Enabling factors in the open labour market and strategies used by individuals with rheumatoid arthritis to maintain their employment

Ancil Prinsloo

Presented in accordance with the requirements of the Department of Occupational Therapy, University of Cape Town, for the MSc in Occupational Therapy.

December 2002

Supervisor: *Prof A.A. Kalla*

University of Cape Town

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Declaration of originality

I, Ancil Prinsloo, student registration number PRNANN002, hereby declare that the thesis titled:

Enabling factors in the open labour market and strategies used by individuals with rheumatoid arthritis to maintain their employment

is the result of my own investigation and research and that it has not been submitted in part or in full for any other degree or at any other university.

Signed by candidate

A. Prinsloo

18. 11. 2002

Date

Acknowledgment

With the most sincere gratitude I would like to thank the following people:

- Dr C Lydell and staff, for assisting with patients at a very busy private practice.
- Drs Halland, Louw and staff, for assisting with patients at a very busy private practice, and just for their friendliness and support.
- Professor A Kalla and staff at the rheumatology clinics, at the Groote Schuur Hospital and Princess Alice Orthopedic Unit, for allowing me to gather information.
- Dr D Whitelaw and staff of the Tygerberg Rheumatology clinic, for allowing me to gather information at the clinic.
- MRC for funding, and especially Dr Maharaj, for affording me the opportunity to do this research.
- R. Laubscher, statistician at the MRC, for all her patience with my requests.
- Sr Gill Brown, for assisting with the questionnaire and generating ideas.
- UCT OT Department, for all the support every time my due date was pushed back even further.
- US OT Department, for support with increasing stress levels.
- Professors Kalla and Watson for reading the final product and suggesting valuable changes.

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Abstract

Objective and overall aim of this research

The objective of this research was to determine the enabling factors that employed individuals with rheumatoid arthritis encounter in the open labour market, and strategies they use to keep their jobs.

Methods

One hundred individuals with rheumatoid arthritis between the ages of 18 and 65 years and employed in the South African open labour market participated in the study. Participants were recruited from two tertiary hospitals and two private practices in the Western Cape. Participants completed a questionnaire and afterwards six volunteers were selected for a one-hour semi-structured interview.

The quantitative part of the study, in the form of a questionnaire, was used to develop a profile in terms of disease level, education level and work categories and status, as well as general demographic information of the participants. It was also used to gather information about the enabling factors encountered in the workplace by the participants, in terms of physical, psychological and social support.

The qualitative part of the study was done in the form of an interview. It was used to gather in-depth information from six selected volunteering participants regarding the personal strategies they use to maintain their employment in the open labour market, as well as the factors they believed enabled them to maintain their employment.

Results

From the quantitative part of the study, self-employment and autonomy over the scheduling of the job, support by colleagues and disclosure regarding the diagnosis to employers and co-workers were all significant work-related aspects that enable individuals with RA to stay employed. Individuals who are self-employed have significantly higher autonomy than other individuals (p=0,004). The individuals who told their employer (p=0,0220) and co-workers (p=0,0795) of their diagnosis felt that their work was of more

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importance to them than those individuals who did not make their diagnosis known. They also reported more support from their employers (p=0,0045) than those who kept their diagnosis secret.

Positive effects on pain were being married (p=0,0345) and using private transport (p=0,0159). The less children individuals had, the better was their self-perceived health status (p=0,0467), as measured by the Stanford Health Assessment Questionnaire (HAQ). An association was found between pain experience and self-perceived health status in working individuals with RA (p<0,0001). The higher the participant's pain experiences, the higher their HAQ scores.

Individuals who were subjected to stressful work requirements (p=0,0067) or indicated that they do physically heavy work (p=0,0432) perceived their work as more important than individuals who were not subjected to such circumstances.

The above quantitative findings were supported by the qualitative findings in that support by colleagues and disclosure regarding their diagnosis enabled them to stay employed. Being self-employed and having the autonomy or flexibility that goes with self-employment, helps individuals to continue working. Individuals not only stay employed for survival, but also because they have a positive attitude towards their work or just for the satisfaction derived from the work that they perform. Self-management skills are another important strategy that individuals with RA use to provide themselves with a sense of self-efficacy. Self-efficacy may be linked to having a strong internal locus of control, which enables individuals with RA to stay employed in the open labour market.

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Conclusion

It is important to realise that factors predisposing individuals to become work-disabled may be counteracted by other factors that actually enable them to remain employed. Health care professionals cannot always change the causal factors of work disability once a diagnosis is made, but they may be able to assist patients to take control of their disease. This can be done by teaching people affected by a disease such as RA how to cope with possible stressors caused by the workplace and how to identify the factors that may cause these patients to become work-disabled.

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Chapter 1

Introduction

1.1 Background to the research problem

As an occupational therapist working with individuals with rheumatoid arthritis (1996 to 1999), I became aware that individuals are often boarded from work within their first year of disease, sometimes even before they are referred to a rheumatologist. When boarded, they usually receive a single payout, according to their total salary and the number of years that they were employed.

Regarding the individuals involved in this study, referral to occupational therapy usually occurred once their money was depleted and the individual wanted to apply for a Government disability grant. At that stage most individuals had already seen a rheumatologist and were receiving sufficient medication to control the disease; thus they were not always disabled enough to qualify for a disability grant.

In most cases the individuals felt that they could not go back to their previous jobs. This meant that they had no income and had to look for a job once again, while they psychologically believed that they could not work, as they had been boarded.

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1.2 Introduction

Rheumatoid arthritis (RA) is a chronic, disabling condition that may affect the lives of those suffering from the disease in many ways. One of the most costly outcomes for individuals as well as the society is work disability. The total direct and indirect cost of the disease in South Africa is not known, but in the United States it is $8,74 billion annually (Newhall-Perry *et al.*, 2000).

What we do know, is that of 135 randomly selected individuals with RA, only 24% were employed in the open labour market at the time of assessment, while 35% were dependent on the South African Government for support (25% disability grant and 10% pension) (Mody *et al.,* 1988). Individuals with RA are also more at risk of losing their jobs when matched with an age and gender matched cohort of local controls without RA (Barrett *et al.,* 2000). Work disability is 4 to 15 (mean 7) times higher for individuals with RA than for the general population (Albers *et al.,* 1999).

In South Africa, with its high unemployment rate, individuals with RA are at a higher risk of becoming unemployed. According to the October 1996 census, 33,9% of the economically active population were unemployed and 6,6% of the total South African population are disabled. According to the Case Disability Survey, (Department of Health) undertaken in 1999 and published in January 2000, it was found that 88% of individuals with disabilities are unemployed. Of these disabled individuals 6% indicated that their disability was due to arthritis.

Individuals with RA and who are employed in the open labour market, are often faced with numerous physical, psychological and social barriers, that in time could cause work disability. Numerous studies have been done internationally to look at the factors that have an impact on work disability, but few actually focus on what enables individuals to maintain their employment status (Yelin *et al.,* 1980; Pincus *et al.,* 1984; Yelin *et al.,* 1987; Reisine *et al.,* 1989; Callahan *et al.,* 1992; Reisine & Fifield, 1995; Doeglas *et al.,* 1995; Mau *et al.,* 1996; Allaire *et al.,* 1996; Wolfe & Hawley, 1998; Fex *et al.,* 1998; Van Jaarsveld *et al.,* 1998; De Roos & Callahan, 1999; Sokka *et al.,* 1999; Albers *et al.*, 1999; Jantti *et al.,* 1999; Young *et al.,* 2000; Barrett *et al.*, 2000; & Chorus *et al.,* 2000).

Paid employment plays an important role in daily life. This is no less true for individuals with RA (Yelin *et al.*, 1987). Work not only provides social status and income, but is also valued for its social support and social distraction. Having a paid job can have positive effects on well-being and quality of life (Chorus *et al.*, 2000).

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In terms of South African legislation on workplace and employment practices, especially the Employment Equity Act of 1998, which focuses on the integration of disabled people into the workplace, disabled people, including individuals diagnosed with RA, should be helped to maintain their employment. This should be possible if we knew which factors cause work disability as well as which factors enable individuals to maintain their employment in the open labour market.

As health care professionals, occupational therapists focus on the functioning of the disabled in everyday life, of which work is a component. With their knowledge of functioning in the work environment, as well as medical background, occupational therapists should be able to assist individuals to maintain their employment for as long as possible, once they have been diagnosed with RA.

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1.3 Importance of this study

As some of the factors that cause work disability are known (see Table 3.1), we should be able to assist individuals with RA to stay employed for a longer period, thus maintaining health and quality of life.

Why are individuals with RA, then, still becoming work disabled if we know what the cause of the problem is? Furthermore, why are individuals that are predisposed to become work disabled when considering the factors that cause work disability, often still employed?

The researcher believes that there are other factors that assist individuals to stay employed, which are not taken into consideration. The interplay between the factors that cause work disability and those which enable individuals to stay employed, is a fine line that needs to be explored with each individual once he/she has been diagnosed.

Individuals with RA are usually first diagnosed when they are in the economically active stage of life, often after having been employed for a few years. In view of the Employment Equity Act and Skills Development Act, individuals as well as their employers could be assisted to make the necessary adaptations to accommodate an employee diagnosed with RA in a reasonable manner, instead of the individual being boarded (Silver & Koopman, 2000).

In the long term this would mean that society saves money in terms of the health budget, a decrease in disability grants and single amount pay-outs as a result of individuals who are boarded, as well as improving the quality of life of the individual diagnosed with RA.

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Chapter 2

Research aims and objectives

2.1 Overall aim

The overall aim of this research study is firstly to determine the enabling factors that employed individuals with RA encounter in the open labour market and secondly, to identify the strategies individuals diagnosed with RA use in order to stay employed.

If we know what it is that enables individuals with RA to maintain their work in the open labour market in South Africa and we combine this knowledge with that which we already know about the causes of work disability, we should be able to make valuable contributions to enable individuals with RA to stay employed once they have been diagnosed. The factors that enable individuals to stay employed in the open labour market have, as yet, not been thoroughly explored. Only one article was found that considered the factors that enable individuals with RA to stay employed (Mancuso *et al.* 2000), and in other cases these factors are regarded as being the opposite of the causes of work disability (Chorus *et al.*, 2000 & Chorus *et al.*, 2001).

In a randomised cross-sectional study among a representative sample of Dutch individuals with RA, it was found that working individuals had significantly fewer disabilities and a better quality of life than individuals who did not work — their physical functioning was better and their role impairment was less (Chorus *et al.*, 2000). In view of South African legislation, especially the Employment Equity Act of 1998 that makes it mandatory for employers to integrate individuals with disabilities into their workforce, we can presume that it should now be easier to promote reasonable accommodation for individuals with RA. If we know what it is that enables individuals with RA in South Africa to stay employed, which strategies they use to continue with their jobs as well as what causes work disability, intervention could be much more timely, focused and complete.

