with its occurrence. A survey study was conducted to explore the likelihood and extent of PPC, and the psychosocial, physical and demographic factors that are associated with and may influence the development of PPC in individuals with RA. The study has explored whether the associated factors are predictive of PPC. This chapter focuses on the collection of the data to meet the objectives of this research study and answer the research questions by reviewing the study's design, sample derivation and the psychometric properties of the data collected.

2.1. Design

In this study quantitative approaches were used, as the data was in numerical form and it was intended to describe the relationship between variables. Quantitative research methods can be divided into experimental and non-experimental designs. However, as this study is not looking at the cause and effect of the variables it is classified as a non-experimental study. A survey study involves the collection of information from a sample of individuals through their responses to questions or interviews; however, interview techniques were not appropriate as a quantitative research approach has been used in this study. The correlational design involves the relationship of one or more variables with another (i.e., multiple regression design).

It is important to quantify the size and nature of a problem within specific populations. Therefore, understanding how prevalence may differ by demographic factors, such as age and gender, can help to generate hypotheses. Identifying factors that are associated with PPC can contribute further to the formulation of hypotheses on causal mechanisms and provide some insight into potential prevention and intervention strategies. This is a key component in building a correlational design study in psychology research. There are several different designs that can be used in survey research. The three general types are: cross-sectional, successive independent samples, and longitudinal studies (Shaughnessy et al., 2011). For the purpose of the current study, a quantitative research design using mixed

methods involving correlational, multiple regression and a cross-sectional design has been used.

A correlational design was employed to examine the relationship between variables as this research is looking at many different factors that contribute towards PPC. PPC, as a form of positive change, has been investigated in relation to other health conditions; however, this research is intended to find out whether there are any positive changes in people with RA. The role of disease and psychosocial factors in people with RA has not been examined before, hence there are no estimates from empirical studies of the association with the related contributing factors. Thus a correlational design has been used to examine the relationship between variables.

Furthermore, the research has aimed to test the conceptual model of PPC. Therefore, a multiple regression design has been used to examine the relationship between the outcome of interest (predictor variables) and other explanatory factors (e.g., criterion variable) in a defined population. In addition, a cross-sectional approach has been used in this study as the data was collected from a sample to describe some characteristics of the population at one specific point in time. Cross-sectional studies may involve special data collection techniques, including questions about the past, but they often rely on data originally collected for other purposes. The use of routinely collected data allows large cross-sectional studies to be carried out at little or no expense. This is a major advantage over others. However, difficulty in recalling past events may contribute towards bias. In a cross-sectional survey, a specific group is looked at to investigate a specific effect. Nevertheless, this cannot give any insight into the causes of population characteristics.

2.2. Survey administration

The data was collected using a questionnaire divided into five parts:

- a) Demographic information, including: date of birth, gender, marital status, education, employment, ethnicity and duration of RA
- b) RA clinical variables comprising: fatigue, pain, prevalence of co-morbid conditions
- c) RA physical health factors, covering: mobility level, walking and bending, hand and finger function and arm function

- d) RA psychosocial factors involving psychological well-being, coping strategies, self-efficacy-pain symptoms, self-efficacy other symptoms, sense of coherence and resilience, social support, social activity, quality of life, depression and level of tension
- e) The designation of the criterion variable and this was predicted. The PPC (criterion variable) was measured using the Silver Lining Questionnaire (SLQ, Sodergren, et al., 2002).

2.3. Participants

The study aimed to include 200 people who have been diagnosed with RA. Eligibility criteria were used to specify the details and precisely define what made an individual appropriate or not appropriate for participation in the study. The inclusion criteria were:

- a) People diagnosed with RA by a rheumatology consultant
- b) Age ≥ 18 and
- c) Time scale after diagnosis of at least two years. Two years was used to make sure the condition is well established. Thus, those who did not meet the study's inclusion criteria were excluded from participation.

2.4. Sample size

Recruitment for the present survey study was based on two sources:

- a) The Salford University's Rehabilitation Research Group, which has an Arthritis Research Panel (ARP), i.e. a database of people with RA who have participated in past studies and were willing to be contacted about future studies run by the Research Group.
- b) Recruitment via advertising on the National Rheumatoid Arthritis Society (NRAS) website and in newsletters. The participants were an opportunity sample of people over 18 years old who were willing to participate in the study. Therefore, they were RA people who were either ARP or NRAS members.

Response rates from previous studies in the same field were 50-60% (i.e., Tennen et al., 1992). It was estimated that approximately 210 individuals with RA participated in this survey. There were at the time about 250 people on the ARP database who were willing to take part in the study. Therefore, according to the estimation, the aim was to gain around 125 participants for the study via the past participant database. On that basis, the study

expected the remaining (125–150) participants to be recruited via advertising through the NRAS and mailing of the study information to NRAS members by the researcher.

2.5. Measurements

The present survey has included validated, widely used health and psychological measures to evaluate RA symptoms, as recommended by NICE and also as illustrated in the International Classification of Functioning (ICF) Core Set for RA patients. It was hoped that if the study identifies the existence of PPC in people with RA, the study outcomes may influence future interventions and models of psychological change, as well as health measures.

The choice of reliable and valid questions for the questionnaire was made following a literature review and feedback from the supervisory team. In total, eight reliable and valid scales were used in this research to collect the data.

The data was collected using the following measures: The Silver Lining Questionnaire (SLQ, Sodergren, et al., 2002); the Arthritis Impact Measurement Scales-2 (AIMS-2, Meenan, et al., 1992); the Bristol Rheumatoid Arthritis Fatigue Scales (BRAFs, Dures et al., 2013); the Arthritis Self-Efficacy Scale (ASES, Lorig et al., 1989); Quality of Life-Rheumatoid Arthritis Scale (QoLRA Scale, Danao et al., 2001): English version; the Coping with Rheumatoid Arthritis Questionnaire (C-RAQ, Englbrecht et al., 2012); the short-form of the Psychological Well-Being Scales (PWB, Ryff, 1995) and the short-form of the Sense of Coherence (SOC, Antonovsky, 1987) (See Table 2.1.).

Table 2.1. Survey study questionnaires

Name	Objective	Total Items
The Silver Lining Questionnaire (SLQ)	Positive change	38
The Arthritis Impact Measurement Scales 2 (AIMS-2)	Physical health (mobility level, 5 items)+ (walking & bending, 5 items)+ (hand & finger function, 5 items) + (arm function, 5 items)= 20 items	20
	Level of tension	5
	Mood (5 items)	5
	Pain (5 items)	5
	Social activity (5 items)	5
	Support from family and friends (4 items)	4
The Bristol Rheumatoid Arthritis Fatigue Scales (BRAFs)	Fatigue	1
The Arthritis Self –efficacy Scale (ASES)	Self-efficacy pain (5 items) & other symptoms (6 items)	11
The QoL-RA Scale is an RA-specific Health Related Quality of Life (HRQoL)	Quality of Life	8
The Coping with Rheumatoid Arthritis Questionnaire (C-RAQ)	Coping skills	18
The short form of the Psychological well-being (PWB)	Well-being	18
The short-form of the Sense of Coherence (SOC)	The ability to manage stress	13
Total		151

2.5.1. The Silver Lining Questionnaire (SLQ; Sodergren, et al., 2002)

The Silver Lining Questionnaire (SLQ) was created by Sodergren and Hyland (2000) at Plymouth University, UK. The aim was to measure the positive consequences of an illness. The scale was used to assess the extent to which people believe their illness has resulted in positive benefits despite the negative consequences of being ill. The scale measures improved interpersonal relationships, positive influence on others, self-improvement, reappraisal of life, restructuring of life, spiritual changes, sensitivity to emotions, skills and new pursuits, self-knowledge and confrontation of current concerns. The total score on the SLQ reflects the general PPC as a consequence of the illness. It comprises 38 items with five response categories, reflecting the extent to which people believe their illness has had a positive effect. Participants were asked to think about the positive aspects of their illness experience and to indicate the extent to which they agreed with the 38 statements using a five-point Likert scale ranging from (1) strongly disagree to (5) strongly agree. Cronbach's alpha was 0.93 across the samples, suggesting a high level of homogeneity among the SLQ items. The Pearson product correlation between the two assessments was $r=0.90$; $P<0.001$, showing good retest reliability.

2.5.2. The Arthritis Impact Measurement Scales 2 (AIMS-2; Meenan, et al., 1992)

The Arthritis Impact Measurement Scales-2 (AIMS -2) is an arthritis specific, self-administered questionnaire which assesses physical, emotional and social well-being using 12 domain scales: mobility level, walking and bending, hand and finger function, arm function, self-care, household tasks, social activities, support from family and friends, arthritis pain, work, level of tension and mood. The questionnaire also collects data about the severity of the disease, health perceptions, other significant illnesses and socio-demographic status. The AIMS-2 is a revised and expanded version of the original AIMS health status questionnaire. The comprehensiveness of the AIMS- 2 has been increased through the addition of items to measure satisfaction with health status, arthritis attribution, and problem prioritisation. The AIMS-2 is considered to be a specialised instrument which has been widely used for assessment, intervention management and outcome evaluation in people living with RA. Evaluation of the scale in 299 patients with RA gave internal consistency coefficients for 12 scales of 0.72- 0.91. The Cronbach's alpha

coefficient: 0.32- 0.87 and the test-retest reported 0.78-0.94 (Meenan et al., 1992). Internal validity was significant ($P < 0.001$); patient designation of a problem was significantly associated with a poorer AIMS-2 scale score in that area. Reliability, factor analysis and validity were consistent with age, sex and education subgroups.

The AIMS-2 subscales can be divided into four categories by considering the purpose of the survey study. The four components which combine the AIMS-2 scales into measures are:

- a) Physical health function, including: mobility level (five items); walking and bending (five items); hand and finger function (five items) and arm function (five items). In total, 20 items were used to assess physical health.
- b) Level of tension (five items) and mood (five items) were used to assess mental health symptoms.
- c) For social activity (five items) and support from family and friends (four items), a total of nine items were used to assess social interaction.
- d) The subscale of arthritis pain (five items) was used to measure arthritic pain.

The short form of the AIMS-2 was used (44) as the questionnaire is long (78) and would be time-consuming for participants to complete; many of the sections are extensive and provide too much detail for a study where the main focus of the present research was to examine physical health and psychosocial factors. The short form of the scale has been widely used by previous authors (i.e., Brekke et al., 2003).

The participants were asked to indicate the extent to which they agreed or disagreed with each statement, using a five-point Likert scale ranging from (1) all days to (5) no days.

2.5.3. The Bristol Rheumatoid Arthritis Fatigue Scales (BRAFs; Dures et al., 2013)

The Bristol Rheumatoid Arthritis Fatigue Scales (BRAFs) was developed to measure fatigue in RA patients. The scale was created in the rheumatology department in Bristol in the UK. For the purposes of this study, only one item from the Bristol Rheumatoid Arthritis Fatigue Numerical Rating Scales (BRAf- NRS) was used. This

is called the Visual Analogue Scale (VAS) with ‘no fatigue’ anchoring the left end and ‘worst imaginable fatigue’ the right end. Subjects were asked to make a mark on the 100 mm line that best indicated their average level of fatigue over the past week. The line is then measured from the left end to provide a score from 0 to 100. Linear analogue scale measures of fatigue have been found to be reliable and valid, especially when comparing subjects to them over time. They have good test-retest reliability and correlations with established methods of assessment for affective symptoms. VAS scales are usually more effective in measuring change over brief periods such as one week or one month than they are over six months or a year. These instruments are easy to use, easily comprehensible to the patients, have been shown to be sensitive to change and to have a strong test-retest reliability coefficient of $r = 0.82- 0.95$ (Dures et al., 2013). The item was ‘Please circle the number which shows your average level of fatigue during the past seven days’.

2.5.4. The Arthritis Self-Efficacy Scale (ASES; Lorig et al., 1989)

The Arthritis Self-Efficacy Scale (ASES) was developed by Lorig et al. (1989) to measure self-efficacy in patients with rheumatic diseases. The questionnaire contains: coping with pain (five items), details concerning function (nine items), and other symptoms related to RA (six items). Each item presents a statement with which the patient could agree or disagree. The scores are expressed as values of between 0 and 100, with a score of 0 representing the lowest possible self-efficacy level. For the present study it was decided not to include the nine questions regarding function so as to shorten the length of the questionnaire by omitting some questions. This research has included questions on self-efficacy as two scores: one for pain and one for other symptoms (fatigue, depression etc.). In some past studies, the ASES subscale ‘function’ has been omitted (Brekke et al., 2003; Hammond, Bryan, & Hardy, 2008). As such, two subscales were used as ‘pain’, $r = 0.87$, and ‘other symptoms’, $r = 0.90$. Cronbach’s α was 0.76 for the pain subscale and 0.87 for the ‘other symptoms’ subscale.

2.5.5. Quality of Life-Rheumatoid Arthritis Scale (QoLRA Scale; Danao et al., 2001): English version

This is a means of rheumatoid arthritis specific, health-related, quality of life assessment. Data for the psychometric analysis came from a sample of women with RA. The QoL-RA Scale, an eight-item scale, took two to three minutes to administer. Each item started with the definition of an element to be considered in rating one's quality of life, followed by a question on rating one's quality of life on a horizontal ten-point scale anchored with one (very poor) at one end and ten (excellent) at the other end. The elements are physical ability, pain, interaction with family and friends, support from family and friends, mood, tension, arthritis and health. The higher the QoL-RA scale score, the higher the Health-Related Quality of Life (HRQoL).

There were significant correlations from the QoL-RA Scale with the AIMS-2 subscales, ranging from 0.25 to 0.66 ($P < 0.01$). The Cronbach's alpha coefficients was 0.90 in the English group (Danao, et al. 2001). The QoL-RA scale appears to meet the assumptions of a summated rating scale.

2.5.6. The Coping with Rheumatoid Arthritis Questionnaire (C-RAQ; Englbrecht et al., 2013)

Coping strategies have been assessed using a validated questionnaire based on the transactional model of stress and coping containing emotion- and problem-focused coping strategies by Folkman and Lazarus (1986). The questionnaire comprises the following coping domains: cognitive reframing, distancing, emotional expression and active problem solving. Each of the 18 items were answered using a scale ranging from zero (not at all) to three (a lot), indicating the extent to which the corresponding coping behaviour was used during the past week to cope with RA, or by indicating in a separate category that the described coping behaviour was not applicable to the patient. The Cronbach's alpha coefficients were constantly ≥ 0.7 , indicating satisfactory internal consistency for all coping strategies with respect to their purpose (Englbrecht et al. 2013).

2.5.7. The short-form of the Psychological Well-Being Scales (PWB; Ryff, 1995)

Psychological Well-Being Scales (PWB, Ryff, 1995) were used to examine the well-being of the target sample. This is a theoretical model of psychological well-being that encompasses six distinct dimensions of wellness, which are: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance. A six-point answering scale was used for all scales, ranging from one (totally disagree) to six (totally agree). The 18 item version of the scale was used by previous authors (Wood & Joseph, 2010). The test-retest reliability coefficients over a six-week period ranged from 0.81– 0.88. Correlations with prior measures of positive functioning ranged from 0.25- 0.73. Correlations with prior measures of negative function are all negative and significant, with coefficients ranging from 0.30- 0.60. The inter-correlations among the measurements themselves showed coefficients ranging from 0.32 - 0.76.

2.5.8. The short-form of the Sense of Coherence (SOC; Antonovsky, 1987)

The short form of Sense of Coherence (SOC, Antonovsky, 1987) has 13 items and has been widely used over the last 13 years to measure resilience. The scale was employed to measure how people manage stressful situations and stay well. The scale assesses a person's ability to manage stressful conditions such as dealing with RA. Five of the items are negatively stated and reversed in scoring. These are item numbers: one, two, three, seven and ten. Therefore, a high score always indicates a stronger SOC. This is reliable and adequately valid. The reliability was found to be between 0.74- 0.91 (Antonovsky, 1993). Each question has seven possible answers with number one and seven being the extreme answers.

2.6. Procedure

For the purpose of the current survey, questionnaire packs were sent to a preselected sample of people, according to the study inclusion criteria, with instructions on how to fill out the survey and return it in the enclosed envelope. Mail surveys have historically been one of the cheapest and most efficient methods of survey distribution. As the researcher does not administer the survey, there are no issues with interviewer bias, and also the survey is taken in private with the assurance of anonymity. Therefore, there is likely to be less social desirability bias and discomfort talking about private issues. However, a mail survey is not

without drawbacks. Due to the fact that the survey is self-administered, participants cannot ask for clarification, meaning there is no way of definitely controlling the order the questions are answered in. In addition, many participants will not fill out the survey, either because they have poor literacy or vision, or simply because they cannot be bothered. In addition, this group of people does not represent an equal distribution of the sample, so the sample may be less representative than it was intended to be. As a solution to deal with sample bias, this research study requested the participants to read the study information sheet before making a decision about whether to take part in the study, to make sure they understood why the research was being carried out and what it would involve for them. They were also asked to submit a question if anything they read was not clear, or if they wanted more information they could contact the researcher at any point. Moreover, an attempt was made to provide appropriate instructions along with easy and understandable wording and format.

On behalf of the Principal Investigator (PI), a member of the Rehabilitation Research Group (RRG) forwarded the invitation pack to the ARP members. This included: the study invitation letter, information sheet, reply form (including contact details) and a freepost envelope sent to the ARP members. This was in order to protect the identity of the ARP participants and for data protection and confidentiality reasons.

Interested ARP members returned the PI reply form and confirmed that they agreed to take part in the study. The PI screened their eligibility. If they were eligible the researcher then informed the RRG member which panel members were willing to participate in the study, so that study participation was logged on the ARP database. Then, for those who met the eligibility criteria, the PI posted the second package to their address. This included the consent form, freepost envelope, a booklet and the cover letter. The participants were asked to sign the consent form and complete the questionnaires within the next seven days and return them to the PI in the freepost envelope enclosed. The same process was undertaken for the NRAS members.

Additionally, the PI discussed the feasibility of recruiting via the NRAS with the Director of External Affairs in collaboration with NRAS' Chief Executive. In the meantime, the PI applied to obtain approval from the University of Salford's Ethics Committee. Subsequent to obtaining approval from the University Ethics Committee the following steps took place via NRAS.

A brief explanation of the study, including: the study advert together with the PI's contact details (name, email address and phone number) was posted on the NRAS website. Those who were interested in participating then contacted the PI directly by email. Afterwards, the PI forwarded the same invitation pack to the NRAS members. These included: the study invitation letter, information sheet, reply form (including contact details) and a freepost envelope. Interested NRAS members returned the PI the reply form and confirmed they agreed to take part in the study. The PI screened their eligibility. If they were eligible then the PI entered their details into the NRAS database and posted the second package to the individuals address.

The PI maintained a study database of all people who agreed to participate in order to track their progress through the study. A thank you letter was sent to the participants following their contribution to the study. Information about the study participants was kept confidential and managed according to the requirements of the Data Protection Act, the Research Governance Framework for Health & Social Care, Ethics Committee Approval and University of Salford Research Governance Procedures. Identifiable data obtained via telephone, email or reply forms (such as name and address) was accessed and used only by the research team at the University of Salford. This was to enable the questionnaires to be mailed out to participants correctly and for reminders to be sent if necessary.

Each study participant was assigned a unique participant number. A master list of participant numbers and addresses was maintained on a study database securely stored on the University of Salford's server. A database (names, addresses and telephone numbers) of those participants that requested a study pack was maintained. Progress through the study was tracked in order to ensure the timely mailing of questionnaires and reminders. This was password protected on a secure file storage area on the University of Salford main server. This was only accessible by the PI and the research team who were directly engaged in the project at the University of Salford. The Principal Investigator was the custodian of the data. Dr. Peter Eachus was lead supervisor for this project. The participants were informed that they would not be identified in any future publications. Source data and databases were stored securely and kept confidential. People were identified by numbers only in statistical records and on questionnaires. Data analysis (SPSS) files only identified participants' survey IDs. Paper versions of the questionnaires and reply forms were stored in separate locked cabinets.

2.7. Ethics

The survey involved collecting an extensive amount of data on participants to determine their demographic: RA clinical; physical health function and psychosocial variables. The project required ethical approval from the University of Salford's Ethics Committee as the study involved human participants. The study pack which included the invitation letter, consent form, information sheets and reply forms was submitted with the protocol for review and approval by the University of Salford Research Ethics Committee. Consequently, the project obtained the required ethical approval from the university's Ethics Committee.

This study was conducted according to the standards of the University of Salford Research Ethics Committee regulations and the University of Salford (College of Health & Social Care) Research Governance policies and procedures. Therefore, the participants were informed that there could be a potential risk of distress caused to them while completing the psychological questionnaires included in the study. In accordance with the Code of Ethics and Conduct (British Psychological Society, 2014), the researcher ensured that all participants in the study were provided with an information sheet describing the elements of the study and sufficient information to make a decision about their participation in the study, and they were reminded of this information at the beginning of the survey questionnaire.

The participants consented freely to the study on the basis of adequate information. Therefore, the participants were free to withdraw or modify their consent during the data gathering phase. Any data they had consented to submit up to the time of withdrawal was used. The participants were informed that reliable and valid questionnaires would be used to gather the data.

If participants had a concern about any aspect of this study, they were directed to speak to the PI or a member of the research team who did their best to answer all their questions. If they remained unhappy and wished to complain formally, they could do so to Dr. Peter Eachus, in the School of Health Sciences, who was the lead supervisor for this project. They were also informed that if they felt disquiet /upset during completing the questionnaires then they could contact their GP.

Participants were informed that any data they provided would be kept confidential. No identifying data was included in any report arising from the study. Participants were informed that they could withdraw from the study at any time. They could do so at any time

during the completion of the paper questionnaire by not returning it in the freepost envelope enclosed; the data would not then be submitted. Any data they had consented to submit up to the time of withdrawal was used.

2.8. Silver Lining Questionnaire-38 scoring system

Sodergren (2002) proposed a bi-modal scoring system for the SLQ-38 in which strongly agree and agree are coded as “1” and all other response options as “0”, in order to examine whether there is any positive change in people with a chronic health condition. However, Sodergren (2000) took an attitude item with a five point Likert scale format and collapsed the data into a simple two point scale of agree/strongly agree and strongly disagree; however, this may have corrupted the measurement by removing the extremity information (Breakwell et al., 2006). In contrast, McBride et al., (2009) note that when the main aim of the research is to assess the effectiveness of an intervention study to promote growth in a specific area, in this case a continuous score on a particular sub-scale may be most useful. Therefore, if the objective of the research is to investigate the hypothesised predictors of growth following illness, calculating and using an overall score of growth might be appropriate as well. To avoid this issue, the present study has focused on the continuous levels of the scale, in which strongly agree (5); agree (4); not sure (3); disagree (2) and strongly disagree (1) have been assigned for the scores. Therefore, a high value is compatible to a high degree of positivity.

2.9. Chapter summary

The present survey study aimed to investigate the likelihood and extent of PPC, the demographic characteristics, and the physical health function, social and psychological factors that contribute towards and may influence the development of PPC within individuals with RA in the UK. The study has explored whether the associated factors are predictive of PPC. The purpose was to expand on the current knowledge and to build a growing awareness of PPC by looking at a particular sample of the RA population. This chapter has discussed the methodology and theoretical perspectives underpinning the study. Non-experimental quantitative research designs (correctional, multiple regression and cross-sectional) were used. Ethical considerations were also taken into account. Finally, the statistical tests identified and the rationales for these have been justified.

Next will be the results chapter in which the findings from the statistical analysis that has been performed, using the Statistical Package for the Social Sciences SPSS (v23) software, will be described. Data will be tested for normality and the parametric or non-parametric statistics used, as applicable. Descriptive statistics will be used to summarise socio-demographic data (e.g. age and gender) as well as the rating scales' total scores. Correlations between variables will be analysed to determine which will be used as independent variables in regression analyses and finally the survey study findings will be discussed.

The next chapter will include a systematic description of the study findings. The most important findings will be highlighted. The descriptive and inferential data analysis will be reported in a logical sequence, and this will also include figures, charts and tables to further illustrate the findings.

Chapter Three: Results

3. Introduction

This chapter starts by presenting the results of the study. This study examines a Positive Psychological Change (PPC) in people with Rheumatoid Arthritis (RA) living in the UK. It was expected that people with RA would show evidence of PPC through their scores measured using the Silver Lining Questionnaire (SLQ-38). There are four research objectives and the results are analysed in this chapter. An analysis was carried out using the statistics computer package SPSS (version 23). A discussion of the results is contained in Chapter Four. The aims of the analysis were to:

1. Investigate the likelihood and extent of Positive Psychological Change (PPC) in people living with Rheumatoid Arthritis (RA) in the UK.
2. Describe the personal characteristics of those people who have reported PPC from their RA experiences
3. Explore potential factors associated with PPC in people with RA
4. Explore predictors of PPC in people with RA

Total SLQ-38 scores were checked for normality at the starting point and compared for each organisation. A summarised description of the study participants has been presented. The distribution of the total SLQ-38 scores was examined and the link between the psychosocial and demographic variables upon the SLQ-38 scores reported. The level of PPC on SLQ-38 scores and the variables on the study have also been examined. A further aim was to include the use of the SLQ-38 as a predictor of health outcomes.

3.1. Recruitment and Participants

The study participants were referred from two different sources: some were directed from the University's Rehabilitation Research Group's Arthritis Research Panel (ARP) database, and some from the National Rheumatoid Arthritis Society (NRAS). The participants are from two organisations of differing sizes and from a range of geographical locations in the UK. In addition, the participants represent a broad spectrum of ages, professions and education levels, and could be said to be as representative as possible of people with RA, as can be seen in Table 3.1. In total, out of approximately 650 potentially eligible participants, 228 participants, both male and female, were identified (Consort flowchart in App. 3.1).

3.2. Response rate and numbers excluded

There were a small number of participants who dropped out of the study. This accounted for n=18 (7.89%) of the original sample. The reasons for drop-out at the first screening process were: in total fifteen people did not meet the study eligibility criteria; twelve people (eight from ARP and four from NRAS) reported that the time scale after a diagnosis of RA was less than two years, and three people (one from ARP and two in the NRAS) stated they had another chronic health condition that might impact on their RA. The possibility of the impact of the co-morbidity of disease was checked with the supervisory team and with the potential study participants for accuracy.

In total, three people dropped out of the second screening process. The reasons were: one person did not meet the questionnaire quality criteria; this questionnaire represented seven items of missing data which was not acceptable for the thesis. One person did not follow the questionnaire instructions- she said that 'I am over 80 and would like to explain the questions in full.' The third person said 'I prefer not to take part'. It was decided to exclude these questionnaires from the further analysis (Consort flowchart in App. 3.1).

All in all, 210 people with RA consented. This comprised 126 (60.0 %) volunteers from ARP, and 84 (40.0%) from the NRAS. The mean age was 62, and the Standard Deviation (SD) was 11.01. The majority of participants were female, 166 (79%) and most 112 (53.3%) had established RA (>10 years). Many of the study participants, 140 (66.7%) reported that they had other health problems other than RA. The demographic characteristics of the sample are presented in Table 3.1.

There were 210 people from both the ARP and NRAS organisation who completed the study questionnaire. This thesis has tested if there is a difference between the two samples, ARP and NRAS members, in their scores on the SLQ-38. The result showed that there were no significant differences in SLQ-38 scores therefore their data was combined and analysed as one group (See Table.3.9.).

Table 3.1. Demographic characteristics of the study participants (N=210)

Characteristics	Frequency/Mean/SD	Percent
Age	Mean: 62 SD: 11.01	
Gender		
Female	166	79.0
Male	44	21.0
Marital status		
Married/ living with a partner	159	5.7
Single	17	8.1
Divorced or separated	17	8.1
Widow/widower	17	8.1
Employment status		
Full time employed	34	16.2
Part-time employed	33	15.7
Homemaker (not usually employed)	6	2.9
Student	-	-
Unemployed	2	1.0
Retired	93	44.3
Early retired through ill-health	38	18.1
Long term sick leave	4	1.9
Education		
No formal educational qualifications	27	12.9
CSE/O Level/GCSE	35	16.7
City & Guilds/GNVQ	18	8.6
A Level/ BTEC	17	8.1
Diploma	31	14.8
Degree	63	30.0
Other	18	8.6
Ethnicity		
White	207	98.6
Mixed	-	-
Black British/Black	1	.5
Asian	1	.5
British/Asian	-	-
other ethnic group	-	-
Prefer not to answer	1	.5
RA duration		
	49	23.3
2-5 years	49	23.3
6-10 years	112	53.3
Over 10 years		
Other health conditions		
Yes	140	66.7
No	70	33.3

3.3. Questionnaire inclusion and exclusion criteria

For this thesis, it was decided that the questionnaires should be coded: “A*” if there is no or one piece of missing data and “A” if there are two or three pieces of missing data. Therefore, if the questionnaire had more than three missing data sets, it was not eligible to put into the study. This is because it is not possible to consider a returned questionnaire of low quality in the study, as this can potentially affect the study results because people tend to answer questions in different ways, depending on certain characteristics. The frequency of the questionnaires utilised in the study is demonstrated in Table 3.2.

Table 3.2. Questionnaire included/excluded

Questionnaire quality	Frequency
No or one missing items	189 (90%)
Two or three missing items	21 (10%)
Excluded	18 (7.89%)

3.4. Data analysis

Questionnaire scores and other descriptive data were logged onto an SPSS (version 23) spreadsheet data file by the researcher after the final visit.

This section sets out the methods used for data cleaning for further data analysis. Once the research data was collected, the process of preparing it for analysis began. This part describes the process of scanning returned questionnaires, cleaning the data, checking for bias in the analysis, missing values and data checks.

The first issues concerned the accuracy with which the data was entered into the data file and also the consideration of factors that could have produced distorted correlations. In doing so, the original file was visually checked, and also because it is a large data file, screening for accuracy involved an examination of descriptive statistics, and for graphic representation of the variables, SPSS (version 23) was used to examine univariate descriptive statistics.

Secondly, any missing data was assessed and dealt with. It is essential to understand the pattern of missing data. The reason for this is that non-randomly missing values are serious, no matter how few of them there are, they will affect the generalisability of the results. The SPSS Missing Values Analysis (MVA) was used, which is specifically designed to highlight patterns of missing values as well as to replace them in the data set. A t- test was requested to see if the matter was related to any of the other variables, with $\alpha = .05$ and tests were carried out only for variables with at least 5% of data missing. The EM syntax requests a table of correlations and a test for whether data are Missing Completely At Random (MCAR). Thus, Little's MCAR test was performed to find out whether the missing data was random or non-random. The output showed that for the Little's MCAR test: Chi-square= 1774.729, DF=1726, Sig=.202. Thus, the decision was made to perform techniques to replace missing data for randomness.

It is important to consider the level of measurement to determine which statistics, graphs and analysis it is possible to use. Some of the variables in this study are nominal or categorical, for example sex. The nominal data is one that has two or more categories, but there is no intrinsic ordering of the categories. Thus, numbers do not imply order. To summarise the data, the frequency/percentages have been used. However, the data is

ordinal. An example of ordinal data is Positive Psychological Change (PPC) upon the Silver Lining Questionnaire-38 (Sodergren, 2000, 2002). These variables are in order, but the interval between variables may not be equal. Likert scales are ordinal data; ordinal data can provide frequencies (percentages). Some psychology researchers believe that the mean should never be calculated for ordinal data. However, it is quite common, particularly in the social sciences and in psychology, to consider people's behaviour and to report the mean values of ordinal data (Nunnally & Bernstein, 1994). To summarise ordinal data the most common summary measures are: frequencies, proportions and sometimes mean. The testing for interval ratio data are: test for a mean; the difference between two means (independent samples) and regression analysis. Therefore, the level of measurement is justifiable, although it is ordinal it could be treated as interval. Psychologists are flexible in terms of the level of measurement, so when the level of measurement is interval, it is also possible to show the result as mean and SD, and it is possible for the data to be shown on a scatter plot (Nunnally & Bernstein, 1994).

In order to determine whether the data has met the assumption for parametric analysis, the data was visualised; the level of measurement of the variables was considered; the Kolmogorov-Smirnov and the Shapiro-Wilk test were employed, and the shape of frequency histograms for the variables was checked.

Finally, a questionnaire was scored and other descriptive data logged onto an SPSS (version 23) spreadsheet data file by the researcher after the final visit. The findings from the study are based upon the information gathered as a result of the methodology that was applied.

3.5. Aim one: The likelihood and extent of Positive Psychological Change

To establish the first aim of the thesis, which is to describe the likelihood and extent of PPC in people with RA, the following procedures were conducted:

- The normality of the data upon the SLQ-38 scale was evaluated.
- The SLQ-38 mean and SD was reported.
- The SD of the scores, which is an estimation of the average variability of a set of data measured in the same units of measurement as the original data, was demonstrated.
- The overall SLQ-38 scores were obtained. The extent to which the participants agree or disagree with the 38 statements using a five-point Likert scale: (1) strongly

disagree; (2) disagree; (3) not sure; (4) agree and (5) strongly agree state that an overall score was obtained by giving a value of '1' to responses of strongly disagree and '5' to strongly agree. Therefore, an overall score reflects the total number of items with which the individual agrees. For the purpose of the current study, the continuous scoring was adopted to avoid an unnecessary amount of information throughout the analysis (Breakwell et al., 2006).

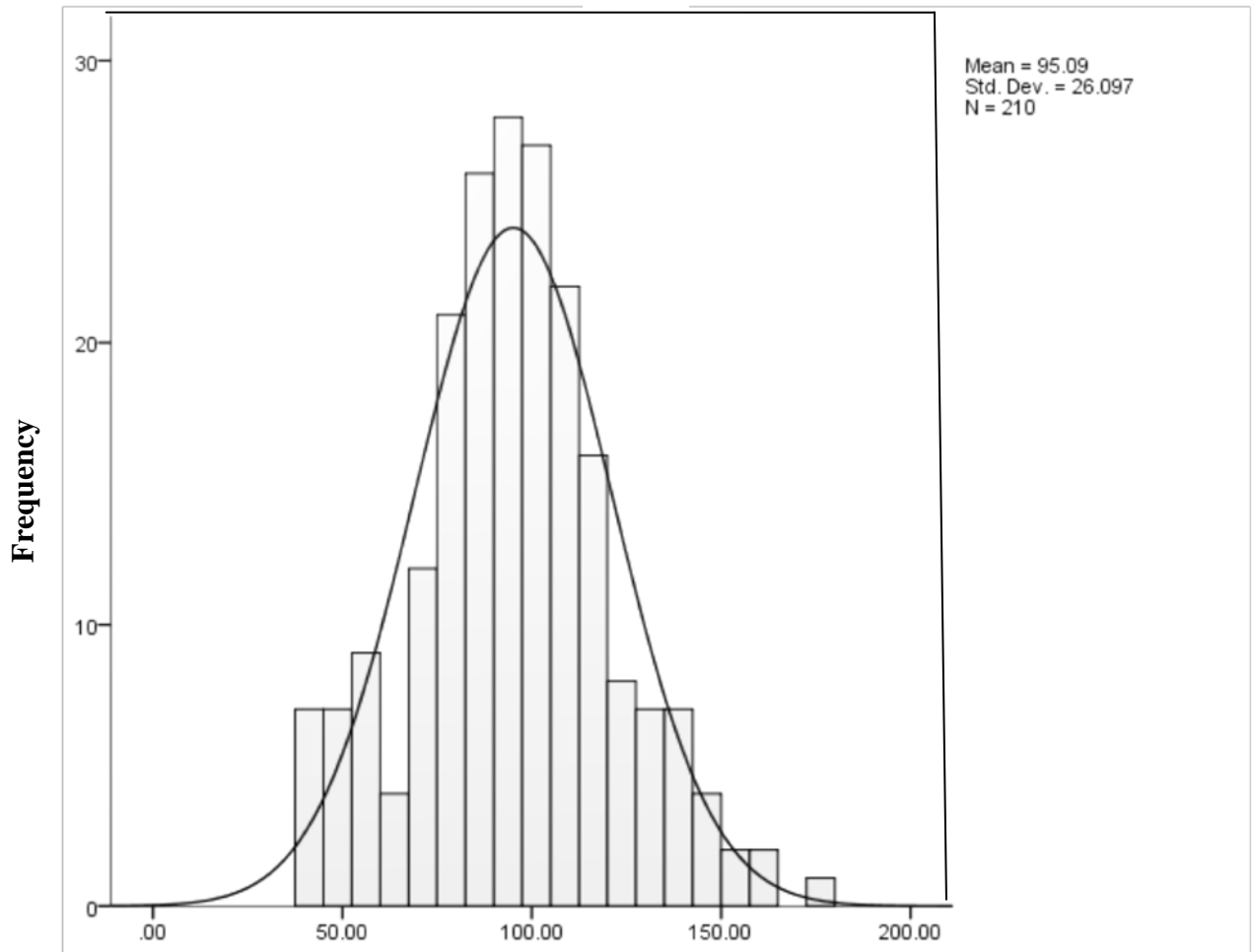
The question of the likelihood of PPC and its extent is the subject of this section. This part explores: what is the proportion of PPC in individuals with RA in their scores on the SLQ-38?

The study hypothesis was: PPC occurs across individuals with RA using the SLQ-38 scores. Data obtained were tested for the normality as explained in statistical analysis in this section. The histogram demonstrated the SLQ-38 scores. The data appears to be normally distributed and seems to show roughly symmetrical distributions, with equivalent means of 95.09 across items, which demonstrates the centre of the distribution of scores upon the SLQ-38 scores. The SD was 26.09, which represents an estimation of the average variability of a set of data measured in the same units of measurement as the original data.

This data has been analysed based on SLQ-38, with the mean score 95.09 \pm 26.09 SD. The Cronbach's alpha, across the present study samples, was .95, which is slightly higher than Sodergren (2000), proposing a high level of homogeneity amongst the SLQ items. The Cronbach's alpha for the overall reliability of the scale was used to determine the extent to which the items on a scale were measuring the same underlying dimension. This is slightly higher at 0.90; $P < 0.001$ (Sodergren et al., 2002), showing good retest reliability among the SLQ-38 items. For the thesis data file, all data have item-total correlations above 0.3 and this is well within the region specified by Kline (2000). Therefore, the SLQ-38 appears to have good internal consistency, $\alpha = 0.95$ and all items appear to be correlated to the total scale to a good degree, suggesting a high level of homogeneity among the SLQ-38 items for this study population. Field (2009) suggests that Cronbach's alpha of around 0.8 is good for a questionnaire. Indeed, if it is supposed that PPC is identified by the scores beyond the one

SD, 121, on SLQ-38 mean, then approximately 34% of the people reported PPC (Graph 3.1, See SLQ).