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Barrett *et al.* (2000) observed that, at a very early stage after onset of RA, those individuals who are working, need to receive a very careful analysis of their work, their workplace, their work commitments and their plans and aspirations regarding their work. Any delay at this stage potentially compromises the chances the individuals may have of remaining economically active, even if the disease then improves. Similar observations were made in South Africa as early as 1981, in a survey of 100 South African individuals diagnosed with RA (Brighton & Louw, 1981).

It is unknown whether these recommendations were widely implemented, but the researcher did not receive any such referrals for the period that she was involved in the treatment of individuals diagnosed with RA in South Africa (1993 – 1994 & 1996 – 1999).

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2.2 Definition of terms

For the purpose of this study the following terms are defined in order to clarify their meaning within the research context.

Autonomy	The control that individuals have over the pace and scheduling of their job.
Boarded	An individual who is declared medically unfit to continue with his/her current job in the open labour market.
Level of education	The highest educational qualification that an individual has obtained.
Employment	Indicates that an individual works regularly part-time or full-time, in the open labour market for financial gain, regardless of whether permanently employed, temporarily or self-employed.
Enable	Empowerment of an individual to be competent in his/her job performance.

Locus of control	The perceptions of individuals of what causes things to happen, whether by chance or luck (*external locus of control*) or by their own influence (*internal locus of control*).
Labour force participation	Having a paid job.
Open labour market	Public or unrestricted job market in South Africa, regardless of whether an individual is employed full-time, regularly part-time, self-employed or a contract worker.
Self-efficacy	The view of ourselves as competent in the tasks that we perform.
Self-management	Those abilities that enable individuals to accomplish their goals, despite stressors and which are often used to describe all the coping skills that individuals apply.
Support	Any form of physical, social or psychological assistance or help experienced by the individual in and outside the workplace, whether from the environment itself or from other people.
Rheumatoid arthritis (RA)	Form of arthritis with inflammation of the joints, stiffness, swelling, synovial hypertrophy and pain.
Work disability	Being unemployed in the open labour market full-time or regularly part-time as a result of, in this case, RA.
Work status	Whether an individual works full-time for someone else, is employed regularly part-time, as a contract worker, or whether he or she is self-employed.

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2.3 Objectives of the study

The objectives of this study can be divided into three separate subsections.

1. *To develop a profile of the study participants in terms of disease level, level of education, work status, work category (according to South African norms), and general demographic information of the individuals with RA that are employed in the open labour market.*

If the characteristics of an individual with RA in terms of the above factors are known, we should be able to form a baseline from which to work when comparing South African findings with overseas findings. Marital status, age at onset of RA, level of formal education, time since onset of RA, level of disability as measured by the HAQ, and the nature of the job are all indicators of work disability (Barrett *et al.*, 2000).

2. *To determine the enabling factors encountered in the workplace by individuals with RA in terms of physical, psychological and social support.*

Information about the forms of support in the workplace that enable an individual to stay employed, would provide the occupational therapist with the ability to give specific guidance to the employers and employees when vocational guidance and reasonable accommodation are investigated and implemented.

3. *To determine which personal strategies individuals with RA apply to maintain their work in the open labour market.*

It is important to learn about the personal strategies that individuals with RA apply in order to maintain their employment. It might not only be the single reason why some individuals manage to stay employed while others become work disabled, but this knowledge could also provide insights for others in the same situation.

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2.4 Research question

During the course of this project the question that will be investigated is:

Which factors have enabled some individuals with RA to continue with remunerated employment in the open labour market?

If the factors that enable individuals with RA to stay employed in the South African open labour market are known, we should be able to assist other individuals with RA to maintain their employment status. This information regarding RA and the employment status of individuals with RA should be combined with the data from international studies, in terms of what causes work disability.

Work and more specifically work disability, have been at the core of occupational therapy for the last seven and a half decades. The reason for this is that occupational therapy is defined as *...the art and science of helping people do the day-to-day activities that are important to them despite impairment, disability, or handicap* (Neistadt & Crepeau, 1998).

Occupational therapy practitioners in the USA find themselves involved with handling the work-related needs of not only their clients, but also of industries and insurance companies. Lost work-time, lost dollars and restricted worker abilities have encouraged employers to become more involved and more knowledgeable about the care and management of their injured workers. In the present atmosphere of change in health care, the guiding principles for a successful industrial rehabilitation programme must be quality care, cost containment and the flexibility to expand services to meet the evolving needs of the marketplace (Neistadt & Crepeau, 1998).

Occupational therapists in South Africa are actively involved in vocational rehabilitation, whether directly with clients, their employers, the industry as a whole, or with insurance companies. In terms of the changing legislation (Employment Equity Act, 1998; Skills Development Act, 1998) occupational therapists have an important role to play in addressing the work-related needs of individuals with RA, not only as far as their patients are concerned, but also in the industries in which these individuals are employed.

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Chapter 3

Literature review

3.1 Incidence of rheumatoid arthritis

RA is a chronic condition characterised by symmetric synovitis affecting peripheral joints, erosion of cartilage surfaces and ultimately joint deformity and destruction. It affects about 0,7% of the US population (Newhall-Perry *et al.*, 2000). The course of RA varies from a mild, even self-limiting disease to a severe destructive form within a few years. There is still no agreement concerning the rate of progression of RA and how best to measure it. Over the first 5 years 40% of people do relatively well (13% remission), 44% follow a relapsing/remitting course with variable, but definite functional impairment, while a small proportion (16%) do badly in terms of the effect that RA has on functional ability and life events (Young *et al.*, 2000).

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3.2 Economic burden

Work disability in individuals with RA has significant socio-economic consequences for the health budget of any country.

Estimates based on the analysis of the 1989-91 National Health Interview Survey suggest that the total annual cost of RA to the US nation is about $8,74 billion, with lost wages among working age patients accounting for 46% of the total annual costs. Newhall-Perry *et al.* (2000) found that during the first year of disease, the average total direct cost was $200/month, while the average indirect cost was $281/month. *Direct cost* was defined as *expenditures for medical care as well as non-medical expenditures as a result of the illness* and *indirect cost* as *costs associated with loss of function arising from disability or death* (Newhall-Perry *et al.*, 2000).

Expenditures for employees with RA were found to be approximately three times that of other employees, when medical, pharmaceutical and disability claims were considered. The annual total employer cost per RA patient in terms of medical, pharmaceutical and

work loss expenditures was $7193 in 1997 (or $9693 per RA employee), for both RA-related and co-morbid conditions (where co-morbid refers to all other non-RA conditions). Such costs are approximately twice as high among both RA Patient Sample and RA Employee Sample when compared to controls without RA (i.e. $3405 and $4819, respectively) (Birnbaum *et al.*, 2000).

RA also has consequences for the economic status of the diagnosed individuals. Of 186 individuals with early RA, 42% were registered as work disabled after 3 years, and nearly a quarter of these individuals experienced an income reduction (Albers *et al.*, 1999). Considering that there are, according to Barrett *et al.* (2000), approximately 22 000 new cases of RA in the UK each year, of which 55% of the patients are of working age at the time of onset of the symptoms, it is quite possible that approximately 3 000 would experience a reduction in income.

With the above findings in mind, the burden of disease in South Africa can only be estimated. The most feasible attempt would be to determine the number of individuals receiving a disability grant due to their rheumatoid arthritis, using a survey of individuals attending the rheumatology clinics at government hospitals, but this data is not always available.

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3.3 Indicators of work disability

Taking into account the cost to society and the individual, one of the most important consequences of RA may be work disability. Research into work disability due to RA has been widely reported and numerous factors contributing to work disability have already been determined, as illustrated in Table 3.1.

Barrett *et al.* (2000) describes three main categories associated with work disability.

1. Employment
    - the nature of the post
    - the level of physical activity required
    - the degree of autonomy, especially regarding the pace of the work

2. Employee
   - age at onset of RA
   - marital status
   - level of formal education

3. Disease
   - time since onset of RA
   - level of disability, as measured by the HAQ

3.3.1 Employment

3.3.1.1 The nature of the post

Barrett *et al.* (2000) noted that factors such as the pace of the work, the physical limitations imposed by the workplace, ease of access to the workplace, as well as the contribution that colleagues, supervisors and managers make, has an effect on the individual's ability to maintain his/her employment.

There were also differences in the overall stress experienced by men and women with RA and who were engaged in paid work. While women had significantly lower personal incomes and a tendency to more demanding work, they had equal or higher levels of autonomy than men. Autonomy, and more specifically schedule autonomy, was measured, using five questions regarding the individual's assessment of his or her freedom to decide when to –

- come in to work;
- when to take a rest break;
- take time off for a doctor's visit;
- take a day off; and when to
- take a week off.

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The differences in emotional distress between workers are primarily the result of differences in functional ability and pain, and secondarily due to the characteristics of the paid work, irrespective of sex. Emotional distress was regarded as depressive symptoms, including a depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite and sleep disturbance. Distress increased with decreasing functional ability, increasing pain and exposure to such work characteristics as low autonomy, low income and high demands (Fifield *et al.,* 1996).

3.3.1.2 The level of physical activity required

According to the literature, manual workers are at a greater risk of becoming work disabled (Barrett *et al.*, 2000). Manual work was found to predict work disability for men in all age groups, but not for women. It is speculated that the association between work disability and physical work for men probably reflects that it is more difficult for manual workers than professionals to stay employed, as their work is less adaptable (Holte *et al.,* 2001).

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3.3.1.3 The degree of autonomy, especially regarding the pace of the work

In the studies by Yelin *et al.* (1980) and Reisine *et al.* (1989) it was found that the single most important factor in determining the risk of work disability was the characteristic of the work. This included factors such as autonomy regarding the pace and scheduling of the work and the physical nature of the work. This matter was discussed in Section 3.3.1 in the subsection dealing with the nature of the posts.

On the other hand, the work factors that have been identified as risk factors for work disability, are a physically demanding job, lack of control over the pace and activities regarding the work, lack of self-employment status, lack of support by employers and colleagues, and also difficulties in commuting (Chorus *et al.*, 2001).

3.3.2 Employee

3.3.2.1 Age at the onset of RA

An age of 50 years or older negatively affects the employment status of an individual with RA (Mau *et al.*, 1996). The findings of Barrett *et al.* (2000) and Young *et al.* (2000) support this. These three groups of researchers found that a higher age negatively affected the ability of an individual with RA to maintain his/her work in the open labour market.