3.1. Silver Lining Questionnaire



Silver Lining Questionnaire

3.5.1. Characteristics of SLQ-38

The following section focuses on the SLQ-38 characteristic; the pattern of the items and the content analysis of the SLQ-38 items.

The mean value is the average scores (add up all the scores/number of items), and this potentially would have provided stronger grounds to report this study's findings. In fact, the findings shows that the SLQ scores were distributed normally, thus the majority of the data forms plots around the centre of distribution (SLQ mean, 95.09). The normal curve is symmetrical and the present study has looked at people who scored at least one SD above the SLQ mean (mean score $95.09+26.09$), to provide some idea about the proportion of PPC. Besides, the large numbers of t-tests conducted in the present research show that there was a difference between those who scored over the SLQ mean and those who scored below the mean, as shown in this chapter in Table 3.4. Therefore, all the values over the SLQ mean represent PPC, however, to make it more meaningful, the criterion for the occurrence of PPC was set at one SD over the SLQ mean (121), identify PPC, then this means that 34% of people scored one SD over the mean, thereby demonstrating PPC. In other words, for this study sample, $n=81$, 34% of the scores above the average disclose positive change, as explained in the discussion section.

3.5.2. The Extent of Positive Psychological Change

According to the present study's data file, when considering the level of PPC, the findings show that the level of SLQ increased (mean per item indicating PPC) as the number of people, frequencies, of those who experience PPC decreased (See Table 3.3.). The findings have been explained in the discussion section.

Table 3.3. Frequencies, percentage and mean scores per item for positive responses*

Items	The total sample, N=210	Mean Per item N=210	Scores over one SD, N=81	Mean Per item N=81
18. My illness made me a more determined person	103(49.1%)	3.13	52(64.2%)	3.61
20. My illness made me more aware of my strengths	97(46.1%)	2.98	46(56.8%)	3.46
1. I appreciate life more because of my illness	93(44.3%)	3.05	41(50.6%)	3.32
23. My illness encouraged me to reflect on how I feel about myself	85(40.0%)	2.96	42(51.8%)	3.29
5. Because of my illness I find it easier to accept what life has in store	89(42.4%)	3.01	40(49.4%)	3.25
26. My illness made me less concerned with the approval of others	91(43.3%)	2.97	40(49.3%)	3.20
6. My illness made me think about the true purpose of life	82(39.0%)	2.93	39(48.1%)	3.20
24. My illness made me face up to problem areas of my life	70(33.4%)	2.71	34(41.9%)	3.20
33. My illness made me less judgmental of others	80(38.1%)	2.91	38(46.9%)	3.17
30. My illness gave me the opportunity to meet new people	81(38.6%)	2.78	44(54.3%)	3.12
13. My illness made me a more tolerant person	73(34.8%)	2.60	38(46.9%)	3.09
4. My illness has made me live life to its fullest	77(36.7%)	2.81	34(42.0%)	3.09
34. I have been an inspiration to others	58(27.6%)	2.78	25(30.9%)	3.01
22. I can face whatever is around the corner because of my illness	56(26.6%)	2.63	28(34.6%)	2.95
35. People can be more open with me since my illness	33(15.7%)	2.56	15(18.5%)	2.90
31. My illness taught me how to stand up for myself	63(30.0%)	2.60	30(37.0%)	2.86
37. My illness changed other people's perception of me for better	32(15.2%)	2.53	18(22.2%)	2.86
25. My illness strengthened my relationships with others	56(26.7%)	2.62	28(34.6%)	2.85
29. I see others in their true colours because of my illness	58(27.6%)	2.66	23(28.4%)	2.80
14. My illness made me realise that I matter as a person	39(18.6%)	2.43	19(23.5%)	2.72
12. My illness made me more mature	47(22.4%)	2.44	20(24.7%)	2.71
38. Other people appreciate me more because of my illness	31(14.8%)	2.42	17(20.9%)	2.71
16. I am less concerned about failure because of my illness	46(21.9%)	2.39	20(24.7%)	2.62
9. My illness made me a better person	28(13.3%)	2.37	10(12.4%)	2.62
28. My illness made me more at ease with others	35(16.7%)	2.33	14(17.3%)	2.56
27. Because of my illness I have more to offer other people	44(21.0%)	2.41	16(17.0%)	2.56
36. My illness changed other people for the better	18(8.6%)	2.31	7(8.6%)	2.56
17. My illness gave me permission to do things for myself	47(22.4%)	2.35	20(24.7%)	2.53
19. My illness helped me find myself	30(14.3%)	2.23	12(14.8%)	2.48
7. My religious/spiritual beliefs deepened because of my illness	29(13.8%)	2.03	16(19.7%)	2.35
11. I am a calmer person because of my illness	29(13.9%)	2.13	12(14.8%)	2.33
32. My illness made me put an end to troublesome relationships	37(17.7%)	2.26	12(14.8%)	2.28
21. Through my illness I discovered a talent I didn't know I had	27(12.9%)	2.10	11(13.6%)	2.27
2. My illness gave me a new start in life	20(9.5%)	1.95	4(4.9%)	2.01
15. My illness gave me more confidence	17(8.1%)	1.90	4(4.9%)	1.98
3. My life is much better now than it was before	15(7.2%)	1.80	7(8.6%)	1.92
8. I am now more open to other religions because of my illness	8(3.8%)	1.70	3(3.7%)	1.90
10. I became a happier person because of my illness	12(5.7%)	1.75	4(4.9%)	1.86

*Presented in descending frequency order for people who scored over one SD on SLQ-38

3.5.3. Differences between people scoring below and over the mean on Silver Lining Questionnaire-38

In a subsequent analysis, the aim was to investigate the difference of the study variables on their PPC scores based on the SLQ-38. In doing so, the thesis has examined whether there is a significant difference between:

- Those whose scores are below the SLQ-38 mean compared to those who attained over the SLQ-38 mean

- Those whose scores are below one standard deviation of the SLQ-38 mean compared to those who attained over one standard deviation of the SLQ-38 mean
- Those whose scores are below two standard deviations of the SLQ-38 mean compared to those who attained over two standard deviations of the SLQ-38 mean

To do so, the difference between each study variables on their PPC scores upon the SLQ-38 mean; one standard deviation and the two standard deviations were calculated. This was followed by conducting the independent sample t-test. The t-test result showed whether the difference was at a significant level. If there is any significant difference between the scores of each variable on the SLQ-38, then the 'P' value is bigger than 0.05. The 'P' value shows the mean difference is significant either at the 0.05 or 0.01 levels. The variables in which people showed significant difference on their PPC scores on the SLQ-38 were: RA duration, arthritis pain, arthritis self-efficacy- pain, fatigue and psychological well-being scales. This indicates that the duration of RA would have had an impact on PPC scores upon the SLQ-38 at the mean level. Arthritis pain is a further factor in which the impact was shown at the two standard deviations upon the SLQ-38 scores. The arthritis self-efficacy- pain scale showed a difference between those who scored on this scale and the PPC scores on the SLQ-38 at the mean level. Similarly, there was a significant difference between people in their score for the rheumatoid arthritis fatigue scale and psychological well-being on their PPC scores based on the SLQ-38 at the mean level. The fact that the t-value was a minus number showed that those who scored below the SLQ-38 mean had a smaller mean than those who scored over the mean of the SLQ-38 in their experiences of PPC. Therefore, the people who attained a high score, over the SLQ-38 mean, showed more PPC. The significant values are shown in bold in Table 3.4.

Table 3.4. shows that the characteristic of someone scoring over the SLQ-38 mean seems to be: presenting longer RA duration, more arthritis self-efficacy to control their pain, less fatigue, and greater psychological well-being. In addition, considering the SLQ-38 over one standard deviation, the characteristic would be different. This appears to demonstrate longer RA duration, less fatigue and more psychological well-being. Finally, taking into account the SLQ-38 greater than two standard deviations, this seems to show more arthritis pain to be controlled.

Table 3.4. Differences between people scoring below and over the mean on SLQ-38 and the variables on the study, N=210*

	Level of PPC, over SLQ mean	Level of PPC, over SLQ 1SD	Level of PPC, over SLQ 2 SD
RA duration	t, -3.15, df, 208, P=.002**	t, -2.04, df, 56, P=.046*	t, -1.82, df, 11, P=.095
Arthritis Pain	t, -.92, df, 208, P=.355	t, -1.44, df, 58, P=.154	t, 2.22, df, 11, P=.048*
Arthritis Self-Efficacy- Pain	t, -2.26, df, 208, P=.025*	t, -1.00, df, 57, P=.318	t, 1.480, df, 11, P=.167
Rheumatoid Arthritis Fatigue	t, 2.60, df, 208, P=.010*	t, 2.66, df, 57, P=.010*	t, -.27, df, 10, P=.788
Psychological Well-Being	t, -3.54, df, 208, P=.000**	t, -3.42, df, 59, P=.001**	t, -.87, df, 10, P=.402

Note: only the significant variables reported.

*. The mean difference is significant at the 0.05 level (2 tailed).

** The mean difference is significant at the 0.01 level (2 tailed).

3.5.4. The extent of items indicating Positive Psychological Change

To expand on this data, a further aim was to explore the proportion of items indicating PPC when considering the SLQ-38. The SLQ-38 measures the extent to which people believe their illness has had a positive benefit, despite the negative consequences of being ill (Sodergren & Hyland, 2000). The findings from the current study reveal that approximately n=81, 34%, of the participants, gained a score over one SD, 121, on SLQ-38, where the mean score is 95.09. Those individuals who have one SD over the SLQ mean should have replied positively at least (24×100/38) to around 62% percent of the items (Table 3.5.).

Table 3.5. Proportion of items answered positively*

Scores	Items responses positively, 4 &/5
95 (SLQ mean)	10-19
121=1SD	20-26
147=2SD	26-30
152	30-32
178	33-36

* Considering the total SLQ-38 scores

3.5.5. Distribution of Silver Lining Questionnaire-38 items

With reference to the frequencies of items answered positively by this study’s contributors, the items have been categorised into the following three groups (38/3= 12.66), based on the items scoring positively over one SD on the SLQ mean (Table. 3.6.). Group one includes the top 13 most positive frequency items; group two contains the 13 middle items answered positively (with moderate frequencies) and the lower positive items frequencies (about one third of the items) forms the bottom category, which comprises of 12 items answered positively by this study’s participants (Table. 3.6.). In this way, the items with the higher frequencies are located at the top; in the middle the items with moderate frequencies are shown, and finally the items with the lower frequencies are shown in the last row, as illustrated in Table 3.6. The item discrepancies show more or less the same pattern of items ranked for those scores over the SLQ mean, and one SD above the SLQ mean scores. Nevertheless, there are some exceptions, as not all the items ranked similarly. For instance, the ranking for items 38 and nine varied depending on the total SLQ scores. The findings have been explained in the discussion section.

Table 3.6. Distribution of items scored positively for those scores over one SD on SLQ-38, N=81*

Groups	Items listed in order**	Average mean scores per items
Top one third items	18, 20, 1, 23, 5, 26, 6, 24, 33, 30, 13, 4, 34	3.23
Middle items	22, 35, 31, 37, 25, 29, 14, 12, 38, 16, 9, 28, 27	2.55
Bottom one third items	36, 17, 19, 7, 11, 32, 21, 2, 15, 3, 8, 10	2.20
Average total SLQ	38 items	2.66

*SLQ-38 overall score was obtained by giving a value of ‘1’ to responses of strongly disagree and ‘5’ to strongly agree

** Frequencies have been considered, extracted from table 3.3.

3.5.6. Positive themes from the Silver Lining Questionnaire-38

Sodergren and Hyland (2000) listed ten themes for positivity as a consequence of illness considering the SLQ-38, which are as follows: improvement in interpersonal relationships, reappraisal of life, positive consequences for others, self-improvement, restructuring of life, spiritual gains, skills and new pursuits, improvement in self-awareness, sensitivity to emotions and confrontation of current concerns. This thesis has presented the themes as reported by n=81 people in the present study for those who scored over one SD on the SLQ mean, that is PPC, to provide some evidence to expand on the knowledge about individuals with RA (see Table 3.7.).

Table 3.7. Positive themes on SLQ-38 in Rheumatoid Arthritis*

Themes	Current thesis Scores over one SD
Improvement in interpersonal relationships	56.0%
Sensitivity to emotions	51.8%
Reappraisal of life	49.37%
Confrontation of current concerns	41.9%
Improvement in self- awareness	35.8%
Self-improvement	24.57%
Skills and new pursuits	24.1%
Positive consequences for others	20.22%
Restructuring of life	18.5%
Spiritual gains	11.7%

* Percentage's average per items calculated to signify themes and listed in order

The findings from the present study provide some evidence to support ten themes of positive consequences from RA, which are included in the SLQ-38 (Sodergren, 2000); these are described below and explained in the discussion section.

3.5.6.1. Improved interpersonal relationships

Considering the SLQ-38 item analysis, an insight was gained in that individuals with RA may go on to discover their illness made them more at ease with others- nearly 17.0%. Some of this study's participants, 34.6%, confirmed that their illness strengthened their relationships with others. Not everybody, but 45.9%, of the people who showed PPC over one SD on the SLQ mean, mentioned that their RA made them less judgmental of others and, finally, nearly 49.3%, of those who scored over one SD on SLQ agreed that their RA made them less concerned with the approval of others.

3.5.6.2. Positive consequences for others

Some of the SLQ-38 items focus on the positive influence on others because of RA. The findings from this research suggest that some individuals endorsed the experience of positive consequences for others, for example, 8.6%, acknowledged that their RA changed other people for the better; yet, nearly 22.2% of people with RA within this study agreed that other people appreciate them more because of their illness (see Table. 3.3.). However, the current findings give the impression that a frequent number, 72.4%, of people out of the total sample, 210, either ‘disagree’ with or are ‘not sure’ if they have been an inspiration to others because of their RA. Correspondingly, 177 (84.3 %) out of the total number of people who participated in this study, 210, were either not sure or disagreed with the statement, ‘People can be more open with me since my illness’ (See Table 3.3.).

3.5.6.3. Self-improvement

The study findings indicate 25.0%, of those who scored over one SD on SLQ acknowledged that their RA has given them permission to do things for themselves and a large number, 64.2%, of those who scored over one SD on SLQ reported that their RA made them a more determined person (Table 3.3.). On the other hand, 77.6% of the total participants, n= 210, in this study confirmed that they are not sure or disagree about whether their RA has made them more mature (See Table 3.3.). In addition, not everybody agreed that their RA had made them a better person- 86.2%. For instance, nearly 65.2% of this study’s participants confirmed that they are not sure or disagree that their RA makes them a more tolerant person (Table. 3.3.).

3.5.6.4. Reappraisal of life

The present findings show 49.0% of those who scored over one SD on SLQ-38 mentioned that their RA made them think about the real purpose of life. However, across this study sample, n= 210, nearly 128 (61%) did not endorse the following item: “My illness made me think about the true purpose of life” (see Table 3.3.). Moreover, a large number of people, 49.4%, of those who scored over one SD on SLQ, confirmed that they found it easier to accept what life has in store (Table, 3.3.).

3.5.6.5. Restructuring of life

According to this study's results, 8.6%, of those who scored over one SD on SLQ-38, agreed that their life is much better than it was. However, 42.0%, of these people stated that their RA has made them live life to its fullest (Table, 3.3.).

3.5.6.6. Spiritual gains

Of those who scored over one SD on SLQ-38, 88.3% did not agree that their RA encouraged them to be more open to other religions. Item 8, 'I am now more open to other religions because of my illness' gained the lowest positive score for the total sample, n=210 and for those who scored over one SD on SLQ-38 for the present study, as reported in Table 3.3. In addition, 71.0 %, disagreed that their spiritual beliefs developed as a result of their RA (Table 3.3.).

3.5.6.7. Skills and new pursuits

It appears that some of the study participants described a development in skills and new pursuits because of their RA. As an example, approximately 13.6% of those who scored over one SD on SLQ-38 reported that they discovered a talent that they were not aware of and 34.6% believed that they can face unknown challenges because of their RA (see Table 3.3.).

3.5.6.8. Improvement in self- awareness

Some of the study participants referred to an understanding of their nature, abilities and motives- an insight into oneself, including any limitations. This includes being more aware of one's mental representation of themselves. For example, 14.8 % of those who scored over one SD on SLQ-38 mentioned that their RA helped them to become more self-confidence. Furthermore, 56.8% of those who scored over one SD on SLQ-38 agreed that their RA made them more aware of their strengths (Table. 3.3.).

3.5.6.9. Sensitivity to emotions

This category refers to whether people with RA agree whether their RA has encouraged them to reflect on how they feel about themselves, for which 51.8% who scored over one SD on SLQ approved this (Table, 3.7.).

3.5.6.10. Confrontation of current concerns

The current study's results indicate that a frequent number of people who scored over one SD on SLQ (41.9%) confirmed that their RA made them face up to the problem areas in their lives (Table, 3.8.).

Table 3.8. Comparisons of the prevalence of positivity themes on SLQ-38

SLQ-38 Themes	Developer*	Scores over 1 SD**
Improvement in interpersonal relationships	100%	56.0 %
Reappraisal of life	93%	49.37%
Positive consequences for others	93%	20.22%
Self-improvement	93%	24.57%
Restructuring of life	84%	18.5%
Spiritual gains	69%	11.7%
Skills and new pursuits	49%	24.1%
Improvement in self- awareness	44%	35.8%
Sensitivity to emotions	16%	51.2%
Confrontation of current concerns	4%	41.9%

* Interviewing, n=55, including patients with cancer, musculo-skeletal, chronic fatigue syndrome and heart disease

** Survey, n=81, percentage average per items calculated to signify the themes

3.6. Aim two: Characteristics of those people who have reported Positive Psychological Change

The second aim of the thesis was to describe the demographic and personal characteristics of those people who have reported PPC from their RA experiences. The question was; what are the characteristics of persons developed PPC? (For example, does PPC changes across age, genders, marital status, employment, education, ethnicity and RA duration?)

3.6.1. Demographic characteristics

3.6.1.1. Hypotheses

With respect to the effect of age on PPC the study hypothesis was:

a) There is a significant difference between PPC and different age groups (the age groups are: 25-45; 46-66 and 67-87 years old)

The study participants were classified into three age groups. These were: 25-45; 46-66 and 67-87 years old. The mean and SD were calculated for the groups as shown in Table 3.9. To compare several means, when those means have come from different groups of people, the

one –way independent ANOVA was used. The analysis showed that there was a significant effect of age on levels of SLQ-38 (See table 3.9.), indicating that as the age increased, the level of PPC increased proportionately. Therefore, the study hypothesis is supported.

It is predicted that:

b) There is a significant correlation between PPC and the study age groups

To investigate whether there is a significant correlation between PPC and the study age groups the Spearman's correlation test was applied. The reason being that the age groups did not normally distribute. Therefore, the data was analysed by the Spearman's correlation test.

The correlation test show that there is no significant correlation between PPC and age groups, $r=.012$, $P=.430$, $P>0.05$. Therefore, the study hypothesis is not supported (Table 3.12.).

3.6.1.2. Hypothesis

With regard to the function of gender on PPC the study hypothesis was: there is a significance difference on PPC between males and females.

The results showed that there were no significant differences in SLQ-38 scores between males as and females as shown in Table 3.9.

3.6.1.3. Hypothesis

Considering the effect of marital status on PPC, the study hypothesis was: there is a significant difference between PPC and marital status.

The mean and SD were calculated for the groups as shown in Table 3.9. The one-way independent ANOVA was used to compare if there is a difference between the levels of marital status on the level of SLQ-38. The analysis showed that there was no significant effect of marital status on levels of SLQ-38, (See Table 3.9.), indicating that there is no significant difference between marital status upon the mean of SLQ-38. Conversely, those who were divorced or separated showed the higher mean, 105.82, $SD=31.05$. Single participants presented the lowest mean scores, 91.64, $SD=29.24$. Therefore, the study hypothesis is not supported.

3.6.1.4. Hypothesis

With respect to the effect of education status on PPC, the study hypothesis was: there is a significant difference between PPC and education status.

The mean and SD were calculated for the groups as shown in Table 3.9. The one-way independent ANOVA was used to compare if there is a difference between the levels of education on PPC. The analysis showed that there was no significant effect of education on PPC (see table 3.9.), demonstrating that there is no significant differences between the level of education upon the mean of SLQ-38. However, the group with the diploma level of education had the higher mean, 102.74, SD= 22.42. The lowest mean score presented at the A level/BTEC, 85.88, SD=24.58 .Therefore, the study hypothesis is not supported.

3.6.1.5. Hypothesis

In regard to the impact of employment on PPC, the study hypothesis was: there is a significant difference between PPC and employment status.

The mean and SD were calculated for the groups as shown in Table 3.9. The one-way independent ANOVA was used to compare if there is a difference between the levels of employment on the SLQ-38 scores. The analysis showed that there was no significant effect of employment on levels of SLQ-38, (Table 3.9.), representing that there is no significant difference between the level of employment on the mean of SLQ. Nevertheless, the group with the full time employees had the higher mean, 97.20, SD= 26.35. The lowest mean scores presented for the long term sick leave participants with a mean level of 86.00, SD=32.03. Therefore, the study hypothesis is not supported.

3.6.1.6. Hypothesis

With regard to the impact of ethnicity on PPC, the study hypothesis was: there is a significant difference between PPC and ethnicity.

The one-way independent ANOVA was used to compare if there is a difference between the levels of ethnicity on the SLQ-38 scores. The analysis revealed that there was no significant effect of ethnicity on the levels of SLQ-38 (See table 3.9.), therefore, the study hypothesis is not supported. The mean and SD were calculated for the groups as shown in Table 3.9.

3.6.1.7. Hypotheses

With reference to the effect of the RA duration on PPC, the study hypothesis was:

a) There is a significant difference in PPC between RA duration groups (the RA duration groups are: 2-5; 6-10 and over 10 years since diagnosis).

The study participants were classified into three groups. These were: 2-5; 6-10 and over 10 years post-diagnosis. The mean and standard deviation were calculated for the groups as shown in Table 3.9. The one-way independent ANOVA was used to compare if there is a difference between the RA duration on the level of SLQ-38. The analysis showed there was a significant effect of RA duration on the level of SLQ, demonstrating that as the RA duration increased, the level of the PPC increased proportionately. Therefore, the study hypothesis is supported (See table 3.9.).

It is predicted that:

b) There is a significant positive correlation between PPC and RA duration (one-tailed)

To investigate whether there is a significant correlation between PPC and RA duration the Spearman's correlation test was applied. The reason being that RA duration was not normally distributed. Therefore, the data was analysed by the Spearman's correlation test.

The correlation test show that there is a significant correlation between PPC and the RA duration, $r=.198$, $P=.002$, $P<0.05$ (one-tailed). Therefore, the study hypothesis is supported (Table 3.12.).

Table 3. 9. Mean differences of study variables on the Silver Lining Questionnaire-38, N=210

Study Variable		N	Mean	SD	t/F	Sig. (2td)	
Silver Lining Questionnaire	Organization	ARP	126	95.00	25.89	t, -0.6	0.95
		NRAS	84	95.21	26.55		
	Age	25-45	17	98.29	27.62	F, 412.20	.000**
		46-66	102	94.14	25.48		
		67-87	91	95.54	27.12		
	Gender	Male	44	94.46	26.62	t, -.17	0.95
		Female	166	95.25	26.03		
	Marital status	Married/ living with a partner	159	94.30	24.39	F, 1.108	.347
		Single	17	91.64	29.24		
		Divorced/separated	17	105.82	31.05		
		Widow/widower	17	95.117	32.54		
	Education	No formal education qualification	27	99.04	34.58	F, 1.202	.307
		CSE/O Level/GCSE	35	91.91	24.96		
		City/Guilds/GNVQ	18	88.22	23.41		
		A level/BTEC	17	85.88	24.58		
		Diploma	31	102.74	22.42		
		Degree	63	95.52	23.35		
		Other	18	95.77	31.81		
	Employment	Full time employed	34	97.20	26.35	F, .158	.987
		Part-time employed	33	95.21	23.48		
Homemaker		6	95.00	11.57			
Unemployed		2	89.50	40.30			
Retired		93	95.45	26.85			
Early retired through ill-health		38	93.44	28.17			
Long term sick leave	4	86.00	32.03				
RA duration	2-5 year	49	85.94	23.10	F, 4.85	.009**	
	6-10 years	49	94.94	25.10			
	>10 years	112	99.54	26.85			
Ethnicity	White	207	95.05	26.22	F, 3.07	1.00	
	Black British/Black	1					
	Asian	1					
	Prefer not to answer	1					

** . It is significant at the 0.01 level (1-tailed).

* . It is significant at the 0.05 level (1-tailed).

3.7. Aim three: Positive Psychological Change and associated factors

The third research objective focused on establishing the relationship between SLQ-38 scores and the potential associated factors in people with RA. Factors that might have contributed towards the development of PPC have been explored, as shown below.

3.7.1. RA clinical characteristics

The association between PPC and clinical variables (fatigue; pain and RA physical health function), have been addressed as below.

3.7.1.1. Hypothesis

The study hypothesis was: there is a significant negative correlation between PPC and fatigue (one- tailed).

To explore whether there is a significant correlation between PPC and level of fatigue the Spearman's correlation test was carried out. The reason being that the fatigue data violated parametric assumptions. Therefore, the data was analysed by the Spearman's correlation test.

The correlation test showed there is a significant negative correlation between PPC and fatigue, $r = -.174$, $P = .006$, $P < 0.001$ (One tailed). Thus the study hypothesis is supported (Table 3.12.).

3.7.1.2. Hypothesis

The study hypothesis was: there is a significant negative correlation between PPC and pain (one-tailed).

To investigate whether there is a significant correlation between PPC and the level of pain the Pearson correlation test was applied. The reason being that the data from the PPC and the Arthritis Pain are parametric and so a Pearson's correlation test was carried out. The study result shows that there is no significant correlation between PPC and the level of pain, $r = -.032$, $P = .320$, $P > 0.05$. Therefore, the study hypothesis is supported (Table 3.12.).

3.7.1.3. Hypothesis

The hypothesis was: there is a significant negative correlation between PPC and physical health function (one-tailed). This includes the rate of mobility level; walking & bending; hand and finger function and arm function scores on the AIMS-2

To examine whether there is a significant correlation between PPC and RA physical health factors the Spearman's correlation test was carried out. This choice was made because RA physical health factors were not normally distributed. Therefore, the data was analysed by a non-parametric correlation test.

The Spearman's correlation test indicates that there is no significant correlation between PPC and RA physical health factors, $r=.054$, $P=.220$, $P>0.05$. Therefore, the study hypothesis is not supported (Table 3.12.).

3.7. 2. RA Psychosocial factors

The association between PPC and RA psychosocial factors variables (psychological well-being, coping strategies, arthritis self-efficacy-pain, arthritis self-efficacy other symptoms, sense of coherence and resilience, social support, social activity, quality of life, depression and level of tension), have been addressed as below.

3.7.2.1. Hypothesis

The study hypothesis was: there is a significant positive correlation between PPC and psychological well-being (one- tailed).

To investigate whether there is a significant correlation between PPC and psychological well-being the Spearman's correlation test was carried out. The correlation test shows that there is a significant correlation between PPC and overall well-being, $r= .258$, $P=.000$, $P<0.001$ (One tailed). Thus the study hypothesis is supported (Table 3.12.).

3.7.2.2. Hypothesis

The further aim was to examine the association between coping strategies used and PPC in people with RA.

The study hypothesis was: there is a significant positive correlation between PPC and coping strategies (one-tailed).

To explore whether there is a significant correlation between PPC and coping strategies used by the people with RA the Spearman's correlation test was conducted. The correlation test indicates that there is a significant correlation between PPC and coping strategies, $r = .136$, $P = .024$, $P < 0.05$ at the 0.05 level (One tailed). Therefore, the study hypothesis is supported (Table 3.12.).

Coping strategies used by RA people

Englbrecht et al., (2012) derived four components from the total of 18 items on the C-RAQ scale. These were: cognitive reframing, distancing, emotional expression and active problem solving. To investigate that knowledge, the thesis aims to present an understanding of which of the four coping strategy components are used more frequently by individual with RA to handle the impact of symptoms.

A further research question is: what are the most frequently used coping strategies employed by an individual with RA? The statistical analysis shows that distancing was the most favourably used coping strategy. This was followed by cognitive reframing, active problem solving and emotional expression expressed accordingly (please see the mean and SD of each factor in Table 3.10.).

Table 3.10. The most frequently coping strategy used by people with Rheumatoid Arthritis

Coping strategy sub-factor	Mean	SD
Distancing	14.09	4.51
Cognitive reframing	8.81	3.38
Active problem-solving	8.69	3.91
Emotional expression	5.60	4.10

Cognitive reframing

To extend the knowledge gained further, the four components of the C-RAQ were examined to understand whether there is a relationship between each component of the C-RAQ and the SLQ-38. The C- RAQ components are: distancing, cognitive reframing, emotional expression and active problem solving.

To clarify this, a series of correlation tests were conducted. Among them, the findings reveal that the SLQ-38 positively correlate with the cognitive reframing subscale as shown in Table 3.11.

Table 3.11. Relationship between the SLQ-38 and coping strategies components

SLQ-38	Correlation Coefficient	Sig.
Distancing	.001	.993
Cognitive reframing	.163	.019*
Active problem-solving	.036	.604
Emotional expression	.131	.065

*. The mean difference is significant at the 0.05 level (2 tailed).

3.7.2.3. Hypothesis

This study predicted that:

a) There is a significant positive correlation between PPC and self-efficacy pain management (one- tailed).

To investigate whether there is a significant correlation between PPC and the Arthritis pain self-efficacy the Pearson's correlation test was carried out. This choice was made because the data from the PPC and the arthritis pain self-efficacy are parametric and so a Pearson's correlation test was applied. The correlation test shows that there is no significant correlation between PPC and Arthritis pain self-efficacy, $r = .094$, $P = .086$, $P > 0.05$. Thus, the study hypothesis is not supported (Table 3.12).

It is predicted that:

b) There is a significant positive correlation between PPC and self-efficacy other symptoms (i.e., fatigue). A one- tailed hypothesis was considered.

To examine whether there is a significant correlation between PPC and arthritis self-efficacy other symptoms used by the people with RA the Spearman's correlation test was conducted. The correlation test indicates that there is no significant correlation between PPC and arthritis self-efficacy other symptoms, $r = .090$, $P = .096$, $P > 0.05$. Therefore, the study hypothesis is not supported (Table 3.12.).

3.7.2.4. Hypothesis

The study hypothesis was: there is a significant positive correlation between PPC and sense of coherence and resilience (one- tailed).

To investigate whether there is a significant correlation between PPC and sense of coherence and resilience the Spearman's correlation test was conducted.

The correlation test demonstrated that there is a significant negative correlation between PPC and sense of coherence and resilience, $r = -.121$, $P = .040$, $P < 0.05$ (One tailed). Therefore, the study hypothesis is not supported (Table 3.12.).

3.7.2.5. Hypothesis

It is predicted that:

a) There is a significant positive correlation between PPC and social support (one- tailed)

To investigate whether there is a significant correlation between PPC and social support from family and friends the Spearman's correlation test was carried out. The correlation test shows that there is a significant negative correlation between PPC and social support, $r = -.131$, $P = .029$, $P < 0.05$ (One tailed).

It was expected that PPC and social support would positively correlate, however the result show that the direction of the association is negative; therefore, the study hypothesis is not supported (Table 3.12.).

b) There is a significant positive correlation between PPC and social activity (one- tailed)

To investigate whether there is a significant correlation between PPC and social activity, the Spearman's correlation test was carried out. The correlation test shows that there is no significant correlation between PPC and social activity, $r = -.033$, $P = .318$, $P > 0.05$. Therefore, the study hypothesis is not supported. It was expected that PPC and social activity would positively correlate, however the result shows that there is no significant association between levels of PPC and social activity; therefore, the study hypothesis is not supported (Table 3.12.).

3.7.2.6. Hypothesis

The study hypothesis was: there is a significant positive correlation between PPC and quality of life (one- tailed).

To examine whether there is a significant correlation between PPC and quality of life the Spearman's correlation test was applied.

The correlation test illustrates that there is no significant correlation between levels of PPC and quality of life, $r = .007$, $P = .461$, $P > 0.05$. Therefore, the study hypothesis is not supported (Table 3.12.).

3.7.2.7. Hypothesis

The study hypothesis was: there is a significant negative correlation between PPC and depression (one- tailed).

To explore whether there is a significant correlation between PPC and the level of depression the Spearman's correlation test was performed. The correlation test shows that there is no significant negative correlation between PPC and the level of depression, $r = -.025$, $P = .362$, $P > 0.05$. Thus, the study hypothesis is not supported (Table 3.12.).

3.7.2.8. Hypothesis

The study hypothesis was: there is a significant negative correlation between PPC and level of tension (one- tailed).

To explore whether there is a significant correlation between PPC and the level of tension the Spearman's correlation test was carried out. The correlation test demonstrates that there is no significant correlation between PPC and the level of tension, $r = -.032$, $P = .322$, $P > 0.05$. Therefore, the study hypothesis is not supported (Table 3.12.). The descriptive statistic for the significant related variables is shown in app. 3.2. The correlation matrix has been reported in app. 3.3.

Table 3.12. Correlation coefficient of the factors associated with the total scores of the SLQ-38 (N=210)

Study variables	Silver Lining Questionnaire
Age	-.012
RA duration	.198**
Fatigue	-.174**
Arthritis Pain	-.032
RA physical health function	.054
Psychological Well-being	.258**
Coping strategies	.136*
Arthritis Self-efficacy-pain	.094
Arthritis self-efficacy other symptoms	.090
Sense of Coherence and Resilience	-.121*
Social support	-.131*
Social activity	-.033
Quality of Life	.007
Depression	-.025
Level of tension	-.032

**Correlation is significant at the 0.01 level (1-tailed).

*. Correlation is significant at the 0.05 level (1-tailed).

Effect size

The correlation coefficients, r , indicates a standardised measure of an observed effect. The findings reveal that the correlation coefficients for some of the study variables (i.e., duration of RA, fatigue, well-being, coping strategies, sense of coherence and resilience and social support) are statistically significant, as shown in Table 4.4. However, regardless of the significance of the correlation tests, it is worth mentioning that the effect size for all correlated variables represented a small effect (± 0.1). The size of the effect refers to a standardised measure of the amount of observed effect (Field, 2009). Although the size of effect for this sample is small, we do not have access to the effect of sizes in the population as a value of interest, thus the effect size in this sample could estimate the likely size of the effect in the wider population. Hence, these findings reveal that the strength of a relationship between variables could explain 1% of the total variance in the population.

3.8. Aim four: To explore predictors of PPC over the Silver Lining Questionnaire-38 for people with RA

Overall, the correlation analyses conducted show that there is significant correspondence between the six study variables in the SLQ-38 scores. Some of the correlations are significant at the .01 level (see table 3.12.). These are: RA duration correlated reliably with the level of PPC upon the SLQ-38 score: $r=.198$, $P=.002$, $P<0.05$ (One tailed). This reveals that the more RA duration a person has, the more he/she will experience PPC. The simple scatter plot (indicate which table/appendix the scatter plot is in so the reader can go and see for themselves) shows that the majority of scores are in a positive linear direction with no obvious outliers, in that most scores seem to fall within the surrounding area of other scores; overall, 0.04 percent of PPC accounted for RA duration.

Fatigue also correlated with the SLQ-38 scores. The analysis provides evidence for a significant negative correlation between PPC and fatigue, $r= -.174$, $P=.006$, $P<0.001$ (One tailed). The scatter plot shows the relationship between fatigue and PPC explored within the context of the regression model. For the data, r has a value of $-.174$ and this value represents a declining line slightly upper left and moving, thus, this reveals a negative correlation between fatigue and PPC. The value of R^2 was 0.024, which suggests that fatigue can account for 0.02 percent of the variation in PPC. In regards to the fatigue scores, the level of PPC increased as the level of fatigue decreased. This implies that the less fatigue felt, the more one will experience PPC.

Similarly, psychological well-being correlated with the SLQ-38 scores: $r= .258$, $P=.000$, $P<0.001$ (One tailed). The results illustrated in a simple scatter plot show the majority of scores emerged in a positive linear direction and there are no obvious outliers in that most scores seem to fall within the surrounding area of other scores; overall, 0.07 percent of PPC is explained by psychological well-being. The analysis indicates that the more a person feels psychological well-being, the more an individual will experience PPC.

The analysis also shows that some of the correlations were significant at the .05 level. One of them is social support: $r= -.131$, $P=.029$, $P< 0.05$ (One tailed), with a significant negative relationship. A simple scatterplot was made to plot two values of interest; these are PPC and social support. The graph shows a weak downhill linear relationship between the two

variables and that explains 0.01 percent of the changeability of PPC due to social support. The findings show that as the social support scores decreased, the level of PPC upon the SLQ-38 scores increased. Similarly, the sense of coherence and resilience: $r = -.121$, $P = .040$, $P < 0.05$ (One tailed) scores, show a significant negative relationship with the SLQ-38 scores at the 0.05 level (One tailed). This indicates that as the level of sense of coherence and resilience decreased the level of PPC upon the SLQ-38 scores increases. A simple scatterplot was constructed to plot two values of interest, these were PPC and SOC. The graph shows a weak downhill linear relationship between two variables since 0.02 percent of the variability of PPC is accounted for by SOC. A further reliable correlation was found between the coping strategy scores and the level of PPC upon the SLQ-38, $r = .136$, $P = .024$, $P < 0.05$ at the 0.05 level (One tailed). The results indicate that the more resources a person has, that is, coping strategies, the more he/she will experience PPC. A general trend in this study's data on the scatter plot shows that most of the data are clustered in the middle region of the coping scale and there are no scores that clearly do not fit the general trend of the scores. The correlation coefficient squared (R^2), shows 0.02 of the variability can be explained by coping strategies.

Aim number four of the thesis was to investigate the contribution of the independent variables: RA since diagnosis, level of fatigue, psychological well-being, social support, sense of coherence and resilience and coping strategies, in the prediction of the SLQ-38 scores, a multiple forced entry regression method was used. Forced entry is a method in which predictors are forced into the model altogether (Field, 2006). The analysis indicates how valid the prediction variables given are when combined.

The multiple regression equation is: $PPC = +\text{psychological well-being} + \text{coping strategies} + \text{RA duration} - \text{fatigue} - \text{social support} - \text{resilience}$. The study provides an insight into the utility of the SLQ-38 as a predictive tool for health outcomes.

R (multiple correlation coefficients) is a measure of the fit between the predicted variables and observed values of Y when all predictor variables are used. Therefore, it is a way of assessing how good a prediction all the predictor variables give when combined together. It ranges from 1 to 0 and the higher it is the stronger prediction. R^2 refers to the proportion of variability in the criterion variable accounted for by the predictor variables together. Adjusted R^2 adjusts for the number of predictor variables used (See table 3.13).

Table 3.13. Positive Psychological Change Model Summary

Model	R	R Square	Adjusted R Square
1	.410 ^a	.168	.143

^aPredictors: (Constant), Total Sense of coherence and resilience, well-being, coping strategies, RA duration, fatigue and social support

By and large (using forced entry method) a significant model emerged (Adjusted R²= .143, $F(6, 203) = 6.828, P = .000$). The analysis showed that out of six, four predictor variables produced a significant prediction and 14.3% of the PPC has been explained.

To summarise, PPC = .243 (psychological well-being) - .224 (sense of coherence and resilience) + .194 (RA duration) - .163 (fatigue) (Table 3.14).

Table 3.14. Positive Psychological Change predictor variables

Predictor variable	Beta	Sig.
Constant		.073
Overall well-being	.243	.000
Sense of Coherence and Resilience	-.224	.001
RA duration	.194	.004
Fatigue	-.163	.017

A stepwise linear regression was also carried out and found the predictors (in order of importance to be): psychological well-being, length of time with RA, sense of coherence and resilience, fatigue and social support. Together these explained 16.7% of the variance in PPC. The analysis is shown in app.3.4.

Finally, the linear model of predictors of PPC, with 95% bias corrected and accelerated confidence intervals reported in parentheses in table 3.15. Confidence intervals and standard errors based on 1000 bootstrap samples presented (Table 3.15).

The gradient of the slope (B) showed how a change of one of the values of the predictor variable would affect the criterion variable. For example, a change of one in the overall well-being would lead to a corresponding change of 1.253 in PPC (See table 3.15).

Table 3.15. Bootstrapping the confidence intervals

Model	B	Standardized Coefficients Beta	P
Consent	51.08		P=.05
Overall well-being	(1.31, 101.75) 1.25	.24	P=.001
Sense of Coherence and Resilience	(.68, 1.82) -.86	-.22	P=.001
RA duration	(-1.33, -.34) 6.15	.19	P=.002
Fatigue	(2.25, 10.00) -1.72 (-3.10, -.35)	-.16	P=.022

Note. R= .410, R²=.168, (Ps<.001).

3.9. Chapter summary

The results have answered the study hypotheses laid out in the methodology section. The SLQ-38 was administered to 210 people with RA in the UK. The study participants were from two organisations: 126 (60.0%) volunteers with RA from the University of Salford Rehabilitation Research Group's Arthritis Research Panel (ARP), and 84 (40.0%) people from the National Rheumatoid Arthritis Society (NRAS). The sample comprised both males and females.

The distribution of the total SLQ-38 scores was examined. The data was normally distributed. The mean and SD have been reported. The likelihood and extent of PPC in people living with RA in the UK has been examined. Beyond that, the link between: demographic; clinical; physical health function and psychosocial variables upon the SLQ-38 scores has been explored. In addition, a link between the subdomains of the coping strategy scale and the SLQ-38 has been recognised. The level of PPC on SLQ-38 scores and the variables on the study have been examined. Finally, the SLQ-38 as a predictor of health outcome has been investigated.

The following chapter presents the discussion and conclusion. Moreover, the outcomes from this chapter, which is entirely about the SLQ-38, will be compared to other studies accordingly.

Chapter four: Discussion and Conclusions

4. Introduction

This study has been designed to explore the likelihood and extent of Positive Psychological Change (PPC), and the psychosocial, clinical, physical and demographic factors that are associated with and may influence the development of PPC in individuals with Rheumatoid Arthritis (RA) in the UK. A survey was thus conducted on individuals with RA to evaluate the likelihood and extent of PPC, the demographic characteristics, the clinical, physical, social and psychological factors that are contributed with and may influence the development of PPC within this population. The study explored whether the associated factors are predictive of PPC.

The pathological features of RA are characterised by inflammation of the joints and tendons, swelling, acute flare-ups and stiffness, mainly of the small joints in the hands and feet, which may eventually result in joint damage and functional impairment in some patients. The course of RA is inconsistent, with the severity of the disease fluctuating over time. The dominant concerns for individuals with RA are dealing with everyday pain, reduced mobility, dealing with fatigue and managing the psychosocial impacts of the illness.

Although clinicians normally aim to achieve reduction of the synovitis and deferment or limiting of functional disability, to minimise the effects of the symptoms, at present there is no cure for RA and treatments are only partly effective. The main features of RA are the unpredictability of both the acute flare-ups and of how patients respond to the medical treatments. This means that control over the disease is often challenging and involves individuals with RA constantly having to adapt to the illness. Consequently, it is important to understand the role of psychosocial factors in the relationship between RA and health outcomes.

PPC refers to the positive consequences as a result of illness which is measured in this study by the Silver Lining Questionnaire (SLQ-38), developed by Sodergren & Hyland, (2000). The SLQ-38 uses items that were originally generated from a qualitative study of people with chronic health conditions such as arthritis. The SLQ-38 was developed by the authors during the second phase of their study to explore positivity as a result of illness. The SLQ-38 includes 10 themes, which are: improvement in interpersonal relationships, reappraisal of life, positive consequences for others, self-improvement, restructuring of life, spiritual

gains, skills and new pursuits, improvement in self- awareness, sensitivity to emotions and confrontation of current concerns.

The present survey study aims to describe the demographic characteristics of those people with RA who have experienced PPC. The demographic variables used include: age, gender, marital status, education, employment, ethnicity and duration of RA.

A further aim was to explore the potential factors related to PPC in people with RA, based on clinical, physical health function and psychosocial factors. RA clinical factors include: co-morbidities, fatigue and pain. The RA physical health function consist of: mobility, walking, bending, hand and finger function, and arm function. The psychosocial variables comprise: psychological well-being, coping strategies, self-efficacy for pain, arthritis self-efficacy for other symptoms, sense of coherence and resilience, social support, social activity, quality of life, depression and level of tension.

Finally, the present thesis assessed whether the associated factors are predictive of PPC in individuals with RA. This thesis looks at the relationship between these variables, as have been addressed in the discussion chapter.

The survey study was conducted with a sample of 210 individuals diagnosed with RA. The cohort was mostly female (79.0%), with a long duration of RA (>10 years) and at least two years post diagnosis. They were recruited from two organisations- the majority were from the Salford University Rehabilitation Research Group's Arthritis Research Panel (ARP, 60.0%) database, and some from the National Rheumatoid Arthritis Society (NRAS, 40.0%).

The key finding from this research is that PPC has been found among 34.0% people with RA and it is positively associated with age and number of years post diagnosis. It is also revealed that higher psychological well-being and coping strategy were significantly associated with PPC. The cognitive reframing coping strategy was positively correlated with the level of PPC. The analysis showed that distancing was the most favourably used coping strategy by those individuals with RA. It has been shown that people with higher self-efficacy are better able to control the level of RA pain and fatigue; however, those with higher pain levels showed less self-efficacy pain control. Significant cross-sectional association was found among lower social support, sense of coherence (resilience) and fatigue with PPC.

The thesis' primary aim was to examine the proportion of PPC in people with RA living in the UK, as discussed below.

4.1. The likelihood and extent of Positive Psychological Changes in individuals with Rheumatoid Arthritis

In order to address the main aim of this research, the likelihood and extent of PPC, a key comprehensive measurement, the Silver Lining Questionnaire (SLQ-38, Sodergren & Hyland, 2000) which contains 38 items with acceptable psychometric properties of reliability and validity, was employed. The SLQ-38 measures the extent to which people believe their illness has had a positive impact, despite the negative consequences of being ill (Sodergren & Hyland, 2000). The Cronbach's alpha across the present study samples was .95, which is to some extent higher than reported by Sodergren & Hyland, (2000). Indeed, Field, (2009) suggests that Cronbach's alpha of around 0.8 is good for a questionnaire.

Considering the total SLQ-38 scores, the extent to which the participants agree or disagree with the 38 statements was discovered by using a five-point Likert scale: (1) strongly disagree; (2) disagree; (3) not sure; (4) agree and (5) strongly agree state. An overall score was obtained by giving a value of '1' to responses of strongly disagree and '5' to strongly agree. Thus, the minimum SLQ-38 scores would be 38 if a person answers all items negatively. On the other hand, the maximum score would be 190 if someone answers all items positively. Therefore, the overall score reflects the total number of items which the individual agrees with. In this study, the mean for n=210 people examined by SLQ-38 was 95.09 and the SD was ± 26.09 .

In fact, the findings shows that the SLQ-38 scores were distributed normally (as reported in chapter there, section 3.5.), thus the majority of data form plots around the centre of distribution (SLQ mean, 95.09), and as the scores begin to move away from the mean, their frequency declines. The shape of the scores around the mean is symmetrical with relatively largely distributed data, SD= 26.09, which results in a flatter wider spread of the scores. Since the set of scores is normally distributed, 68% of the scores drop within the limits of the \pm one SD. This means that 68.0% of the RA population would be expected to experience some level of PPC between 69 (95.09-26.09) and 121(95.09+26.09). Equally, 95% of a set of normally distributed scores drop within the range of the SLQ mean, \pm two SD. Therefore,

95% of the individuals with RA would be expected to have experienced PPC equal to \pm two SD, which is between the score 43 ($95.09 - (2 \times 26.09)$) and 147 ($95.09 + (2 \times 26.09)$), thus, 5% must have experienced PPC outside of these limits. Since the normal curve is symmetrical, this means that half of 5% must be experiencing PPC less than the score of 43, and the remaining half of this proportion, 5%, must have experienced PPC over two SD, 147. Therefore, it is possible to say that those RA people who showed PPC are in the top 2.5% of the population as far as their PPC is concerned.

The proportion of normal distribution is helpful when considering the SLQ scores over two SD, which fall somewhere between + two SD (147) and + three SD (173). Considering the characteristic of normal distribution 99.7% of a set of scores fall in the range of the mean \pm three SD. Thus, 99.7% of the RA population would be expected to have PPC scores somewhere between the limits of - three SD (17) and + three SD (173). Although these are only rough estimations, in real life it may be that the true amount is (to some extent) different from these theoretical standards. However, it is useful since it gives some ideas in relation to the sample scores; it provides a fair idea of how the scores stand in relation to the rest of the population.

4.1.1. SLQ-38 average scores

The present study's findings show that the average score per item is 2.50, ($95.09/38$), which means that, in general, people do not see the bright side of RA very much because the maximum SLQ score is five, demonstrating strongly agree, and the minimum score is one, indicating strongly disagree. Thus, the present study's findings show that the average score per item is 2.50, which is halfway between the value of three, representing not sure, and the value of two, signifying disagree.

In addition, considering the scores over one SD, the mean score per item ($121/38$) is 3.18, indicating not sure, and the value of four representing agree; hence, it can be suggested that the participants, in general, were not sure or agree regarding the extent to which they believe that their RA has had a positive benefit when considering the negative impact of having RA. Furthermore, when looking at the score over two SD, 147, the mean score per item ($147/38$) is 3.87, which shows the average score is still lower than the value of four indicating agree.

For this research, the criterion for the occurrence of PPC was set at one SD over the SLQ-38 mean (121), indicating PPC. Thus, the current research has looked at people who scored at least one SD above the SLQ-38 mean (mean score 95.09+26.09), to give some idea about the ratio of PPC based of this survey study's dataset. This is because it might be a common experience to show PPC where the SLQ mean scores is 95.08. However, to capture the scores over one SD, 121, someone might have confirmed at least between 20-26 items positively, obtaining a score of (4), agree, and (5), strongly agree, indicating experiencing PPC, despite living with the RA symptoms (Table 3.5.). On the other hand, gaining scores over two SD, 147, on the SLQ, means that someone has reported a positive answer for at least 26 SLQ items positively- mostly scoring four and five. Thus, it seems likely that it is not easy to reach to scores beyond two SD on SLQ-38.

In addition, applying properties of the SLQ central tendency, mean and SD, was preferred because, according to the present data file, there have been items with the same number of people and frequencies, but their mean score per item was not the same. For instance, item 16 and 17, for the present data file, show the same frequencies and percent, n=20 (24.7%), but different mean values per item, at 2.62 and 2.53. On the other hand, there are some items with the same mean scores per item but dissimilar frequencies, for instance item six and 24. The mean score for both items was 3.20 but the frequencies differed at 48.1% and 41.9% respectively. Therefore, for the current research, it was decided to utilise the mean and SD scores to explore PPC in this sample, as this data has revealed that the quantity of people who scored on one or the other item positively may not essentially show the level of PPC in RA. Thus, for this research, the criterion for the incidence of PPC was set at one SD above the SLQ-38 mean (121), indicating PPC.

Besides, for the purpose of the clinical implications, it might be more applicable to encourage individuals diagnosed with RA toward higher levels of PPC and capture the scores over one SD. It is also worth mentioning that the present findings reveal that only n=29, 14%, of participants with RA showed PPC over two SD, thus for the present thesis, the criterion for the occurrence of PPC was set at one SD over the SLQ mean (121). Hence, the current research has looked at people who scored at least one SD above the SLQ-38 mean (mean score 95.09+26.09), to give some idea about the ratio of PPC based of this survey study's dataset. Therefore, this finding shows that within this sample n=81 (34%) of people scored one SD over the mean, thereby demonstrating PPC. In other words, for this

study sample, $n=81$, 34.0% of the scores above the average reveal positive change. Hence, there are lots of RA burdens that impede the majority of RA persons, 66.0%, from experiencing PPC. Thus, this could provide potential grounds for future studies to increase knowledge in this field through conducting further research with a bigger sample size to contribute towards developing and increasing positive changes in people with RA and other chronic health conditions.

4.1.2. The Scope of Positive Psychological Change

Interestingly when considering the extent of PPC, this study's findings show the level of SLQ improved, demonstrating PPC, and the number of people of those who experience PPC declined. This means that RA people showed a range of positive change, as measured by SLQ-38. Thus, exploring the areas that were not adequately supported by individuals with RA might be grounds for further studies to be discovered. However, it is possible that RA is a significant barrier to allowing these positive adjustments to occur. For instance, considering item three: 'My life is much better now than it was before', a large number of RA people (nearly 91.4%) disagreed. Similarly, for item 36, 'My illness changed other people for the better', 91.0% of this study's population did not confirm that their RA changed other people for the better, suggesting that future intervention studies might be helpful to expand on this knowledge further through encouraging self-improvement and considering self-strengths in individuals with RA (See Table 3.3.).

4.1.3. Items indicating Positive Psychological Change

This finding shows that one SD for the current study was roughly ($95.09+26.09=121$), which means that people would have answered positively to over at least 20 items if they respond to value four indicating agree, and over 24 items if they respond to value five representing strongly agree. The reason is because if people answer all 38 items positively, the range of the scores would be between 152 (38×4) and 190 (38×5). Thus, for one SD over the SLQ mean, 121 is equal to $(121 \times 38) / 190$ which is equal to just over 24 items. Roughly speaking, those people who have one SD over the SLQ-38 mean should have answered positively at least $(24 \times 100 / 38)$ to 62.0% percent of the items. Thus, over $\frac{2}{3}$ of the SLQ items have to be answered positively, indicating PPC. Yet, it is more meaningful to look at the range of scores, one to five, rather than just positive scores. The reason for this is because, even though mathematically this calculation might be correct, when considering the data for this sample and counting the positive responses for each person for those who

scored over one SD, the outcome was varied because the present research has considered the total SLQ scores, one to five, rather than the single positive items. This finding has been illustrated in Table 3.5.

4.1.4. Silver Lining Questionnaire-38 items analysis distribution in those with Rheumatoid Arthritis

It might be possible that someone who scores positively over the SLQ-38 mean would have gained total scores of over 121, with the highest score on about 20-26 items mostly '4', indicating agree and/ '5' strongly agree, as shown in Table. 3.5. However, the total SLQ scores might be varied due to obtaining various combination of scores from 1-5, as the research has looked at the continuum range of scores. In addition, the items with the highest frequency scores possibly would have been from top one third items, as shown in Table 3.6.

The average mean score per item and the items' distributions for scores over one SD on SLQ-38 are shown in Table 3.6. As can be seen, the top one third of items generated the higher mean, 3.23, scores. The second highest categories, the middle items, provide the mean score, 2.55, and the lowest row displays the 12 items listed at the bottom of the scale with the lowest mean level, 2.20. For the total overall items, 38, the average score is 2.66, which is slightly higher than the average score per item, 2.50, when considering the overall sample, n=210. However, individual differences and some other unknown factors might have impacted on the choice of answering positively to one item, rather than the other, thus indicating that further studies are required to expand on the current findings.

4.1.5. Content of the items scored positively over one SD

With respect to the content of the items the questionnaire has been divided in three sections. The top one third items (13 items) were related to the following topics: positive illness representation, stronger self and accepting the condition while dealing with others positively, as shown below.

Item

Interpretations

Top one third items	These items were focused around at least three main topics, as briefly discussed below: At the top the person with RA who is experiencing PPC over one SD on SLQ represents positive illness perception when considering living with RA, with more purpose to life and taking into account more appropriate ways to be able to control the consequences of RA symptoms. Thus, someone with this score might accept the condition and explore life further by considering his/her strengths in facing up RA problems. Secondly, the individual with RA considers other people around as a positive opportunity to deal with RA and, more importantly, takes into account how much he/she can offer to others rather than focusing on expectations in relation to others. In short, feeling good about herself, others and life are the most important messages in the top questions with higher frequencies. An example of this category is item 18 with the highest frequencies, at over 64%: 'My illness made me a more determined person '.
Middle items	Some of the items in this section refer to an understanding of an individual's nature, abilities and motives- an insight into oneself including any limitations. This includes being more aware of one's own mental representation, for example, item 22, 'I can face whatever is around the corner because of my illness'. Around 30.9% of those who scored over one SD on the SLQ mean agreed that they had been an inspiration to others. The second topic in this category is self-improvement, for instance 46.9% of the current data file said that their RA made them a more tolerant person. On the other hand, nearly 95% acknowledged that their RA has not given them more confidence. 87.6% of the current data file, of those who scored over one SD above the SLQ, disagreed that their RA made them a better person. Similarly, about 80.3% of those who scored over one SD disagreed with item 7, 'My religious/spiritual beliefs deepened because of my illness.'
Bottom one third items	An example of this category is item eight regarding being more open to other religions is located in this category, however, the majority, 96.3%, of people who scored over one SD over the SLQ said they disagree with item 8, which means they are not more open to other religions.

4.1.6. Comparisons of the themes with the original SLQ-38

With respect to the literature a few studies have been carried out on RA, as reported in the introduction section. From among them, the following section will consider the study conducted by (Sodergren & Hyland, (2000).

The aim of the study conducted by, (Sodergren & Hyland, (2000), was to identify the experience of positivity as a result of illness among 55 people including, n=13 males and 42

females, average age 53 years and experiencing chronic health conditions. The contributors had experienced various illnesses such as cancer, arthritis, osteoporosis, chronic fatigue syndrome or heart disease. The sample were interviewed either face to face or the questionnaires were posted to their address. Questions were delivered in a semi-structure format following an additional eight questions regarding the individual's personal experiences of their illness. The data was analysed by employing a thematic analysis method and the themes are recognised in order of descending frequency as follows: Improvement in interpersonal relationships (100.0%), reappraisal of life (93.0%), positive consequences for others (93.0%), self-improvement (93.0%), restructuring of life (84%), spiritual gains (69.0%), skills and new pursuits (49.0%), improvement in self- awareness (44.0%), sensitivity to emotions (16.0%) and confrontation of current concerns (4.0%).

The findings from the present research provide some evidence to back up ten features of the positive consequences of RA included in the SLQ-38 (Sodergren & Hyland, 2000) and these are reported in the results section in Table 3.7. It seems that, for the majority of individuals diagnosed with RA who showed PPC, over one SD on SLQ, the most important consequence of their illness has been enhancing their relationships with others. This may be a very important point to consider, as RA people require a deeper and stronger positive relationship with others, in particular in their marital relationships, to avoid isolation as a result of pain and potential disability. It is common in RA that people become emotionally dependent on others, mostly because, while they have to deal with other commitments, such as housekeeping, they might be in pain and feel fatigued. Thus, it is reasonable for them to ask other people around to support them. Therefore, this could be a focus of future intervention studies: how to enhance positive interpersonal relationship in this target sample to develop stronger positive relationships with others (Table 3.7.).

Contrary to Sodergren's study, the findings from the present research show that some individuals with RA reflect on how they feel about themselves to become more aware of their own emotions and those of the people around them, to help face up to a number of distressing areas of their life, such as RA symptoms. As an example, some people in the present study identified that their RA has helped them find themselves and become more aware of their strengths. Some reflected on the true purpose of life. That is, they reviewed what life has brought to them; what they might do with their life, and/or how the illness has impacted on their perception of their life. Some of this study's participants reported that they have seen some benefits, although not everybody agreed. Some emphasised that,

although life is hard, it can change quickly, therefore simple pleasures are precious, and so they appreciate life more as a result of their RA.

Sodergren & Hyland, (2000) state that 93.0% of their study's participants reported self-improvement as a consequence of their illness. However, the findings from the present research show little evidence of this, 25.0% of people showed PPC over one SD and agreed that they have experienced some positive changes to their character as a consequence of their RA. For instance, some confirmed that their RA has made them a more determined and/or tolerant person. On the other hand, the majority of individuals with RA disagreed that they have become a happier and/or calmer person because of their RA. Thus, although a number of RA people gained some positive changes due to their condition, the one thing that makes RA different from other stressful conditions is that the majority of individuals with RA have to live with pain, thus it is reasonable that RA people do not experience being a calmer or happier person, or even having more confidence, as a result of their RA. This might be because of the nature of the illness, mostly as a result of excessive pain and the limitations that impact on them because of the RA symptoms. Therefore, these might be the areas that future studies could take into account to develop intervention studies to enhance people with RA's self-improvement capacity to be able to cope with the impact of the RA symptoms.

Compared to some of the themes in the study performed by Sodergren & Hyland, (2000), the findings from the current research provide some verification with regard to perceptions of the impact of their illness equipping people with new skills and presenting them with novel activities. For instance, some mentioned that they can face dealing with the problems and disasters in life as a consequence of their RA, and a small number reported that they have discovered a talent that they did not know they had.

Many people in Sodergren's and colleagues' study cited that their illness not only had some positive consequences for themselves, but it has also had some positive consequence for people around them, such as their families and friends. Some of those who showed PPC in the current study reflected that they have been an inspiration to others, and a smaller number stated that their RA has changed other people's perceptions of them for the better. Besides, some of the participants in this study agreed that other people can be more open with them since their illness. In addition, 20.0% of those who showed PPC agreed that other people appreciate them more because of their RA; similarly, 22.2% of this research's participants

proposed that their illness has changed other people for the better. In general, it seems that it would be beneficial for future studies to consider the impact of RA on people's perceptions of themselves, and the influence of that on their relationships with others, as stated earlier in this section.

The majority of Sodergren's and Hyland's contributors suggested that their condition had encouraged them to restructure of their life. However, compared to the study conducted by Sodergren & Hyland, (2000), 18.5% of those who showed PPC agreed with this theme. Among them, the majority emphasised that their RA has made them live their life to its fullest, and a few even agreed that their life is much better now than it was before. Thus, for some people, their illness has had some positive consequences for them, but not for others. In agreement with Sodergren & Hyland, (2000), it seems like a reasonable restructuring of life is related to the reappraisal of life, since it often encourages changes in the way people lead their lives. However, according to the present research's findings there is a split between people's perceptions of their reappraisal of life and their restructuring of life. Thus, this point might be important to be considered in future research to understand the relationship between reappraisals and the restructuring of life, and the mechanisms behind this, as it seems like the stronger appraisal of life would lead to a better restructuring of life and vice versa (Table 3.7.).

Positive changes as a consequence of illness have been described in relation to spiritual gains in Sodergren and Hyland's study (2000), as 69.0% of their study participants reflected on the importance of spirituality in encouraging them to live with their RA. However, this theme has a lower proportion when considering the people who showed PPC in RA. Thus, not only did some RA people disagree with the point mentioned, but 88.0%, of those who showed PPC feel that their religion or spiritual beliefs did not develop because of their RA; moreover, many of this study's participants did not state that they are more spiritual or open to other religions as a consequence of their illness. That is, their RA did not lead to a strengthening of their spiritual thoughts or to appreciating a spiritual life. Interestingly, this finding is inconsistent with Sodergren and Hyland's study (2000) and some other previous studies conducted by Tedeschi & Calhoun, (1996). This might be because of the nature of the illness, since people with RA experience a lot of pain and RA burdens that strongly impact on their spirituality and beliefs. This also might be because of the nature of the method that has been used in the present research's survey, as the research has not measured

individuals with RA spiritual gains in advance; or it might be because of some unknown factors which could be taken into account in future research.

In brief, RA is dissimilar in nature to other health conditions, therefore it is reasonable if the present research's findings are to some extent dissimilar to other studies, for instance Tedeshi and Calhoun's study. Furthermore, the methodology of semi structured interviews was utilised by Sodergren and colleagues, in comparison to the current research, which presents the findings from a survey conducted with individuals with RA. Moreover, these findings are based on a small sample size, thus further research is required to provide some evidence from a larger sample considering RA and other health conditions to explore these findings further.

4.1.7. Positive change following traumatic events

With respect to the past studies, for instance Linley & Joseph, (2004), conducted a systematic review which considered 39 studies examined positive change. The review reported that, altogether, 30-70% of survivors revealed various sort of positive change, although these findings are based on a range of traumatic or stressful life events such as transportation accidents, interpersonal experiences or medical disease.

The systematic review performed by Linley & Joseph, (2004) reports the proportion of some sort of positive change for medical health patients with: breast cancer (97.6%), a bone marrow transplant (96.0%), spinal cord injury (79.0%), heart attack (58.2%), HIV (83.0%), RA (83.0%) and Multiple Sclerosis (MS), although the ratio of positive change for MS has not been published. Overall, Linley & Joseph, (2004) claim that the prevalence ranges varied from three to 98 percent. Thus, the rates should be interpreted with caution since none of the studies have used random sampling techniques, therefore the findings may not be a true representation of the general population. Furthermore, there are some discrepancies in the study's findings due to their choice of study design. For instance, the study conducted by

Affleck, Tennen, Croog, & Levine, (1987) in people with heart attack used a single item scale and reported a perceived benefit of 58.2%. This differs from Fromm, Andrykowski, & Hunt, (1996) as they stated the amount of positive change as being 96.0%, when interviewing 90 people who had gone through a bone marrow transplant. Beyond that, some authors assumed that PPC is more common, over 95.0%, if a person reports just one positive

change (i.e., Sodergren, 2000), yet, it is certainly open to question whether positively answering one item, out of 38 questions, could identify PPC. Thus, not enough thought has been given to make any sense of whether PPC occurs and to determine how the impact of illness should be measured.

4.1.8. Benefit Finding in Rheumatoid Arthritis

Of the few studies that have considered Benefit Finding (BF) in RA so far, Tennen et al., (1992) measured positive changes in relation to experiencing pain. Their study findings illustrate how the participants' ability to identify benefits are linked to lower levels of functional limitations, for instance, fewer days in which activities were restricted as a result of moderate to severe pain. Danoff-Burg and Revenson (2005) explored BF in relation to interpersonal relationships. Their findings show that 71.3% of their sample in RA confirmed some kind of interpersonal benefits, for instance, an appreciation of the support from a valued person and a increase of rise compassion. Similarly, BF in people with RA in Japan was taken into account by Sato et al., (2008), who confirmed that 97.5% of their study participants reported some kind of positive change, as mentioned in the introductory section.

Among studies focused on BF, Tennen et al., (1992) explored the benefits of experiencing pain and perceived pain control in 54 people with RA over 75 days. Participants were asked to answer five benefit items, all focusing on pain. The participants were asked to control their pain and also report the pain's strength; the impact of pain on their daily activities and the limitations, and their mood when experiencing pain. The findings reveal that those with highly perceived pain control experience lower daily pain, however, with increased pain, higher perceived pain control is connected to lower positive mood. The current study's results show that there is a significant difference between those whose scores are lower for the SLQ-38 mean compared to those who attained the SLQ-38 mean. Moreover, in the case of more severe RA pain, other factors might lend a hand in lowering the level of pain experienced, for instance, a higher level of self-efficacy pain control might assist in attaining the higher level of PPC. The present thesis has discussed the ratio of 34.0% PPC for the study's database; however, the study conducted by Tennen et al., (1992) has not reported the mean and the proportion of benefit findings from the study sample.

Of those studies that explored BF, the study performed by Sato et al., (2008) has aimed to explore commonalities in BF as well as the association between BF and social factors amongst the target sample. The participants were 364 individuals with RA, males, n=76 and

females n=288, aged 20-59 years. A web-based survey was conducted to measure BF through an 11 item questionnaire based on a study conducted by Mohr et al., (1999) and Antoni et al., (2001), as well as meeting a focus group of six RA persons in Japan. The study reports that 97.5% of their participants agreed with one or more items. The highest frequent, 84.1%, item is, ‘Living with RA has helped me appreciate things that previously were not important to me’ and the least common, 44.4%, item is, ‘Living with RA has brought me new interests or pleasure’.

Interestingly, there are some similarities between the current study’s findings and Soto’s and colleague’s study, as addressed below.

Sato et al., 2008		Present thesis	
		People who showed PPC on SLQ-38	
Items	Frequencies	Items	Frequencies
Living with RA has helped me appreciate things that previously were not important to me	84.1%	I appreciate life more because of my illness	49.37%
Living with RA has led me to deal better with stress and problems	67.3%	My illness made me face up to problem areas of my life	41.9%
Living with RA has led me to meet people who have become some of my best friends	53.3%	My illness gave me the opportunity to meet new people	54.3%
Living with RA has led me to be patient	66.2%	My illness made me a more tolerant person	46.9%
Living with RA has taught me how to adjust to things I cannot change	62.5%	Because of my illness I find it easier to accept what life has in store	49.4%

*adapted from Sato et al., p.54.

Although there are some similarities between a few items in Sato’s study and the present research, which has employed SLQ-38, the studies conducted by Tennen et al., (1992); Danoff-Burg and Revenson (2005) and Sato et al., (2008), explored only a narrow range of such domains and provided some degree of evidence with respect to how BF and its positive effects might be attained; nevertheless, PPC can be manifested in various life domains and the relationship between PPC and health variables has not been well examined to date.

The present research has found that the most frequent item is number 18, at 64.2%, as reported by people who scored over one SD on SLQ: ‘My illness made me think about the true purpose of life’. The least common item for the present study is item eight, ‘I am now

more open to other religions because of my illness' with only 3.7% positive responses, as reported in Table 3.7. With reference to the content of the items, although the two studies, Sato's and the current research, have more or less explored the same concept, Sato's study looked in particular at the narrow aspect of BF, that is, social factors, for instance general support difficulties and emotional support networks and self-care activities. On the other hand, the present research has considered general positive change as a result of illness, as explained by Sodergren & Hyland, (2000) and measured through SLQ-38.

With respect to the measurement, it is worth mentioning that the present research has taken the central tendency of normal distribution, such as mean and SD, to explain how the scores have similar or different variations in relation to the SLQ mean. The reason for employing the SLQ central characteristics is to provide a stronger analysis, such as mean and SD, to be able to compare and contrast the study's findings. Beyond that, the SLQ-38 provided more possible areas to be explored, that is, ten aspects of positivity that improve interpersonal relationships, as discussed earlier in this section.

Although Sato's study has examined some interesting points, such as 9.5% of the variance in BF can be explained by social factors, the study has a Web based design, therefore only those people who had access to the internet and were familiar with computers could take part in the study. Thus, although it might be possible for certain age groups of RA people, for instance younger people, to have access to a computer and be aware of the Web based survey study being conducted, not everybody would have access to a computer. In addition, there might be some cultural differences which might impact on the study findings. Thus, the findings from Sato's study and the present thesis are to some extent dissimilar. Therefore, it might be worth exploring the area further by conducting studies to explore the notions in more depth.

Largely, these studies, Tennen et al., (1992); Danoff-Burg and Revenson (2005) and Sato et al., (2008), signify that BF is common in individuals with RA; however, the present research findings illustrate that PPC in RA is not as common as the previous studies have claimed. However, the overall scores for the present data file show that everyone has replied positively at least to one item, since the minimum score for the present data file was 39, although this research has not considered a positive answer to one item to indicate PPC. The reason for this is people might answer one or a few items positively, but that may not mean

that they experience PPC. Thus, PPC was not shown to occur frequently by the current research in comparison to the past studies conducted on RA. This might be because in this research it was decided to consider one SD over the SLQ mean, indicating PPC rather than the frequencies (percentages).

Among those studies reviewed by Linley and Joseph (2004), a few have explored positive change in people with arthritis, including the study conducted by Abraído-Lanza, Guier, & Colón, (1998) and Evers et al., (2001), which will be discussed accordingly. The study conducted by Abraído-Lanza, et al., (1998), looked at factors that promote thriving within Latinas' challenging various adversities such as poverty and chronic illness. The purpose was to explore socio-cultural and personal resources that support thriving experiences in which respondents reported positive growth. The concept of psychological thriving is based on the 'value-added model', that is, a person's experience of growth beyond equilibrium, and more specifically, finding new insights or meanings in life as a result of illness Abraído-Lanza, et al., (1998). The participants were a sample of 106 females from South America, with chronic health conditions and inadequate social class income; the age range was 50 years and having had RA for over 13 years.

Abraído-Lanza's and colleagues' study design was longitudinal and took place over three years. In the first phase of the study, qualitative face to face interviews were used, in which the participants confirmed a number of experiences, for instance appreciation of life. The Thriving Scale (TS) was developed by authors during the second phase of the study to explore various socio-cultural and personal factors three years later. The TS is a combination of 18 items borrowed and modified from both the Stress-Related Growth Scale (Park et al., 1996) and Post-traumatic Growth Inventory (Tedeschi & Calhoun, 1996), along with two items developed by the authors, Abraído-Lanza, et al., (1998).

The study employed a number of measurements, for instance psychological well-being was measured using the Positive and Negative Affect Scale (PANAS; Watson, Clark, & Tellegen, 1988). Sense of Competence was assessed using two scales, the self-esteem (Rosenberg, 1965) and the self-efficacy scale. The self-efficacy scale was incorporated from two subscales, self-efficacy pain (6 items) and self-efficacy other symptoms (7 items) developed by Lorig, Chastain, Ung, Shoor, & Holman, (1989).

The cohort in the study by Abraído-Lanza, et al., (1998), included those suffering from various arthritic diseases, such as lupus or osteoarthritis, or experiencing more than one type of arthritis and half were rheumatoid arthritis patients. Moreover, the study considered only 106 females living with the conditions from various geographic locations in South America; therefore, the findings are limited in their focus. Furthermore, Abraído-Lanza, et al., (1998), confirmed the ratio of psychological thriving, 83.0%, based on the analysis of open-ended interview findings. The study has reported various thriving experiences, for instance the top one which is enhanced appreciation and meaning of life (30.2%), and the lowest one which is gaining patience (4.7%). Nevertheless, the current study has looked at n=210 RA people, male and female, who scored at least one SD beyond the SLQ mean (mean score 95.09+26.09), to give some sense of the ratio of PPC; that is, 34.0% of this study's participants gained a score of over one SD based on this survey study's dataset. Hence, the present study has used a different methodology and so this finding is dissimilar.

Furthermore Abraído-Lanza, et al., (1998), state that neither illness characteristics (i.e., duration of illness), nor age had an effect on thriving. In contrast, the present study's findings reveal that age and duration of RA seems to have benefits for psychological health by increasing coping strategies, in particular cognitive reframing, to adjust to uncontrollable RA symptoms. Nevertheless, the results of the study conducted by Abraído-Lanza, et al., (1998) raise several interesting points. For example, looking at the impact of psychological well-being and the concept of psychological thriving, which was mediated by self-efficacy and self-concept and also predicted psychological thriving. In general, the present study's findings (in relation to psychological well-being) are fairly similar to Lanza and colleagues' findings; however, the current study suggests that psychological well-being can be directly referred to the PPC. However, in the study conducted by Abraído-Lanza, et al., (1998) positive affect and self-esteem play important roles in thriving in people with limited social resources, although it is unclear whether better social class and income would have led to the improved thriving. Moreover, the conceptualisation of thriving as gaining positive growth as a result of improving the person's philosophy on life may have a closer link to positive affect and self-esteem than if thriving had been defined in a different way.

To extend that knowledge, the study developed by Evers et al., (2001) aimed to generate a self-report scale to measure three illness cognitions in relation to adjusting to chronic health conditions. These were: helplessness (which refers to the negative meaning of the disease),

acceptance as a way to reduce the unfavourable meaning, and perceived benefits to assess favourable meanings given to the illness. The study participants were n= 263 people with RA and n=167 individuals with MS. The majority of RA people were female (66.0%) with a mean age of 58.1, married, and time since diagnosis of 10 years on average. The characteristics of the MS participants were mostly female (67.0%), mean age of 40.6 years, married and time since diagnosis of 9.4 years on average.