3.3.2.2 Marital status

Single persons are less likely to become work disabled than individuals who are married or who have previously been married, even when controlled for race, age or sex (Yelin *et al.*, 1980).

Homemaker role responsibilities have a significant effect on work status in that women who reported fewer responsibilities in the instrumental aspects of the homemaker role at the onset of RA, were more likely to be unemployed at the time of the interview. Instrumental aspects of the homemaker role included cooking, cleaning and shopping. These findings suggest that larger family responsibilities may be beneficial to social functioning, rather than undermining it. Having more responsibilities in the homemaker role may contribute to a sense of self-worth that enhances, rather than undermines social functioning (Reisine *et al.*, 1989). Absence of support in the home accounts for higher depression scores in working women with RA. A supportive relationship seems to foster better coping strategies, which leads to better psychological adjustment (Reisine, 1993).

Spouse criticism and support affect coping with RA. Individuals with a highly critical spouse engaged in more maladaptive coping behaviours and reported poorer psychological adjustment, whereas individuals who perceived their spouses as being supportive, engaged in more adaptive coping behaviour (Manne & Zautra, 1989).

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Work disabled individuals with RA reported a significantly lower total household income. Depressive symptoms are also higher in individuals who are work disabled, even though no difference was found in the amount of social support that they receive (Newhall-Perry *et al.*, 2000). The ability to maintain paid work after the onset of RA is related to lower reports of both pain and depressive symptoms, irrespective of the severity of the disease (Fifield *et al.*, 1991).

3.3.2.3 Level of formal education

A low level of education increases the risk of work disability (Fex *et al.*, 1998). It is important to link level of education with income level and work status. Level of education has a direct effect on the types of work for which an individual qualifies (Leigh & Fries, 1991). Younger, male or more highly educated individuals with RA are more likely to remain working ($p<0,05$). Labour force participation by men with RA who had a primary level education was decreased in men between the ages of 20–29, 40–49 and 50–59, when compared to the general population. In both male and female individuals with RA who had secondary school level education, it was found that labour force participation was only reduced in the highest age category. In individuals with a high level of education, labour force participation was only significantly reduced for women in the age categories 40-49 and 50-59 years (Chorus *et al.*, 2000).

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3.3.3 Disease

3.3.3.1 Time since the onset of RA

According to Jäntti *et al.* (1999) 31% of individuals with RA stopped working as a result of RA one year after the onset of the disease (n=103). The cumulative work disability rate gradually increased, and 20 years later had reached 80%. In a random sample of a Dutch RA population (n=1056), disease duration of six years and more was negatively associated with labour force participation. There was only a slight decrease in paid jobs when compared to a cohort of the Dutch population of the same age, sex and level of education (Chorus *et al.*, 2000). Barrett *et al.* (2000) reported that many people stop

working very early in the disease process, often before they are referred to hospital or before being started on disease-modifying anti-rheumatic drugs (DMARD). The fastest decline in employment rate for individuals with RA was found within the first three years after the onset of the disease (Mau *et al.* 1996).

3.3.3.2 Level of disability as measured by the HAQ

In predicting work disability, self-reported health status, as measured by the Stanford Health Assessment Questionnaire (HAQ), is one of the major determinants of work status and it is found to be a better predictor of work disability than work, social or home factors (Reisine *et al.*, 1989).

The HAQ, originally constructed at the Stanford Arthritis Center (California), has repeatedly been shown to possess high reliability and validity. It has been developed specifically for use in patients with arthritis. The HAQ (range 0 – 3) was found to have several levels of clinical relevance. It correlates with and can act as a summary measure in the following cases:

- clinical variables – grip strength, joint count, and pain
- psychological variables – anxiety and depression
- universally performed laboratory tests – Erythrocyte Sediment Rate (ESR).

Moreover, with time, changes in the HAQ move in the same direction as changes in the other clinical variables, thus serving as a global measure of how well or poorly the patient is doing. Current scores of the HAQ predict future service utilisation and mortality. However, prediction of utilisation is not only a prediction of economic impact; it is also a prediction of sickness and of severity.

In view of the World Health Organisation model of disability, the HAQ operates entirely at the level of disability, where it is a summary measure of the effects of impairment (Fries *et al.* 1982 & Wolfe *et al.*, 1988).

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The clinical relevance of the HAQ as an indicator of work disability in RA is easier to understand in view of the above, since it is disease and impairment that drive the HAQ in describing functional disability. The risk of work disability increased with higher HAQ scores and was found to be the best predictor of work disability (Fex *et al.*, 1998; Barrett *et al.*, 2000; Newhall-Perry *et al.*, 2000; Young *et al.*, 2000). Barrett *et al.* (2000) found that baseline HAQ scores or self-perceived health status at diagnosis of 1,50 or more was associated with a 3-fold increase in the odds of stopping work.

In an inception cohort study of 103 patients diagnosed with RA, the mean HAQ scores were found to be lowest amongst individuals still at work after twenty years (mean HAQ score = 0.96). There was no difference between the HAQ scores of individuals retired because of RA, those retired because of another disease or those retired because of age (Jäntti *et al.*, 1999).

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3.3.3.3 Pain scale

Self-reported pain, as measured by the visual analogue scale (VAS), has been investigated in numerous studies researching work disability. So far, no association has been found between the level of pain and work disability (Sokka *et al.*, 1999; Wolfe & Hawley, 1998; Van Jaarsveld *et al.*, 1998; Fifield *et al.*, 1996).

An association has been found between self-reported pain, as measured by the VAS, and psychological distress. Increasing levels of psychological distress are associated with more severe levels of self-reports of pain (Wolfe, 1999).

Barrett *et al.* (2000) drew up a table (see Table 3.1), taking all the relevant information from different studies into account.

Table 3.1 Statistics of work disability (Adapted from the table by Barrett *et al.* (2000))

Reference	Rate of work disability	Factors associated with work disability	Country
Yelin et al., 1980	62% at 10 years follow-up	• Stage of disease • Work autonomy • Marital status (married>single)	USA
Pincus et al., 1984	85% at 9 years follow-up		USA
Yelin et al., 1987	50% at 10 years follow-up 90% at 30 years follow-up	• Physical post • No control over pace of work	USA
Pincus et al., 1989	Males → 43,9% Females → 69%		USA
Reisine et al., 1989	43% were work disabled at assessment date Females → 122	1. Higher HAQ (self-reported disease measure) 2. Characteristics of the work • Lack of autonomy regarding pace and scheduling of the work • Physical nature of the job 3. Age 4. Family factors • Having more responsibility in homemaker role enhances social functioning (Physical disability, as measured by HAQ, produced the best predictive variable of work-disability, followed by characteristics of the workplace, age and family factors)	USA
Callahan et al., 1992	128 patients working full-time at the onset of disease and who are under 65 years of age at assessment 43% work disabled 28% continued to work	• Demographic distribution • Functional measures • Type of occupation • Duration of disease • Age	USA
Reisine et al., 1995	267 employed females	• Older • Female	USA
Doeglas et al., 1995	42% at 2 years follow-up	• Disease-related variables • Education level • Manual job • HAQ	The Netherlands
Mau et al., 1995	37% at 7 years follow-up	• Older age at onset • Functional disability • Physical job • High erythrocyte sedimentation rate	Germany

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Allaire et al., 1996	21,7% at 7 years follow-up	• Older • Less educated • Disease duration • Physical job • More pain • Lower salary • Worse functioning	USA
Wolfe & Hawley, 1998	22,5% at 5 years follow-up 31,5% at 10 years follow-up	• Less formal education • More tender joints • Higher BMI • Higher pain score • Poorer grip strength	USA
Fex et al., 1998	37% at 3 years follow-up	• HAQ • Educational attainment • Age at onset	Sweden
Van Jaarsveld et al., 1998	37% at 2,8 years follow-up		The Netherlands
De Roos & Callahan, 1999	26,5% at 11 years follow-up	• Age • Duration of disease • Education • Marital support • Poorer functioning • Higher pain score	USA
Sokka et al., 1999	23% at 2 years follow-up 38% at 10 years follow-up	• Age at onset • Level of educational • Physical job • Number of swollen joints	Finland
Albers et al., 1999			The Netherlands
Jäntti et al., 1999	31% at 1 year follow-up 80% at 20 years follow-up	• HAQ	Finland
Young et al., 1999	40% at 5 years follow-up	• Manual workers • Age at onset • Severity of disease • Socio-economic status • HAQ	United Kingdom

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3.4 Work disability in South Africa

It is important that the findings of the 1996 National Population Census are taken into account when considering the relevant literature. According to the 1996 census the South African population comprises 40,58 million people, of whom 6,6% are disabled individuals. Only 9,7% of the total population reside in the Western Cape, of whom 3% are disabled in some way. Of the disabled individuals in the Western Cape, 0.9% have physical disabilities. Of the South African population, 57,4% are in the economically active age group of 15 to 65 years. Of these, only 66% are gainfully employed in the open labour market. As many as 82% of the Western Cape population in the economically active age group are employed in the open labour market. The distribution of employed individuals in the economically active age group, according to occupational categories, are shown in Graph 3.1.

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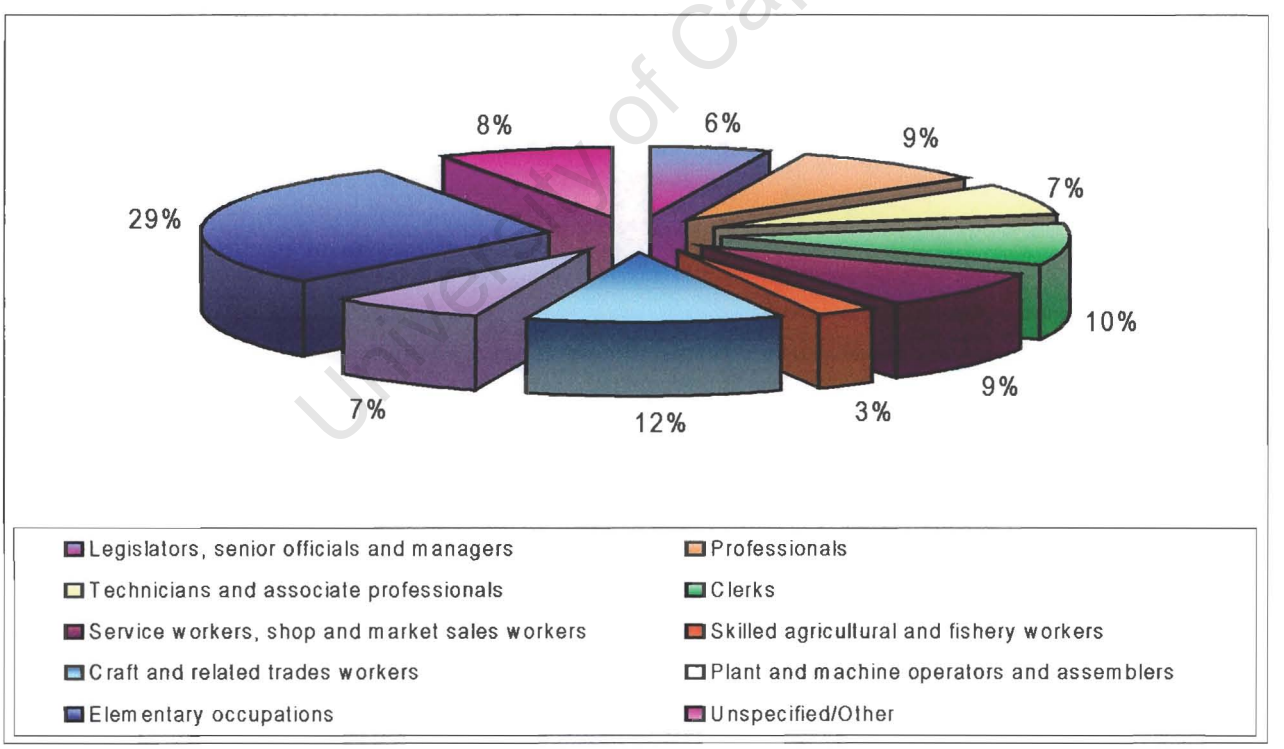
Graph 3.1 Western Cape occupational categories



In the South African study by Mody *et al.* (1988), involving a population of 135 individuals diagnosed with RA, it was found that 24% of the individuals were employed at the time of the assessment. Of the employed individuals, 85% were employed full-time and 15% were employed part-time. Of the individuals not employed, 50% had worked in the past and two-thirds had stopped working due to their arthritis. State-dependency in the group was 35% of which 10% was in the form of a grant for aged persons and the rest were disability grants. The individuals involved in this study indicated that after pain (96%) and stiffness (80%), finances (58%) constituted their main problems. Of the individuals, 33% also indicated that they saw the inability to work as a major problem. This can be linked to the fact that 35% of the individuals were dependent on the state for support. Currently (August 2002), disability grants are R620 per month.

In the study by Brighton and Louw (1981) on a South African population of 100 individuals diagnosed with RA, it was found that while 61% of individuals interviewed were not working, the rest were employed. Of the non-working group, 50% were unable to work due to their arthritis, 44% did not need to work and 6% were retired people receiving a grant for aged persons. Of the 39 employed individuals, 57% felt that they had adapted well and that they were, as yet, not experiencing any problems at work as a result of their RA. The other 43% were experiencing problems, but could not afford to stop working. Of the working individuals 20% had to change their jobs for a lesser paid post due to their arthritis. Of this group, some felt that with adequate preparation they could have obtained alternative qualifications and, in doing so, could have maintained their economic status. Only 10% of the working individuals had deliberately improved their qualifications in order to qualify themselves for a more suitable post and had actually improved their financial position.

The most important findings from the results of the study by Brighton and Louw, (1981) was that little attention is given to occupational suitability in the early course of the disease and that vocational guidance is thus of paramount importance. Brighton and Louw, (1981) believe that further training could greatly help patients to acquire employment of a less strenuous nature. Furthermore, these authors emphasised the fact that many patients expressed the regret that they had not been warned about the course of the disease and the necessity for occupational adaptation.

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Brown *et al.* (1987), in their study of 345 patients in the metropolitan area of Cape Town who suffer from chronic arthritis, found that there is a need for improved communication between employers and the medical team(s) involved with the treatment of individuals with chronic arthritis. Brown *et al.* (1987) felt that this would enhance understanding of the problems of the arthritic in the workplace and thought that it might increase the number of job opportunities for individuals with chronic arthritis.

In a more recent study by Barrett *et al.* (2000) these researchers found that studies of the predictors of work disability produce remarkably similar results regardless of their country of origin. Barrett *et al.* (2000) also established that individuals with manual jobs and those with less work autonomy are more likely to stop working. Ease of access, in the form of transport, has also been identified as being relevant. This study also revealed other factors that contributed to employment status, such as the pace of the work, physical limitations imposed by the workplace, access to the workplace and the contribution that colleagues, supervisors and managers make to help the individual with RA to maintain his/her employment. Barrett *et al.* (2000) furthermore found that, when recruiting an age- and gender-matched cohort of local control subjects, that in view of the labour market and prevailing economic conditions, individuals with RA are more at risk of losing their jobs than individuals without RA.

Barrett *et al.* (2000) suggest that, at a very early stage after the onset of RA, those individuals who are working need a very careful analysis of their work, their workplace, their work commitments and their plans and aspirations. Any delay at this stage potentially compromises their chances of remaining economically active even if their disease subsequently improves.

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3.5 Occupational therapy and work

Occupational therapists are experts in the performance of occupations, (i.e. self-care, work, leisure and play) and especially, work disability. **Occupational therapy** is defined as: the *therapeutic use of self-care, work and play activities to increase independent functioning, to enhance development and to prevent disability. It may include adaptation of a task or the environment to achieve maximum independence and to enhance the quality of life.* This view of occupational therapy is supported by Engelhardt (1977)

according to Christiansen & Baum (1997): *In viewing humans as engaged in activities, realizing themselves through their occupations, occupational therapy supports a view of the whole person in function and adaptation often absent in somatic medicine, the psychological health care professions, and social work as well. The virtue of occupational therapy is engagement in the world.*

In terms of the South African Employment Equity Act, No. 55 of 1998, work disability is an aspect that needs to be investigated. Occupational therapists, with knowledge of adaptation, are able to assist disabled individuals to adapt to their workplace, or vice versa. The paradigm of adaptation suggests that the role of occupational therapy is to facilitate the internal adaptation process of clients with an approach that is holistic and client-centred in order to enhance occupational performance. Occupational therapists can also guide their clients to independence through their knowledge of ergonomics and job site analysis, which is used in adaptation of the workplace (Neistadt & Crepeau, 1998). According to the Employment Equity Act, of 1998, ...*reasonable accommodation means any modification or adjustment to a job or to the working environment that will enable a person from a designated group to have access to or participate or advance in employment.*

If it can be determined what has helped individuals to maintain their employment, guidelines can be set for employers in which attention is given to reasonable accommodation, rather than boarding of an individual. In view of the high unemployment rate in South Africa, the possibility of an individual with RA being re-employed in the open labour market, is fairly slim.

The primary purpose of the Skills Development Act of 1998 is to develop the skills basis of the South African workforce and to encourage employers to invest in education and training in the labour market in order to improve the return of that investment. The Skills Development Act aims to develop the quality of life of the workforce, to improve prospects of employment and employment mobility (Silver & Koopman, 2000).

When occupational therapists make recommendations to employers, other avenues are opened. Individuals performing heavy labour can, for instance, now be trained for jobs where their needs are taken into account, permitting they have the potential for the specific training.

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In the study by Straaton *et al.* (1996) it was found that, after vocational rehabilitation of 456 individuals with arthritis, 64% were competitively employed at case closure compared to only 8% who were working prior to the work rehabilitation. Straaton *et al.* (1996) found that, in view of the prevalence and economic impact of arthritis-related work disability, the utilisation of the vocational rehabilitation services by individuals with arthritis was fairly low as a result of the disproportionately small number of individuals with arthritis referred by health care professionals. These authors also found that health care professionals might be able to reduce work disability among arthritis patients by increasing the number of appropriate and timely referrals. Firstly, retraining may then lead to less physically demanding employment that does not put too much stress on affected joints. Secondly, retraining for positions, involving more flexibility and self-autonomy, may influence employability. Lastly, retraining may lead to either increased remuneration or greater motivation to remain in the workforce.

Whether the individuals involved in the vocational rehabilitation mentioned by Straaton *et al.* (1996) were occupational therapists, is not known. In South Africa, vocational rehabilitation is primarily the role of the occupational therapist.

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3.6 Work enablers

There are certain patients who do not admit defeat, despite poor prognostic indicators (Wolfe and Hawley, 1998). Few studies have actually looked at the factors that enable individuals with RA to stay employed in the open labour market.

According to Manusco *et al.* (2000), individuals with RA managed to stay employed by adapting their work hours and changing the number of days they worked per week. Some took shorter breaks so that they could work more slowly, while still managing to produce the same amount of work. One third of the individuals with RA changed their jobs, declined promotions or drastically altered their career paths secondary to their RA in order to stay employed. Some individuals rely on family members to drive them to work or to perform household chores. This leaves the individual with RA with more energy to perform their work tasks. Others who can afford it, even employ a housekeeper. Some individuals even went as far as curtailing their social activities in order to have more time to rest and sleep so that they would have more energy to perform their work tasks.

According to Yerxa (1998), Jahoda (1981) asked, "Why is work, as Marx observed, such a fundamental condition of human existence that people eat to work, not the other way round?"

In order to understand why people work, it is important to consider the five latent consequences of employment as identified by Jahoda:

- employment imposes a time structure on one's day;
- employment implies regularly shared experiences and contacts with persons outside one's immediate family;
- employment links persons, goals and purposes transcending their own;
- employment defines important aspects of personal status and identity;
- employment enforces activity, providing a predictable demand for action.

Jahoda's observation supports the importance of work for health, even though they do not address the satisfaction of simply doing work, which is an important product for many people (Yerxa, 1998).

Another aspect that is discussed by Yerxa (1998), and which needs to be taken into consideration, is what is called the *hardy personality* as it might be this factor alone that enables individuals with RA to stay employed. According to Yerxa (1998), Kobasa (1982) developed this theory of the *hardy personality* from her research. The three characteristics contributing to hardiness are *commitment, control* and *challenge*.

- **Commitment** is the ability to believe in the value of who one is and what one is doing, involving oneself fully in life, including work, family and social institutions. An overall sense of purpose, goals, and priorities acts as a buffer to stress.

- **Control** is a tendency to believe and act as if one can influence the course of events. Stress is viewed as a predictable consequence of one's own activity and subject to one's own direction.

- **Challenge** is a belief that change rather than stability is the normative mode of life. Stress is viewed as an opportunity or incentive rather than a threat.

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As health care professionals, occupational therapists should be able to make more applicable recommendations in terms of job-fit when an individual is initially diagnosed with RA or when problems are encountered with disease progression.

From the literature it is clear to see that the factors that cause work disability and enable individuals with RA to stay employed are numerous. The ability to stay employed in the open labour market once diagnosed with RA needs to be investigated from different perspectives in order to ensure that the different factors are investigated optimally. For this reason, the researcher decided to make use of both qualitative and quantitative research methods.