The study findings from Evers et al., (2001) support the reliable and valid measurement, Illness Cognition Questionnaire, which uses 18 items to assess illness cognition across various chronic health conditions. Evers et al. show that acceptance and perceived benefits are positively correlated in people with RA; however, there is no significant correlation between age and perceived benefits. In contrast, the present study's findings show that there is a positive connection between PPC and age, indicating that the older the age, the more likely the person is to employ appropriate coping strategies and achieve PPC. In addition, Evers et al., (2001), confirmed that longer RA duration was related to increased helplessness, suggesting that increased helplessness is negatively linked to perceived benefits in individuals with RA. However, when calculating the duration of RA for those who had the illness for over five years, the findings show that there was a significant impact for perceived benefits in relation to acceptance, indicating that the patients developed acceptance during the early years of the illness. In the same way, the current findings show that the longer a person has been living with RA, the more likely they are to have experienced more PPC, indicating that there might be more chance of enhancing the sufficient cognitive coping skills necessary to live with RA.

On the other hand, acceptance is highly correlated with the use of active coping and stronger social support in the study conducted by Evers et al. Similarly, the findings from the present study show that there is a positive relationship between PPC and cognitive reframing, in that cognitive reframing as a way of experiencing the illness to find a more positive point of view, is linked to PPC. On the contrary, there is an inconsistent finding in that the current study shows that social support correlates negatively with PPC, which has been discussed in more detail under aim three. Although Evers et al., Evers et al., (2001) developed a valuable generic measurement to assess illness cognition, the psychometric properties of the scale are unclear as the study did not explore the relationship between the scale and associated constructs in relation to perceived control more directly (i.e., self-efficacy). This

is important since the current study's findings show that people with a higher capacity for self-efficacy for pain might be better able to control the impact of RA symptoms, in particular their pain. Moreover, the proportion of perceived benefits has not been published by Evers and colleagues. On the whole, there is some evidence that supports a positive relationship between positive illness cognition (i.e., acceptance) and positive outcome (Evers et al., 2001), which is supported by the present study when the impact of positive change is taken into account.

To conclude, the findings from the literature reviews discussed in Chapter One, reveal that the frequency of positive change has not been clearly reported for this target sample prior to the present study. Furthermore, the prevalence of positive change for the medical conditions is mixed, dependent upon the illness, events and the study method; therefore the findings from the current study are not similar to the previous studies.

The key aim of the present research was to examine the likelihood and extent of PPC in RA and the thesis has revealed that only 34.0% of the study population showed PPC, as discussed throughout this chapter. The current research has looked at people who scored at least one SD above the SLQ mean (mean score 95.09 ± 26.09), to give some impression of the ratio of PPC according to this study's dataset. The findings show that PPC exists for $n=81$ out of 210 people, who scored over one SD on SLQ-38. This means that the remaining people, 66.0%, showed PCC to some extent, since the present research has looked at the SLQ continuum level, 1-5. Nevertheless, it is acknowledged that focusing on one SD over the SLQ-38 mean is open to criticism as the cut-off point that is produced is dependent on the responses from the small sample and the mean that they produce. Thus, if the mean of a sample is very low, then the cut-off point would also be very low in terms of scores on the SLQ-38. Hence, exploring the SLQ characteristics, frequencies, mean and SD for those who scored positively may have provided some ideas for future studies to expand on this knowledge further. Even so, the approach has sought to produce evidence of PPC from the present sample; hence, these findings might be a starting point for future researchers to develop this further. It could be improved by providing evidence from a bigger sample size and by improving the psychometric properties of the measurement employed. Accordingly, the research could support future researchers to be able to compare the proportion of PPC in people with RA and also to associate the findings with other medical health conditions. Consequently, there are potential grounds for encouraging people with RA to improve their

levels of PPC, and this may be possible by conducting further longitudinal interventions studies considering the topic in individuals with RA.

4.2. Aim two: Demographic characteristics of people with Rheumatoid Arthritis who reported Positive Psychological Change

The further aim of this research was to describe the demographic characteristics of those people with RA who have reported PPC over one SD from their RA experiences. The association between PPC and demographic variables in individuals with RA have been addressed as below.

4.2.1. Age

The present study's findings show as age increases, people report more experiences of PPC in the face of RA. This finding is in line with Curbow et al., (1993) and Blore (2012), who found specific types of positive consequences reported among other sufferers of chronic illness (i.e., bone marrow transplant patients), suggesting that older people are more likely to restructure their lives to learn to adjust to RA by modifying their expectations and to employ effective coping strategies to be able to control RA pain, as reported by Newman (1993). Moreover, there is also the possibility that individuals with RA, who showed PPC over one SLQ mean, might use some types of positive self-statements to distract from concentrating on the pain. This self-distracting reaction may have two potential benefits. First, it could perhaps give directions to the person in order to avoid focusing on pain. Secondly, a person might be encouraged to focus on something different. This could be something like utilising appropriate coping skills to deal with the pain and the RA condition. Together, avoiding and focusing on something else, would perhaps be helpful to empower an individual who is in pain to attain more positive emotional feelings, as well as to open up a self-control capacity to not only reduce the RA pain but also to reach to some level of PPC. However, the present study has not measured the impact of positive self-statements and the usefulness of a distraction approach to reducing RA pain, but it might be useful to examine whether positive self-statements would be beneficial in leading to experiencing positive change in individuals with RA in future studies. On the other hand, not everybody agrees with this finding from the present study. For instance, Sodergren (2000) found that a positive attitude with illness is unrelated to age when she examined n=195 people with various chronic respiratory illnesses. However, this might be due to the characteristics of the

other conditions rather than RA. Beyond that, the mean age of the present study's participants was 62, thus these results may be seen as being characteristic of this age group and it is in doubt if this finding would be moving over into an older range, therefore further research is recommended to check this finding against other age groups. Clearly, future research may discover different results and this could be because of the different needs of other RA age groups, for instance, younger people living with RA might be more anxious to be active, but the difficulties of living with RA do not allow them. Thus, considering the influence of age when measuring PPC in individuals with RA is recommended.

4.2.2. Gender

With regard to the function of gender with the SLQ, this study's hypothesis was: there will be significance difference between male and female participants in their scoring for PPC on the SLQ. It is worth noting that a significant impact from gender was not found. This finding is similar to a study conducted by Sodergren (2000), who explored the issue of gender for diverse illnesses. Sodergren (2000) presents no evidence for the gender influence across five groups (n=194) of patients with various chronic respiratory illness groups, employed SLQ-38 scores. Yet, she confirms that, in total, more females supported the positive consequences of their illness compared to their male counterparts. Controversially, some studies state that gender plays a significant role in growth experiences, for example, females have been found to score higher in studies conducted by Park et al., (1996) and Tedeschi & Calhoun (1996). However, these findings have not been replicated by the current research, as the PPC did not differ significantly between males and females in this study. This finding may highlight the influence of employing various methods and measurements in studies, or it might be as a result of the nature of the conditions. With reference to the influence of the study design on study outcome, it is worth noting that, in prospective study designs, information about possible elements is collected at the baseline and ahead of the development of the outcome of interest. The cohorts could then be followed up for a certain period of time to record the progression of any of the outcomes of interest. In this case, the researcher has the opportunity to answer many questions and examine various probable determinants to discover whether they differ at the baseline. Thus, if a range of factors are included in advance, at the baseline, then it is possible to reach more precise and predictable outcomes. Therefore, in order to expand on this thesis' knowledge, additional research will be required to further examine this concept.

4.2.3. Marital status

This study aimed to examine the influence of marital status on the PPC scores and so the study hypothesis was: there is a significant difference between PPC and marital status. Contrary to expectations, the research findings reveal that there was no significant effect from marital status on levels of SLQ-38, indicating that there is no significant difference in marital status for the mean of SLQ-38. On the other hand, those who are divorced or separated showed a higher SLQ mean. This finding is similar to the study conducted by Reese et al., (2010), suggesting that maybe satisfaction in marriage is more important than just being in a marital relationship. Furthermore, this finding shows that single participants presented the lowest SLQ mean scores, which then again could confirm the importance of a happy marital status for this target sample. There is a good reason for this suggestion, as individuals diagnosed with RA might need assistance with personal needs, so this is very important to be understood by their partners. However, it is also important to consider that this finding is based on unequal group members and the sample size in each group. Moreover, the majority of this study's participants were female, so this finding may not be generalised to other RA people. Even so, it is worth taking into account that, despite some progress in the context of RA research, important work still lies ahead with respect to the possible impact of lifestyle, which could form the subject of further research from a public health perspective.

4.2.4. Education

With respect to education status, the aim was to investigate whether there is a difference according to the level of education in the level of SLQ-38. The study hypothesis was: there is a significant difference between PPC and education status. This might be explained by more educated people possibly having more access to the knowledge required to be able to deal with RA symptoms, which might encourage greater psychological well-being and PPC. Contrary to the prediction, this analysis showed that there was no significant effect from education on PPC; although the group with a diploma level of education had the highest SLQ mean and the lowest mean score was presented for the A level/BTEC level. This finding is important since the majority of this study's participants have a degree qualification, but the level of education did not reveal significant evidence on the level of SLQ scores. The reason for this finding might be that there are some other potential factors which could be more important in reaching PPC, for instance coping skills and

psychological well-being, and these factors may not necessarily be related to the level of education and reaching PPC. Although a higher level of education might assist in gaining access to more knowledge about RA in general, it may not directly impact to cause positive change. On the other hand, perhaps it might be the case that a higher level of PPC could be related to how much a person with RA has the self-efficacy ability to control the RA pain, which might lead to more psychological well-being. However, it is still too early to understand the mechanism underlying these relationships, but this may become clear by conducting more research to discover the impact of education on the level of PPC.

4.2.5. Employment

In regard to the influence of employment on PPC scores, the aim was to investigate whether there is a difference according to employment status in the level of SLQ-38. The study hypothesis was: there is a significant difference between PPC and employment status. The analysis reveals that there was no significant effect from employment on PPC scores, suggesting that there is no significant difference between the levels of employment on the mean of SLQ. Nevertheless, the group with the full time employees had the higher SLQ mean, and the lowest mean scores were presented by the long term sick leave participants. The present findings do not confirm the studies conducted by some of the previous authors, for instance Bengtsson et al., (2005), although this might be as a result of the small sample size or the nature of the study; however, the mechanisms underlying this finding could be examined by employing a larger sample and conducting a longitudinal study to expand on this finding further.

4.2.6. Ethnicity

This study aimed to investigate whether there is a difference according to ethnicity in the level of the SLQ-38. The hypothesis was: there is a significant difference between PPC and ethnicity. The analysis has revealed that there was no significant effect from ethnicity on PPC scores. This is mainly because over 99 percent of the current study participants are white with a British background.

4.2.7. RA duration

In view of the duration of RA, it was predicted that there is a significant correlation between PPC and RA duration. Interestingly, this finding not only confirmed the study's hypothesis

but also illustrates that the duration of RA could be a strong predictor of PPC. Thus, the more years post diagnosis, the greater the level of PPC recounted by the study participants. This, in turn, supports the suggestion that time is associated with being better adjusted to the burden of RA. This finding suggests that PPC may increase over time, even when considering the influence of the adverse impact of the illness. This outcome is consistent with Newman (1993), suggesting that as people live for a longer period with their illness they can probably learn to cope with the symptoms and can potentially generate higher levels of PPC. This finding is important because the majority of the participants have lived with RA for over 10 years, hence this finding might be because people learn to live with the condition, and therefore the characteristics of RA may not be the same as with other long-term health conditions. Consequently, future research may stand or fall on the repetition of this finding.

In a succeeding analysis, the thesis aimed to explore the difference of the study variables, RA duration, on the level of PPC scores based on the SLQ-38 scores. In doing so, the thesis has examined whether there is a significant difference between those whose scores are lower the SLQ-38 mean compared to those who attained the SLQ-38 mean. This shows that the duration of RA would have had a significant impact on the level of PPC on the SLQ-38 scores at the SLQ-38 mean and one SD level, suggesting that those people with longer RA duration might experience more PPC. A longer RA duration may support employing effective coping skills such as cognitive reframing, which might potentially lead to greater psychological well-being. This finding is consistent with the study conducted by Treharne et al., (2007) who examined the effectiveness of coping strategies in relation to psychological well-being by implementing a longitudinal study design with individuals with RA. Treharne et al. (2005) showed that people with established RA, over seven years, revealed higher social support to reduce RA fatigue, yet this study's findings do not support a positive relationship between social support and PPC. On the other hand, the lower level of fatigue and social support is related to higher PPC. This might suggest the importance of satisfaction with social support in relation to fatigue in persons with RA while considering the longer duration of RA. However, more work is required to understand the mechanisms that contribute to these relationships.

4.3. Aim three: Factors associated with Positive Psychological Change

The third aim of the thesis was to investigate potential factors (clinical and psychosocial variables), associated with PPC in people with RA.

4.3.1. The clinical characteristics

The association between PPC and clinical variables (co-morbidities of RA, fatigue, pain and physical health function), have been addressed as below.

4.3.1.1. Common co-morbidities

Approximately two thirds of the current study's participants stated that they have other health conditions. These are mainly osteoarthritis, osteoporosis and fibromyalgia. Some earlier researchers have reported on other health conditions, with 80.0% involving individuals with RA. For instance, Petri et al. (2010) and Michaud and Wolfe (2007) reported that the rate of osteoporosis is nearly twice as much in people with RA. However, those people with other long term physical or mental health conditions that might have influenced the present findings were screened, as reported in the method section.

4.3.1.2. Fatigue

It was initially expected that PPC would be negatively correlated with fatigue, as there is evidence of the multidimensional action of the fatigue through physiological and psychological pathways, as explained by Louati & Berenbaum, (2015). The findings from the current research highlight the important role of fatigue in relation to PPC, as greater fatigue is significantly associated with decreasing levels of PPC.

In addition, in a follow up analysis, the study aimed to investigate the differences in the study variables for fatigue, concerning the level of PPC scores based on the SLQ-38 scores. In the process, it has been examined whether there is a significant difference between those whose scores are lower than the SLQ-38 mean, compared to those who attained the SLQ-38 mean. This suggests that fatigue would have had a significant impact on the level of PPC on the SLQ-38 scores at the SLQ-38 mean and one SD level, signifying that those people with lower fatigue might experience more PPC. On the whole, the findings indicate that people who scored higher in their level of PPC were more able to control their fatigue, possibly through their self-efficacy-pain ability. This means that there might be many factors that can

explain this variation, however, the model includes overall well-being, sense of coherence and resilience, RA duration and fatigue, which may explain 14.3% of it; among this value, fatigue can be explained by only 0.02% of the variation. Thus, there must be other variables that have an effect as well.

It is worth noting that some previous studies have confirmed that fatigue, pain and depression are often associated with a complex and dynamic mechanism concerning psychosocial factors and RA illness beliefs (i.e., Dures et al., 2013). In addition, some earlier studies (i.e., Repping-Wuts et al., 2008) suggest that the severity of fatigue could minimise the perceived ability to cope with RA. In line with these findings, the current research supports the study hypothesis and suggests that effective coping strategies, in particular cognitive reframing, are positively related to lower levels of fatigue and also higher levels of PPC. This might be due to the impact of self-efficacy-pain ability, which may assist in minimising the influence of RA fatigue. The second possibility is the impact of a combination of other factors, for example, psychological well-being and the level of coping strategies, in particular the cognitive reframing capacity, as this might help in reducing the level of fatigue. Thus, the suggestion is that the changes in the levels of fatigue are possibly as a result of a collaboration of other factors, including psychological well-being, lower pain experience, and longer RA duration. However, this research is a preliminary exploration and the current thesis did not measure fatigue at the baseline, thus it can be assumed that this finding might be due to the nature of the study when considering the level of fatigue. In addition, the influence of the combination of these factors to reduce fatigue is in doubt. Therefore this could be another interesting topic to be explored in the future.

Alternatively, some previous studies show that higher levels of fatigue are linked to more severe mental health problem in people with RA (i.e., Pollard et al., 2006; Munsterman et al., 2013). In what follows, the present study suggesting that lower levels of fatigue are associated with poorer pain experience, which might contribute towards enhancing psychological well-being and utilising effective coping strategies to handle the RA burden, which might lead to increasing the level of PPC experienced by individuals with RA. Thus, PPC is positively connected to lower levels of fatigue and pain and not psychological symptoms such as depression and the level of tension. The lack of information in this area

could be addressed in future research, so that these findings can assist in moving toward developing a range of applications to effectively meet the needs of people with RA.

4.3.1.3. Pain

This study primarily predicted that PPC is negatively correlated with ratings of arthritis pain scores, yet the study hypothesis has not been confirmed. Nevertheless, in a later analysis, the thesis aimed to examine the difference of the pain on the level of PPC scores based on the SLQ-38 scores. Thus, the thesis has examined whether there is a significant difference between those whose scores are lower the SLQ-38 mean compared to those who attained the SLQ-38 mean. This shows more severe RA pain might be controlled only at higher levels of PPC, over two SD, suggesting that those diagnosed with RA are differ in their level of PPC if they experience more pain. However, in this case, other variables might assist in decreasing the level of pain experienced due to the higher level of psychological well-being; higher level of self-efficacy pain control and the lower fatigue experienced.

Previous research has shown an association between self-efficacy and changes in daily pain (Brekke et al., 2001), fatigue (Barlow et al., 2002) and well-being (Cross, March, Lapsley, Byrne, & Brooks, 2006). The self-efficacy-pain scenario emphasises that if people with RA believe that they are capable of controlling their pain, they are more able to organise and accomplish the action necessary to achieve this and control their pain. In addition, if they expect positive outcomes (self-efficacy expectation, i.e., controlling their pain), they are more likely to control their pain (outcome expectation, Bandura, 1977). Besides experiencing higher pain, RA might interfere with other social roles, for instance house holding (Hirsh et al., 2006), leading to poorer quality of life (Olofesson et al., 2013) and experiencing higher levels of psychosocial distress (Evans et al., 2005). In this case, the research has shed light on the significant role of PPC in mediating the association between arthritis, self-efficacy pain and psychological well-being. The more people with RA can manage the impact of pain, perhaps through self-efficacy pain ability, the more psychologically well they are and PPC. Hence, future research might consider self-efficacy pain beliefs as a core concept in self-management programmes to identify those positive beliefs that can influence pain management in individuals with RA.

4.3.1.4. Physical health function

This research hypothesis was that the level of PPC on the SLQ negatively correlates with the total physical health factor scores. The physical health function included the rate of

mobility; walking bending; hand and finger function and arm function scores on the AIMS-2. The assumption was that individuals with RA commonly live with lots of stress due to the unpredictability of the condition and experiencing lots of pain. This might cause a person to lose the ability to function as normal, which might lead to depression and anxiety. However, an unexpected finding was that there was no significant relationship between PPC and physical health function. The reason for this result might be because the content of the AIMS-2 focuses largely on function and the essential tasks of everyday living, for instance writing with the hands and being able to walk around the house. Thus, one of the reasons for this finding is that this cohort was initially healthy enough to be able to handle their daily tasks. The reasons for this suggestion is that this data has been collected based on the information received from those who were unpaid volunteers, either from ARP or NRAS organisations, thus the cohort might underrepresent the population, so the existing findings might not address some aspects of the population; therefore, the findings should be considered with caution. Although it is critical to consider a representative sample, it is common and not always possible to consider the databases' combined demographic data from an entire RA population; however, this finding provides some evidence for future studies to investigate the point further. Another suggestion is that the study did not measure physical health function at the baseline because of the nature of the study with its cross-sectional design, so it can be assumed that this finding might be due to the nature of the study when measuring the physical health factors. Thus, the present findings may flag up that further researchers should investigate this by conducting prospective studies, as data about possible elements is collected in advance and then compared to see if it differs at baseline when considering the same elements, which would assist in examining the field in more depth.

4.3.2. Psychosocial factors associated with Positive Psychological Change in people with Rheumatoid Arthritis

The third aim of the thesis was to explore potential factors associated with PPC in people with RA. Of the potential psychosocial factors, psychological well-being and coping strategies, are positively associated with coexisting levels of PPC, and there is a significant negative association between social support and a sense of coherence and resilience with the PPC scores. The psychosocial factors will be discussed as follows.

4.3.2.1. Psychological well-being

Findings in the present thesis suggest that PPC has a direct significant relationship with the psychological well-being in people with RA, as measured by the Psychological Well-being Scale (PWBS, Ryff and Keyes, 1995). Moreover, psychological well-being is a predictor of PPC, while mediating for the impact of fatigue, RA duration and sense of coherence. These findings might be due to the influence of self-efficacy pain capacity in reducing the level of pain and fatigue, which might lead to enhanced psychological well-being and a level of PPC. Besides that, the present study has revealed some evidence on the impact of coping strategies and longer RA duration. People that have spent years and years living with RA might learn to cope with the condition and improve their psychological well-being and PPC.

In a later analysis, the thesis aimed to look at the difference of the study variables, psychological well-being, on the level of PPC scores based on the SLQ-38 scores. In doing so, the thesis has explored whether there is a significant difference between those whose scores are lower the SLQ-38 mean compared to those who attained the SLQ-38 mean. This shows that the psychological well-being would have had a significant impact on PPC scores upon the SLQ-38 at the SLQ-38 mean and one SD level, suggesting that those people with higher psychological well-being might experience more PPC.

Some previous studies have pointed out the influence of psychological well-being in people with RA, for instance Bartlett et al., (2003) and Coty and Wallston (2008). However, Bartlett and colleagues examined quality of life as the measure of well-being, and Coty and Wallston compared the influence of positive and negative affect as an evaluation of well-being. Nevertheless, examining quality of life and positive affect can only show the partial impact of well-being in people's life. Norton et al., (2014) measured negative and positive illness representation and stated that those with positive illness representation showed greater positive perceptions, which is in the opposite direction to distressing symptoms. On the other hand, those with negative illness representation showed high levels of pain, distress, functional disability and lower control over their RA symptoms. However, the current study has not measured illness representation, although positive perceptions of illness might have a noticeable influence over people being able to cope with the RA symptoms.

The present study's findings indicate that some people with RA demonstrate better psychological well-being while experiencing RA difficulties. Thus, in the light of the fact that a number of integrated factors, such as coping skills, reduced pain and fatigue, age, and years post RA diagnosis, might have been supported the relationship between psychological well-being and PPC, it is suggested that much more research is needed to explain how an individual with RA might experience PPC. The recommendation for further studies could include considering a longer time span for psychological well-being (PWBS, Ryff and Keyes, 1995) to expand this knowledge further. This could open new avenues by investigating various dimensions of psychological well-being in individuals with RA. For instance, future researchers might find a relationship between the PPC and the sense of autonomy in elements of PWBS in people with RA. Having a sense of autonomy in thought and action might support the idea that those individuals who can cope effectively with the difficulties of RA are more able to consider their autonomy while managing their environment to suit their personal needs. This is also another area which has not been looked at so far.

4.3.2.2. Coping strategies

It was predicted that coping strategies would positively correlate with PPC, as RA results in pain, uncertainty and possible physical disability. An additional finding presented by the thesis is the significant association between coping strategies and PPC on SLQ when employing the Coping with Rheumatoid Arthritis Questionnaire (C-RAQ; Englbrecht et al., 2012). The concept refers to the various efforts, both behavioural and psychological, that people apply to deal with the specific internal or external stress that might potentially form a danger to their well-being. Succeeding with this, people assess the stress factors that they might face and the resources that are available. A person who attained a higher score in PPC and the coping strategies used might accept the condition even though they are aggravated with the RA, and might say that some days their RA drives them mad but they have found something to get rid of that trouble. Thus, some people might find an alternative option, rather than focusing on RA pain, to handle the stressful circumstances that challenge their normal coping behaviour. Among them, one could be positive RA reappraisal, which has been linked to positive outcomes, as stated by Holtzman et al. (2004). Applying an effective coping strategy might potentially reduce the influence of mental health symptoms such as depression and anxiety. Then again, the more people utilise constrictive coping skills, the

more they might be encouraged to handle RA's instability, which might lead to enhance self-efficacy concerning RA pain and psychological well-being. There is some evidence to show that effective coping strategies are typically connected to positive thinking (i.e., Evers et al., 2001) and positive health outcomes, as cited by Sharp (2016).

The present thesis finding is congruent with the conclusion of some of the past studies (e.g. Newth and DeLongis, 2004; Holzman, et al., 2004). On evaluating the stressors and available resources, the outcomes fluctuate between persons, thus in certain circumstances, someone might experience stress whereas another person does not. As a consequence of the disabling impacts of RA, strategies which people use to cope with the illness are normally crucial. Although coping strategies are important, as supported by previous work (Engbrecht et al., 2012), this factor does not predict PPC. However, this might be because the coping strategy is not as important as other variables in the regression equation, therefore future studies are required to repeat this finding and to explore the topic in more detail.

4.3.2.2.1. What is the most common coping strategy used by RA people?

The thesis then addressed the question of what the coping strategies are in people with RA to be able to handle the impact of illness. These findings show that the most common coping strategy used by people with RA was distancing which represents efforts to avoid admitting or communicating the scope of the pain and its connected distress. The consequence of the use of distancing coping strategies appears to be more susceptible to decreases in psychological well-being which may ultimately affect in PPC. Moreover, there is some evidence that shows that a negative representation of illness is associated with stronger levels of pain and functional disability, which impacts on the level of distress experienced over a long period. Psychological distress in RA is associated with adverse clinical outcomes, patients' illness perceptions and functional disability (Norton et al., 2014). In addition, RA pain, fatigue and depressed mood are related to lower levels of self-efficacy (Barlow et al., 2002). Then again, psychological distress remained fixed above a 12 month period (Barlow et al., 2002), and two (Smedstad, Vaglum, Moum, & Kvien, 1997) and five (Uhlig et al., 2009) years respectively. Given this finding, it is grounds for concern and suggests that some people with RA may require extra support to encourage positivity. It seems that the negative perception of RA might trigger a chain of negative feelings, leading

to unfavourable coping mechanisms with RA, such as distancing, which correlates with lower psychological well-being and PPC.

The present study's findings have revealed that those RA sufferers who use more cognitive reframing coping strategies showed higher levels of PPC. However, not everybody uses cognitive reframing coping strategies, since there are some people who utilise problem solving and emotional expression. Active problem solving is linked to positive health outcomes, as cited by Sharpe, (2016), but this is not the case for this database. Finally, emotional communication is related to gain more interpersonal support in order to decrease the pain they are experiencing, which is shown in a study conducted by Affleck et al. (1999). Although coping strategies might be important in dealing with RA symptoms, the findings from the present study might be said to be limited in focus as a result of the small sample size. Even so, these findings might provide the basis for future studies to consider PPC in relation to the coping strategy domain, and developing this knowledge further by planning intervention studies focusing on enhancing coping skills, in particular cognitive reframing, in those individuals with RA who require more support to encourage positive change and psychological well-being.

Finally, the thesis has revealed the magnitude of the role that both coping and psychological well-being can play in generating PPC. Nevertheless, it is possible that coping and psychological well-being are two independent processes that are jointly influential ultimately to encourage a person with RA to reach PPC. Given this, one interpretation includes the hypothesis that psychological well-being appears to influence the burden of RA by encouraging the use of explicit coping strategies, for instance those who reported higher PPC were connected with higher use of cognitive reframing coping strategies. This provides evidence to support a model in which psychological well-being works to reduce negative perceptions of illness and to decrease distress by helping the persons to reinterpret their circumstances in more positive ways through one of the many coping strategies, such as downward social comparison, that means individuals with RA may compare themselves with others who are in a less well state and perceive their illness or disabilities as not as bad as the others. Therefore, the suggestion of downward social comparison is related to better outcomes and preserving their psychological well-being, as suggested by past researchers (e.g. Newman, 1993). It is also worth noting that some of the past studies have indicated that coping self-statements and ignoring RA symptoms are related to lessening the pain and depression experienced (Watkins et al., 1999). Similarly, Stewart & Knight, (1991) have

shown that the higher coping self-statements are inversely related to RA pain; however this thesis did not measure the influence of self-statements in RA. In short the consequence of the negative illness perception appears to be more vulnerable to decreases in the level of PPC and psychological well-being. However, further research would provide a valuable opportunity to discuss emotional issues and the coping strategies needed to reach PPC and favourable psychological well-being.

4.3.2.2.2. Cognitive reframing

Coping strategies were assessed by using the Coping with Rheumatoid Arthritis Questionnaire (C-RAQ; Englbrecht et al., 2012), which consists of 18 questions covering four domains, which are: cognitive reframing, distancing, emotional expression and active problem solving, as explained in the methodology section. The additional finding that should be highlighted is that cognitive reframing was significantly correlated with PPC. Cognitive reframing is a way of considering and experiencing the event, ideas, concepts and emotions in order to find more positive viewpoints. This refers to almost any conscious change in one's mental perspective, which can be either positive or negative change (Beck, 1997). This term includes identifying and challenging maladaptive thoughts for the good with the aim of reconsidering negative thoughts and turning them into positive thoughts (Beck, 1997). However, this can occur either voluntarily or automatically.

As stated earlier, all other relationships with PPC are not significant, but a notable exception is the positive correlation between cognitive reframing and PPC, which corresponds with the previous findings (Englbrecht et al., 2012). Taken as a whole, positive change has been linked to important cognitive performance outcomes, for example, having flexibility and improving problem solving abilities (Ashby & Isen, 1999). Additionally, it is also related to enhance immune function (Cohen, 1995 & 2015; Stone et al., 1994).

Cognitive reframing might be useful in various ways; one of them could be coping with RA in a way that individuals with RA change their outlook on their RA symptoms, finding a meaning in the condition and changing the person's perspectives in expressing the stressors that might have positive outcomes (Woolfson, 2003). Some individuals with RA might frequently evaluate their condition by comparing their physical health conditions with those who are in a worse situation and thus identifying some positive consequences as a result of their RA, which might be linked to experiencing less pain and stronger PPC. Moreover, higher use of cognitive reframing is connected with lower levels of pain (Newman, 1993).

This result provides some support for the existing evidence considering that cognition plays a role in pain management and suggest that the employing cognitive reframing is generally an adaptive way of coping with RA pain as cited by Williams, Robinson, & Geisser, (1994) and Newth and DeLongis (2004). In support of this premise, some may argue that downward social comparison and positive self-statements is one of the many forms of coping strategies that appear to be an adaptable way of coping with RA and has been tied with poorer pain experience, as reported by previous researchers (e.g. Newman, 1993 and Watkins et al., 1999).

It seems that it would be possible to manage RA pain to some extent if individuals with RA keep away from negative appraisals and/or occupy in positive appraisals. However, the moderating impact of psychological well-being on the relationship between cognitive reframing and RA pain is unclear (Newth and DeLongis, 2004). The present findings suggests that PPC is might be determined more by what people with RA bring to the illness in terms of internal resources for example, their positive illness perspective, psychological well-being and copying strategies, rather than situational factors, such as the characteristics of the illness itself and the accessibility of successful social support from close people around. However, it is important to maintain a degree of caution with regard to these findings, as a number of other unknown factors possibly play an important role in determining PPC, for example personality factors, although the thesis did not aimed to measure these. Thus, this can also be discussed in future research.

Then again, adjustment to RA, which can be considered because of the coping process, may perhaps play an important role in the intermediary for the emotional response to stress triggered by RA. Consequently, the present research findings provide some evidence for considerations that future researchers might focus on, such as increasing cognitive reframing coping strategies to improve the adjustment to RA, which may decrease the influence of pain and fatigue on peoples' psychological well-being and quality of life in general. Thus, it is clear that future research is essential to understand this association.

4.3.2.3. Self-efficacy-pain management

The term self-efficacy is used, by agreement, to refer to an individual believing (accurately or not) that they have the power to carry out a given task or activity under certain circumstances using their own skills (Bandura, 1995). The primary expectation was that the

capacity for self-efficacy would be higher in people who attained a higher score for PPC. However, the current research's results show that while there is a relationship between PPC and self-efficacy- pain, it is not at a significant level. However, in a following analysis, the thesis targeted to investigate the difference of the study variables, arthritis self-efficacy- pain, on PPC scores based on the SLQ-38. Thus, the thesis has explored whether there is a significant difference between those whose scores are lower than the SLQ-38 mean compared to those who attained the SLQ-38 mean. An interesting finding is that there was a significant difference between people over and below the SLQ-38 mean in their level of self-efficacy for pain. This shows that the arthritis self-efficacy- pain would have had a significant impact on PPC scores upon the SLQ-38 at the SLQ-38 mean level, suggesting that those people with higher arthritis self-efficacy- pain ability might experience more PPC.

This finding indicates that only people with a certain level of self- efficacy, over the mean, are able (to some extent) to control their pain. To clarify, this finding shows that people who scored higher in their level of PPC are more able to control their arthritis pain through their self-efficacy-pain capacity. Moreover, people with a lower score for PPC claimed to suffer more pain. Therefore the suggestion, based on the level of PPC in the SLQ scores, is that people display different characteristics. In fact, if it is assumed that the SLQ-38 level is above the mean (>95.00), the characteristics of someone scoring over the SLQ-38 mean looks to be: existing longer RA duration, more arthritis and self-efficacy to control their pain, a smaller degree of fatigue, and greater psychological well-being. Moreover, if it is proposed that the SLQ-38 level is greater than two standard deviations, this seems to show more arthritic pain that needs to be controlled.

On the other hand, Barlow et al., (2002) found that arthritis self-efficacy is positively associated with acceptance and positive mood. To expand, both physical and psychological health statuses correlate positively with self-efficacy for people with arthritis (Barlow et al., 2002). Besides, self-efficacy might mediate the association between physical and psychological well-being (Barlow et al., 2002). This result supports some studies which argue that cognitive-behavioural and self-management interventions are shown to be effective in enhancing self-efficacy; reducing RA barriers and increasing the possibility of recovery to some extent (i.e., Barlow et al., 2002; Riemsma et al., 2003). Even though arthritis self-efficacy-pain appears to be important in this study and is also supported by previous work, it was not at a significant level to correlate with PPC in the present study;

however, past researchers did not measure the relationship between PPC and self-efficacy-pain in the way that this research has done so. Thus, because of this research finding, it is suggested that self-efficacy-pain might facilitate coping with stress at the cognitive appraisal stage. Thus, individuals with RA with high levels of self-efficacy-pain might have an increased belief that they can perform behaviours that affect RA pain and have the skills and knowledge that are essential to achieve this and vice versa. Hence, as a general point, the discrepancies could be explained by the nature of the illness and by having various and complex mechanisms of biological links and inflammation could be one of them. Thus, future research is essential to further explore this finding and to investigate the assumption that people experiencing stronger pain might experience lower PPC.

4.3.2.3.1. Arthritis self-efficacy-other symptoms

It was primarily expected that the score of PPC on the SLQ would positively correlate with the ratings of positive impact on the Arthritis self-efficacy other symptoms scale. This was mainly because it was anticipated that people with RA would believe that they can do something to cope with their difficulties cause by RA. However, contrary to what was expected, the present study's findings do not show a significant result between PPC and the level of arthritis self-efficacy-other symptoms. This might be due to both the measurement and the nature of the condition. To clarify, the arthritis self-efficacy-other symptoms has been designed to explore how certain individuals with RA are that they can achieve a specific task. For instance, 'How certain are you that you can manage your arthritis symptoms so that you can do the things you enjoy doing?'. Thus, the respondent has to decide whether they can control their fatigue or how certain they are to be able to manage the frustration from having RA. On the other hand, previous studies stated the importance of the nature of uncertainty with RA. Uncertainty might have its root in the assumption around not being sure about RA health related outcomes, for instance, on a good day a person with RA might believe that she/he can handle the RA symptoms; however, this is not the case on a bad day, when RA pain and fatigue are severe. Moreover, a person with RA might not be sure whether the next day is going to challenge- a bad or a good day. Therefore, the condition is unpredictable and thus persons with RA who experience uncertainty at a certain level might not be able to find a relationship between the expected variables. Moreover, the present study has not measured the level of uncertainty for this dataset, thus this study's participants might be at a higher level of improbability. Yet, whatever the possible

suggestion is, this finding may lay the groundwork for examining the impact of uncertainty on people with RA. Moreover, the issue might be essential to take into account while planning intervention studies to measure the level of uncertainty and capacity at the baseline and later on. This may assist with providing a better picture of how individuals with RA deal with the psychological features- in this case uncertainty- of the condition, and also the impact of this when responding to the particular measurement, for instance the Arthritis self-efficacy other symptoms scale.

4.3.2.4. Sense of coherence and resilience

It was proposed that the PPC positively correlates with ratings of Sense of Coherence (SOC) and resilience, however, the findings indicate a negative relationship between the SOC and PPC, so that the higher level of PPC was coupled with the lowest level of SOC and resilience. The current study's results are congruent with the findings of some of the previous studies, such as Nicassio (2016), Levine, et al., (2009) and Brockhouse, Msetfi, Cohen, & Joseph, (2011). Levine et al., explored the concept of Post-traumatic Growth (PTG) in two studies in a sample of people exposed to terror and war, and Brockhouse et al., (2011) investigated vicarious exposure to trauma and growth in therapists where partakers were experienced psychotherapy professionals. These studies suggest that having a strong SOC negatively predicted growth, both generally and in relation to others. On the other hand, there are some studies which demonstrate either no relationship between SOC and growth (Linley & Joseph, 2007), or confirm a positive association between personal growth and SOC (Gillen, 2011).

There could be some potential explanations for the negative association between the two concepts, PPC and social support, in the present study. At the top, SOC is diversely defined and measured (e.g. Bonanno, 2004). For instance, SOC refers to a multi-faceted range of personal characteristics (Eriksson & Lindström, 2005), and these might have influenced the current study's results. Moreover, this study has aimed to describe the impact of PPC on the SLQ, as referred to by Sodergren (2000) and Joseph (2004), rather than SOC. On the other hand, a further explanation debated in the literature suggests that the SOC appears to measure how people deal with stressful situations and keep well (Eriksson & Lindström, 2005). Furthermore, this relationship could be explained due to more resilient people being able to cope with the impact of their illness and therefore being more capable of reducing their stress; as a result, they are less likely to struggle with the implications of an illness. Thus, resilient people may have little need or opportunity for PPC. Beyond that, it is also

possible that as PPC develops, people become more effective copers, so it is reasonable that SOC is incompatible with PPC. However, because of the complexity of the concepts, this falls ahead of the scope of the present research. A longitudinal form of research in the future would be appropriate for examining the different conceptualisations and their contributions towards PPC.

4.3.2.5. Social support

The thesis firstly anticipated that the level of PPC positively correlates with ratings of positive impact on the social support scores. Unexpectedly, an inverse association was found concerning the association between social support and PPC, so that a top level of PPC is coupled with a lower level of social support from family and friends, however, this was not based on the majority of previous findings. Surprisingly, a tiny number of studies have shown that disappointment with social support might have negative impact on the psychological state of people with RA (Holtzman et al., 2004). In a study performed by (Griffin et al., 2001) the potential destructive effects of adverse social support on physical well-being amongst people with chronic pain was explained. The study confirms that those people who cope by communicating their emotions perceived unpleasant responses from close individuals and this is also linked to poorer disease outcomes over time. Some research in this area does not support the relationship between social support availability and positivity for instance, Sodergren, (2000). In line with those studies, the findings from the present thesis showed that PPC is negatively associated with social support. However, the majority of past research that investigated social support amongst people with RA has concentrated on the advantages of social relationships, with their worsening reflected in the probability of negative effects. Considering this, a handful of earlier studies have recognised that the adverse aspects of social relationships might be as dominant as psychological well-being, if not more (Walen & Lachman, 2000). Moreover, this finding appears to be striking, as scrutiny of the literature reveals that social support has advantageous impacts on levels of pain and disability amongst people with RA (Savelkoul, et al., 2000). Thus far there are studies that have demonstrated that there is an inconsistent relationship between social support and pain in individuals with RA (e.g. Affleck et al., 1994). This interpretation may depend on how the nature of emotions is discussed and how they are communicated- the response from people around could be either positive or negative. This would justify the association of this strategy with greater ratings for mutual satisfaction and dissatisfaction with support (Holtzman et al., 2004). The thesis findings show that at times when people

with RA report being dissatisfied with the support they have received, they have a tendency to employ a higher level form of coping strategy that is associated with higher pain control: cognitive reframing as suggested by Holtzman et al., (2004). However, this result is inconsistent with research and theories signifying that adverse social interactions are connected with dysfunctional ways of coping (see Holtzman et al., 2004; Schreurs & de Ridder, 1997). Social support is well known as a buffer to mental illness and stress responses and there is some evidence suggesting that individuals with RA may experience depression and anxiety (Dures & Hewlett, 2013). Surprisingly, the current research findings verify that support alone cannot shield people from the negative effects of RA symptoms. This finding is highly interesting as people with RA normally experience an inclusive range of daily stressors such as worries about carrying out household tasks; difficulties participating in social activities, and causing a further burden to friends and family members. Undoubtedly, knowledge about the mechanism through which social support is beneficial in relation to coping, as a mediators and PPC in individuals with RA, is still incomplete.

4.3.2.5.1. Social activity

It was predicted that the level of PPC on the SLQ would positively correlate with the ratings for positive impact on the social support sub-scales of the AIMS-2. Social activity was examined using five items and the content of these items mainly focused on how often the participants go to meet friends in his /her house or invite friends to come to their house. In another example, the respondents were asked how often they spend on the telephone with close friends or family members. However, this study's findings do not show a significant relationship between PPC and social activity. This finding might be mostly due to the nature of RA. For instance, it might be difficult for those with RA to manage a day with no pain or less pain, so this finding might be evidence that RA people are more socially lonely as a result of their condition. Thus, planning an intervention study to avoid social isolation and enhance social relationships might be beneficial. This is essential since the more people become physically dysfunctional, the more they need emotional support to be able to cope with the difficulties of RA. The other suggestion concerning this finding might be that it is simply as a result of the nature of this study. This is because it is a cross-sectional study and so this finding only shows that there is no significant relationship between these two variables for this dataset, but this result does not reveal why and how this might occur;

therefore future study would be useful to bring to light the multifaceted mechanisms underlying this relationship.

4.3.2.6. Quality of life

Some of the previous research has cited that RA has a negative influence on people's Quality of Life (QoL, Borman, et al., 2007). Past researchers have assumed that individuals with RA are forced to face up to the condition, which involves an unpredictable and painful future. Consequently, considering its serious consequences, the related effects of RA on QoL are important topics for research (Sivas, et al., 2004). On the other hand, the present research proposed that psychological factors might be essential in sustaining psychological well-being. Furthermore, positive illness perception might be linked to the coping strategies used by RA people in order to be able to re-evaluate the impact of their condition and find a positive change in RA. Therefore, those who present a positive impact from RA may be psychologically well-adapted to the condition and presume positive outcomes on their life as a result of RA. Thus, it is assumed that the level of PPC positively correlates with ratings of its impact on the QoL. The expectation was that RA might have a positive impact on the perception of people in their appraisal of life; hence the more people experience PPC, the more they evaluate their life as having positive change. By this means, the research has used a well-known measurement (Danao et al., 2001, QoLRA Scale) to examine this topic. Unexpectedly, the present study findings demonstrate that there was no relationship between the target variables. It is recognised that a possible reason for this finding might be the nature of the concept, as QoL is an indefinable, multidimensional factor that has produced a large amount of research, yet it has been operationally defined in a variety of ways by previous investigators (Coons, Rao, Keininger, & Hays, 2000).

Furthermore, past research showed that people with RA had poorer scores on functional disability, depression and pain (Baykara, et al., 2013). Thus the association of RA with QoL might lead to a significant decrease in functional capacity and QoL, as well as an increase in pain and depression. Therefore, further research looking into the sensitivity of QoL in considering both positive and negative change in people with RA is recommended to avoid further worsening of the psychological impact of RA.

4.3.2.7. Depression

It was predicted that the PPC score on the SLQ negatively correlates with the level of mood, presenting the depression, on the AIMS-2 scores. Contradictory to what was expected no

association has been found between the level of PPC and depression. Some of the past research indicates that psychological distress is connected to both functional disability and disease activity, as such those with RA experience more activity losses which might lead to depression and anxiety (e.g. Affleck et al., 1999 ; Treharne et al., 2005). In turn, mental or emotional impairment also might lead to an impact on functional limitation, which eventually could increase the overall impact of the illness and potentially might result in disability.

The present thesis, at the start, predicted that the more an individual with RA experiences PPC, the greater the adverse impact on experiencing mental health symptoms such as low mood and depression. Interestingly, no associations have been found between the level of PPC and depression as measured by the AIMS-2. The main focus here is on the possibilities of PPC as a consequence of RA, which typically might prompt disagreeable psychological reactions such as depression and anxiety. Thus, it seems appropriate to consider that individuals with RA face psychological distress, in particular for sets of circumstances that threaten the person's independency, which in turn might impact negatively on psychological well-being. Reaction to the diagnosis of RA and further living with the condition for a long period typically includes a general desire for things to be different. Thus, it was predicted that general feelings of negative emotions, such as depression, might frequently be observed in people dealing with RA; however, no association has been found based on the present study's data. Considering the current findings it can be argued that the extent of PPC is less likely to vary as a consequence of people's experiences.

In addition, this might be because of the nature of the condition in which the range of PPC and psychological distress often exist concurrently. Thus, the more someone experiences positive change, the more they are able to control the adverse impact of depression and anxiety. It is also worth considering that this study is the first to identify PPC in persons with RA, therefore the findings from this study highlight the central role of PPC and suggest that PPC is best understood in terms of the repetition of these findings. Accordingly, future studies are essential to understand the nature of this association and to evaluate how PPC alters over time and interacts with depression.

4.3.2.8. Level of tension

It was expected that the PPC score on the SLQ would negatively correlate with the level of tension rating score on the AIMS-2. Unexpectedly, this finding was inconsistent with those

reported by some of the past studies, for example Ho et al., (2011) and Matcham et al., (2013).

Given that the earlier literature revealed the relationship between mental health factors and RA, it is likely that other factors not mentioned here are compatible with this finding or could influence the consequences of the survey study. This finding suggests that, together, both positive and negative changes might be critical in totally understanding individual differences in adjusting to RA. However, the role of possible constructive thinking to adapt to RA has received far less attention, and there is a general lack of supporting its beneficial and health promoting effects. With this in mind, the replication of this finding is recommended.

4.4. Aim four: Predictors of Positive Psychological Change in people with Rheumatoid Arthritis

The fourth aim of the current thesis was to examine which associated factors are predictive of the PPC. The present study has found significant cross-sectional associations between RA longer duration, psychological well-being, coping strategies, social support, sense of coherence and resilience, fatigue, and PPC. After controlling for the inconsistent pattern of the disease and the relevant variables, the associated variables were entered into the regression model, in which psychological well-being, Sense of Coherence (SOC) and resilience, RA duration and fatigue were significant and explained 14.3% of the variance in PPC. Therefore, PPC could be predicted from psychological well-being; the lower the SOC, the longer the RA duration and the lower the level of fatigue. The only study in this area is Sodergren (2000), who performed a multiple linear regression analysis with an extraversion sub-scale of the five big personality questionnaires with the religion/spirituality variable entered as potential predictors of positivity. Sodergren reported that 8.5% of the variance was explained by equal variables that were significantly independent predictors of the SLQ-38. These results reflect our shortage of understanding of the positive change in people with a chronic health condition, in particular those with RA, which might be reflected in how people take action, understand, or cope with their illnesses. However, noticeably, future studies are required to fill in the gap in the current knowledge on positive psychology and the rheumatology literature. The predictive variables explained in order as below.

4.4.1. RA duration

The present study's findings reveal that RA duration positively predicted PPC, signifying that the longer the RA duration, the more learning opportunities there are to cope with the condition, which indicates the possibility of psychological adjustment to reach PPC.

4.4.2. Fatigue

This study's findings suggest that lower fatigue predicts PPC, revealing the importance of RA's clinical manifestations in providing supporting evidence that some of the RA clinical factors are linked to future positive psychological outcomes, for instance PPC.

4.4.3. Psychological well-being

The current study's findings suggest that psychological well-being positively contributes to PPC, meaning that psychological factors have supplied reasonably convincing evidence that can affect the course of the condition in people with RA.

4.4.4. Sense of Coherence and Resilience

This study has revealed that experiencing a strong SOC negatively predicts PPC, suggesting that those RA people who showed PPC over more than one SD are perhaps more able to decrease their stress, thus they might be less likely to suffer from the burden of RA. Thus, in light of the fact that a number of hypotheses could have emerged concerning the relationship between PPC and the health outcomes measured in this study, it is concluded that much more research is required to understand the mechanisms that lead an individual with RA to experience PPC, and why this is more likely in one person and less likely in others.

Collectively, these findings suggest that the longer the duration of RA; the less fatigue occurs; the higher psychological well-being and the less sense of coherence and resilience can predict PPC in people with RA. This result supports the view that psychological adjustment might be one of the factors that leads to RA symptom reduction (Fava & Ruini, 2003). This thesis suggests that further interventions focusing on psychological well-being for people with RA who are at risk of distress syndrome, may positively influence long-term outcomes in RA. Jointly considering the findings from Sodergren (2000) and the current study supports the favourable effects from positive psychological factors in chronic health conditions and additional work in relation to understanding the mechanisms underlying these associations is recommended.

4.5. Proposed Bio-psycho-social model

As a consequence of experiencing RA, people may face new situations that challenge their previous coping strategies. Accordingly, they need to find new ways of adjusting to the changed circumstances. The findings from the present study show that PPC can occur in response to the burden of RA. Thus, some people can psychologically recover from the adverse impact of their RA, and in notable exceptions the pressure from the stressor, handling their RA and living on for many years.

While the thesis has considered the equally positive and negative impact of the RA correspondingly in both research and practice, as recommended by Wood & Tarrrier, (2010), a bio-psycho- social model of PPC in people with RA is considered a positive aspect of the illness. Indeed, the model is based on stress and a coping exemplar, as suggested by Folkman et al., (1986). The aim of including this was to explain various, apparently puzzling, phenomena and provide a preliminary framework for future studies by identifying some key points for positive change in the target sample. In fact, the findings of the current study provide initial support for some aspects of the model (See PPC bio-psycho-social model, Graph 4.1.).

Graph 4.1. Positive Psychological Change in Rheumatoid Arthritis: Biopsychosocial model



The proposed model suggests that a diagnosis of RA, or the daily hassle of living with RA, provokes a stressful response to possible hallmarks of the illness, such as pain and disability. Thus, reaction to RA for some people might signify exposure to psychological stress. Stress occurs due to the unsuccessful link between one's appropriate coping strategy and the environment, which might be viewed as challenging or beyond someone's resources and put their psychological well-being at risk. It might involve feeling a spectrum of emotions such as denial, confusion, fear, avoidance, anger and worry about handling the reaction of others. Even when symptoms have been presented for some time, living with the condition might be upsetting as it is a stressful experience for most people. The literature surrounding the field cites that RA patients are at risk of psychological disorders (Dures & Hewlett, 2013); they might experience depressive symptoms, which are related to increased pain and reduced work-status (Hewlett, et al., 2011). Besides, pain and depression are essential predictors of fatigue (Munsterman et al., 2013). Therefore, the thesis suggests that individuals with RA can come up with several scenarios to adapt to the psychological changes and regain equilibrium or reach PPC. Firstly, they could use effective coping mechanisms to be able to continuously change cognitive and behavioural efforts to deal with stress. For example, according to the findings that have emerged from the current study, it is seems that the most beneficial coping strategy is to employ cognitive reframing which is characterised by attempts to perceive one's existing circumstances positively through positive reappraisal and downward social comparison, as suggested by Newth and DeLongis (2004).

Psychological well-being is a comprehensive concept that includes subjective, social, psychological components, and health related dimensions (Ryff and Keyes, 1995). In total, it seems that a higher score reflects being more comfortable with the areas of psychological well-being, such as personal growth and autonomy. The following describe the example statements, indicating agreement with the hypothesis that predicted that the level of PPC positively correlates with ratings of positive impact on the psychological well-being scale. A person who possesses a high score for PPC seems to display a positive approach toward the self, and recognises and accepts manifold aspects of the RA, including the good and the bad side of the illness; overall, feeling positive about his/ herself, the illness and life. Considering the viewpoint that a person is able to refuse to go along with the pain of RA may pressure them to think and react in certain ways, for example to regulate behaviours internally and evaluate the actions according to personal standards. Someone with a strong

level of psychological well-being might have a strong sense of power to control the pain and manage the environment by considering flexibility and at the same time the controllability of external activities. People with RA are able to create suitable contexts to adapt to their personal needs and to be able to make effective use of environmental opportunities. It is possible to create goals and give meaning to life when living with RA, for example a spiritual gain might give the person an aim and purpose for living. Even though RA pain might be durable and also incredibly intensive, someone might see themselves growing, expanding and improving over time. Changing to open up to new experiences and reflecting more is effective in continued development. The person may be capable of forming satisfying and trusting relationships with family and friends while understanding the nature of balancing positive and friendly relationships. However, it is important to highlight that constructive relationships have to be informative, compassionate and encourage independency to maintain the affiliation.

Self-efficacy-pain involves people's perceived confidence in their capability to perform behaviours that can potentially control their pain and decrease the extent of their disability (Bandura, 1997). Considering this, a person can estimate that a particular task will lead to certain outcomes such as a decrease in pain for example, "*If I want to reduce my pain, I know I can do it*" (Personal communication, 14.3.2016). The thesis has shown that enhancement of self-efficacy-pain might be at least one of the mechanisms through which a person with RA can change their symptoms and improve their health status. Moreover, intervention studies designed to enhance perceived self-management have been shown to do so. In addition, increases in self-efficacy-pain for arthritis have been revealed to be associated with improvements in anxiety and fatigue (i.e., Somers, Kelleher, Shelby, & Fisher, 2016; Somers, Wren, & Shelby, 2012). Thus, self-efficacy-pain management provides important considerations for mental health providers and rheumatology practice that can help people to manage symptoms and lead to further active participation in order to promote psychological well-being, while at the same time leading to PPC.

Considering this, some demographic characteristics (e.g. age) and illness characteristics including RA clinical factors (i.e., fatigue) might contribute towards more PPC. However, this is not an exclusive outcome, as someone might have other capacities to add to these qualities, for example accommodating higher levels of psychological well-being, utilising sufficient coping mechanisms, and employing a stronger self-efficacy-pain capacity. Thus,

under more positive circumstances, a fortunate person with RA might have all these and subsequently it is more possible for someone to experience higher levels of PPC. On the other hand, it is also possible that some person will react to the burden of RA by developing distress syndrome, reaching breaking point or even giving up. It is also suggested that whatever the outcome of living with RA is (an adaptive coping strategy used or developing distress syndrome), it has to be taken into account that there are a variety of reactions to RA in the means of a continuum level. A person might at the same time experience some extent of positive feeling that might lead toward PPC, or negative feelings which in turn might direct them towards distress syndrome.

Then again, it is also beneficial to employ coping strategies such as constructive thinking to deal with stress effectively. This could be through reflecting on personal resources in a more favourable way for example "*I have a great family to support me, or I know what I need to do*" (Personal communication, 14.3.2016), which in turn can strengthen cooperation and positive feelings and beliefs (i.e., acceptance of the illness and the probability of impaired function). PPC mediated by psychological well-being and the utilisation of effective coping strategies also incorporates some key elements, such as demographic characteristics (e.g. the more age the more PPC); longer RA duration (e.g. the more years living with RA, the more PPC), and also self-efficacy pain beliefs. PPC may occur while individuals with RA process the stressful consequences of dealing with RA and develop their overall well-being. Hence, positive perceptions of illness could effectively be incorporated to strengthen the link between stress related factors such as constructive thinking and positive feelings. Largely, a positive perception of illness could perhaps provide various alternatives to handle the challenges brought about by the stressor- RA. Firstly, it could reduce the level of stress related factors, for example pain and possible disability function; secondly it could have an influence on adopting positive thinking by searching for more positive reappraisals to manage the impact of the stress; thirdly, it could have a positive impact on a person's behaviour such as a more healthy lifestyle. Finally, this entire evidence works as a system to describe the human ability to deal with distress, pain and fatigue in people with RA; however, this explains only a small aspect of psychological well-being.

Finally, there is accumulating evidence that convincingly argues that psycho-social factors may indeed have an influence on disease activity and connected physical functioning through physical, biological and neuro-endocrine pathways. For instance, under chronic stress, levels

of inflammation increase (Cohen et al., 2012); also cortisol is released in response to stressful conditions (Cohen et al., 2012) and cortisol has an effect on the immune system preventing the inflammation (Hassett and Clauw, 2010). Thus, it appears that living under stressful conditions, such as with RA, might release more cortisol, which in turn could adversely influence and increase inflammation. On the other hand, less stress will be more effective in not only controlling the level of inflammation through decreasing cortisol levels, but also in developing psychological well-being. The present thesis did not aim to measure stress related factors in relation to PPC, therefore this is not included in the current proposed model, however, it would be useful to consider this for further research. Moreover, there is some evidence on how positive repetitive thoughts might contribute towards health promoting behaviour such as coping with RA pain (i.e., Watkins., 2008; Dijkstra & Brosschot, 2003). Therefore, the suggestion is that a PPC model in the context of RA will not be complete unless careful attention is paid to the influence of bio-psycho-social factors. Besides, a future comprehensive model could integrate negative as well as positive aspects of RA collectively, and may provide a useful framework for describing the influence of psychosocial variables on physical function as well as the other way round.

4.6. The thesis contributions: The thesis suggested conceptual and methodological direction for future studies.

4.6.1. Theoretical implications

The main contribution of the current thesis is that personal growth can occur in people with RA without referring to the trauma, and can also lead to a level of recovery beyond what is expected, as suggested by Tedeschi & Calhoun, (1996). The survey study conducted and the characteristics of people with RA show PPC can occur. This appears to be the first study that has explored the conceptual understanding of PPC in people with RA, and the thesis has demonstrated the probabilities of some potential factors associated with PPC. Furthermore, the possible predictors have been explored and explanations of the relationship between the various aspects of the model, based on psycho-social factors, have been presented.

The indications for this findings is that not everybody attains PPC, in some way, as a consequence of their illness and therefore those who do not hold to PPC may not be able to cope with the condition. Consequently, they may not be able to enhance their psychological well-being over time. Logically, they might be in danger of distress symptoms such as

depression and anxiety. Therefore, the health policy providers might need to reconsider that people with RA might be at risk for further mental health problem because of not being able to cope with the RA properly. As a result, they might need help from mental health professionals, such as mental health teams, psychologists and psychiatrists, as soon as they got the RA diagnosis. The mental health team could potentially support those who need to learn the best ways to cope with the condition soon after the diagnosis, such as adherence to take the medications; adaptation with their condition and to help them to prevent mental health problems and to move forward.

4.6.1.1. Conceptualisation of Positive Psychological Change in the context of Rheumatoid Arthritis

By and large, the thesis suggests that PPC might be conceptualised as a consequence of experiencing RA and a number of factors such as demographics (e.g. age); RA clinical factors (e.g. pain and fatigue), and also psychological elements (e.g. psychological well-being) and personal resources (e.g. coping strategies). These shape the relationship with the illness, in turn affecting the outcome of struggling with RA, such as controlling and reducing the level of burden of RA that potentially might lead towards a positive change and possibly experiencing more PPC. Considering this approach, the more identifying RA using positive reappraisal and operating effective coping strategies (e.g. cognitive reframing), the more personal growth is suggested; however, choosing a distance coping strategy will not help. Perceiving PPC requires the incorporation of a positive appraisal of illness and employing adaptive learning processes to accommodate the occurrence of PPC, which might in turn assist in reducing the level of pain, fatigue and distressing symptoms accordingly.

Some previous research has cited that the level of self-efficacy, mood, psychological well-being, independency and capacity to work are usually affected as RA develops (i.e., Hewlett, et al., 2011; 2012). Correspondingly, the present thesis suggests that living with RA does not only mean weakening in strength for physical tasks, but also worsening psychological and social actions. To expand, this part provides a conceptual framework to describe what a person with a high score (one SD over the SLQ mean) would be like. The main message is that there might be a rich grounds concerning the range of responses to living with RA, ending with the positive viewpoint of seeing the bright side of the illness and creating PPC. PPC might occur in people who emphasise incorporating negative experiences with positive ones, since personal growth can generate because of such encounters with pain and fatigue.

PPC demonstrates that people with RA might report a life with less pain, which highlights how an individual can grow psychologically to live with a long-term health condition such as RA.

4.6.1.2. Perceived reasons for possible Positive Psychological Change in people with Rheumatoid Arthritis

In the following part of the thesis, a brief description will be provided of some perceived reasons for the psychological growth that might occur as a consequence of RA. From this perspective, PPC is in relation to the correlation between a person's positive reappraisal of the illness and the coping with life as a consequence of RA. This agreement can be achieved not just by altering one's perspective, but also by learning, coping and adapting to the RA. The dynamic interaction between PPC and stressful life circumstances, in this case RA, arises from considering negatives aspects of the illness such as pain and depression. Nevertheless, some people are hopeful of positive change but fail to avoid both negative thinking and feelings, which may actually prevent them from personal growth and could make them susceptible to depression and anxiety, and that in turn might direct them to experience more pain and fatigue. With this in mind, the thesis describes some sets of examples that represent the crucial challenges faced by a person who may experience the aftermath of life with RA.

Positive, understanding and trusting relationships with people around could help an individual with RA to avoid being isolated, which could potentially lead to depression and anxiety. The present research's findings show that 56% of those who gained SLQ scores over one SD in this study cited that their RA has enhanced their interpersonal relationships when considering positive themes, as shown in Table 3.7.

It is worth noting that some of the RA people need to ask for help sometimes, even for tiny personal things such as taking a shower and organising kitchen stuff. Thus, the possession of quality relationships with others could potentially help to deal with RA efficiently. Thus, one might give a positive meaning to the RA by perceiving the potential positive influence of others and dealing with RA in everyday life, including beliefs about the meaning of human existence or almost any other facet of existence.

Positive beliefs are associated with several favourable outcomes, such as improved physical and psychological functioning, less anxiety, lower depression, self-actualisation, positive

relationships with others, and stronger rates of self-acceptance (Conversano et al., 2010). For example, some might feel that: *“sometimes I feel really down because I cannot physically do the demanding tasks and this makes me feel annoyed and worried. But I want to be an independent person, which I feel it is restricted because of my RA”* (Personal communication, 17.3.2016). Other than that, *“I have found a solution to help me to break the worrying habit and achieve a relaxed life and also reduce anxiety and problems with depression”* (Personal communication, 14.3.2016). Hence, one might say that, *“for many things, I have to ask my husband or even my kids to help me. I can discuss so many things about my RA even when I have a bad flare up and my husband does understand and I know he can see the pain and what I am going through. He is always there to offer help, and at the end of the day I think my family have learned to be compassionate due to my RA”*, (Personal communication, 14.3.2016) although the situation may not be the same for those RA people who live on their own.

In addition, some individuals with RA may rethink fundamental questions in relation to the ones used in the process of investigating and searching for some meaning. For example, what defines me when the illness affects me? What is life like after experiencing RA? Is RA all I can get from my life? What should I do with my life? How can I develop a deep and meaningful life as a result of my RA?. All these kinds of tough questions are related to the inner self, and the answers could open up the vision and the facts about life regardless of the ultimate knowledge gained. In addition, this process of thought could provide a richer understanding of life and the interpretation of both positive and negative aspects of the illness in order to describe the human talents for positive change and growth. For instance, nearly half of those who scored over one SD on the SLQ are convinced that in those difficult times of living with RA, their beliefs have been aided to identify the purposeful and meaningful aspects of life (Table 3.7.). The suggestion is that having goals and a sense of direction in life could lead to coping more effectively with RA pain and fatigue, and developing PPC further. A purposeful life reveals a sole psychological dimension around which RA persons might organise their lives, goals, values and intentions, which leads their behaviour to be guided by this philosophy (Bartlett, et al., 2003).

There are also some people who might feel frustrated by the everyday problems of RA. They might go on struggling, perhaps even feeling aggrieved during their bad days with a sense of annoyance at what they consider to be the misfortunate life has meted out to them. For

instance, one might find life even more difficult if doing things as a mother with small kids and having a part time job while suffering horrendous pain and fatigue. But they possibly could think: *“I tried my best to stay positive and to be more active to help myself, my family and to keep going with my job”* (Personal communication, 14.3.2016). In saying this, the present thesis does not ignore or minimise the problems of living with RA, but neither allows them to dominate. The findings of this research reveal that some people with RA, who scored over one SD on SLQ, have noted some positive changes in their self because of living with the RA, such as considering themselves to be a more determined person. There could be a number of reasons for this, for example it might be as a consequence of learning how to cope with the difficulties of RA and also accepting life with the condition.

Besides, while for some, RA symptoms might be debilitating due to struggling with their pain, they may also struggle to understand the purpose of life, which might lead to being more aware of their strengths and thus leading to an improved sense of control, self-improvement and finding meaning in illness. This could be seen as gaining some relief from pain and fatigue to some extent and making changes through the restructuring of life. Beliefs about their strong abilities may provide the grounding and the peace of mind to cope with RA pain and to improve health perceptions, which may perhaps offer a framework for interpreting positive meanings and purposes behind having a condition such as RA. Consequently, this might facilitate acceptance and enhance self-awareness, resulting in better adaptation to living with RA, and it could be associated with PPC as well as psychological well-being. Therefore, investigating personal strengths might have a potential protective role regarding health, through accumulative positive mood states, which might have led to positive health perceptions in this target sample.

Identifying some positive change as a consequence of living with RA may allow someone to experience positive emotional relief and lead to generating a positive life appraisal, which could alter their basic expectations of life and the meaning their RA may have. For example, some people with a higher score of over one SD on SLQ, confirmed that because of their RA they have more opportunities to meet new people as well as being less judgmental of others. Some people acknowledge a greater impact from their RA in prompting changes in the way they lead their life. Some people perceive their RA as an opportunity to reflect on how they feel about themselves, and that might be one of the reasons why a recurrent message has been conveyed by some of this study’s participants who confirmed that their RA has made them live life to its fullest.

Findings in the present thesis suggest that PPC has a direct significant relationship with the notion of psychological well-being in people with RA, as measured by the Psychological Well-being Scale (PWBS, Ryff and Keyes, 1995). The present thesis' findings indicate that people of higher age and also greater number of years post diagnosis have confidence in their ability to manage their RA and demonstrate better psychological well-being. These dimensions comprise a range of well-being that incorporates positive valuation of oneself and one's past life. Also, self-acceptance, in which a person might possess a positive perception of illness and RA and accept manifold aspects of self, for example by saying that "*I have accepted the condition but am also frustrated by it, as some days it drives me mad, yet I have accepted it as it is my life and I just got used to it*" (Personal communication, 17.3.2016). One might experience a sense of constant personal growth through being active and attending courses to be able to make positive changes in ways that reflect more self-awareness and effectiveness.

Not everybody, but some of the current study's participants, mentioned that their RA has taught them to stand up for themselves. This might be because of thinking that "*I had RA for a long time and it does not matter since I just got used to it, so I know what to do with my RA and I feel all is fine now*" (Personal communication, 25.3.2016). As an another option, someone might say that "*I had to rethink everything and I found the right solution to my problems so I learned that if I count on myself, I can get positive results, so I know I can lean on my past experiences as I can see myself as a powerful person that can make a difference*" (Personal communication, 25.3.2016). A person with high levels of PPC might have a greater sense of controlling RA pain and the complexity of the disease by experiencing a higher level of self-efficacy- pain ability. For example, their RA gave them permission to do things for themselves. This also supports making the environment accommodating and making effective use of opportunities for change, such as adapting the kitchen and adjusting the car to be able to assist mobility. This helps an individual with RA to be able to create an environment that is suited to her/his personal needs and values to decrease the limitations forced on them by RA.

There might be an emotional element to the RA difficulties so that someone might possibly be capable of thinking the issue through using appropriate justification. For one reason or another, it might not easy for a person with RA to accommodate the negative mood, but there might be some further personal resources such as discovering a new skill or hobby to

challenge the RA symptoms. Besides, someone might recognise a talent in being able to face up to his or her fears, in particular the fear of becoming disabled. Through the RA process, someone might learn what you can do, which is all about damage limitation, and someone can learn to protect themselves. For instance, the person might go for a little walk today, but turn around and go back because they know if they go too far they will suffer the day after. People with RA who show PPC might have learned to balance their day, just reminding themselves they can work on their RA.

It is also possible to take control over uncertain circumstances, as one might say that, "*I just sometimes talk to myself positively and reassure myself that I just have to make the best of what I have, so whatever happens I do my best and I never can go over on my best*" (Personal communication, 25.3.2016). Naturally, one might be pleased by any little positive words for example, "*I have said to myself bringing about such an impressive encouraging result*" (Personal communication, 25.3.2016). This can help someone to recognise you need to keep going since this is your life. In this case, the power of positive words may channel a personal power through one's thoughts and feelings. This might help in overcoming the RA obstacles that typically might beat a person living with the condition. However, the direction of this relationship is unclear since the present thesis does not know whether dealing with RA is behind these changes. This is because of the correlational nature of the current survey study; therefore further longitudinal experimental studies are crucial to examining this further.

Moreover, it is worth considering that Ryff and Keyes (1995) have confirmed that the multiple indicators of depression show a consistently negative associations with all dimensions of well-being, with the strongest patterns evident for self-acceptance and environmental mastery. This finding is important, as the prevalence of depression estimates in people with RA are considerably higher than the general population (14.8%- 38.8%), depending on the way it is measured, and it is associated with poorer RA outcomes (Waraich, Goldner, Somers, & Hsu, 2004). On the other hand, across the literature there is accumulating evidence that suggests that a lack of psychological well-being might be a substantial warning of depression, independent of the continuation of unconstructive functioning and weakened physical health (e.g. Wood & Joseph, 2010). In addition, people with a low level of positive well-being are 7.16 times more likely to be depressed during the next ten years (e.g. Wood & Joseph, 2010). However, identifying depression in the context of RA is challenging and unclear. Furthermore, although, maintaining good psychological well-

being can be an important protective factor when it comes to experiencing several physical or psychological problems in people living with RA, the current research findings might be because the majority of the study participants are older sufferers, as they had their arthritis for a long time compared to those people just starting to put up with it for the last four to five years; therefore the findings might be as a consequence of the demographic characteristics of the study participants. The further suggestion is that people with high levels of PPC might have other qualities, such as strong coping abilities to adapt to the RA symptoms; however, the hope is that the current findings will open new windows for further research to discover more about this field.

In short, the suggestion is that over time someone with RA might learn to take better care of themselves, and learn more about the illness so they can utilise that learning and change their lifestyle, rather than settling down for a life of endless pain and fatigue. However, further research is needed to duplicate these possibilities, as there might be some other unknown factors that the research has not considered. For instance, maybe these people were strong and learned according to their background and struggling with lots of challenges in their life to be a strong person and to cope with the RA. On the other hand, there is no evidence that RA made them strong enough to be able to cope effectively with the burden of RA itself, so it will be useful to discuss this in future studies. Thus, the question might be: are these qualities part of the resilience? Alternatively, it might cause the resilience.

The literature surrounding PPC in the context of RA is limited so far, therefore the interaction that occurs between PPC and health variables is unclear. The present study aimed to examine the relationship between PPC and some factors that previous research has cited that might be connected to PPC; however, these factors are not comprehensive since there might be some factors that the study has not measured, for example personality factors, such as optimism. Moreover, correlation analysis does not imply that one factor causes the other. Yet someone might come up with two possible scenarios that have emerged from the general literature review that perhaps people with higher levels of PPC are stronger people and have learned from their background and experiences to struggle with lots of challenges in their life, so the resources are already available; hence, they can cope effectively with the RA. The second scenario is that it might be because they have other qualities, such as positive psychological well-being and the cognitive reframing abilities to adapt successfully to RA symptoms. In light of the fact that a number of hypotheses could have emerged concerning the

relationship between PPC and the health outcomes measured in this study, it is concluded that much more research is required to understand the mechanisms that lead an individual with RA to experience PPC, and why this is more likely in one person and less likely in others.

4.6.2. Practical implications

Some of the past research suggests the possibility of improving physical health through coping effectively with stressors (Antoni et al., 2001). In fact, psycho-neuroendocrine research draws attention to the way that in response to stressors, cognitive appraisal and feelings of controlling the impact of stress can convert the impact of damaging stressors to improve health outcomes (Cohen et al., 2012). Apparently, the move from the perception of a disease as a stressful condition (negative illness perception) to identifying recovery from physical illnesses (positive illness perception) can be a unique pathway, mediated by physiological responses to the disease. The findings from clinical research into Cognitive Behaviour Stress Management (CBSM) intervention studies highlight a dynamic equilibrium that exists between psychosocial stressors and physiological elements in various long-term conditions, in particular cancer, which could be mediated by neuroendocrine and immune factors, as addressed in the introductory chapter.

Considering positive aspects of the illness potentially means there could be a number of implications for counsellors and psychotherapists when focusing on psychological distress. The suggestion is that if an individual starts to concentrate on negative aspects of a stressful condition, this might lead to psychological distress, which could adversely impact on the recovery process. Alternatively, thinking with constructive consequences can facilitate reducing the impact of negative thought, which in turn would increase the contribution of constrictive thought. This evidence is reliable with a number of psychological therapies (e.g. CBT) in which the patients are reassured to reduce psychological distress to build up success, mastery and pleasurable activities, thereby improving self-esteem and consolidating a more accessible positive cognition (for further review see Watkins, 2008). In addition, in Well-Being Therapy (Fava & Ruini, 2003), the main aim is to encourage psychological well-being according to Ryff's multidimensional model that consists of six scopes: self-acceptance, autonomy, purpose in life, positive relationships with others, environmental mastery, and personal growth (Fava & Ruini, 2003). Besides, CBT and WBT techniques could be used to develop an intervention programme applicable to people with RA.

4.7. Limitations

The study has a couple of key methodological limitations that must be considered. Foremost, in accordance with the limited time allocated for this PhD, the survey study conducted has used the cross sectional method. However, in the future, a longitudinal study will be required to further evaluate and demonstrate this concept in individuals with RA regarding causality, as this cannot be concluded from a cross-sectional study design.

The next potential limitation includes the way that the data was collected from people with established RA (>2years) and has adopted a methodology which enables the whole range of possible affects; however, for persons with recent onset of the disease, it is possible that different patterns of outcome may exist. The research screened people who had received treatment or had symptoms onset of less than two years, although there is significant evidence reflecting a stronger awareness of a reduction in diagnostic delay (i.e., Sørensen & Hetland, 2015). Undoubtedly, more research is needed to show whether these findings can be generalised to other RA populations, as the findings based on this highly selected sample are questionable. In addition, the small sample size could be seen as a limitation. To gain definite proof of the study hypotheses, further research with a bigger sample size is required.

The information in this study is based on self-report measures, rather than peer-reporting or consulting ratings on the level of RA. However, a consultant rheumatologist has previously diagnosed the participants. Finally, the main measurement of PPC used in the current study is new and more information is needed regarding its psychometric properties. Although, the scales have been shown previously to have adequate reliability and have been recommended by past researchers (Joseph and Linley, 2012), who recommend the use of a newly developed tool, the SLQ-38, to examine the positive aspects following illness. However, the psychometric properties of this scale, to date, have yet to be examined. Thus, future studies might consider this to improve the psychometric properties of the SLQ-38 for chronic illness conditions, in particular RA.

This thesis is not meant to be, and undoubtedly could not be, extensive. Given the comprehensiveness of the literature relevant to psychological factors and RA, it is likely that there are some additional factors, for example personality traits (i.e., optimism and extroversion), which have not been included in the survey study. The main reason was the

length of the questionnaires, as this was influenced by the study participants' likely ability to fill in the booklet.

Despite these methodological shortcomings, this thesis has yielded a number of interesting findings. The limitations of this study could be addressed just by providing the opportunity to create the way forward for future research.

4.8. Future research and applications

4.8.1. Can Positive Psychological Change be enhanced?

There is the probability that PPC can be enhanced, but its role in RA is multi-faceted; among them is the suggestion that PPC could be improved by the following:

- Considering the physiological and biological pathways of RA to reduce the level of stress and considering the vital role of stress hormones (i.e., cortisol) in reducing the impact of psychological distress (i.e., depression and level of tension).
- Focusing on learning to reduce the impact of stress on everyday life, as stressful circumstances can trigger the release of stress hormones. Experiencing long term stress can have unfavourable effects on individuals diagnosed with RA, and although it may not be possible to control the stressors in the life, it is believed that people can learn to change their reaction to stressors. In order to recover, it is vital for people with RA to gain control over the stressors to be able to have a sense that they are able to reduce the impact of the stress on their RA.
- Improving lifestyle to be more active, for instance increasing the level of physical activity could have a wide variety of positive impacts on physical and mental health.
- Improving the psychological well-being of people with RA can be enhanced by choosing a new goal in life, exposing themselves to new educational experience and learning novel skills to enhance a sense of self-efficacy and feeling of engaging more in their lives. Topics that could have a positive impact are stress management skills and problem solving.