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Chapter 4

Research design

4.1 Format of study

A descriptive, quantitative-qualitative study design was employed. As discussed by Katzenellenbogen (1991), a *descriptive study* sets out to quantify the extent of a problem, thus telling us what the size of the problem is, who is affected, where it is found, or when it occurs. With this study regarding individuals with RA in the workplace, the objective was to develop a profile of the individual, diagnosed with RA and employed in the open labour market, and to answer some of the questions regarding the enabling factors encountered in the workplace as well as the strategies used by individuals diagnosed with RA in order to stay employed in the open labour market.

Research questions for *quantitative* descriptive research focus on the characteristics of a specific group relative to the question. The purpose of such research is to answer a clearly defined question about a specifically identified sample population. In the case of this study it was to research the three objectives above, as discussed in Section 2.3. The sample population consisted of 100 individuals, with a minimum age of 18 years, diagnosed with RA and employed in the open labour market.

Phenomenological research was used for the *qualitative part* of the research study as this part of the study was directed at understanding the perspectives of those individuals diagnosed with RA and employed in the open labour market, and explicating their lived experience. Phenomenological research strives to uncover meanings and understandings that we may have, but have not expressed, in other words to make the tacit (unknown) explicit (stated). The qualitative part of the research explored the enabling factors encountered in the open labour market, as well as personal strategies used by individuals with RA to retain their work. This type of research provides insights that allows a fuller understanding of everyday lived experience. According to Hammel *et al.* (2000), qualitative research provides a more holistic approach to problems pertinent to the rehabilitation disciplines, of which occupational therapy is one.

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The two research methods – qualitative and quantitative – were combined as the question was not whether one or the other was more suited to answer the research question, but how best to observe all the different aspects posed by the research question. The study complied with the view of Polit and Hungler (1993) who advocated the use of multi-method research, combining qualitative and quantitative methods in order to minimise the effects of the limitations of either method used in isolation.

4.2 Research population and sample

The research population consisted of 100 individuals who were gainfully employed in the open labour market. Of these, 95 were diagnosed with RA and five with Juvenile Chronic Arthritis (JCA). The sample population ranged from 18 years of age, with only two females older than 65 years, and were obtained from three rheumatology clinics at two tertiary hospitals in the Cape Metropolitan area and two private practices, one in the Southern suburbs and one in the Northern suburbs. The diagnosis was made by a consultant rheumatologist.

A sample of convenience was used for the quantitative part of the study, as individuals attending the clinics or private practice between January 2001 and July 2002 were approached. According to Stein and Cutler (2000), it is valid to select randomly from a convenience population as long as the researcher does not generalise the results to include that portion of the population that was not sampled. Data was collected over a period of one and a half years, first completing research in the government hospitals and then starting with the individuals attending the private practice. All individuals approached and fitting the selection criteria were included in the study and the sample was not randomised further. This type of data-collection however limits the generalisability of the study to other members of the RA population.

The researcher or the research assistant identified six information-rich candidates (five females and one male) who volunteered when completing their questionnaire. When contacted, they were asked whether they were still interested in participating in an approximately one-hour interview, which would be voice-taped. Information regarding the qualitative research participants can be seen in Table 4.1.

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In the case of qualitative research, the researcher selects people who are likely to increase understanding of the research topic (Hammel *et al.*, 2000). The sample may be either purposive or convenience. The sample also needs to be broad enough to encompass some variety and variability. The characteristics of the participants, recorded in Table 4.1, display this variety. The quality and completeness of the information collected when repetitive information is obtained, determine the actual sample size. This is an indication of saturation (DePoy & Gitlin, 1994). The researcher decided before the study to use only six individuals, of whom one had to be male, as shown in Table 4.1.

Table 4.1 Qualitative research participants

	Year of birth	Gender	Year of diagnosis	Level of education	Employment category
SB	1938	F	1995	6	9 Elementary occupations
BL	1966	F	1985	12 & Bachelors degree	2 Professionals
SL	1952	F	1978	11	4 Clerks
KS	1963	F	1966	12 & Masters degree	4 Clerks
AP	1952	M	1996	12 & Masters degree	1 Legislators, senior officials and managers
CJ	1957	F	1979	7	8 Plant and machine operators and assemblers

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Three individuals refused to participate in the quantitative part of the study when approached with the questionnaire. Two were working as domestics and one was a private patient who was in the process of being boarded. These individuals were not asked why they refused, as they had a choice whether they wanted to participate or not. Of the 100 individuals that completed the questionnaire, 56 indicated that they would be interested in participating in the interview. None of the individuals who indicated that they were interested to participate in the interview refused to do so when contacted telephonically.

4.3 Tools and materials

4.3.1 Quantitative – Questionnaire

After reviewing the literature, a self-administered questionnaire (attached as Appendix A & B) was compiled using some questions from other studies relating to RA and work disability.

4.3.1.1 Information included

Questions included in the questionnaire covered aspects such as:

- Name and surname
- Date of birth
- File number
- Residential area
- Level of education
- Number of children and their ages (where applicable)
- Race, gender and marital status
- Type of transport used

The individual's **name**, **surname** and **folder number** were used for identification purposes. The **folder number** was also used to determine which facility the individual uses for the medical management of the RA.

Date of birth was included in order to ensure that participants from a wide age distribution were selected.

The question regarding **residential area** was included to determine whether the individuals represent the whole Western Cape or just the Cape Metropolitan area.

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The **level of education** was included in order to determine if there is an association between the level of education, income level and type/level of work. This was also deemed important in order to ensure that a representative distribution of the population was included, when compared with the statistics of the 1996 South African census.

The **number of children** and their **ages** were included in order to determine whether the children were still dependent and whether they were of primary or high school age or of a financially independent age.

Race was included in order to determine whether the sample represented the South African population distribution of the Western Cape.

Gender was included to determine whether the sample represented the 3:1, female:male distribution found in RA.

Marital status was included to look at possible support that individuals receive at home, as the literature shows that married individuals with RA within a supportive relationship feel more needed than individuals who are not married. This seems to help them to maintain higher levels of social and psychological functioning in order to meet the expectations of the significant other (Reisine, 1993; Reisine & Fifield, 1995).

The question as to whether an individual uses private or public **transport** was included to determine whether there were differences in accessibility. The question should have been more specific regarding availability of transport and whether they currently experience problems with their mode of transport. In the study by Manusco *et al.* (2000) transport was one of the factors that individuals with RA had to adapt in order to stay employed.

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4.3.1.2 Disease characteristics

The characteristics of RA as manifested in the sample selection were determined by making use of the following questions:

- Date marking the onset of RA
- Stanford Health Assessment Questionnaire (HAQ)
- Visual analogue pain scale

Patients were asked about the **date marking the onset of RA** to ensure that the sample included a wide distribution of years and progression of disease.

Stanford Health Assessment Questionnaire (HAQ)

Fries *et al.* (1980) developed the HAQ on the basis that outcome should be measured in terms of the patient's value system. The framework used for the development of the HAQ was based on the belief that a patient desires to be alive, free of pain, functioning normally, experiencing minimal treatment toxicity and being financially solvent. The HAQ is currently based on 20 questions covering eight domains of activities of daily living. Each domain is scored on a scale of 0 – 3, with a score of three representing total inability to perform a specific activity. The HAQ disability index is the mean value for the eight domains. For statistical analysis the HAQ score was converted to an interval scale of 1, 2 or 3 for each participant as well as a continuous scale of 0 – 3 in 0,25 intervals. The HAQ is a good measure of function and has been tested extensively for reliability and validity. It is concise, sensitive to change, can be self- or interview administered and is suitable for use in the community. According to Barrett *et al.* (2000) the HAQ has been found to be the only statistically significant indicator of work disability in individuals with RA.

Pain was assessed, using a visual analogue pain scale (VAS) to determine whether pain has an effect on the HAQ and what the extent of the pain is, as experienced by individuals with RA and who are employed. Participants were asked to rate their pain in the previous week on a 10cm scale of 0 to 10, with 0 representing no pain and 10 representing the most pain possible. In a comparitive study of self-rating pain scales in RA patients, Bellamy et al. (1999) found that the Likert scale, the VAS and their variations were more responsive than more complex measures. These authors confirmed that there is a positive correlation between subjective pain rating and subsequent pain response.

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4.3.1.3 Employment

The following categories were used to identify individual employment status:

- Current occupation in the open labour market
- Employment status
- Occupational history since diagnosis with RA
- Occupational changes since diagnosis with RA
- Sick leave and drugs
- Occupational changes and actions during an acute episode
- Importance of the occupation to the individual
- Occupational support
- Further qualifications
- Occupational autonomy
- Individual monthly income
- Occupational demands

Current occupation in the labour market was included in order to match the participant's occupation with one of the nine categories as divided in the Employment Equity Act of 1998, thus making it exclusively South African.

Employment status was divided into full-time/permanent, regular part-time, contract worker and being self-employed, in order to determine whether individuals with RA work full-time or have adapted their working hours or status.

Employment history since diagnosis with RA was included to determine how may jobs subjects had since diagnosis and how long they were employed in each job. Next to each entry in this section, individuals had to indicate whether the specific job was characterised by any (or all) of the following:

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- the position made it possible for the individual to sit all day
- tasks were of light to medium nature
- tasks were of medium to heavy nature
- tasks required fine hand functioning
- tasks were of a repetitive nature

The individuals taking part then also had to indicate whether they had changed their jobs due to RA-related reasons, for non-RA-related reasons or whether they were at that stage still employed in the same job. These questions were asked to determine whether individuals, diagnosed with RA, in the South African labour market, tended to change jobs as a result of RA, or not. Furthermore it was necessary to determine whether there was a tendency to remain in the same job after being diagnosed and, in the case where there was a change in job or position as a result of RA, what the characteristics were of the new job or position.

Occupational changes since diagnosis with RA was used to look at the different aspects that have been changed in a job due to RA. Regarding each aspect the individual had to indicate whether the aspect had increased, remained the same or had decreased.

Visits to the doctor due to RA and **sick leave** were included to determine how often individuals, diagnosed with RA and employed in the open labour market, took sick leave, visited their doctors in connection with RA and the usual duration of sick leave.

The question whether the individuals in the sample were on any **disease-modifying anti-rheumatic drugs (DMARD)** was asked to determine whether there was a correlation between the level of the individuals disease and whether they were on DMARD or not.

The **changes in the work during an acute episode** was included to determine whether the individuals thought their work was affected during an acute episode and whether they made any adaptations as a result of an acute episode. This was also included to determine which specific actions individuals took during an acute episode.