- Focusing on increasing personal resources in people with RA, for instance through developing cognitive coping skills and positive self-talking. The suggestion is that people can purposely take into account what they are feeling and thinking. The more they can control their negative feelings about their RA, the better they can feel about themselves to gain a heightened sense of control over their feelings and their experiences of RA, which in turn can have an impact on their behaviour. Even though sometimes it may not be possible to completely control the forces of the impact of RA on their lives, thinking about positive reactions and accepting the condition can lead to greater self-understanding, which can help equalise their RA's negative impact.
- Connecting through positive social relationships with others, in which other people are found to be supportive and encouraging to increase a personal feeling of being important and find a sense of meaning in life.
- Conducting intervention programmes to develop and enhance positive illness perceptions through reducing the potential impact of the disease and disabilities. People with RA need to learn to cope with distressing circumstances and being uncertain about their illness, so they need to feel they can control the negative impact of RA when control is not fully possible.
- Taking into account that each small step can work collectively to build up a positive sense of self will work towards PPC.

4.8.2. Barriers and restrictions to experiencing Positive Psychological Change in Rheumatoid Arthritis

Some have had negative experiences of living with RA, as over the years the invisible nature of RA has gradually caused aspects of their lives to slip away, bit by bit. They might have difficulties overcoming barriers and may continue with their RA having a negative influence on their lives. Thus, there could be a number of barriers that restrict them moving forward and experiencing PPC, for instance the severity of their RA and also experiencing difficulties regarding acceptance and self-involvement in the illness. Once again, it is not hard to miss a walking cane, and a knee replacement in a young male with an ill-fitting knee. The joint

deformities in female hands and fingers and a hip replacement for a young female who wishes to have a successful pregnancy and deliver a baby, may not seem possible to cope with. A seemingly healthy person with a cane may draw a lot of eyes and could be especially difficult when strangers feel the need to ask what is wrong with you? Some RA people might feel that they are exhausted from answering the same question. So far their lack of mobility is just a little more visible as they walk on the street with a cane, crutches or other mobility aids; however, this might result in negative appraisal by a person with RA in public places, which might lead to increased social isolation and eventually a range of psychological difficulties, such as depression and anxiety. These characteristics could play an important role in how individuals with RA manage the disruption to their life goals or plans facing an illness and avoiding personal growth. However, for one reason or another, PPC in the context of RA is a relatively new concept and has not been extensively reviewed, thus replicating this study's findings will be required to further develop the notion in a target sample.

In fact, the thesis reveals that the present survey study is limited in its findings as it was only a cross-sectional study; however, the current study could form a platform for a future researchers to plan a longitudinal study to either support or be against the present results. In addition, it can be concluded that the complexity of RA provides the basis for a combination of quantitative and qualitative methods to add novel perspectives to the phenomenon under investigation in more depth and to gain rich knowledge. The different types of method should not be seen as too varied, but as equally valid and necessary to obtain a richer and more comprehensive picture of the topic under exploration.

In the light of the present study's findings, there are many potential avenues to explore the characteristics of the SLQ-38 in people with RA, as the thesis established some relationships, mainly the main effect between the outcome variables (criterion, PPC), and predictor variables (e.g. well-being). However, some theories suggest that the association between PPC and predictors will be richer when considering the influence of moderator variables (e.g. cognitive reframing). This affect the strength or direction of an association between a predictor variable and an outcome variable (Baron & Kenny, 1986) and are theoretically essential since they are often believed to be variables that precede the predictor (Kraemer, Wilson, Fairburn, & Agras, 2002). They are also important in terms of identifying the ways in which clinicians can be supported in their work as recommended by previous researcher (Brockhouse et al., 2011).

There appears to be little known about the psychometric properties of the SLQ-38, specifically in people with RA, therefore the scale could be improved by creating disease specific measurements for RA, in order to assess PPC. Attention should be paid to standardising the scale to develop a more comprehensive and sensitive version in order to develop special disease measurement to evaluate positive change in people with RA and expanded health status scales with excellent measurement properties, and this would be valuable in RA clinical trials and in outcomes research. In addition, it seems that although SLQ-38 has been well defined and focuses on the patient's experience as a consequence of their illness, as discussed in the introductory chapter, it is important to realise the proportion of people who display PPC, as there has been no clear cut-off point in the scale established in the past research. Therefore, further research should continue to explore this further. Also worth noting that having a single cut-off could be seen as essential to make a clear assumption about the proportion of the illness; however, this thesis suggests that having a single cut-off might be too arbitrary to take into account real situations, as recommended by Brain (2002). Moreover, it is not easy to decide how many deviations would be enough to confirm PPC, even though the cut-off point is agreed. This is due to supporting the viewpoint that there could be a continuum of PPC. This thesis suggested that PPC is not all or none phenomenon, it is about 'the level' or the 'continuum'. This means people can have a minimum, over the SLQ mean, or even they can have a maximum level of PPC. The suggestion of continuum of PPC is the other way of getting round the issue of deciding just what PPC is to go about it a completely different way and look at it based on clinical judgement rather than SLQ-38 cut-off. This thesis suggested that the resolution might be to look at those items that the majority of the study participants scored positively to clustering the items that seem to go together to interfere the meaning of PPC. This could help to come across to establish certain concepts that might be underling the concept of PPC in people with RA which can be a useful way when considering what the characteristics of those with RA are who reported PPC. In this case, the greater the PPC, the more people might have the self-efficacy to control their arthritic pain and fatigue and the other way around.

In the present study, the preference has been to examine PPC, as measured by the SLQ-38 (Sodergren, 2000 & 2002), in a sample of people with RA. There are several reasons for the preference as discussed in the introductory section, however, this could provide an opportunity for future studies to investigate the structure of PPC in SLQ in individuals with RA or other patient groups.

Females are more at risk to develop RA due to the impact of hormonal factors. For instance, some RA people go through the menopause at an earlier age, which might put them more at risk of adverse emotional reactions, and in turn this may influence their potential ability to achieve PPC. Moreover, in the general population, females are more at risk of emotional health problems; therefore they might be potentially at risk of suffering more distressing symptoms if they develop RA at some point in their life. The other suggestion is that even those RA people who suffer more from distressing symptoms might be people who had higher levels of symptoms of distress initially, before experiencing RA, and that is why effectively coping with RA is difficult for them. Therefore, they might display more symptoms of distress and, accordingly, it is hard to achieve PPC. Even so, the varied findings may mirror individual differences in how individuals with RA react, recognise, or cope with their condition; however, the current thesis methodologically used a correlational design and so there was a lack of power in finding out the causality. Moreover, because of the time limit for this PhD, the research had to be completed within a certain timeframe, so future research is highly recommended, including utilising different experimental study designs and considering the impact by performing longitudinal studies.

Finally, from a psychotherapeutic standpoint, and to best address the needs of people with RA, it is recommended that researchers who have illustrated positive outcomes from their studies should undertake secondary analyses to investigate whether any demographic characteristics might predict better outcomes. It will be useful to create clinical trials in Cognitive Behaviour Stress Management (CBSM), to discover the influence of positive affect on immune system functioning and their overall linking of positive illness perception in relation to the extent of PPC in people with RA. The overall outline of evidence suggests the probability that psychosocial interventions can influence immune functioning in cancer patients by raising growth and modulating cortisol levels (Cruess et al., 2000 & 2001). Undoubtedly, future research is required to explain these types of mechanisms in other health conditions such as RA.

4.9. Conclusions

Historically, the past studies have mainly focused on the role that psychological distress, levels of tension and depression, play with the physical problems associated with chronic health conditions. More recently, evidence has been accumulating that reveals the health protecting role that positive illness appraisal plays, as it has been linked to subjective well-

being (Diener, 2013) and positive future health prospects (Pressman & Cohen, 2005). This thesis focuses on a central theme which is the proportion for Positive Psychological Change (PPC) in people living with Rheumatoid Arthritis (RA) in the UK. The thesis has discussed a number of issues relevant to the description and assessment of PPC in people with RA by means of positive response following RA diagnosis, and includes four chapters that address the research objectives.

In Chapter One, a broad overview of the extant research on PPC is presented to examine the impact of RA and provide a comprehensive review to describe various aspects of PPC. A literature review has been conducted to discuss the key concept, PPC, followed by discussing the physiological aspects of RA before moving on to the physio-psychological elements of the illness. Having searched the literature, it is clear that PPC has been considered in numerous studies, using many different terms, and the concept has been examined through a diverse range of measurements. To examine the specific elements in this area in more detail, the literature review was extended to identify aspects of PPC in individuals with RA. To support this, some quantitative and qualitative studies have been considered. Chapter Two focuses on reviewing the survey study design and the sample derivation, and discusses some of the psychometric characteristics of the measurements employed. This is followed by a quantitative research design using quantitative methods involving correlational, multiple regression and a cross-sectional approach, to describe whether PPC occurs in people with RA. The survey study results include four research aims and the subsequent analysis shows the impact of some imperative potential psychosocial factors as well as their possible association with PPC in individuals with RA. This has been addressed in Chapter Three, before moving to the final section of the thesis in Chapter Four which discusses the main findings with respect to the conceptual issues and methodological recommendations. It concludes with a proposed bio-psychosocial model and the implications and recommendations for future studies, as well as discussing the limitations of the thesis.

This current survey study ties together and extends the growing knowledge in the positive psychology literature on people with RA, and although much remains to be learned about the validity of positive change in people with RA, the extant research has shed considerable light on this contentious issue.

This is the first time that such effects have been observed in persons with RA. The use of this topic has revealed several novel aspects of positive change and patterns of coping with

disease and disabilities that might otherwise have not been evident. Although this work is still in its infancy and much research remains to be done in this area to examine whether positive aspects of psychological well-being may be differentially related to PPC and possible illness perceptions in individuals with RA, it may therefore be a useful starting point for future psychological interventions.

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Appendices 1.1.

Table 1.5. Psychometric properties of the survey study Questionnaires

Questionnaire	Content validity	Internal consistency	Criterion validity	Construct validity	Reproducibility Agreement Reliability	Responsiveness	Floor or ceiling effect	Interpretability	Conclusion
The Silver Lining Questionnaire (SLQ), Sodergren et al., 2002	55 people either currently sick or having recovered from their illness, were recruited if they reported positive consequences of illness. These included arthritis, cancer, cardiac disorder, fatigue syndrome and the Obstructive Pulmonary Disease (COPD) patients. They were questioned about their experiences of illness, 41 by semi-structured interview and 14 by open-ended questionnaire and responses were classified into 17 categories. The content of the interviews and questionnaires was used to construct a 66-item questionnaire about positive consequences of illness, which was then completed by 62 male and female; opportunity sample. This includes: 33 participants living with COPD and 29 were cardiac patients. The participants were recruited from the rehabilitation department at the UK hospitals (e.g., Glenfield and Leicester).	The Cronbach's alpha was 0.93 across the samples, suggesting a high level of homogeneity among the SLQ items. The Pearson product correlation between the two assessments was =0.90; $P < 0.001$ showing good retest reliability.	A principal components analysis was conducted for the group as a whole and showed that a single first factor accounting for 27% of the variance. There was no clear evidence of any further factors. 62 items received a factor loading about 0.30	Extraversion correlated significantly with the SLQ item. ($r(173) = .18; p < .05$)	The Pearson product moment correlation between the two assessments for the control condition was $r(20) = 0.90$; $p < 0.001$ showing good retest reliability.	The interaction term of a 3 (group: control, COPD, MI) \times 2 (assessment time: first versus second) repeated measures analysis of variance was significant, $F(2, 81) = 4.24$; $p < 0.05$, showing that there was a significant difference between pre- and post-assessment scores different between the three groups.	Change in total SLQ scores varied between -8 and 18.	COPD: Pre-rehab.: $M = 7.51$ & SD, 5.83. Post-rehab.: $M = 10, 37$ & SD: 6.63. Cardiac: Pre-rehab.: $M = 13.21$ & SD: 5.88 Post-rehab.: $M = 17.28$ & SD: 8.10 Chronic Fatigue patients $M = 12.17$ & SD= 7.99. Respiratory patients: $M = 12.12$ & SD= 8.44.	

Table 1.5. Continued

Questionnaire	Content validity	Internal consistency	Criterion validity	Construct validity	Reproducibility Agreement Reliability	Responsiveness	Floor or ceiling effect	Interpretability	Conclusion
The Arthritis Impact Measurement Scales 2 (AIMS-2, Meenan, Mason, Andersson, Guccione, & Kazis, 1992)	Measurement performance was tested in 408 subjects: 299 with rheumatoid arthritis (RA) and 109 with osteoarthritis (OA);	Internal consistency coefficients for the 12 sales were 0.72-0.91 in the RA group and 0.74-0.96 in the OA group. Cronbach's alpha coefficient: 0.32-0.87. All within-scale factor analyses produced single factors, except for mobility level in OA. Validity analyses in both the RA and the OA groups showed that patient designation of an area as a problem or as a priority for improvement was significantly associated with a poorer AIMS2 scale score in that area		Clinical validity; or discriminant validity: information not specified	45 of these subjects completed a second AIMS2 within 3 weeks Test retest=0.78-0.94. Questionnaire completion times in a pilot study of 24 subjects averaged 23 minutes, and evaluations were positive regarding the instrument's length and ease of completion, and the subjects' willingness to complete serial forms and return them by mail.	Information not specified for the population for which the instrument was developed	Floor and ceiling effects have been observed depending on the patient group observed (Rosemann & Szecsenyi, 2007)	Minimal Important Difference (MID): not evaluated	AIMS scale items were revised and 3 new scales were added to evaluate arm function, work, and social support. Sections were also added to assess satisfaction with function, attribution of problems with arthritis, and self-designation of priority areas for improvement. Reliability, factor analysis, and validity results were consistent with age, sex, and education subgroups. Satisfaction was moderately correlated with the level of function in the same health status area, and the satisfaction items formed a reliable scale. In general: the AIMS2 is a revised and expanded health status questionnaire with excellent measurement properties that should be useful in arthritis clinical trials and in outcomes research.

Table 1.5. Continued

Questionnaire	Content validity	Internal consistency	Criterion validity	Construct validity	Reproducibility Agreement Reliability	Responsiveness	Floor or ceiling effect	Interpretability	Conclusion
The Bristol Rheumatoid Arthritis Fatigue Scales (BRAFs, Dures et al., 2013)	<p>Eighty-three consecutive patients were invited to take part in the study: 59 accepted and 24 declined. Of those 59, 9 were withdrawn from the study due to non-completion of the questionnaires at one time point. Fifty patients participated, with similar characteristics to the study.</p> <p>For reliability studies, a comparison study estimate of 50 complete data sets is needed to produce correlation coefficients of ≥ 0.4 as statistically significant with a power of 82%.</p>	<p>The Multi-Dimensional Questionnaire (BRAf-MDQ) has a global score and four subscales (Physical Fatigue, Living with Fatigue, Cognitive Fatigue and Emotional Fatigue), while three numerical rating scales (BRAf-NRS) measure fatigue Severity, Effect and Coping.</p>			<p>Reliability: 50 patients completed the same procedure with a re-worded BRAf-NRS Coping. Sensitivity to change: 42 patients being given clinically a single high dose of i.e. glucocorticoids completed questionnaires at weeks 0 and 2. BRAf-NRS Coping had lower moderate reliability in both wording formats ($r = 0.62, 0.60$). The BRAf-NRS severity was sensitive to change, with effect sizes (ESs) of 0.33-0.56.</p>	<p>Almost identical Coping VAS was used and was very responsive to an intervention designed to improve fatigue coping skills (ES0.79)</p>	<p>Floor & ceiling effects are unlikely to be significant. For total fatigue, <1% for living with fatigue and in patients recruited with a fatigue VAS >5 out of 10. (Nicklin, 2009).</p>	<p>?</p>	<p>The BRAf scales show good reliability and sensitivity to change. The lack of BRAf-NRS Coping responsiveness to medication supports the theory that coping with fatigue is a concept distinct from severity and effect that is worth measuring separately.</p> <p>The reliability of the BRAf-NRS Coping was less strong, but adequate, at $r = 0.62$, based on accepted levels for PROM validation</p>

Table 1.5. Continued

Questionnaire	Content validity	Internal consistency	Criterion validity	Construct validity	Reproducibility Agreement Reliability	Responsiveness	Floor or ceiling effect	Interpretability	Conclusion
The Coping with Rheumatoid Arthritis Questionnaire (C-RAQ, Englbrecht et al., 2013)	Four hundred thirty-four rheumatoid arthritis (RA) patients (77% female; mean age 55.96 ± 13.34 years) were included. Distancing was the coping strategy used most frequently in RA patients (mean ± SD 1.89 ± 0.78 on a scale ranging from 0 to 3).	A confirmatory principal component analysis to validate the questionnaire's content in a larger cohort. Illustrated 4 principal components : a) Distancing; Cronbach's alpha = 0.82; eigenvalue =4.93 b) Active problem-solving; Cronbach's alpha = 0.76; eigenvalue =2.36 c) Cognitive reframing; Cronbach's alpha = 0.70; eigenvalue = 1.58 d) Emotional expression; Cronbach's alpha = 0.73; eigenvalue= 1.39	Cronbach's alpha coefficients were constantly ≥0.7, indicating satisfactory internal consistency of all coping strategies with respect to their purpose	HAQ-DI: Mean± SD;1.00 ± 0.73 95% CI:0.94-1.07 DAS28: Mean ±SD; 4.13± 1.62 95% CI:3.96-4.29 Fatigue (NRS): Mean± SD; 5.65 ±2.22 95% CI:4.53-5.04 SF-36: ?=0.43, <i>F</i> (9, 400) = 1.92; <i>P</i> =0.042).	Coping effectiveness was directly related to the SF-36 mental component summary scale (<i>P</i> = 0.006) and disease duration (<i>P</i> =0.003), while disease activity as represented by the DAS28 was negatively correlated to coping effectiveness (<i>P</i> = 0.025).		?	?	Overall: the result reflecting satisfactory internal consistency of the coping domains, Cronbach's α reached from 0.70 to 0.82 for each of the principal components reflecting satisfactory internal consistency of the coping domains, while the Kaiser-Meyer-Olkin-criterion as a measure of sampling adequacy was 0.81, implying a very good feasibility of the items for a principal component analysis. Eigenvalues of these coping domains ranged from 1.39 to 4.93

Table 1.5. Continued

Questionnaire	Content validity	Internal consistency	Criterion validity	Construct validity	Reproducibility Agreement Reliability	Responsive -ness	Floor or ceiling effect	Interpretability	Conclusion
<p>The QoL-RA Scale is an RA-specific Health Related Quality of Life (QoLRA Scale, Danao, Padilla, & Johnson, 2001)</p>	<p>The population for the study consisted of Caucasian/ English and Hispanic/Spanish females, aged 18 and older, with RA in 5 health care facilities in the Los Angeles metropolitan area. A consecutively accrued sample of 107 homebound Caucasian/English and 80 homebound Hispanic/Spanish females with RA participated in the study.</p>	<p>Cronbach’s alpha coefficients of 0.90 in English group and 0.87 in Spanish group</p>	<p>Significant scale and item correlations with AIMS2 subscales, LSNS, and CES-D, criterion measures that were administered simultaneously with the QOL-RA scale, suggested criterion-related concurrent validity</p>	<p>Significant correlations of the QOL-RA Scale with the AIMS2 subscales, LSNS, and CES-D, ranging from 0.25 to 0.66 ($P < 0.01$)</p> <p>The HRQOL of persons with RA is expected to vary indirectly with severity of illness. Using 3 RA severity subgroups of mild (Caucasian/English, n 527; Hispanic/Spanish, n 510), moderate (Caucasian/English, n 554; Hispanic/Spanish, n 546), and severe (Caucasian/English, n 526; Hispanic/Spanish, n 524), the analysis of variance test was used to compare the QOL-RA Scale and item scores across the 3 severity subgroups. By discriminating across RA severity subgroups, construct validity was supported. The 2-factor factor structure, which showed that the psychological function loaded substantially on both physical function and social function, supported construct validity as well.</p>			<p>Less than 10% floor and ceiling effects</p>	<p>+</p>	<p>The QOL-RA Scale, in both English and Spanish versions, appears to meet the assumptions of a summated rating scale and the criteria of relevance, reliability, validity, feasibility, and adaptability to several languages. Because the results on scale characteristics, floor and ceiling effects, inter-item correlations, internal consistency, criterion-related concurrent validity, and construct validity were equivalent across the Caucasian/English and Hispanic/Spanish groups, it appears that the English and Spanish versions of the QOL-RA Scale have satisfactory Psychometric properties.</p>

Table 1.5.*Continued*

Questionnaire	Content validity	Internal consistency	Criterion validity	Construct validity	Reproducibility Agreement Reliability	Responsiveness	Floor or ceiling effect	Interpretability	Conclusion
The short-form of the Sense of Coherence (SOC, Antonovsky, 1987)	The SOC scale was developed, using a Facet-theoretical design, to operationalize this construct and provide one way of testing this hypothesis. By many colleagues points to a high level of content, face and consensual validity.	Consistently high internal consistency has been found in a considerable variety of populations, in different languages and cultures. The factor structure of the scale is considered, pointing to one clear dominant factor.	Criterion validity is examined by presenting correlational data between the SOC and measures in four domains: a global orientation to oneself and one's environment (19 r's); stressors (11 r's); health, illness and wellbeing (32 r's); attitudes and behaviour (5 r's).	A high level of construct validity. With Quality of life (N= 148, r= 0.76) Well-being: (N=107), r= 0.64). Distress:(N= 107), r= -0.50 Anxiety trait: (N= 93), r= 0.69	The average alpha, unweight for sample size, in the 5 published studies is 0.82 (range, 0.74-0.91); in the 4 theses/dissertations, 0.81 (range 0.78-0.84); in the 7 unpublished studies, 0.78 (range, 0.74-0.84).	Test-retest correlations show considerable stability, e.g. 0.54 over a 2-year period among	1.1% of the retirees and 1.5% of the kibbutz members were so classified.	?	The alphas of 16 studies using a SOC-13 range from 0.74 to 0.91. A high level of construct validity. There is no 'gold standard' for the SOC. The crucial question is whether the SOC scale does correlate (preferably predictably) with phenomena, external to the SOC, with which the theory argues it should be correlated. There are various normative data for the scale for example; U.S. male pts at VA clinics, 55+, N= 240, Mean: 61.9 & SD= 17.8 The coefficient of variation 9SD/M), a measure of heterogeneity of responses in a sample= 0.288

Table 1.5. Continued

Questionnaire	Content validity	Internal consistency	Criterion validity	Construct validity	Reproducibility Agreement Reliability	Responsiveness	Floor or ceiling effect	Interpretability	Conclusion
<p>The sort form of the Scales of Psychological Well-Being (SPWB, Ryff & Keyes, 1995)</p>	<p>Data are reported from a national probability sample of non-institutionalized, English-speaking adults, aged 25 or older, residing in the 48 contiguous states in the United States. The total sample size was 1,108, of which 59% were female, 87% were Caucasian, and the average age was 45.6 years (<i>SD</i> - 14.8 years). Most respondents, about 70%, were married. About 60% of the sample in each age group was female. The sample size after listwise deletion is <i>n</i> = 928, compared with a total sample size of 1,108. The authors reports, “the shortened scales correlated from 0.70 to 0.89 with 20-item parent scales. Each scale included both positively and negatively phrased items”. Each scale included both positively and negatively phrased items. The response scale was a 6-point continuum, ranging from <i>completely disagree</i> to <i>completely agree</i>. Respondents were interviewed by telephone, and RPWB items were administered using an unfolding technique</p>	<p>The largest correlations were between self-acceptance and environment mastery (0.76), self-acceptance and purpose in life (0.72), purpose in life and personal growth (0.72), and purpose in life and environmental mastery (0.66). Inter-correlations are modest, ranging from .13 (e.g., Purpose in Life and Autonomy) to .46 (Self-Acceptance and Environmental Mastery). Estimates of internal consistency (alpha) coefficients were low to modest, ranging from .33 (Purpose in Life) to .56 (Positive Relations With Others). The alpha coefficient is a conservative estimate of internal reliability for most (congeneric indicators) scales (Bollen, 1989).</p>	<p>The internal consistency coefficients were quite high (between 0.86 and 0.93) Examining the intercorrelations of RPWB subscales provides a cursory test of the multidimensionality of RPWP.</p>	<p>Across these data sets, measures of happiness (affect balance or single-item indicators) show modest to strong associations with Self-Acceptance and Environmental Mastery, somewhat weaker links with Purpose in Life, and still weaker ties to Positive Relations With Others, Personal Growth, and Autonomy. Parallel, although generally stronger, patterns of association are evident for life satisfaction (measured both as a multi-item scale and as single-item indicators)—strongest relations are evident for self-acceptance and environmental mastery, Correlation coefficients with Happiness and Life satisfaction scales showing weak to modest associations. The multiple indicators of depression show consistently negative associations with all dimensions of wellbeing, with the strongest patterns again evident for Self-Acceptance and Environmental Mastery.</p>	<p>The test-retest reliability coefficients for a subsample of the participants over a six week period were also high (0.81-0.88)</p>		<p>For questions including positive item content, responses to the lowest levels of well-being were few, often as little as 1–2% of responses to that question. (Abbott, et al., 2006).</p>	<p>?</p>	<p>The high internal consistency correlations can indicate a problem because: “as the coefficients become stronger, they raise the potential problem of the criteria not being empirically distinct from one another” (Ryff, 1989b p. 1074) The provisional conclusion based on the Ryff’s well-being scale is that there is more to being well than feeling happy and satisfied with life.</p>

Table 1.5. Continued

Questionnaire	Content validity	Internal consistency	Criterion validity	Construct validity	Reproducibility Agreement Reliability	Responsiveness	Floor or ceiling effect	Interpretability	Conclusion
The Arthritis Self – efficacy Scale (ASES, Lorig, Chastain, Ung, Shoor, & Holman, 1989)	<p>All 1600 patients living with RA in Oslo participated to the study. Out of that 1024 (66.4%) answered the questionnaire in 1994.</p> <p>In 1996 the questionnaires was mailed to the 1620 patients in the registration list, of whom 1153 (71.2%) responded positively. Among the respondents were 815 patients who had also answered the questionnaire in 1994. The data from these 815 patients were analysed to generate the scale. Contains five items concerning coping with pain, nine items concerning function and six items concerning other symptoms related t RA.</p> <p>Patients with Juvenile arthritis disease onset before the age of 16 years were excluded.</p>	<p>The subscales demonstrated good internal consistency in this sample (Cronbach’s 0.88 – 0.92).</p>		<p>All three subscales correlated to present and future health status. There was a significant correlation between the changes over a 2-yr span and baseline self-efficacy and for the baseline level of the AIMS-2, the bodily pain, mental health and vitality scales of the Short Form-36 (SF-36). All $p < 0.001$, $r = 0.32-0.53$</p>	<p>Pearson correlations were used to test the reliability of the questionnaire and were reported for each of the subscales: ‘pain’, $r = 0.87$; ‘function’, $r = 0.85$ and ‘other symptoms’, $r = 0.90$.</p>	<p>For all health status measures, there was a significant correlation between the change over a 2-year span and the baseline self-efficacy.</p>	<p>There is no instruction for this, items do not appear difficult to complete; in the initial validation, 85% of the respondents completed more than 90% of the items and no item was consistently omitted.</p>	<p>?</p>	

Table 1.6. Summary of the assessment of the measurement quality

Questionnaire	Content validity	Internal consistency	Criterion validity	Construct validity	Reproducibility Agreement Reliability	Responsiveness	Floor or ceiling effect	Interpretability
The Silver Lining Questionnaire (SLQ), Sodergren et al., 2002	+	+	+	+	+	+	+	?
The Arthritis Impact Measurement Scales 2 (AIMS-2)	+	+	?	+	+	+	+	+
The Bristol Rheumatoid Arthritis Fatigue Scales (BRAFs)	+	+	?	?	+	+	+	?
The Coping with Rheumatoid Arthritis Questionnaire (C-RAQ)	+	+	+	+	+	?	?	?
The QoL-RA Scale is an RA-specific Health Related Quality of Life (HRQOL)	+	+	+	+	?	?	+	+
The short-form of the Sense of Coherence (SOC)	+	+	+	+	+	+	+	?
The Scales of Psychological Well-Being (SPWB, 18 items, Ryff)	+	+	+	+	+	?	+	?
The Arthritis Self –efficacy Scale (ASES)	+	+	?	+	+	+	0	?

Rating: += Positive; 0=intermediate; - =poor; ? =no information available

Appendix 2.1. Ethical approval



28 July 2014

Dear Fatemeh,

RE: ETHICS APPLICATION HSCR14/54 – Positive psychological change in people with Rheumatoid Arthritis

Based on the information you provided, I am pleased to inform you that application HSCR14/54 has been approved.

If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible.

Yours sincerely,

Rachel Shuttleworth

Rachel Shuttleworth
College Support Officer (R&I)

**Research, Innovation and
Academic Engagement Ethical
Approval Panel**

College of Health & Social Care
AD 101 Allerton Building
University of Salford
M6 6PU
T +44(0)161 295 7016
r.shuttleworth@salford.ac.uk
www.salford.ac.uk/

Appendix 2.2. Organization letter

The College of Health and Social Care
School of Health Sciences
L731 Allerton Building
University of Salford
Frederick Road
Salford M6 6PU

20.12.2013

Dear,

It was nice to talk to you today.

My research title is "Psychological change in people with Rheumatoid Arthritis." Over the last few months, my supervisory team at the University of Salford have helped me to finalize the protocol and the supplementary documents, such as the patient information sheet, consent form.

As we discussed, the project required ethical approval from the University's Ethics Committee in advance and before posting the advert on the NRAS website. Meanwhile, I would like to have clarity about the various methods of recruitment available, the costs and the timescale of placing an advert on your website. Additionally, is it possible for you to e-mail members with RA with study information directly? If so, what would be the cost of this?

I would also appreciate if you could forward me a letter indicating you are willing to help advertise the study via NRAS. This is in order to provide evidence to the UoS ethics committee that we are discussing recruitment and it is feasible for NRAS to facilitate recruiting for the project.

I am pleased to forward you a copy of the protocol as we agreed in our phone call today. I hope this provides sufficient information about the study. If you have any comments or suggestions, you are welcome to let me know.

Yours Sincerely

Fatemeh Sani Pour
Postgraduate Research Student

Appendix 2.3. National Rheumatoid Arthritis Society advert



The College of Health and Social Care
School of Health Sciences
L731 Allerton Building
University of Salford
Frederick Road
Salford M6 6PU

Are you willing to share your experience of Rheumatoid Arthritis? Please would you consider taking part in this research

I am a PhD student at the University of Salford. My supervisors are Dr. Peter Eachus, Prof. Alison Hammond and Dr Linda Dubrow-Marshall. My project is a study into **Psychological Change in People living with Rheumatoid Arthritis**. The study has the approval of the University of Salford Ethics Committee.

Research Aims-

To find out about:

- How your rheumatoid arthritis experience may affect your quality of life
- Any changes in your feelings that you may have experienced since you were diagnosed with rheumatoid arthritis
- The coping strategies you use to cope with rheumatoid arthritis

Participants-

- Over 18
- Living in UK
- Diagnosed with RA for at least 2 years



You would be asked to-

- Complete a questionnaire booklet, taking about 30-45 minutes in your own time at home.

If interested in taking part, I will mail the questionnaire to you with a Freepost envelope for your reply

Fatemeh Sani Pour: f.sanipour@edu.salford.ac.uk

Appendix 2.4. Introductory letter



The College of Health and Social Care
School of Health Sciences
L731 Allerton Building
University of Salford
Frederick Road
Salford M6 6PU

Date: 10.12. 2014

Dear Sir/Madam

Re: Research study: Psychological Change in people with Rheumatoid Arthritis

I am writing to you to ask for your assistance with the above research study. I am contacting you because either:

- a) You kindly agreed to join the University of Salford Rehabilitation Research Group's Arthritis Research Panel (ARP). Prof Alison Hammond has given support to this study and the Group are forwarding this letter to you on my behalf. (For data protection reasons, I do not have your contact details).

- b) You are a member of the National Rheumatoid Arthritis Society (NRAS), or a user of their website. The NRAS have agreed to advertise this study on their websites. I do not have your contact details.

I am a Trainee Health Psychologist, studying for a Doctorate in Health Psychology. This study is investigating any changes in your feeling that you may have experienced since you were diagnosed with Rheumatoid Arthritis (RA), and what type of changes occurs, if any. The study will help us find out more about the nature of psychological changes in people living with RA.

The study involves completing a questionnaire booklet once. This will take 30-45 minutes at most, and is done in your own time at home. You then mail this back to us in the Freepost envelope supplied. The information is kept completely confidential.

Enclosed is an information sheet explaining the study and what your involvement might include. It is up to you to decide whether or not to take part.

If you are interested in taking part in the study, and have any questions now or at any stage during the study, please feel free to contact me (Fatemeh Sani Pour) on 07473611202 and I will be happy to resolve your queries.

Thank you for considering this.

Yours Sincerely

Fatemeh Sani Pour

Postgraduate researcher

Appendix 2.5. Cover letter

The College of Health and Social Care
School of Health Sciences
L731 Allerton Building
University of Salford
Frederick Road
Salford M6 6PU



Ethics Ref No: HSCR14/54

Date: 13.08.2014

Dear Sir/Madam

Re: Psychological Change in people with Rheumatoid Arthritis

Many thanks for agreeing to take part in this study. I appreciate your help.

Please find enclosed a copy of the questionnaire and a consent form for your completion.

Please could you sign and date the consent form attached to the front of the questionnaire and check you *initial* (not tick) the boxes next to each statement?

You do not need to complete this all in one go. It is a great help to me if you can check that you have answered every question.

Please return the completed consent form to me using the FREEPOST envelope provided in this pack. Upon receipt, I will countersign the consent form and return a copy to you for your records.

If you need any help to fill in the consent form or the questionnaire, or you have any questions, please do give me a call. I am happy to help.

Yours sincerely,

Fatemeh Sani Pour (Postgraduate researcher)

Tel: xxxxxx

Email: f.sanipour@edu.salford.ac.uk

Appendix 2.6. Study information sheet

The College of Health and Social Care
School of Health Sciences
L731 Allerton Building
University of Salford
Frederick Road
Salford M6 6PU



Study Information Sheet

Title of Project: Psychological Change in people with Rheumatoid Arthritis

Part One: Introduction

We would like to invite you to take part in a research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. The lead researcher (Ms Fatemeh Sani Pour) can be contacted using the contact details provided at the end of this sheet. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

There are studies which have investigated psychological changes in people with Rheumatoid Arthritis (RA). These tend to focus on negative changes, but positive changes may also result. So there is a need to investigate any psychological changes which may occur in a balanced way, so we can understand more fully the type of changes which can occur. This can help us, and other health psychologists, in future to develop approaches to help people with RA experience better quality of life. The purpose of this study is to find out about any psychological changes (positive and negative) that you may have experienced since you were diagnosed with RA. For example, in what way your RA experience affects your quality of life, or outlook on life.

Why have I been invited?

We are offering the opportunity to take part in this questionnaire study to:

- a) Everyone who is a volunteer in the University of Salford Rehabilitation Research Group's Arthritis Research Panel (ARP), who has rheumatoid arthritis, and has participated in the group's past research.
- b) Anyone with rheumatoid arthritis who is a member of, or accesses information provided by, the National Rheumatoid Arthritis Society.

We are asking everyone if they would be willing to take part in this study. We want to include about 200 people in our study over the next few months.

We would like people to take part who:

- Have Rheumatoid Arthritis, diagnosed by a Consultant Rheumatologist
- Are 18 years of age or older
- Have had RA for at least 2 years.

Do I have to take part?

It is up to you to decide whether or not to take part. You can telephone us to discuss the study further. Kindly read through this information sheet and ask any queries you may have. If you agree to take part, we will ask you to sign a consent form to indicate that you have agreed. You are free to withdraw from the study at any time, without giving a reason. Please return the reply slip indicating if you would like to take part or not. If you would like us to telephone you to discuss this further, please indicate this.

What will happen to me if I take part?

1. ***If you wish to take part***, we are asking you to complete a questionnaire booklet. It will take at most 30-45 minutes to fill in and you can complete this at home. The questions are related to the effects of RA on your life. We provide Freepost envelopes for you to post back your reply.

2. If you do not wish or are unable to take part:

If you do not wish / or are unable to take part, you do not need to reply to this request. We will send out one reminder request, in case this letter has been lost in the post. Please ignore this if you have chosen not to participate.

Expenses and payments

There is no expense to you in completing the questionnaire, as we will provide a Freepost envelope for the reply.

What are the possible benefits of taking part?

This study will not directly help you now. The information from your replies will help us and health professionals to understand more about the psychological health of people with RA, and provide treatment which better meets their needs.

Part Two: Will my taking part in this study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence and stored securely. All information which is collected about you during the course of the research will be kept strictly confidential. Any information pertaining to you at the University of Salford research centre will have your name and address removed so that you cannot be recognized. The questionnaires will only identify you by your study number. Your information will only be viewed by staff involved in the research study.

What will happen if you don't want to carry on with the study?

If you withdraw from the study, all your identifiable data will be destroyed.

What will happen to the results of the research study?

The findings will be written up and submitted for publication to enable other health professionals to learn from our experiences. You would not be identified in any report or publication.

Who is organising and funding the study?

The study is being conducted within the School of Health Sciences. There is no external funding for the study. The study is being supervised by Dr. Peter Eachus (PhD lead supervisor) Professor Alison Hammond and Dr Linda Dubrow-Marshall.

Will I get to know what the results are?