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The **importance of the individual's work** was included to determine whether this could be a contributing factor to a specific individual still being employed in the open labour market. The question should have been more inclusive, asking whether these individuals are employed because they have to work, or whether they are employed because they want to work. A visual analogue scale of 0 to 10 was used, where 0 meant that the work had no importance and 10 meant that the work was very important.

The question regarding amount of **support** was included to determine whether the individuals with RA and employed in the South African Labour market experienced a high level of support from their employers, direct supervisors or co-workers.

The questions whether they have acquired any **other qualifications** since being diagnosed with RA, were asked to determine whether the participants felt that it was necessary to make themselves more employable and to broaden their prospects in the open labour market once diagnosed with RA.

Occupational autonomy was determined by using four of the five questions on schedule autonomy developed by Yelin *et al.* (1980), and used again by Fifield *et al.* (1996) in order to determine how much freedom individuals with RA have to make decisions at work.

Individual monthly **income** level was required to ensure that a broad spectrum of incomes was obtained and that individuals with RA and employed in the open labour market were not selected from the higher income groups only, as these groups might have more occupational autonomy.

Questions regarding **occupational demands** were included to determine how the individuals rated the frequency of demands made on them by the work. This frequency of demands was indicated on a five-point scale, ranging from *never* to *always*. This included the work demands as developed by Karasek *et al.* (1988) and used again by Fifield *et al.* (1996).

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4.3.2 Qualitative – Interviews

According to Hammel *et al.* (2000), data collected in qualitative research are descriptive. It may include the words of subjects as they are expressing their feelings and ideas, as well as observations and even personal or official documents in the form of diaries or medical notes. In semi-structured interviews the researcher presents the study purpose and starts with a broad general question. Other questions emerge as the participant responds to this initial question.

In this study the questions were based on the objectives of the study. Initially the following broad question was asked:

What, do you believe; has enabled you to stay working since you have been diagnosed with rheumatoid arthritis?

Once the individual, with prompting, had nothing more to add to this subject, the following two more specific questions were asked, with the second one only once the first one was completely answered.

Which factors in the workplace itself have enabled you to maintain your work? That would be the physical, psychological as well as social aspects.

Which personal strategies did you use to maintain your work in the open labour market since being diagnosed with rheumatoid arthritis?

All interviews were voice-taped and then transcribed. After transcription the researcher once again reviewed the transcribed data to ensure that there were no mistakes.

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4.4 Pilot study

4.4.1 Quantitative – Questionnaire

Ten individuals completed the questionnaire. Eight had been diagnosed with RA and were employed in the open labour market and two did not have RA. The two individuals who did not have RA, were selected on the grounds that they have designed and used questionnaires in research before. They were first asked to look at the questionnaire from the researcher's perspective and therefore they completed the questionnaire first. After each set of feedback the questionnaire was adapted according to the feedback received. The eight individuals with RA were then approached at one of the clinics over a period of approximately one month, and asked whether they would be willing to complete the questionnaire as part of a pilot study. The researcher sat with them while they completed the questionnaire in order to document any problems that the individual might experience with the questionnaire. After each participant had completed the questionnaire, the problem area was adapted, until the researcher was certain that there were no more variables to consider.

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4.4.2 Qualitative – Interviews

An interview was conducted with an occupational therapist with RA, and who is currently employed in the open labour market, in order to determine what she believed had helped her to stay employed in the open labour market. She was also asked which questions she believed were essential to ask individuals with RA in order to find out what assisted them to stay working since diagnosed with RA. Another interview was conducted with an individual with RA as part of the pilot study. Only one general question was asked with further questions leading from the interviewee's response. Afterwards it was decided to ask three open-ended questions in order to ensure that the objectives of the study were met.

4.5 Research procedure

At the tertiary institutions, all the folders of the individuals attending the clinic on a specific day were screened to determine whether they had RA, were older than 18 years of age and employed in the open labour market. If found that they met the criteria, they were approached and, after a brief explanation, they were asked whether they wanted to participate. After signing the consent form, individuals with RA completed a questionnaire while waiting to be seen by the doctor. The researcher assisted with questions that were unclear, or in the case of individuals who were unable to write due to their level of education or severity of hand-pain. At the private practices the same procedure was followed, except that at one practice the receptionist screened the folders of the patients attending the practice that week for the inclusion criteria. At the other practice the nursing sister responsible for the patient's blood tests did the screening on a daily basis. The researcher then phoned to find out whether there were patients and would then ensure that there were no mistakes by either looking in the folder that day or asking the patient themselves when approaching them with the questionnaire. This was done to ensure that all participants met the selection criteria.

Due to time constraints, interviews were started before all the quantitative data were collected. Halfway through the research project three information-rich individuals were identified and approached telephonically. An appointment was set up with them for a time and place that suited them best. The same process was followed with the other three information-rich individuals, except that they were identified on an ongoing basis at a later stage of the study.

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4.6 Ethical Considerations

The study protocol was submitted to the University of Cape Town ethical committee and approved. Permission was obtained from the head of the Rheumatology Clinics at Groote Schuur Hospital, the Princess Alice Orthopedic Unit and Tygerberg Hospital. Two private practitioners, who were willing to assist with the research, were also approached.

A letter of consent – see Appendix C – was signed by the researcher and attached to each questionnaire. Participants were informed that they had a choice whether they wanted to participate in the study or not.

Each of the six individuals who participated in the qualitative part of the research volunteered when completing their questionnaire. When phoning them, they were once again given an option whether they still wanted to participate in the interview. The interview was set up at a time and place that suited the individual, and before the interview was started, a letter of consent was once again completed – see Appendix D.

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Chapter 5

Data collection

The quantitative data collection started in January 2001 and was completed at all the facilities in July 2002. The researcher or research assistant approached individuals older than 18 years of age and employed in the open labour market after it was confirmed that they had been diagnosed with RA. At the government hospitals this information was obtained from the identified individual's medical folder. It was only accepted that they had a definite diagnosis of RA after the necessary blood tests were completed and a definite diagnosis of RA based on the ACR criteria, had been made. Age and employment status were indicated on the front-page of the medical/hospital folder. Age was generally correct, but employment status was often incorrect, so patients would be asked when approached whether they were still employed in the open labour market.

The aim of the study was explained to each individual approached and confidentiality was promised. All the questionnaires were going to be destroyed after the study was completed and the information was only going to be used in this study. As the data was going to be coded, anonymity could be assured, even though the researcher or research assistant was to have access to the information while it was gathered. No individual was pressurised to participate in the study, as everyone was given a choice whether to participate or not.

Once the individuals had indicated that they were interested in participating in the study, they were provided with a questionnaire on a clipboard and a pen. Patients were also given the choice as to whether they required assistance completing the questionnaire, or not, as some were unable to write because of hand pain or their low level of education. All patients were asked to complete the consent form first and then the questionnaire. The researcher or research assistant stayed within calling distance of individuals completing the questionnaire independently in order to answer any questions. Afterwards the questionnaire was checked for any incomplete sections and the individual concerned was then approached to determine whether he or she had not understood the questions or had objections completing any specific section. The researcher did not encounter any participant who objected to completing a specific section.

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After the questionnaires had been completed, the researcher entered the data according to the codes – see Appendix E – into an Excel spreadsheet for statistical analysis.

The researcher used two research assistants, as the first one had obtained more permanent work and a second assistant had to be trained. Both research assistants only assisted with data collection at one of the facilities. The researcher met with each research assistant and explained the goal of the research to her and provided her with an English and Afrikaans questionnaire, which were talked through with her. At the next meeting the assistants had to administer both the Afrikaans and the English questionnaires to the researcher in a trial run, in order to ensure that the same explanation was given when the purpose of the study was explained and questions regarding confidentiality were asked. As both the assistants were English-speaking, the researcher had to ensure that they used the correct terms to explain specific questions and the goal of the study in Afrikaans. The process was also necessary to ensure that the same meaning was attached to questions and that the questions were understood in the same way by the researcher and research assistants alike. The researcher then met with the assistants at the facility and showed them how to screen the folders for possible subjects. Thereafter, the assistant had to approach a possible subject and present the questionnaire to the individual with RA under supervision of the researcher in order to ensure that there were no problems. Both research assistants were occupational therapists who had graduated in 2000.

At the private practices the researcher made use of the rheumatologist's secretary and the nursing sister after meeting with the rheumatologist and obtaining permission to make use of individuals attending their practice for the study. The secretary or nursing sister identified individuals older than 18 years, who had been diagnosed with RA and were still employed in the open labour market on the basis of information contained in their medical folders. The researcher then checked the information in the medical folders or with the patients themselves if the medical folder was not available, to ensure that the diagnosis was confirmed by the doctor. When approaching the patients, the researcher also asked them whether they were still employed in the open labour market.

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During 2001 the qualitative data were collected as information-rich individuals were identified. The researcher tried to ensure that a variety of individuals was selected. Factors like different age groups, different levels of education, years of the disease, employment levels and whether the patient was male or female were all taken into account. These factors are summarized in Table 4.1.

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Chapter 6

Data analysis

6.1 Quantitative data analysis

The researcher entered the quantitative data on an Excel spreadsheet according to the codes – see Appendix E – identified at the study onset. The data were converted by the statistician into SAS, from where it was analysed.

Descriptive as well as inferential statistics were used in order to analyse the data. Descriptive statistics was used to describe, organise and summarise the data. This included frequency, percentages, descriptions of central tendency (mean, median) and descriptions of the relative position (range and standard deviation). Inferential statistics was used to make comparisons between categories in order to determine whether there were statistically significant associations between groups. The type of data also differed, as the researcher made use of nominal data, ordinal data, and interval data as well as ratio data.

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As the nominal and ordinal data are known as nonparametric data, Chi-square was used as a non-parametric test. Where data cells were < 5, the Fisher exact test was used. As the interval data and ratio data did not adhere to the rules needed for parametric tests (the sample should be representative of the target population or that random selection occurred) the following non-parametric statistical tests were used: the Wilcoxon Two-Sample Test (where two variables are compared) and the Kruskall-Wallis Test (where more than two variables are compared, to test for significance). According to Stein & Cutler (2000) the Wilcoxon Test for paired data samples is a non-parametric alternative to the t-test for correlated samples, while the Kruskal-Wallis test is a non-parametric alternative to the one-way ANOVA when comparing three or more independent groups.

According to Bailey (1997) substantial differences must be found between sets of scores before those differences are considered meaningful, because non-parametric data do not meet strict statistical criteria. Statistical significance was indicated by $p < 0,05$, thus as a 95% success rate. Associations were also considered to be marginally different if $0,05 \leq p < 0,1$.

6.2 Qualitative data analysis

The qualitative data was analysed according to the process as set out by Burnard (1991). In the process of analysing, he identified 14 stages of analysis. This consisted of notes made throughout the research after each interview about the topics that were discussed during that specific interview. After the data had been transcribed, the researcher made notes on the general themes that emerged after reading the transcripts with the aim of becoming immersed in the data. The transcripts were then read again and as many headings as necessary were written down in order to describe all aspects of the content as part of the open coding process. The list of categories was then surveyed by the researcher and grouped under high-order headings with the aim of reducing some of the categories by making them part of a more comprehensive category. Thus a new list of categories and sub-heading was worked through, and repetitions or very similar headings were removed while doing so.

One colleague was then asked to generate category systems independently from the researcher. The two lists of categories were discussed afterwards, with the aim of validating the categories and guarding against researcher biases. The transcripts were then re-read along with the agreed list of categories and sub-headings in order to ensure that the new lists covered all aspects of the interviews. Each transcript was then worked through with the list of categories and sub-headings and after highlighting the different areas, these areas were cut and pasted electronically so that the necessary text would fall under each heading.

A key informant, in the form of one of the respondents, was then asked to check the appropriateness of the category system in order to find out whether the quotation from the interview referred to the specific category. Once this was completed, the researcher started writing up the data, linking it where possible with existing data.

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6.2.1 Trustworthiness of qualitative data analysis

The trustworthiness of the qualitative part of the research project needs to be considered, based on the model of Guba (1981), as discussed by Krefting (1991). This model is based on the identification of four aspects of trustworthiness: **truth-value**, **applicability**, **consistency** and **neutrality**.

In qualitative research **truth-value** is usually obtained from the discovery through human experiences as these are lived and perceived by informants and it is also termed **credibility**. **Applicability** refers to the degree to which the findings can be applied to other contexts and setting or with other groups. It is the ability to generalise data from the findings and apply it to larger populations, and can also be termed **transferability**. **Consistency** or **dependability** has to do with the ability to decide whether findings would be consistent if the inquiry were replicated with the same subjects or in a similar context. **Neutrality** or **conformability** is the freedom from bias in the research procedures and results.

The researcher tried to ensure trustworthiness by using triangulation of the data source. This implied making sure that a variety of ages, subjects with varying durations of the disease, both genders and various occupational categories were included in the research sample. One of the female participants was diagnosed with Juvenile Chronic Arthritis (JCA) when still a child, and she was included in the qualitative part of the research in order to add another perspective to the data.

Member-checking was used, as one of the participants was asked to check whether she agreed with the categories and whether they accurately reflected her experiences of what enabled her to stay employed since diagnosis. The participant was selected on the basis that she is in adult education and should therefore have been able to understand the meaning of terms used to describe categories.

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Peer-examination was also used in that one of the colleagues of the researcher, who had recently completed a qualitative study, was asked to generate themes independently of the researcher. Afterwards the categories generated were once again discussed by the researcher and her colleague in order to exclude bias. The researcher also discussed the categories she had identified during the research process with two other colleagues in order to ensure that her understanding of terms selected to describe a category matched what the participants had actually said during an interview.

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Chapter 7

Results

7.1 Quantitative results

7.1.1 Profile of the employed individual with rheumatoid arthritis

The 100 individuals who participated in the study were mainly from within the Cape Metropolitan area, but some also came from other areas in the Western Cape.

Of the 100 individuals 36 came from the two private practices, and 64 from the three Rheumatology Clinics at the two tertiary facilities as tabulated in Table 7.1.

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Table 7.1 Medical facilities

	Groote Schuur Hospital	Princess Alice Orthopedic Unit	Tygerberg Hospital	Private practice Southern suburbs	Private practice Northern suburbs
N	**19**	**13**	**32**	**14**	**22**
Percentage	19,00	13,00	32,00	14,00	22,00

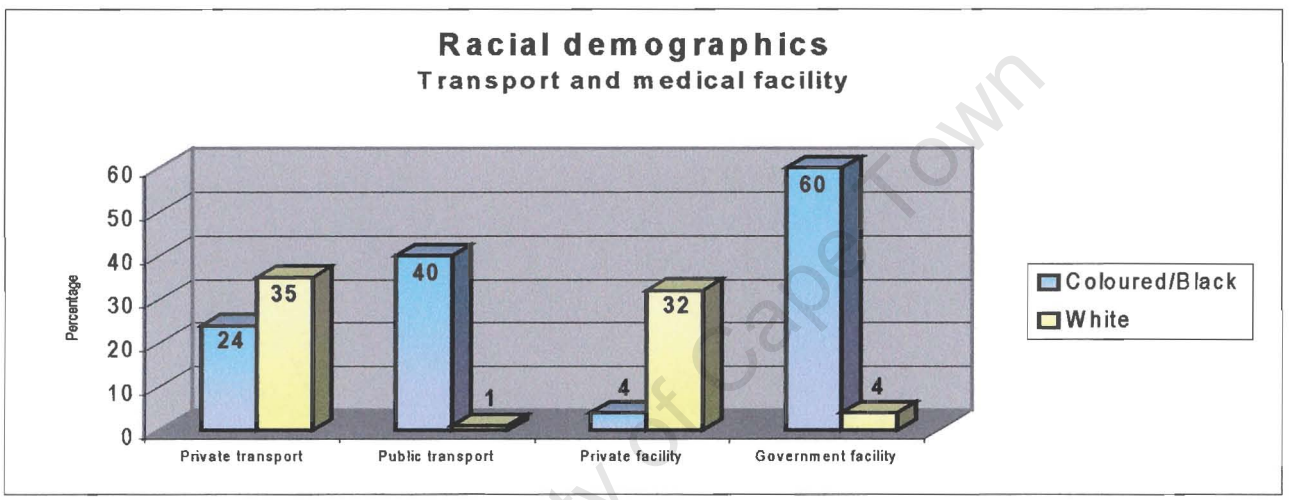
Individuals attending private practice had significantly higher levels of education than individuals attending government facilities ($p < 0,0001$). Table 7.2 gives the percentages of patients from the various medical facilities, together with their mean levels of education.

Table 7.2 Level of education and medical facility

		Medical facility			
		Groote Schuur Hospital	Princess Alice Orthopedic Unit	Tygerberg Hospital	Private practice
Years education	**N**	**19**	**13**	**32**	**36**
	Mean	8,68	9,38	8,25	12,94
	SD	2,83	1,98	3,71	1,84
	Min	5,00	6,00	0,00	7,00
	Max	15,00	12,00	15,00	17,00
	Median	8,00	10,00	9,00	13,00

The race distribution was found to be 60% Coloured, 36% White, 4% Black and 0% Indian. For analysis purposes, the black individuals were grouped with the coloured individuals in order to provide only two categories, i.e. White and Coloured/Black. Significantly more white individuals made use of private facilities, while more coloured/black individuals made use of government facilities (p<0,0001). Coloureds/blacks also used significantly more public transport than whites (p<0,0001). A summary of this information can be seen in Graph 7.1.

Graph 7.1 Racial demographics – transport and medical facility



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With the above in mind it was found that whites also had a significantly higher level of education (p<0,0001) and income (p<0,0001) than coloured/black individuals as tabulated in Table 7.3 below.

Table 7.3 Level of education and racial group

		Race	
		Coloured/Black	White
Years education	**N**	**64**	**36**
	Mean	8,56	13,03
	SD	3,17	1,58
	Min	0,00	10,00
	Max	15,00	17,00
	Median	9,00	13,00

Of the participants, 83% were female and 17% male, which was not truly representative of the 3:1 female to male ratio usually found in rheumatoid arthritis.

The mean age of the 83 females was 45,40 years and that of the 17 males 50,61 years. Even though the male individuals in the study were marginally older than the females, the age difference was not statistically significant (p = 0,0575). The age/gender distribution is summarised in Table 7.4.

Table 7.4 Age and gender

		Gender	
		Male	Female
Age	**N**	**17,00**	**83,00**
	Mean	50,61	45,40
	SD	10,41	10,03
	Min	33,35	26,19
	Max	65,12	74,50
	Median	52,74	44,27

The gender distribution with respect to race was fairly similar, with 70,59% of the males coloured/black and 29,41% of the males white. Of the women, 62,65% were coloured/black and 37,35% were white.

Of the 100 participants, 66% were married, while 34% were not married. When comparing marital status with gender it was found that significantly more females than males were in single relationships (p=0,0336). For the purpose of the statistical analysis, the five possible answers were grouped into two categories, namely *married* and *other* (which included *single, divorced, separated, widowed*). This information is summarised in Table 7.5.

Table 7.5 Marital status and gender

Frequency Percentage	Gender	
	Male	Female
Married	**15** 15,00	**51** 51,00
Other	**2** 2,00	**32** 32,00

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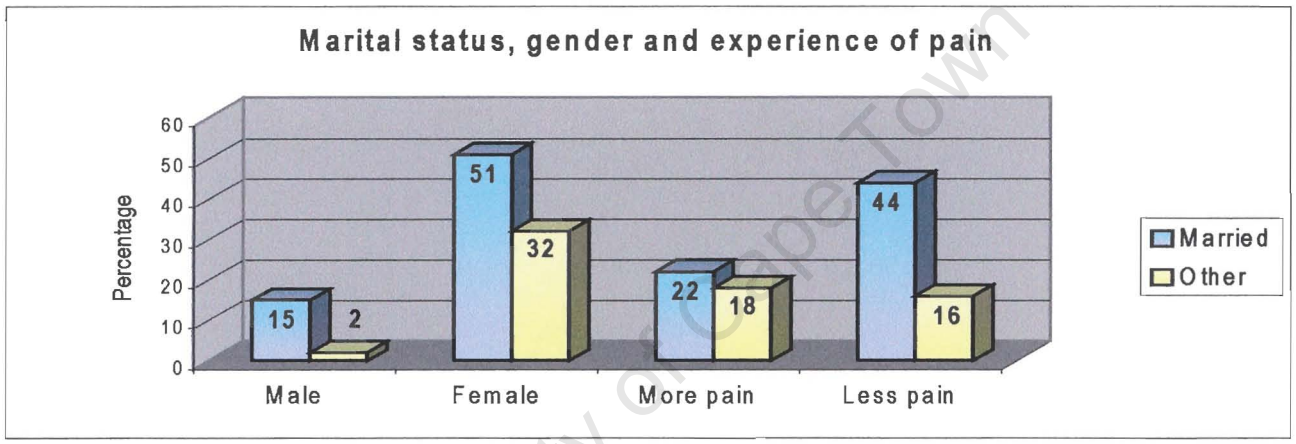
Single individuals had a significantly lower level of education than married individuals (p=0,0025). Single females also had a significantly lower income than married male and female individuals (p=0,0003). Income was determined by asking individuals what their personal gross monthly income was. Even though married individuals seemed to experience less pain than single individuals (p=0,0345) it was found that single females experienced only marginally more pain than married males and females (p=0,0605). The information regarding marital status, gender and experience of pain is summarised in Graph 7.2.