Because this is a large study, the results will not be available for about three years. A summary of the report will be sent to you by post or e-mail.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to me (Fatemeh Sani Pour) or a member of research team who will do their best to answer all your questions [07473611202]. If you remain unhappy and wish to complain formally, you can do so to, Dr. Peter Eachus, in the School of Health Sciences, who is the lead supervisor for this project.

Who has reviewed the study?

All research at the University of Salford is reviewed by an independent group of people, called the Research Ethics Committee, to protect your interests, safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the Research Ethics Committee, University of Salford.

Further information and contact details

If you have any questions or concerns about the study or wish to participate; please contact the researcher leading the study:

Fatemeh Sani Pour

The College of Health and Social Care
School of Health Sciences
L731 Allerton Building
University of Salford
Frederick Road
Salford M6 6PU

Researcher's e-mail address: f.sanipour@edu.salford.ac.uk
Mob: 07473611202

If you have any general queries about participating in research you can find general information on the Involve website (www.invo.org.uk). *INVOLVE* is a national advisory Group, funded by the Department of Health, which supports active public involvement in NHS, public health and social care research.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Salford but you may have to pay your legal costs.

Finally

Many thanks for considering participation. Please keep this information sheet for future reference.

Appendix 2.7. Research participant consent form

The College of Health and Social Care
School of Health Sciences
L731 Allerton Building
University of Salford
Frederick Road
Salford M6 6PU



Research Participant Consent Form

Title of Project: Psychological Change in people with Rheumatoid Arthritis

Ethics Ref No: HSCR14/54

Participant Identification Number:

Please initial each

Name of Researcher: Fatemeh Sani Pour

I confirm that I have read and understood the information sheet for the above study

(Version: 1- date: 04.08.2014) and what my contribution will be. I have had the opportunity

to consider the information, ask questions and have had these questions answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any

time, without giving any reason, and without my legal rights being affected.

I agree that my contact details can be held by the researchers at the University of Salford.

I understand that relevant sections of my data collected during the study may be looked at by

individuals from regulatory authorities and by the research team at the University of Salford.

I give permission for these individuals to access this data.

I understand that my anonymous data will be retained for 3 years after completion of the

study and may be shared with third parties, for use in future studies which may be carried out.

I understand that my anonymised data will be used in this study and may also be

used in other related studies.



I agree to take part in the above study.

Name of patient

Date

Signature

Name of researcher

taking consent

Date

Signature

When completed: Original for the researcher; 1 copy to participant.

Appendix 2.8. Reply form

Research Study: Psychological Change in people with Rheumatoid Arthritis

Reply Form

Name _____

Address _____

Tel No: (day) _____ eve (if different) _____

Do you have rheumatoid arthritis? Yes No

Your date of birth _____

Your Consultant's name _____

Are you interested in taking part in this study (tick if applicable)? Yes

Apart from rheumatoid arthritis, do any other health conditions affect your ability to carry out daily activities? Yes No

If yes, what is this (e.g. stroke etc) _____

Time since diagnosis (tick please)

Less than 2 years

2-5 years

6-10 years

Over 10 years

**Please delete as applicable*

Please return to (in the Freepost envelope provided: no stamp needed)

FREEPOST RHSC- TRSU- TABY

Fatemeh Sani Pour, Postgraduate Research Student

School of Health Sciences (Psychology)

L731 Allerton Building

University of Salford

Frederick Road

Salford

M6 6PU

PC-RA reply formv1 28.07.2014

Appendix 2.9. Risk assessment of projects

UNIVERSITY OF SALFORD

Research Governance and Ethics Committee

HEALTH AND SAFETY

RISK ASSESSMENT OF PROJECTS

All projects should undergo risk assessment. It may be possible that risk involved is minimal and no further action would be necessary, but you are required to demonstrate that risk has been considered.

Please answer the following questions with regards to the project.

1. What is the title of the project?

Psychological Change in people with Rheumatoid Arthritis

2. Is this project purely literature based: No

If YES, please go to the bottom of the page and sign where appropriate.

3. What are the ethical issues to be considered?

There could be a potential risk of distress caused to participants while completing the psychological questionnaires included in the study. In accordance with the Code of Ethics and Conduct (BPS, Code of Contact) the researcher will ensure that:

- All participants in the study will be provided with an information sheet describing the elements of the study and sufficient information to make a decision about their participation in the study and will be reminded of this information -at the beginning of the survey questionnaire.
- Participants consent freely to the study on the basis of adequate information. So the participants are free to withdraw or modify their consent during the data gathering phase. Any data they have consented to submit up to the time of withdrawal will be used.
- Reliable and valid questionnaires will be used.
- The study pack that includes the invitation letter, information sheets and reply forms will be

submitted with the protocol, for review and approval by the University of Salford Research Ethics Committee.

-If participants have a concern about any aspect of this study, they should speak to me (Fatemeh Sani Pour) or a member of research team who will do their best to answer the questions [xxxxx]. If they remain unhappy and wish to complain formally, they can do so to, Dr. Peter Eachus, in the School of Health Sciences, who is the lead supervisor for this project.

-They will be informed that:

If they feel disquiet/ upset during completing the questionnaires then they might contact to their GP.

-In the event that something does go wrong and they are harmed during the research and this is due to someone's negligence then they may have grounds for a legal action for compensation against the University of Salford but they may have to pay their legal costs.

4. Does the project involve the use of ionising or other type of "radiation".
NO

5. Is the use of radiation in this project over and above what would normally be expected, for example, in diagnostic imaging?
NO

6. Does the project require use of hazardous substances?
NO

7. Does the project carry any risk of injury to the participants?
NO

8. Does the project require participants to answer questions that may cause disquiet / or upset to them?
YES

If the answer to any of the questions 4, 5, 6, 7 or 8 is YES, a risk assessment of the project is required.

Signature of PI.....

Date

Appendix 2.10. Research protocol

Research Protocol

Positive Psychological Change in people with Rheumatoid Arthritis

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Appendix 1: Participant invitation letter

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Appendix 6: Risk assessment

Appendix 7: Organization letter

Research Protocol:

Title: Positive Psychological Change in people with Rheumatoid Arthritis

	NAME	APPOINTMENT	DEPARTMENT
1. Research Team:			
Principal Investigator	Fatemeh Sani Pour	Postgraduate Research Student	Centre for Health Sciences Research, University of Salford
Main Supervisor	Dr. Peter Eachus	Director of Psychology and Public Health	Centre for Health Sciences Research, University of Salford
Co-Supervisor	Professor Alison Hammond	Professor of Rheumatology Rehabilitation	Centre for Health Sciences Research, University of Salford
Co-Supervisor	Dr. Linda Dubrow Marshall	Programme Leader MSc Applied Psychology	Centre for Health Sciences Research, University

Research Protocol:

Positive Psychological Change in people with Rheumatoid Arthritis

2. Background information

A number of literatures, philosophies and religions throughout human history have conveyed the idea that there is personal gain to be found in suffering. The observation that adversity can aggravate positive changes is also contained within existential philosophy and humanistic psychology. It has also been recognized that positive changes can come about as a result of suffering and stressful events. But it is only within the last few decades that the topic of PPC following adversity has become a focus for empirical work.

Recent Developments

The topic of positive change has become a magnet for research, due in large part to the pioneering work of Tedeschi and Calhoun in 1995, who created the term Post-traumatic Growth (PTG). The positive changes associated with traumatic events have been conceptualised as PTG (Tedeschi & Calhoun, 1995). These positive changes include those associated with the emotions, cognitions and the subject's basic beliefs regarding the way people view the world, their relationship with others and their identity as individuals (Janoff-Bulman, 1992). The five subdivided categories of PTG are: an increased appreciation of life, setting of new life priorities, improved closeness of intimate relationships, a greater sense of personal strength and positive spiritual change (Tedeschi & Calhoun, 1996, 2004).

Although, Tedeschi and Calhoun represent a step toward a better conceptual understanding of the phenomena by providing a complex theoretical model of the development of PTG, however, the concept of positive change is described using a variety of terms interchangeably (Linley & Joseph, 2004). For example, Tedeschi and Calhoun (2004) stated that they use the terms trauma, crisis, highly stressful event, and others interchangeably as roughly synonymous expressions. This is due to their usage of these terms is a bit broader and less restrictive than their usage in some literatures (e.g., American Psychiatric Association, 2013).

There is now a significant literature documenting positive changes following a wide range of stressful and traumatic events (Linley & Joseph, 2004). The events for which growth outcomes have been reported include transportation accidents, natural disasters, interpersonal experiences, medical problems including: cancer, heart attack, brain injury, spinal cord injury, HIV / AIDS, multiple sclerosis and rheumatoid arthritis (Linley & Joseph, 2004; Joseph, 2005).

As well as posttraumatic growth, the positive changes that are observed following these traumatic events have been referred to as positive changes (Joseph, Williams, & Yule, 1993), stress-related growth (Park, Cohen, & Murch, 1996), Benefit- Finding (BF, Tennen & Affleck, 2002), perceived benefits (McMillen & Fisher, 1998), and thriving (Abraido-Lanza, Guier, & Colon, 1998), and most recently, adversarial growth (Linley & Joseph, 2004). Due to this complexity and controversy, positive psychology researchers choose not to provide a clear definition, preferring instead to use

the term in a manner which assumes that all clinicians and researchers have a common understanding of what it corresponds to (Wortman, 2004). It is worth noting that, despite the similarities between the terms describing the topics, there is emerging evidence that positive change is a developing field for which there is yet no standard terminology.

It must be emphasized that how positive change is conceptualized and operationalized within empirical studies may be critical in determining the ultimate success of the outcomes. It is recognized that a number of studies reflect interest in the positive effects reported by those who have experienced chronic illness such as cancer (e.g., Bower, 2005 & Mosher, 2006) and Rheumatoid Arthritis (RA, Dirik & Karanci, 2008), that produce extreme stress and typically defined as traumatic events (e.g., Bower, 2005 & Mosher, 2006). However, the word 'trauma' refers primarily to the damage or injury that results from a violent attack and, thus, highlights the negative effects of such events. In this respect, after having identified the characteristics that distinguish RA from traumas of an acute nature, this study carefully analysed the possibility that the PTG is not an appropriate concept to discover a serious medical condition such as RA. This is due to the fact that RA can be a highly stressful condition largely because of the pain, functional disability and long term pharmacological treatment. However, RA is not considered as a traumatic event. As such, PTG is not appropriate concept to investigate within this target sample.

Rheumatoid Arthritis

RA is a chronic, progressive and disabling auto-immune disease. RA prevalence is 0.8% (Symmons et al., 2002). Around 400,000 people in the UK have RA and about 12,000 people develop RA per year (NICE, 2009a). Over twice as many women as men suffer from this condition (NICE, 2009b).

The impact of RA

RA can have a significant impact not only on individuals in the UK but also their families, their career, the NHS, and society in general, including the economic effects of early mortality and lost productivity. For example, the economic impact of RA has been estimated between £3.8 to £4.75 billion per year (NICE, 2009a). Approximately one third of RA patients become work disabled because of the disease within two years of onset and this increases in subsequent years. A survey conducted by the British Society for Rheumatology (2008) estimated that when a patient stops work due to RA, it represents an average loss of productivity equivalent to £287,544. Clearly this represents a huge cost to the UK economy and an enormous cost to individual patients.

Living with RA

RA patients have been identified as a medical population at risk for psychological disorders, largely because of the pain and functional disability that are the hallmarks of this disease. The diagnosis of RA has the potential to make profound changes in a person's life, resulting in significant exposure to psychological stress. For example, 15% - 23% patients experience depressive symptoms, which correlate with pain and work-status (Pincus, 1996), and the relationship between depression and health status variables is complex. There is some evidence that pain and depression are important predictors of fatigue (Rupp et al., 2004; Repping et al., 2007). Fatigue is an important symptom interfering with quality of life (Repping et al., 2008). More recently, Munsterman et al. (2013)

conducted a cross-sectional study to explore whether physical activity is associated with fatigue, when controlling for age, gender, pain and depressive symptoms in persons with RA. The findings show a statistically significant relationship with depressive symptoms which explained 33% of variance of fatigue. As a result, the authors concluded that depression contributed to fatigue, and not physical activity.

Positive Psychological change

The field of positive psychology is about valued subjective experiences: well-being, contentment, and satisfaction (in the past); hope and optimism (for the future); and flow and happiness (in the present) (Seligman & Csikszentmihalyi, 2000). Psychology is not only studying human weakness and pathology but also the study of strength, virtue, insight and growth. Thereby, positive psychological researchers aim to discover human strengths that act as buffers against mental illness (Seligman & Csikszentmihalyi, 2000). As such, the major psychological theories have underpinned a concept of strength and resilience. No longer do the dominant theories view the individual as a passive vessel responding to stimuli; rather, individuals are now seen as decision makers, with choices, preferences, and the possibility of becoming masterful, efficacious, or in malignant circumstances, helpless and hopeless (Bandura, 1986; Seligman, 1992).

Factors contributed to development of PPC

I. Coping strategy

It is important to consider psychological factors which may act to modify the extent of the symptoms reported, the course of the illness, and the RA patient's feelings of well-being. One of the potentially useful concepts to bridge the gap in the current knowledge between disease, disability and psychological wellbeing is coping. A typical definition of coping is the cognitive, behavioural and emotional efforts individuals exert to manage specific external or internal demands (Lazarus & Folkman, 1984). How an individual with RA copes with his /her pain and disability constantly linked to psychological adjustment outcomes (Smith et al., 1997). Researchers have recognized several distinct components of the coping process. Mainly among these are appraisals of the harm or threat to self-worth caused by the stressor, and the degree of controllability of the outcome and repetition of the stressful situation (Zautra & Manne, 1992). The appraisal process is founded on the assumption that individuals are constantly appraising their relationship to the environment (Folkman & Greer, 2000). The stress process begins when the individual becomes aware of a change in the status or faces a threat towards present goals and concerns. Hence, appraisals of an event, for example, after being diagnosed with RA, patients are confronted with new situations that challenge their usual coping behaviour. As a result, they must find new ways to cope with their current condition. Some patients eventually reach a good psychological status. Those who report positive changes could be potentially linked to better coping with the disease-related demands. These changes comprise the following personality related domains: relationships with others, perception of new possibilities, self-understanding, new dimensions of personal strength, spiritual changes and appreciation of life. Coping strategies should therefore be considered as an important factor in determining overall well-being and PPC in people with RA. RA results in pain, uncertainty, physical disability, loss of independence, depression, fear and psychological distress over long periods of time (Persson et al. 1999). Indeed, pain has been significantly related to both anxiety and depression

(Kraaimaat et al. 1995). Thus, RA imposes an immense burden on the individual's ability to cope and may greatly diminish Quality of Life (QOL) and psychological well-being (Huyser et al. 1998).

II. Quality of Life

Quality of life (QoL) can be thought of as the overall impact of the illness and its treatment on patients, and their response to these impacts (Hunt, et al., 1993). Measuring QoL has become a vital and often required part of health outcomes appraisal. For populations with chronic disease, measurement of QoL provides a meaningful way to determine the impact of health care when cure is not possible. It is an intangible, multidimensional concept that has generated a great deal of research, controversy and debate during the last three decades. It has been operationally defined and measured in different ways by different investigators. Initially, measures to assess QoL were derived from objective indices of living conditions such as: education, health and employment. The concept later widened as subjective factors such as productivity, intimacy and emotional well-being. These subjective factors also influenced an individual's judgement of overall QoL.

III. Psychological Well-being

Well-being is a dynamic concept that includes subjective, social, and psychological dimensions as well as health-related behaviours. Based on Ryff's, Psychological Well-Being (PWB, 1995) specifically focuses on measuring multiple facets of the concept. These facets include the following: self-acceptance; the establishment of quality ties to other; a sense of autonomy in thought and action; the ability to manage complex environments to suit personal needs and values; the pursuit of meaningful goals and a sense of purpose in life and finally continued growth and development as a person. Thus, this perspective of psychological adjustment may be useful for investigation in RA. Recognition of psychological adjustment as a process that constantly changes over time may help people with RA to face the changes in their condition. For example, fluctuations in pain and activity limitations will invariably modify the level of PPC.

IV. Sense of Coherence and Resilience

Dealing with stress is an inevitable part of life. At some point, everyone experiences setbacks of varying degrees. Some of these challenges might be relatively minor while others are disastrous. How individual's deal with these problems can play a major role in not only the outcome, but also the long-term psychological consequences. The Salutogenic theory (Antonovsky, 1992) explains why people stay healthy whereas the pathogenic model, Junck & Wagnalls, (1977, cited in Buch, 2006)) focuses on what makes people ill. Antonovsky introduced the concept of Sense of Coherence (SOC) as a personality characteristic that refers to a disposition to look at life and its problems in a manner that makes coping with stress easier. The consistent body of research suggests that most people exposed to stressful condition retain a stable equilibrium without reactive psychopathology. This has been described as resilience (Bonanno, 2004; Lepore & Revenson, 2006).

V. Self-efficacy experiences

The basic premise of self-efficacy theory is that “people’s beliefs in their capabilities produce desired effects by their own actions” (Bandura, 1977, p. vii). Beliefs about self-efficacy influence health in two ways. First, self-efficacy influences the adaptation of healthy behaviours, the cessation of unhealthy behaviours, and the maintenance of behavioural changes in the face of challenges from stressors. Second, self-efficacy beliefs influence a number of biological processes such as the hypothalamic-pituitary-adrenal axis that, in turn, influence health and disease (Bandura, 1977, p. vii). Self-efficacy beliefs play a crucial role in psychological adjustment, psychological problems, and physical health, as well as professionally guided and self-guided behavioural change strategies (Bandura, 1986). Gilbar and Dagan (1995) have demonstrated that self-efficacy is strongly related to intention and action. Therefore, it is expected that self-efficacy appraisals regarding the potential ability and success of coping strategies with a rheumatic condition may play a key role in determining the level of psychological adjustment in people living with RA.

Positive change in people with RA

Exploring positive change in RA patients has received little attention so far. The only study (Dirik & Karanci, 2008) has examined the structure of the Post-traumatic Growth Inventory (PTGI) to evaluate PTG in Turkish RA patients. The results showed that the PTGI has three domains: relationship with others, philosophy of life and self-perception. Perceived social support appeared as a significant factor for the total PTG levels and for the three domains. However, the small size and female dominated study sample necessitates caution in generalizing from the study findings. Moreover, as mentioned earlier, the concept of PTG is not proper term to be used in people with RA.

BF refers to identification of benefit from adversity and manifests itself in various ways, including awareness of deepened interpersonal relationships, an enhanced sense of spirituality and life purpose, and an overall increased appreciation for life (e.g., Tennen & Affleck, 2002). In a few last studies BF has been documented (e.g., Danoff-Burg & Revenson, 2005 & 2006; Sato et al., 2008; Tennen et al., 1992), in RA people. One of these, a longitudinal study, used mixed methods to identify and describe the positive effects of illness on relationships, examine correlates of BF and test the relationship between BF and adjustment outcomes. When asked about benefits of their illness, 71.3% of the respondents described interpersonal benefits, whereas 16.2% reported another type of benefit, and 12.5% reported no benefits. Interpersonal BF predicted lower levels of disability at 12-month follow-up (Danoff-Burg & Revenson, 2005). However, there is a sample bias in this study, as an appreciable number of participants (13.9%) left the question blank in spite of being asked to focus on a particular conceptual domain i.e. interpersonal relationships resulting from RA. Therefore, this means that the participants did not clearly recognise the research question. In sum, there is some evidence that positive change can occur; however, the extent to which it occurs is a neglected aspect of health experience in RA patients.

3. The survey study

The survey study investigates psychological changes, especially PPC, as they occur in people living with RA. The aim is to expand current knowledge and to build up a growing awareness in PPC by looking at a particular sample of people living with RA. This study investigates the extent and the

nature of psychological change, especially PPC, in people with RA. Factors that might contribute to development of PPC will be explored. The relationship of PPC with a range of mental and physical health outcomes will be examined. The survey provides plenty of scope for discussion of the coping strategies used by RA people. Factors that might predict PPC will be examined. The implication of the study will be discussed in the light of present theories to increase the understanding of adaptation to chronic health condition in people living with RA. The findings of this study will extend the current knowledge in positive psychology literature.

The rationale for investigating psychological change in people with RA

There is a need to investigate PPC in people with RA for the following reasons.

- For the last three decades, a wealth of literature has been developed to study mental health symptoms such as depression, anxiety and other negative symptoms. Measuring the perceptions of PPC among those who have experienced stressful condition such as RA is one method of balancing the emphasis on mental health syndromes.
- Investigating PPC might have clinical value. It may help us to estimate what kind of PPC might occur in people living with RA and what avenues of potential positive change are unexplored. By understanding this we might be able to help people to explore avenues that are most likely to lead to positive outcomes.
- More research is needed to investigate specific disease-related profiles of positive change and the complex mechanisms which underlie the relationships between PPC and the process of recovery.
- Refining current understandings of growth following chronic illness is an appropriate approach to examining the different conceptualizations and to find out the link between mental health symptoms, resilience and PPC.
- There is a possibility of helping people with RA and promoting their well-being. This is possible by focusing on educating about resilience, which might help them to reduce incidences of mental health syndromes.
- By understanding the true possibilities for achieving PPC, the author challenges the assumption that resilience in the face of pain and disability in RA people is more common than is often believed.
- Findings from the survey study invite further exploration to investigate the implication of the present study into the real world. In general, this knowledge may help us to foster the overall positive adjustment of chronically ill patients (Barskova & Oesterreich, 2009).

The study question

In this survey, reliable and valid measures will be used to investigate nature and the extent of PPC occurs in people with RA. The study seeks to expand current understanding of the illness experience by focusing on PPC among people living with RA.

The main question is:

Q: What are the extent and the nature of PPC in people living with RA?

The sub-questions are:

Q: What are the factors associated with occurrence of PPC in people living with RA?

Q: What is the association between coping strategies used and PPC in people living with RA?

4. Study aims and objectives

Little research has been undertaken to understand whether PPC is possible in RA patients.

The main aim is:

- Exploring the nature and the extent to which PPC occurs in people with RA.

The sub-aims are:

- To explore factors associated with PPC in people living with RA.
- To investigate the extent to which PPC is associated with overall well-being in people with RA.
- To examine the association between coping strategies used and PPC in people living with RA.

In relation to the field of clinical and health psychology, it is hoped that if the study identifies the existence of PPC in people with RA, the study outcomes may influence future interventions, models of change and growth and will extend the growing knowledge in positive psychology literature.

5. Method

a) Design

This is a cross sectional survey investigating nature and the extent of PPC among those who live with RA. The study will be conducted using two methods to recruit people: The recruitment will be from a) volunteers with RA in the University's Rehabilitation Research Group's Arthritis Research Panel and b) people with RA who see the study advert on the National Rheumatoid Arthritis Society (NRAS) website. The participants will be mailed the paper based questionnaires.

b) Participants

Inclusion criteria:

These are:

- People diagnosed with RA by a Rheumatology Consultant
- Age ≥ 18
- The time scale after diagnosis is at least 2 years. (Two years is being used to make sure the condition is well-established by that time).

c) Ethical approval

The recruitment will be from a) volunteers with RA in the University's Rehabilitation Research Group's Arthritis Research Panel and b) people with RA who see the study advert on the National Rheumatoid Arthritis Society (NRAS) website. Hence, the study does not require NHS research

committee approval. The project will require ethical approval from the University's Ethics Committee as the study involves human participants.

d) Recruitment & Consenting

Procedure

- **Postal questionnaire via Arthritis Research Panel**

- 1- The University's Rehabilitation Research Group has an Arthritis Research Panel (ARP), i.e. a database of people with RA who have participated in past studies and are willing to be contacted about future studies run by the Research Group.
- 2- On behalf of Fatemeh Sani Pour, a member of the Rehab. Research Group (RRG) will forward the invitation pack to the ARP. These are:
 - Invite letter
 - Study information sheet including the study eligibility criteria
 - Reply form (with contact details)
 - A Freepost envelope
- 3- This approach means that the identity of ARP members is initially protected. Interested ARP members will return to Fatemeh a reply form and confirm if they are agree to take part in the study.
- 4- Fatemeh will check their eligibility and will screen people. If they are eligible then she will inform the RRG member which panel members are willing to participate in the study, so that study participation can be logged on the ARP database.

- **Online recruitment via National Rheumatoid Arthritis Society**

Fatemeh Sani Pour (postgraduate research student) will discuss the feasibility of recruiting via the NRAS with Ms.xxxx, Director of External Affairs, the NRAS, in collaboration with the NRAS Chief Executive, Ms.xxxx . In the meantime, Fatemeh will apply to obtain approval from the University's Ethics Committee. If feasible to recruit via NRAS following approval by the University Ethics Committee the following steps will take place via NRAS.

A brief study explanation including:

- The study advert including Fatemeh's contact details (Name, e-mail address and phone number) will be posted on the NRAS website.

The following information will be e-mailed to the NRAS member through NRAS:

- The study information sheet including the study eligibility criteria
- The study introductory letter

Those who are interested to participate can then contact Fatemeh direct by e-mail. Fatemeh will then screen for eligibility. If the applicants meet the eligibility criteria Fatemeh will be send the same study invitation pack to their address.

Fatemeh will maintain a study database of all people agreeing to participate to track progress through the study.

A thank you letter will be send to the participants following their contribution to the study.

A summary of the study result will be sent to the participants either by post or e-mail.

e) Data collection

The survey will collect the following information.

- I. Personal and demographic factors:** This section requests personal and demographic information including: date of birth, gender, ethnicity, education, employment and marital status. These variables will be used to investigate the descriptive statistics
- II. RA related variables:** included: duration of illness, perceived disease severity, type of treatment, pain, fatigue and prevalence of co-morbid conditions
- III. RA psychosocial factors:** These are: mood, social support, well-being, coping strategies, quality of life, resilience and self-efficacy

f) Questionnaires content

The data will be collected using the following reliable and validated measures. These are:

- **The Silver Lining Questionnaire (SLQ; Sodergren, et al., 2002)** will be used to assess the extent to which people believe their illness has had a positive benefit despite the negative consequences of being ill. The scale measures: Improved interpersonal relationships, positive influence on others, self-improvement, reappraisal of life, restructuring of life, spiritual changes, sensitivity to emotions, skills and new pursuits, self-knowledge and confrontation of current concerns. The total score on SLQ reflected the general PPC following the illness. It comprises 38 items with five response categories, reflecting the extent to which people believe their illness has had a positive benefit. Participants will be asked to think about the positive aspects of their illness experience and to indicate the extent to which they agree with the 38 statements using a five-point Likert scale ranging from (1) strongly disagree to (5) strongly agree.

The Arthritis Impact Measurement Scales 2 (AIMS-2; Meenan, et al., 1991) considered as a specified instrument which has been used widely for assessment, intervention management, and outcome evaluation in people living with RA.

Four component model which combines the AIMS-2 scales into measures of:

- e) Physical health including: mobility level (5 items); walking & bending (5 items); hand & finger function (5 items) and arm function (5 items). In total 20 items will be used to assess physical health.

- f) Level of tension (5 items) and Mood (5 items) will be used to assess mental health symptoms.
- g) Social activity (5 items) and Support from family and friends (4 items), in total 9 items will be used to assess social interaction.
- h) The subscale of arthritis pain (5 items) will be used to measure arthritis pain.

Overall, 44 items of the AIMS-2 will be used.

The participants will be asked to indicate the extent to which they agree or disagree with each statements, using a five-point Likert scale ranging from (1) all days to (5) no days.

- **The Bristol Rheumatoid Arthritis Fatigue Scales (BRAFs; Dures et al., 2013).** The scale was created in the Rheumatology department at Bristol, UK. and will capture the fatigue experience within RA patients. For the purpose of this study only one item from the “Bristol Rheumatoid Arthritis Fatigue Numerical Rating Scales (BRAf- NRS) will be used. This is item number one which is “Please circle the number which shows your average level of fatigue during the past 7 days”. This is scored from 0 to 100 (i.e. 0= no fatigue and 100=totally exhausted).
- **The Arthritis Self-Efficacy Scale (ASES, Lorig et al., 1989).** The ASES developed to measure self-efficacy in patients with rheumatic diseases. The questionnaire contains: coping with pain (five items), concerning function (9 items), and other symptoms related to RA (six items). Each item presents a statement with which the patient may agree or disagree. The scores are expressed as values between 0 and 100, a score of 0 representing the lowest possible self-efficacy level. The study chose not to include the nine questions regarding function. It is due to cut the length of the questionnaire and therefore had to omit some questions, among them the self-efficacy as two scores: one for pain and one for other symptoms (fatigue, depression etc.) will be uses.
- **Quality of Life-Rheumatoid Arthritis Scale (QOL-RA; Danao et al., 2001): English version.** This is an RA-specific Health Related Quality of Life (HRQOL) instrument. It is an 8-item scale that measures the HRQOL of persons with RA. Each item starts with the definition of an element to be considered in rating one’s quality of life, followed by a question on rating one’s quality of life on a horizontal 10-point scale anchored with 1 (very poor) at one end and 10 (excellent) at the other end. The elements are physical ability, pain, interaction with family and friends, support from family and friends, mood, tension, arthritis, and health. The higher the QOL-RA Scale score, the higher the HRQOL. The scale took 2 to 3 minutes to administer.
- **The Coping with Rheumatoid Arthritis Questionnaire (C-RAQ; Englbrecht et al., 2012).** Coping strategies will be assessed by a validated questionnaire based on the transactional model of stress and coping containing emotion-and problem-focused coping strategies by Lazarus and Folkman and Lazarus (1986). The questionnaire comprises the following coping domains: cognitive reframing, distancing, emotional expression, and active problem-solving. Each of the 18 items had to be answered on a scale ranging from 0 (not at all) to 3 (a lot), indicating the extent to which the corresponding coping behaviour had been used during the

past week to cope with RA or by indicating in a separate category that the described coping behaviour was not applicable to the patient.

- **The short form of the Psychological Well-Being Scales (PWB; Ryff, 1995).** The six scales were 18 items in total. The subscale length varied between six items (Self-acceptance, Positive relations with others, Environmental mastery, Purpose in life), seven items (Personal growth) and eight items (Autonomy). A six-point answering scale will be used for all scales, ranging from 1 (totally disagree) to 6 (totally agree).
- **The short-form of the Sense of Coherence (SOC; Antonovsky, 1987)** will be used to assess a person's ability to manage stressful conditions such as dealing with RA. Each question has seven possible answers with number 1 and 7 being the extreme answers.

g) Sample size

It is expected to identify and recruit 500 participants for the survey study. The first reason is based on the past studies the response rate is approximately between 50%-60% (e.g. Tennen et al. 1992). The second reason is the researcher wishes to use multiple regression analysis in a study. To use multiple regression analysis, the ratio of 10 observations for each independent variable was reported optimal by Miller and Kunce (1973). It is expected taking into the regression analysis study 20 independent variables therefore the sample size (for categorical data) would be around 200 people. There are currently about 250 people on the ARP database who are willing taking part to the study. Therefore the estimation is to get around 125 participants in the study via past participants database. On this basis we expect the remaining (125-150) participants will be recruited via advertising on the NRAS website and e-mailing the study information to the NRAS members via NRAS.

h) Data Analysis

Statistical analysis will be performed with the Statistical Package for the Social Sciences SPSS (v20) software. Data will be tested for normality and parametric or non- parametric statistics used as applicable. Descriptive statistics will be used to summarise socio- demographic data (e.g. age and gender) as well as rating scales total scores. Correlations between variables will be analysed to determine which will be used as independent variables in regression analyses. Univariate and multivariate logistic regression will be conducted to establish factors predicting PPC. Results will be summarised as odds ratios (ORs) with 95% Confidence Intervals (CI).

6. Data Handling and Record Keeping

- a) Survey data will be collected via paper based questionnaires. Information about study participants will be kept confidential and managed according to the requirements of the Data Protection Act, the Research Governance Framework for Health & Social Care, Ethics Committee Approval and University of Salford Research Governance Procedures.
- b) Identifiable data obtained through telephone, email or reply forms (such as name and address) will be accessed and used by only the research study team at the University of Salford. This will enable questionnaires to be mailed out to participants correctly and reminders sent if necessary.

- c) Participants will be informed that any data they provide will be kept confidential. No identifiable data will be included in any report arising from the study.
- d) Participants will be informed that they can withdraw from the study at any time. They can do so at any time during completion of the paper questionnaire, by not returning the Freepost envelope enclosed. Data will not then be submitted. Any data they have consented to submit up to the time of withdrawal will be used.
- e) Each study participant will be assigned a unique participant number. A master list of participant numbers and address will be maintained on a study database which will be securely stored on the University of Salford Server. A database (names, addresses and telephone numbers) of those participants requesting a study pack will be maintained. Progress through the study will be tracked in order to ensure timely mailing of questionnaires and reminders. This will be password protected on a secure file storage area on the University of Salford main server. This will only be accessible by Fatemeh Sani Pour and the research team who are directly engaged upon the project at the University of Salford.
- f) The Principal Investigator (Fateme Sani Pour) is the Custodian of the data. Dr. Peter Eachus is lead supervisor for this project.
- g) Participants will not be identifiable in any future publication.
- h) Source data and databases will be stored securely and kept confidential. People will be identified by numbers only in statistical records and on questionnaires. Data analysis (SPSS) files will only identify participants' survey ID. Paper versions of the questionnaires and reply forms will be stored in separate locked cabinets.

7. Study Monitoring, Audit and Inspection

The investigator will permit study-related monitoring and inspections by the University of Salford Ethics Committee. The study will be monitored in accordance with the University of Salford Research Governance procedures. The investigator will ensure that any regulatory authority is given access to all study related documents and study related facilities.

8. Ethical Considerations

This study will be conducted according to the standards of the University of Salford Research Ethics Committee regulations and University of Salford (College of Health & Social Care) Research Governance policies and procedures.

This protocol and any amendments will be submitted to University of Salford Research Ethics Committee for approval of the study conduct.

There could be a potential risk of distress caused to participants while completing the psychological questionnaires included in the study. In accordance with the Code of Ethics and Conduct (BPS, Code of Conduct) the researcher will ensure that:

- All participants in the study will be provided with an information sheet describing the elements of the study and sufficient information to make a decision about their participation in the study and will be reminded of this information -at the beginning of the survey questionnaire.

- Participants consent freely to the study on the basis of adequate information. So the participants are free to withdraw or modify their consent during the data gathering phase. Any data they have consented to submit up to the time of withdrawal will be used.
- Reliable and valid questionnaires will be used.
- The study pack that includes the invitation letter, information sheets and reply forms will be submitted with the protocol, for review and approval by the University of Salford Research Ethics Committee.
- If participants have a concern about any aspect of this study, they should speak to me (Fatemeh Sani Pour) or a member of research team who will do their best to answer all their questions [07473611202]. If they remain unhappy and wish to complain formally, they can do so to, Dr. Peter Eachus, in the School of Health Sciences, who is the lead supervisor for this project.
- If they have any general queries about participating in research they can find general information on the Involve website (www.invo.org.uk). *INVOLVE* is a national advisory Group, funded by the Department of Health, which supports active public involvement in NHS, public health and social care research.
- In the event that something does go wrong and participants are harmed during the research and this is due to someone's negligence then she/he may have grounds for a legal action for compensation against the University of Salford but they may have to pay their legal costs.

9. Study management

The study will be conducted by Fatemeh Sani Pour (postgraduate research student) under the supervision of, Dr. Peter Eachus, Prof. Alison Hammond and Dr. Linda Dubrow Marshall at the University of Salford.

10. Facilities available to support the study: Centre for Health Sciences Research, University of Salford

Fatemeh will be based within the Centre. Office, library, statistical and information/ computing services support are available at the University of Salford. The statistical analysis will be conducted by Fatemeh Sani Pour, under the supervision of, Dr. Peter Eachus, Prof. Alison Hammond and Dr. Linda Dubrow Marshall.

11. Dissemination of findings

On completion of the study, the findings will be submitted for review in a peer-reviewed Rheumatology or Psychology journal and also will be submitted to related conferences.

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Appendix 2.11. Ineligible participants

The College of Health and Social Care
School of Health Sciences
L731 Allerton Building
University of Salford
Frederick Road
Salford M6 6PU



Date: 03.02.2015

Dear Sir/ Madam

Re: Psychological Change in people rheumatoid arthritis

Thank you very much for returning the reply form indicating your interest in participating in the above study. Unfortunately, I am unable to include you in the study, as you did not meet the inclusion criteria for this study. However, the research team might contact you to help us in our future studies.

Please feel free to contact me should you require any additional information.

Thank you again for your time and interest in this study.

Yours Sincerely,
Fatemeh Sani Pour
Postgraduate researcher
School of Health Sciences
Allerton Buildings,
University of Salford
M6 6PU

Appendix 2.12. Reminder

Ref No: HSCR14/54

Date: 26.11.2014

Dear Sir/Madam

Research study: Psychological Change in people with Rheumatoid Arthritis

Thank you very much for agreeing to take part in this study. This is just a reminder that I have not yet received back the questionnaire from you. My apologies for this reminder, if you have just recently posted it back and my letters are crossing in the post. If you have mislaid the questionnaire and need another one, just give me a ring/ send me email.

I appreciate that completing the questionnaire does take time, but it is very helpful to me. Your help is very much appreciated. I look forward to hearing from you.

If you have now decided that you would prefer not to take part, then just leave a message or send a note and I will not send any further reminders.

If you have any questions now or at any stage during the study, please feel free to contact me (Fatemeh Sani Pour) on 07473611202 and I will be happy to resolve your queries.

Yours Sincerely

Fatemeh Sani Pour

Postgraduate researcher

Email: f.sanipour@edu.salford.ac.uk

Study measurements included as below.

Arthritis Impact Measurement Scales-2 (AIMS-2). The AIMS-2 refers to: Mobility level; walking and bending; hand and finger function; arm function; social activity; social support ; arthritis pain; level of tension and mood.

The Silver Lining Questionnaire (SLQ)

Orientation to Life Questionnaire

Arthritis Self-Efficacy Scale (ASES): arthritis pain and arthritis other symptoms

Bristol Rheumatoid Arthritis Fatigue Numerical Rating Scales (BRAFF-NRS)

The Coping with Rheumatoid Arthritis Questionnaire (C-RAQ)

Quality of Life-Rheumatoid Arthritis Scale (QOLRA Scale)

Scales of Psychological Well-Being (SPWB)

Office use:

Organization name **Participants number**

Date: _____

**PSYCHOLOGICAL CHANGE IN PEOPLE LIVING WITH RHEUMATOID
ARTHRITIS**

Thank you for taking part in this study.

It may take you about 30-45 minutes to complete, depending on how much time you wish to spend on it. However, it does not all have to be completed at one sitting and if preferred could be done over **a week**. As you complete, don't spend too much time on any one question.

There are **two** sections:

1. Information about you and your arthritis
2. Questions to evaluate change

We also want to remind you that your answers will be kept completely confidential.

If you have any queries, please contact Fatemeh Sani Pour

Mob: 07473611202

Email: f.sanipour@edu.salford.ac.uk

Please return to (in the **Freepost envelope** provided: no stamp needed)

FREEPOST RHSC- TRSU- TABY

Fatemeh Sani Pour, Postgraduate Research Student
School of Health Sciences (Psychology)
L731 Allerton Building
University of Salford
Frederick Road
Salford
M6 6PU

Part One:

Firstly, please tell us something about yourself and your rheumatoid arthritis.

Please tick \surd the boxes below where relevant.

1. Are you: Male Female

2. What is your date of birth? _____

3. Are you:

Married or living with a partner Single Divorced or separated

Widow/widower

4. Are you: Employed: full time

Employed: part-time

Homemaker (i.e.: not usually employed):

Student:

Unemployed:

Retired:

Early retired through ill-health:

Long term sick leave:

5. Do you have any other health problems rather than rheumatoid arthritis?

Yes No

If "Yes" please state what this/these are:

6. How long have you had rheumatoid arthritis (approximately)? Please ✓

Less than 2 years

2-5 years

6-10 years

Over 10 years

7. What is your current medication **for your rheumatoid arthritis**? (Please state drugs name)

a. _____

b. _____

c. _____

d. If you are not sure what is the name of your current medication

please ✓ the box.

8. Please ✓ level of formal education you have received:

No formal educational qualifications

CSE/O Level/GCSE

City & Guilds/GNVQ

A Level/ BTEC

Diploma

Degree

Other

9. Ethic group: please ✓ the group which you consider applicable to you:

White

Mixed

Back British/Black

Asian

British/Asian

other ethnic group

Prefer not to answer

Part TWO: Questions to evaluate change

Psychological Change in People Living with Rheumatoid Arthritis

(The Psychological Change Scales: PC)

Instructions: How do I complete this questionnaire?

On the next few pages, there are some statements about your Rheumatoid Arthritis (RA) experience. Please indicate the extent to which you agree or disagree with each statement by marking an appropriate number. There are no right or wrong answers. Your own personal views are important.

For the following questions all you need to do is:

- Check (X) boxes. For example:

	All Days	Most Days	Some Days	Few days	No Days
	(1)	(2)	(3)	(4)	(5)
1. How often were you physically able to drive a car or use public transportation?	_____	_____ X _____	_____	_____	_____

After completing the questionnaires, please return it to us in the Freepost envelope provided.

Thank you for your assistance.

ARTHRITIS IMPACT MEASUREMENT SCALES 2- (AIMS2)

Instructions: Please answer the following questions about your health. Most questions ask about your health during the **past month**. There are no right or wrong answers to the questions.

Please check (X) the most appropriate answer for each question about yourself.

These questions refer to **MOBILITY LEVEL**.

	All Days	Most Days	Some Days	Few days	No Days
DURING THE PAST MONTH...	(1)	(2)	(3)	(4)	(5)
1. How often were you physically able to drive a car or use public transportation?	_____	_____	_____	_____	_____
2. How often were you out of the house for at least part of the day?	_____	_____	_____	_____	_____
3. How often were you able to do errands in the neighborhood?	_____	_____	_____	_____	_____
4. How often did someone have to assist you to get around outside your home?	_____	_____	_____	_____	_____
5. How often were you in a bed or chair for most or all of the day?	_____	_____	_____	_____	_____

Please check (X) the most appropriate answer for each question about yourself.

These questions refer to **WALKING AND BENDING.**

	All Days	Most Days	Some Days	Few days	No Days
DURING THE PAST MONTH...	(1)	(2)	(3)	(4)	(5)
6. Did you have trouble doing vigorous activities such as running, lifting heavy objects, or participating in strenuous sports?	_____	_____	_____	_____	_____
7. Did you have trouble either walking several blocks or climbing a few flights of stairs?	_____	_____	_____	_____	_____
8. Did you have trouble bending, lifting or stooping?	_____	_____	_____	_____	_____
9. Did you have trouble either walking one block or climbing one flight of stairs?	_____	_____	_____	_____	_____
10. Were you unable to walk unless assisted by another person or by a cane, crutches, or walker?	_____	_____	_____	_____	_____

Please check (X) the most appropriate answer for each question.

These questions refer to **HAND AND FINGER FUNCTION.**

	All Days	Most Days	Some Days	Few days	No Days
DURING THE PAST MONTH...	(1)	(2)	(3)	(4)	(5)
11. Could you easily write with a pen or pencil?	_____	_____	_____	_____	_____
12. Could you easily button a shirt or blouse?	_____	_____	_____	_____	_____
13. Could you easily turn a key in a lock?	_____	_____	_____	_____	_____
14. Could you easily tie a knot or a bow?	_____	_____	_____	_____	_____
15. Could you easily open a new jar of food?	_____	_____	_____	_____	_____

Please check (X) the most appropriate answer for each question about yourself.

These questions refer to **ARM FUNCTION**.

	All Days	Most Days	Some Days	Few days	No Days
DURING THE PAST MONTH...	(1)	(2)	(3)	(4)	(5)
16. Could you easily wipe your mouth with a napkin?	_____	_____	_____	_____	_____
17. Could you easily put on a pullover sweater?	_____	_____	_____	_____	_____
18. Could you easily comb or brush your hair?	_____	_____	_____	_____	_____
19. Could you easily scratch your low back with your hand?	_____	_____	_____	_____	_____
20. Could you easily reach shelves that were above your head?	_____	_____	_____	_____	_____

Please check (X) the most appropriate answer for each question.

These questions refer to **SOCIAL ACTIVITY**.

	All Days	Most Days	Some Days	Few days	No Days
	(1)	(2)	(3)	(4)	(5)
DURING THE PAST MONTH...					
21. How often did you get together with friends or relatives?	_____	_____	_____	_____	_____
22. How often did you have friends or relatives over to your home?	_____	_____	_____	_____	_____
23. How often did you visit friends or relatives at their homes?	_____	_____	_____	_____	_____
24. How often were you on the telephone with close friends or relatives?	_____	_____	_____	_____	_____
25. How often did you go to a meeting of a church, club, team or other group?	_____	_____	_____	_____	_____

Please check (X) the most appropriate answer for each question about yourself.

These questions refer to **SUPPORT FROM FAMILY AND FRIENDS.**

	All Days	Most Days	Some Days	Few days	No Days
DURING THE PAST MONTH...	(1)	(2)	(3)	(4)	(5)
26. Did you feel that your family or friends would be around if you needed assistance?	_____	_____	_____	_____	_____
27. Did you feel that your family or friends were sensitive to your personal needs?	_____	_____	_____	_____	_____
28. Did you feel that your family or friends were interested in helping you solve problems?	_____	_____	_____	_____	_____
29. Did you feel that your family or friends understood the effects of your arthritis?	_____	_____	_____	_____	_____

Please check (X) the most appropriate answer for each question.

These questions refer to **ARTHRITIS PAIN.**

	Severe	Moderate	Mild	Very Mild	None
DURING THE PAST MONTH...	(1)	(2)	(3)	(4)	(5)
30. How would you describe the arthritis pain you usually had?	_____	_____	_____	_____	_____
	All Days	Most Days	Some Days	Few days	No Days
	(1)	(2)	(3)	(4)	(5)
31. How often did you have severe pain from your arthritis?	_____	_____	_____	_____	_____
32. How often did you have pain in two or more joints at the same time?	_____	_____	_____	_____	_____
33. How often did your morning stiffness last more than one hour from the time you woke up?	_____	_____	_____	_____	_____
34. How often did your pain make it difficult for you to sleep?	_____	_____	_____	_____	_____

Please check (X) the most appropriate answer for each question.

These questions refer to **LEVEL OF TENSION.**

DURING THE PAST MONTH...	Always (1)	Very often (2)	Sometimes (3)	Almost Never (4)	Never (5)
35. How often have you felt tense or high strung?	_____	_____	_____	_____	_____
36. How often have you been bothered by nervousness or your nerves?	_____	_____	_____	_____	_____
37. How often were you able to relax without difficulty?	_____	_____	_____	_____	_____
38. How often have you felt relaxed and free of tension?	_____	_____	_____	_____	_____
39. How often have you felt calm and peaceful?	_____	_____	_____	_____	_____

Please check (X) the most appropriate answer for each question about yourself.

These questions refer to **MOOD**.

DURING THE PAST MONTH...	Always (1)	Very often (2)	Sometimes (3)	Almost Never (4)	Never (5)
40. How often have you enjoyed the things you do?	_____	_____	_____	_____	_____
41. How often have you been in low or very low spirits?	_____	_____	_____	_____	_____
42. How often did you feel that nothing turned out the way you wanted it to?	_____	_____	_____	_____	_____
43. How often did you feel that others would be better off if you were dead?	_____	_____	_____	_____	_____
44. How often did you feel so down in the dumps that nothing would cheer you up?	_____	_____	_____	_____	_____

Thank you for completing this section. If you feel well enough please continue to the next questionnaire, If you would prefer to leave the next one until another time please do so.

The Silver Lining Questionnaire (SLQ)

Although illness can be a distressing experience, some people who have or have had an illness talk about its positive aspects. These questions ask you about the experience of being ill. Please indicate the extent to which you agree or disagree with each statement by circling the answer that best describes your personal views of your **Rheumatoid Arthritis**.

An example to help you:

Please **circle** the number that best reflects your opinions.

	Strongly agree	agree	not sure	disagree	Strongly Disagree
I appreciate other people more because of my illness.	5	4	3	2	1

If you strongly feel that you appreciate other people more now as a result of your RA, you would circle the number five.

There are no right or wrong answers, your own personal views are important.

Please **circle one** number for each statement.

	Strongly agree	agree	not sure	disagree	Strongly Disagree
1. I appreciate life more because of my illness	5	4	3	2	1
2. My illness gave me a new start in life	5	4	3	2	1
3. My life is much better now than it was before	5	4	3	2	1
4. My illness has made me live life to its fullest	5	4	3	2	1
5. Because of my illness I find it easier to accept what life has in store	5	4	3	2	1
6. My illness made me think about the true purpose of life	5	4	3	2	1
7. My religious/spiritual beliefs deepened because of my illness	5	4	3	2	1

Please **circle one** number for each statement.

	Strongly agree	agree	not sure	disagree	Strongly Disagree
8. I am now more open to other religions because of my illness	5	4	3	2	1
9. My illness made me a better person	5	4	3	2	1
10. I became a happier person because of my illness	5	4	3	2	1
11. I am a calmer person because of my illness	5	4	3	2	1
12. My illness made me more mature	5	4	3	2	1
13. My illness made me a more tolerant person	5	4	3	2	1

Please **circle one** number for each statement.

	Strongly agree	agree	not sure	disagree	Strongly Disagree
14. My illness made me realise that I matter as a person	5	4	3	2	1
15. My illness gave me more confidence	5	4	3	2	1
16. I am less concerned about failure because of my illness	5	4	3	2	1
17. My illness gave me permission to do things for myself	5	4	3	2	1
18. My illness made me a more determined person	5	4	3	2	1
19. My illness helped me find myself	5	4	3	2	1
20. My illness made me more aware of my strengths	5	4	3	2	1

Please **circle one** number for each statement.

	Strongly Agree	agree	not sure	disagree	Strongly Disagree
21. Through my illness I discovered a talent I didn't know I had	5	4	3	2	1
22. I can face whatever is around the corner because of my illness	5	4	3	2	1
23. My illness encouraged me to reflect on how I feel about myself.	5	4	3	2	1
24. My illness made me face up to problem areas of my life	5	4	3	2	1
25. My illness strengthened my relationships with others	5	4	3	2	1

Please **circle one** number for each statement.

	Strongly agree	agree	not sure	disagree	Strongly Disagree
26. My illness made me less concerned with the approval of others	5	4	3	2	1
27. Because of my illness I have more to offer other people	5	4	3	2	1
28. My illness made me more at ease with others	5	4	3	2	1
29. I see others in their true colours because of my illness	5	4	3	2	1
30. My illness gave me the opportunity to meet new people	5	4	3	2	1
31. My illness taught me how to stand up for myself	5	4	3	2	1

Please **circle one** number for each statement.

	Strongly agree	agree	not sure	disagree	Strongly Disagree
32. My illness made me put an end to troublesome relationships	5	4	3	2	1
33. My illness made me less judgmental of others	5	4	3	2	1
34. I have been an inspiration to others	5	4	3	2	1
35. People can be more open with me since my illness	5	4	3	2	1
36. My illness changed other people for the better	5	4	3	2	1
37. My illness changed other people's perception of me for better	5	4	3	2	1
38. Other people appreciate me more because of my illness	5	4	3	2	1

Thank you for completing this section. If you feel well enough please continue to the next questionnaire, If you would prefer to leave the next one until another time please do so.

Orientation to Life Questionnaire

Here is a series of questions relating to various aspects of over lives. Each question has seven possible answers. Please mark the number which expresses your answer, with numbers 1 and 7 being the extreme answers. If the words under 1 are right for you, circle 1; if the words under 7 are right for you, circle 7. If you feel differently, **circle** the number which best expresses your feeling.

Please give only **one** answer to each question.

1. Do you have the feeling that you don't really care about what goes on around you?

1

2

3

4

5

6

7

Very seldom
or never

Very often

2. Has it happened in the past that you were surprised by the behaviour of people whom you thought you knew well?

1

2

3

4

5

6

7

Never happened

Always
happened

3. Has it happened that people whom you counted on disappointed you?

1

2

3

4

5

6

7

Never happened

Always
happened

Please circle the number which best expresses your feeling.

4. Until now your life has had:

1 2 3 4 5 6 7

No clear goals or
purpose at all

Very clear goals
and purpose

5. Do you have the feeling that you're being treated unfairly?

1 2 3 4 5 6 7

Very often

Very seldom or
never

6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do?

1 2 3 4 5 6 7

Very often

Very seldom or
never

7. Doing the thing you do every day is:

1 2 3 4 5 6 7

A source of deep
pleasure and

A source of pain
and boredom

satisfaction

Please **circle** the number which best expresses your feeling.

8. Do you have very mixed-up feelings and ideas?

1

2

3

4

5

6

7

Very often

Very seldom or
never

9. Does it happen that you have feelings inside you would rather not feel?

1

2

3

4

5

6

7

Very often

Very seldom or
never

10. Many people – even those with a strong character – sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?

1

2

3

4

5

6

7

Never

Very often

Please **circle** the number which best expresses your feeling.

11. When something happened, have you generally found that:

1

2

3

4

5

6

7

You overestimated
or underestimated
its importance

You saw things in
the right
proportion

12. How often do you have the feeling that there's little meaning in the things you do in your daily life?

1

2

3

4

5

6

7

Very often

Very seldom or
never

13. How often do you have feelings that you're not sure you can keep under control?

1

2

3

4

5

6

7

Very often

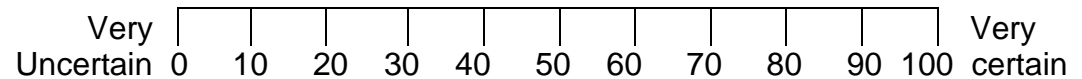
Very seldom

Arthritis Self-Efficacy Scale (ASES)

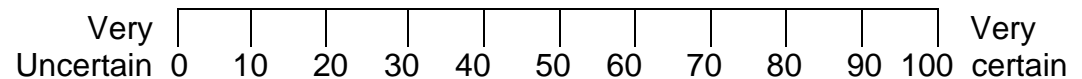
In the following questions, we'd like to know how your **arthritis pain affects you**.

For each of the following questions, please **circle** the number which corresponds to your certainty that you can **now** perform the following tasks.

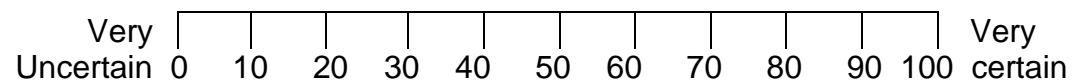
1. How certain are you that you can decrease your pain **quite a bit**?



2. How certain are you that you can continue most of your daily activities?

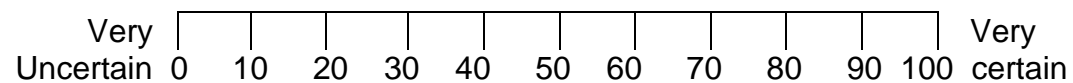


3. How certain are you that you can keep arthritis pain from interfering with your sleep?

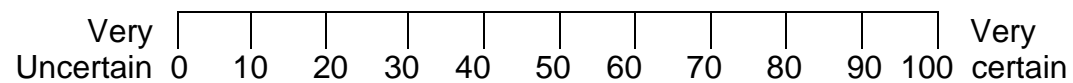


Please **circle** the number which corresponds to your certainty that you can **now** perform the following tasks.

4. How certain are you that you can make a **small to moderate** reduction in your arthritis pain by using methods other than taking extra medication?



5. How certain are you that you can make a **large** reduction in your arthritis pain by using methods other than taking extra medication?

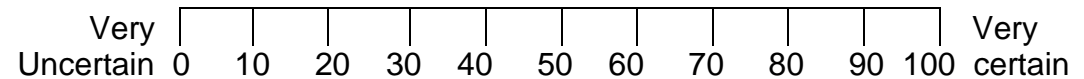


Arthritis Self-Efficacy Other Symptom Scale

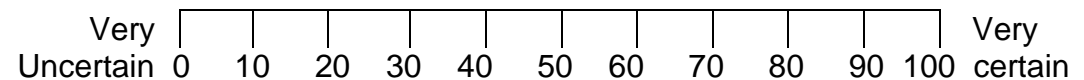
In the following questions, we'd like to know how you feel about your ability to **control your arthritis**.

For each of the following questions, please **circle** the number which corresponds to the certainty that you can **now** perform the following activities or tasks.

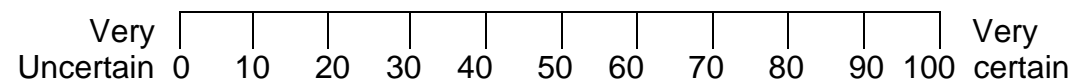
1. How certain are you that you can control your fatigue?



2. How certain are you that you can regulate your activity so as to be active without aggravating your arthritis?

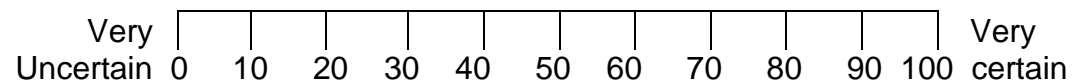


3. How certain are you that you can do something to help yourself feel better if you are feeling blue?

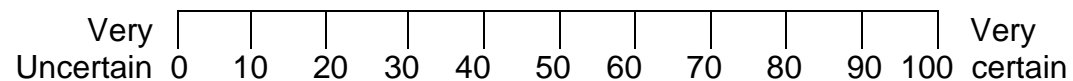


Please **circle** the number which corresponds to your certainty that you can **now** perform the following tasks.

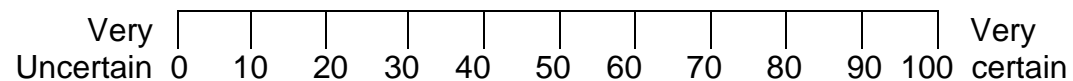
4. As compared with other people with arthritis like yours, how certain are you that you can manage arthritis pain during your daily activities?



5. How certain are you that you can manage your arthritis symptoms so that you can do the things you enjoy doing?



6. How certain are you that you can deal with the frustration of arthritis?



Thank you for completing this section. If you feel well enough please continue to the next questionnaire, If you would prefer to leave the next one until another time please do so.

Bristol Rheumatoid Arthritis Fatigue Numerical Rating Scales (BRAf-NRS)

Please **circle** the number which shows your **average** level of fatigue during the past **7** days.

0 1 2 3 4 5 6 7 8 9 10

No
fatigue

Totally
exhausted

The Coping with Rheumatoid Arthritis Questionnaire (C-RAQ)

Please answer the following items indicating the extent to which the corresponding coping behaviour had been used during the **past week** to cope with RA or by indicating in a separate category that the described coping behaviour **was not applicable** to you.

These questions are about the corresponding coping behaviour had been used during the Past week to cope with RA.

Please indicate the extent to which the following coping skills have been used by you to cope with your Rheumatoid Arthritis.

If you do not do an activity for reasons other than your arthritis, you should mark "Does not apply to me" and go to the next activity

Please **circle** the number that best reflects your opinion.

Please **circle** the number that best reflects your opinion.

	Not at all			A lot	Does not apply to me
1. Tried to keep my pain from interfering with Other things too much	0	1	2	3	
2. Made light of the situation: refused to be upset	0	1	2	3	
3. Went on as if nothing had happened	0	1	2	3	
4. Didn't let it get to me: refused to think about it too much	0	1	2	3	
5. Tried to keep my pain to myself	0	1	2	3	
6. Kept others from knowing how bad it was	0	1	2	3	
7. Concentrated on what I had to do-the next step	0	1	2	3	
8. I knew what I had to so I increased my efforts to make things work	0	1	2	3	
9. Made a plan of action and followed it	0	1	2	3	
10. Changed or grew as a person in a good way	0	1	2	3	

Please **circle** the number that best reflects your opinion.

	Not at all			A lot	Does not apply to me
11. I thought about someone who is in a worse situation	0	1	2	3	
12. Realized how, in some ways, I'm more fortunate than others	0	1	2	3	
13. Reminded myself how much worse things could be	0	1	2	3	
14. Rediscovered what is important in life	0	1	2	3	
15. I let my feelings out somehow	0	1	2	3	
16. Expressed anger	0	1	2	3	
17. Talked to someone about how I	0	1	2	3	
18. Accepted sympathy and understanding from someone	0	1	2	3	

Quality of Life-Rheumatoid Arthritis Scale (QOLRA Scale)

The following questions are about how your arthritis affects your quality of life. For each of the following questions, please **circle** the number that best reflects your opinions.

	Very poor										Excellent
1. Considering your physical ability, how would you rate your quality of life?	0	1	2	3	4	5	6	7	8	9	10
2. Considering the help that you receive from family and friends, how would you rate your quality of life?	0	1	2	3	4	5	6	7	8	9	10
3. Considering your arthritis pain, how would you rate your quality of life?	0	1	2	3	4	5	6	7	8	9	10
4. Considering your level of tension, how would you rate your quality of life?	0	1	2	3	4	5	6	7	8	9	10
5. Considering only your health, how would you rate your quality of life?	0	1	2	3	4	5	6	7	8	9	10

Please **circle** the number that best reflects your opinions.

**Very
poor**

Excellent

6. Considering only your arthritis, how would you rate your quality of life?

0 1 2 3 4 5 6 7 8 9 10

7. Considering your level of interaction with your family and friends, how would you rate your quality of life?

0 1 2 3 4 5 6 7 8 9 10

8. Considering your mood, how would you rate your quality of life?

0 1 2 3 4 5 6 7 8 9 10

Scales of Psychological Well-Being (SPWB)

Please **circle** the number that best describes the degree to which you agree or disagree with each statement.

	Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
1. I tend to be influenced by people with strong opinions	1	2	3	4	5	6
2. In general, I feel I am in charge of the situation in which I live.	1	2	3	4	5	6
3. I think it is important to have new experiences that challenge how you think about yourself and the world.	1	2	3	4	5	6
4. Maintaining close relationships has been difficult and frustrating for me.	1	2	3	4	5	6
5. I live life one day at a time and don't really think about the future.	1	2	3	4	5	6

Please **circle** the number that best describes the degree to which you agree or disagree with each statement.

	Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
6. When I look at the story of my life, I am pleased with how things have turned out	1	2	3	4	5	6
7. I have confidence in my opinions, even if they are contrary to the general consensus.	1	2	3	4	5	6
8. The demands of everyday life often get me down.	1	2	3	4	5	6
9. For me, life has been a continuous process of learning, changing and growth.	1	2	3	4	5	6
10. People would describe me as a giving person, willing to share my time with others.	1	2	3	4	5	6
11. Some people wander aimlessly through life, but I am not one of them.	1	2	3	4	5	6

Please **circle** the number that best describes the degree to which you agree or disagree with each statement.

	Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
12. I like most aspects of my personality.	1	2	3	4	5	6
13. I judge myself by what I think is important, not by the values of what others think is important.	1	2	3	4	5	6
14. I am quite good at managing the many responsibilities of my daily life.	1	2	3	4	5	6
15. I gave up trying to make a big improvements or changes in my life a long time ago.	1	2	3	4	5	6
16. I have not experienced many warm and trusting relationships with others.	1	2	3	4	5	6
17. I sometimes feel as if I've done all there is to do in life.	1	2	3	4	5	6
18. In many ways, I feel disappointed about my achievements in life.	1	2	3	4	5	6

Thank you for completing these questions!

Many thanks indeed for taking the time to answer this, which we very much appreciate. **Please could you go back and check you have not left out a page or any questions by mistake.**

To make sure please check each section and ✓ the following box: Have you completed the:

ARTHRITIS IMPACT MEASUREMENT SCALES 2- (AIMS-2). The AIMS-2 refers to:

- MOBILITY LEVEL
- WALKING AND BENDING
- HAND AND FINGER FUNCTION
- ARM FUNCTION
- SOCIAL ACTIVITY
- SUPPORT FROM FAMILY AND FRIENDS
- ARTHRITIS PAIN

• LEVEL OF TENSION

• MOOD

The Silver Lining Questionnaire (SLQ)

Orientation to Life Questionnaire

Arthritis Self-Efficacy Scale (ASES)

• ARTHRIIS PAIN

• ARTHRITIS OTHER SYMPTOM

Bristol Rheumatoid Arthritis Fatigue Numerical Rating Scales (BRAFF-NRS)

The Coping with Rheumatoid Arthritis Questionnaire (C-RAQ)

Quality of Life-Rheumatoid Arthritis Scale (QOLRA Scale)

Scales of Psychological Well-Being (SPWB)

Thank you

A summary of the study result will be sent to you. How would you prefer us to send it to you either by:

Post

E-mail

Please return to (in the Freepost envelope provided):

FREEPOST RHSC- TRSU- TABY

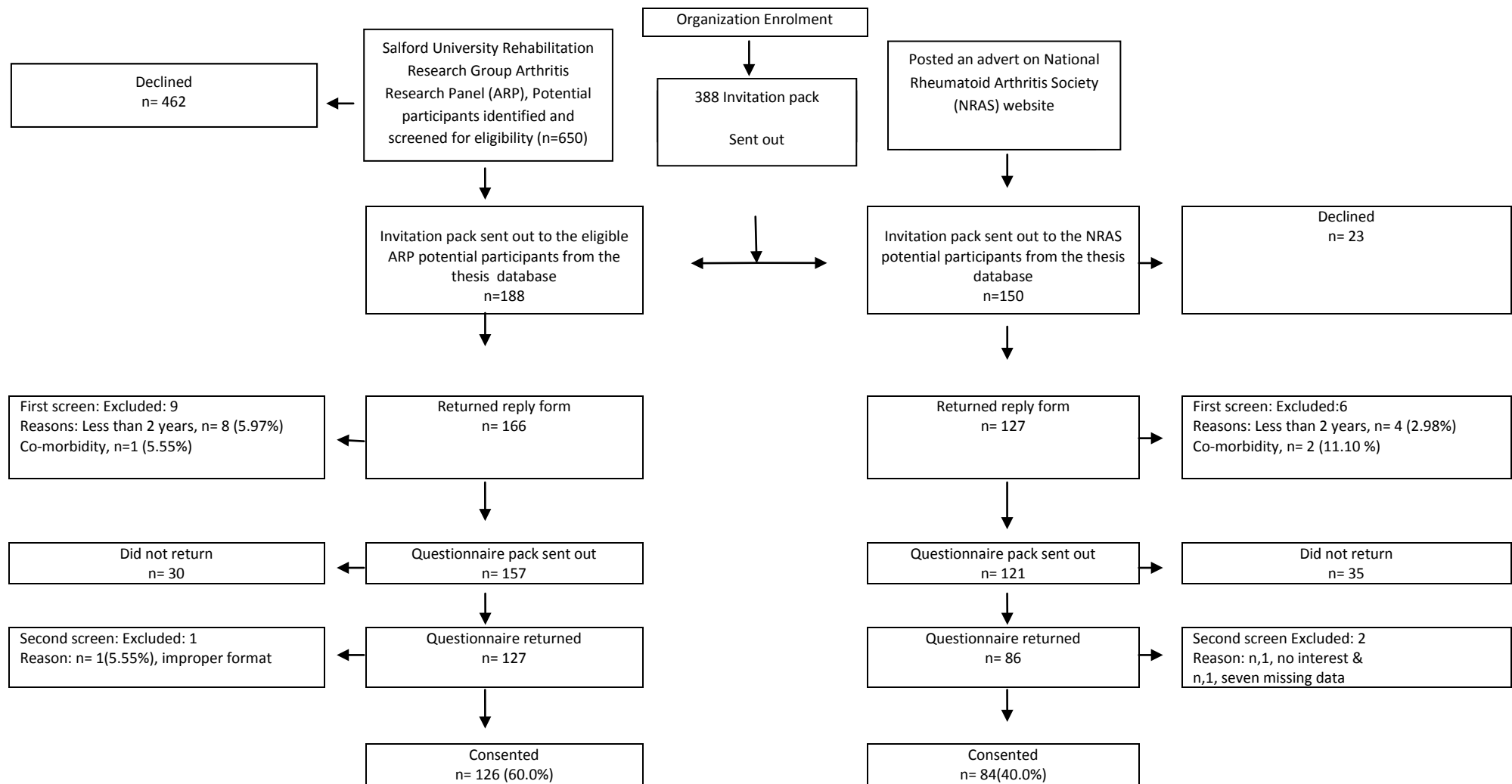
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Appendix 3.1. Study Flowchart



Appendix 3.2. Descriptive statistics for variables related to Positive Psychological Change in Rheumatoid Arthritis*

Study variables	Mean	Std. Deviation	Cronbach's Alpha
Positive Psychological change	95.09	26.09	.95
Psychological Well-being	67.96	5.06	.45
Coping strategy	36.77	10.36	.88
RA duration	3.30	.82	
Social support	8.63	4.69	.93
Sense of coherence and resilience	56.54	6.75	.27
Fatigue	5.69	2.46	-

*N=210

Appendix 3. 3. Correlation matrix for variables related to Positive Psychological Change in Rheumatoid Arthritis*

Study variables		Positive Psychological Change	Psychological well-being	Coping strategy	RA duration	Social support	Sense of coherence and resilience	Fatigue
Pearson Correlation	Positive Psychological Change	1.000	.237	.067	.211	-.107	-.121	-.169
	Psychological well-being	.237	1.000	.000	.048	.018	.008	.073
	Coping strategy	.067	.000	1.000	.104	-.143	.111	-.153
	RA duration	.211	.048	.104	1.000	-.094	.188	-.199
	Social support	-.107	.018	-.143	-.094	1.000	-.263	.192
	Sense of coherence and resilience	-.121	.008	.111	.188	-.263	1.000	-.185
	Fatigue	-.169	.073	-.153	-.199	.192	-.185	1.000
Sig. (1-tailed)	Positive Psychological Change	.	.000	.165	.001	.061	.040	.007
	Psychological well-being	.000	.	.498	.243	.397	.454	.145
	Coping strategy	.165	.498	.	.066	.019	.054	.013
	RA duration	.001	.243	.066	.	.088	.003	.002
	Social support	.061	.397	.019	.088	.	.000	.003
	Sense of coherence and resilience	.040	.454	.054	.003	.000	.	.004
	Fatigue	.007	.145	.013	.002	.003	.004	.
N	Positive Psychological Change	210	210	210	210	210	210	210
	Psychological well-being	210	210	210	210	210	210	210
	Coping strategy	210	210	210	210	210	210	210
	RA duration	210	210	210	210	210	210	210
	Social support	210	210	210	210	210	210	210
	Sense of coherence and resilience	210	210	210	210	210	210	210
	Fatigue	210	210	210	210	210	210	210

Appendix 3. 4. Stepwise regression analysis

Variables Entered/ Removed ^a			
Model	Variables Entered	Variables Removed	Method
1	How long you have had RA?, Coping strategy, Social support, Psychological well-being, Fatigue, Sense of coherence and resilience ^b	.	Enter

a. Dependent Variable: Positive Psychological Change

b. All requested variables entered.

Variables Entered/ Removed ^a

Model	Variables Entered	Variables Removed	Method
1	Psychological well-being	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
2	How long you have had RA?	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
3	Sense of coherence and resilience	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
4	Fatigue	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
5	Social support	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: Positive Psychological Change

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.437 ^a	.191	.167	23.22865

a. Predictors: (Constant), How long you have had RA?, Coping strategy, Social support, Psychological well-being, Fatigue, Sense of coherence and resilience

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.269 ^a	.072	.068	24.57597
2	.326 ^b	.106	.098	24.17988
3	.370 ^c	.137	.124	23.82174
4	.403 ^d	.162	.146	23.52596
5	.424 ^e	.179	.159	23.33961

a. Predictors: (Constant), Psychological well-being

b. Predictors: (Constant), Psychological well-being, How long you have had RA?

c. Predictors: (Constant), Psychological well-being, How long you have had RA? Sense of coherence and resilience

d. Predictors: (Constant), Psychological well-being, How long you have had RA? Sense of coherence and resilience, Fatigue

e. Predictors: (Constant), Psychological well-being, How long you have had RA? Sense of coherence and resilience, Fatigue, Social support

ANOVA ^a						
Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	9805.989	1	9805.989	16.236	.000 ^b
	Residual	125627.526	208	603.978		
	Total	135433.515	209			
2	Regression	14407.561	2	7203.780	12.321	.000 ^c
	Residual	121025.955	207	584.666		
	Total	135433.515	209			
3	Regression	18533.627	3	6177.876	10.887	.000 ^d
	Residual	116899.888	206	567.475		
	Total	135433.515	209			
4	Regression	21972.007	4	5493.002	9.925	.000 ^e
	Residual	113461.508	205	553.471		
	Total	135433.515	209			
5	Regression	24307.086	5	4861.417	8.924	.000 ^f
	Residual	111126.429	204	544.737		
	Total	135433.515	209			

a. Dependent Variable: Positive Psychological Change

b. Predictors: (Constant), Psychological well-being

c. Predictors: (Constant), Psychological well-being, How long you have had RA?

d. Predictors: (Constant), Psychological well-being, How long you have had RA? Sense of coherence and resilience

e. Predictors: (Constant), Psychological well-being, How long you have had RA? Sense of coherence and resilience, Fatigue

f. Predictors: (Constant), Psychological well-being, How long you have had RA? Sense of coherence and resilience, Fatigue, Social support

Coefficients^a

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	7.801	21.632		.361	.719
	Psychological well-being	1.274	.316	.269	4.029	.000
2	(Constant)	-6.058	21.849		-.277	.782
	Psychological well-being	1.206	.312	.255	3.868	.000
	How long you have had RA?	5.606	1.998	.185	2.805	.006
3	(Constant)	30.488	25.437		1.199	.232
	Psychological well-being	1.169	.308	.247	3.800	.000
	How long you have had RA?	6.555	2.000	.216	3.278	.001
	Sense of coherence and resilience	-.656	.243	-.177	-2.696	.008
4	(Constant)	44.213	25.717		1.719	.087
	Psychological well-being	1.218	.304	.257	4.002	.000
	How long you have had RA?	5.654	2.008	.186	2.816	.005
	Sense of coherence and resilience	-.735	.242	-.199	-3.033	.003
	Fatigue	-1.696	.680	-.164	-2.492	.013
5	(Constant)	52.635	25.836		2.037	.043
	Psychological well-being	1.279	.303	.270	4.214	.000
	How long you have had RA?	5.511	1.993	.182	2.765	.006
	Sense of coherence and resilience	-.854	.247	-.231	-3.455	.001
	Fatigue	-1.492	.682	-.145	-2.187	.030
	Social support	-.752	.363	-.139	-2.070	.040

a. Dependent Variable: Positive Psychological Change

Excluded Variables ^a

Model		Beta In	t	Sig.	Partial Correlation	Collinearity Statistics
						Tolerance
1	Social support	-.124 ^b	-1.855	.065	-.128	.989
	Sense of coherence and resilience	-.139 ^b	-2.105	.037	-.145	.999
	Fatigue	-.170 ^b	-2.577	.011	-.176	.997
	Coping strategy	.121 ^b	1.804	.073	.124	.982
	How long you have had RA?	.185 ^b	2.805	.006	.191	.994
2	Social support	-.106 ^c	-1.597	.112	-.111	.978
	Sense of coherence and resilience	-.177 ^c	-2.696	.008	-.185	.968
	Fatigue	-.138 ^c	-2.073	.039	-.143	.956
	Coping strategy	.110 ^c	1.655	.099	.115	.978
3	Social support	-.160 ^d	-2.390	.018	-.165	.917
	Fatigue	-.164 ^d	-2.492	.013	-.172	.940
	Coping strategy	.126 ^d	1.930	.055	.134	.970
4	Social support	-.139 ^e	-2.070	.040	-.143	.898
	Coping strategy	.119 ^e	1.841	.067	.128	.968
5	Coping strategy	.110 ^f	1.719	.087	.120	.964

a. Dependent Variable: Positive Psychological Change

b. Predictors in the Model: (Constant), Psychological well-being

c. Predictors in the Model: (Constant), Psychological well-being, How long you have had RA?

d. Predictors in the Model: (Constant), Psychological well-being, How long you have had RA? Sense of coherence and resilience

e. Predictors in the Model: (Constant), Psychological well-being, How long you have had RA? Sense of coherence and resilience, Fatigue

f. Predictors in the Model: (Constant), Psychological well-being, How long you have had RA? Sense of coherence and resilience, Fatigue, Social support