Graph 7.2 Marital status, gender and experience of pain



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Females had a significantly higher level of education than males (p=0,0446). Females had a mean level of education of 10,51 years and males a mean of 8,53 years. This could have been the result of the sample size not representing the 3:1 female to male RA ratio, as shown in Table 7.6.

Table 7.6 Level of education and gender

		Gender	
		Male	Female
Years education	N	17	83
	Mean	8,53	10,51
	SD	3,89	3,28
	Min	0,00	0,00
	Max	15,00	17,00
	Median	10,00	12,00

Significantly more married individuals (male and female) made use of private transport when compared to individuals who were not married (p=0,0005), but there was no association regarding gender and transport. As mentioned before, coloureds/blacks also made significantly more use of public transport than whites (p<0,0001).

Individuals who used private transport, on the other hand, had significantly higher levels of education than individuals who used public transport (p<0,0001). A summary of the information regarding levels of education and transport utilisation is given in Table 7.7.

Table 7.7 Level of education and transport utilisation

		Transport	
		Public transport	Private transport
Years education	N	41	59
	Mean	8,15	11,58
	SD	3,00	3,04
	Min	0,00	0,00
	Max	12,00	17,00
	Median	8,00	12,00

There was no association between race and type of occupation or work status. Significantly more females performed work as *professionals*, *technician and associate professionals*, and *clerks* (p=0,0052), whereas males performed work as *legislators, senior officials and managers*, *craft and related trades*, and *plant and machine operators and assemblers*. A fairly even number of men and women belonged to the *service and sales workers* category and *elementary occupations* category. None of the participants fell in the skilled agricultural and fishery workers category. The distribution regarding employment, race and gender is depicted in Table 7.8.

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Table 7.8 Employment category, race and gender

Frequency Percentage	Race		Gender		Total
	Coloured/Black	White	Male	Female	
Legislators, senior officials and managers	0 0,00	7 7,00	3 3,00	4 4,00	7 7,00
Professionals	2 2,00	12 12,00	1 1,00	13 13,00	14 14,00
Technicians and associate professionals	7 7,00	3 3,00	0 0,00	10 10,00	10 10,00
Clerks	10 10,00	12 12,00	1 1,00	21 21,00	22 22,00
Service and sales workers	7 7,00	1 1,00	1 1,00	7 7,00	8 8,00
Skilled agricultural and fishery workers	0 0,00	0 0,00	0 0,00	0 0,00	0 0,00
Craft and related trades	8 8,00	1 1,00	5 5,00	4 4,00	9 9,00
Plant and machine operators and assemblers	9 9,00	0 0,00	3 3,00	6 6,00	9 9,00
Elementary occupations	21 21,00	0 0,00	3 3,00	18 18,00	21 21,00
Total	64 64,00	36 36,00	17 17,00	83 83,00	100 100,00

When comparing race and whether an individual was permanently employed for the whole day, part-time employed or contract worker or self-employed, it was found that significantly more whites than coloureds/blacks were self-employed or had their own businesses (p=0,0015). It also seems that there were no coloureds/blacks participating who were employed as legislators, senior officials or in managerial posts, while at the same time there were no whites participating who were employed as plant and machine operators or working in the elementary occupations.

For statistical analysis the occupational categories were grouped together to form three groups. Legislators, senior officials and managers, professionals and technicians and associate professionals were grouped together as most of these jobs would require post-graduate training. Clerks and service and sales workers were grouped together, as most of these jobs would require secondary education. Craft and related trades, plant and machine operators and assemblers and elementary occupations were grouped together as it was decided that individuals employed as such would require more primary education and some secondary education to be part of these occupation categories. The distribution of the respective categories can be seen in Graph 7.3.

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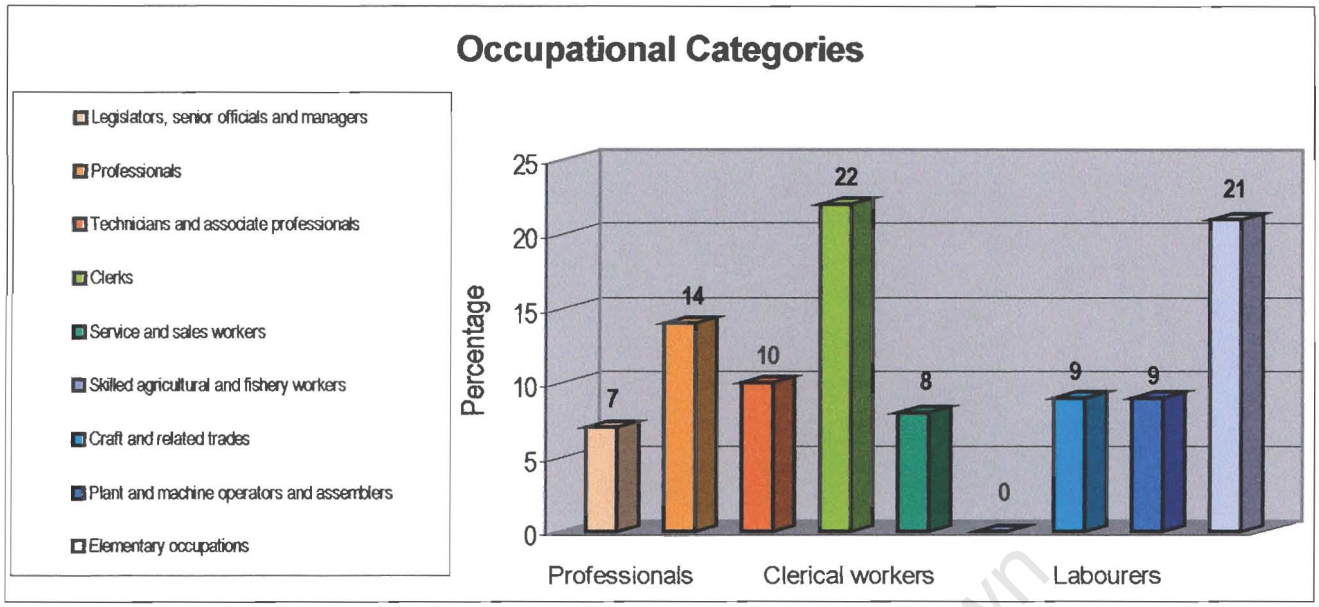
Graph 7.3 Occupational categories



When the above three occupational groups were compared to race, it was found that quite a large number of coloured/black participants were employed as labourers. On the other hand it was also found that whites were mostly employed in professional positions ($p<0,0001$).

Further significant employment-related information came to light while comparing the above three occupational groups to gender and medical facility respectively. Significantly more men and individuals attending Tygerberg Hospital and Groote Schuur Hospital were employed in the craft and related trades or working as plant and machine operators and assemblers or in the elementary occupations ($p=0,0471$). Individuals attending private practice, however, were mostly employed as legislators, senior officials and managers, professionals and technicians, and associate professionals ($p<0,0001$). The distribution for medical facilities and occupational groups is displayed in Table 7.9.

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Table 7.9 Gender, medical facility and occupational group

Frequency Percentage		Occupational Groups			Total
		Professionals	Clerical workers	Labourers	
Gender	Male	**4** 4,00	**2** 2,00	**11** 11,00	**17** 17,00
	Female	**27** 27,00	**28** 28,00	**28** 11,00	**83** 83,00
Medical facility	Groote Schuur Hospital	**3** 3,00	**4** 4,00	**12** 12,00	**19** 19,00
	Princess Alice Orthopedic Unit	**3** 3,00	**5** 5,00	**5** 5,00	**13** 13,00
	Tygerberg Hospital	**3** 3,00	**8** 8,00	**21** 21,00	**32** 32,00
	Private practice	**22** 22,00	**13** 13,00	**1** 1,00	**36** 36,00
Total		**31** 31,00	**30** 30,00	**39** 39,00	**100** 100,00

Fifteen participants were found to have no children, 20 had only one child, 27 had two children, 17 had three children, 14 had four children, five had five children, one had six children and one had seven children. The mean number of children was 2,19. The distribution according to the number of children is illustrated in Graph 7.4.

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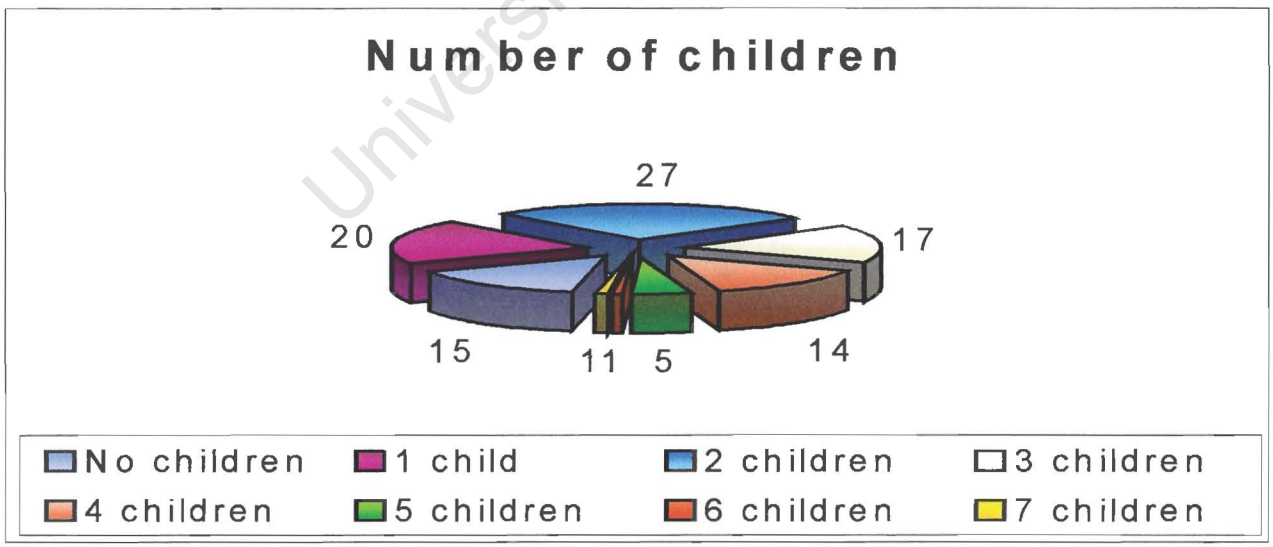
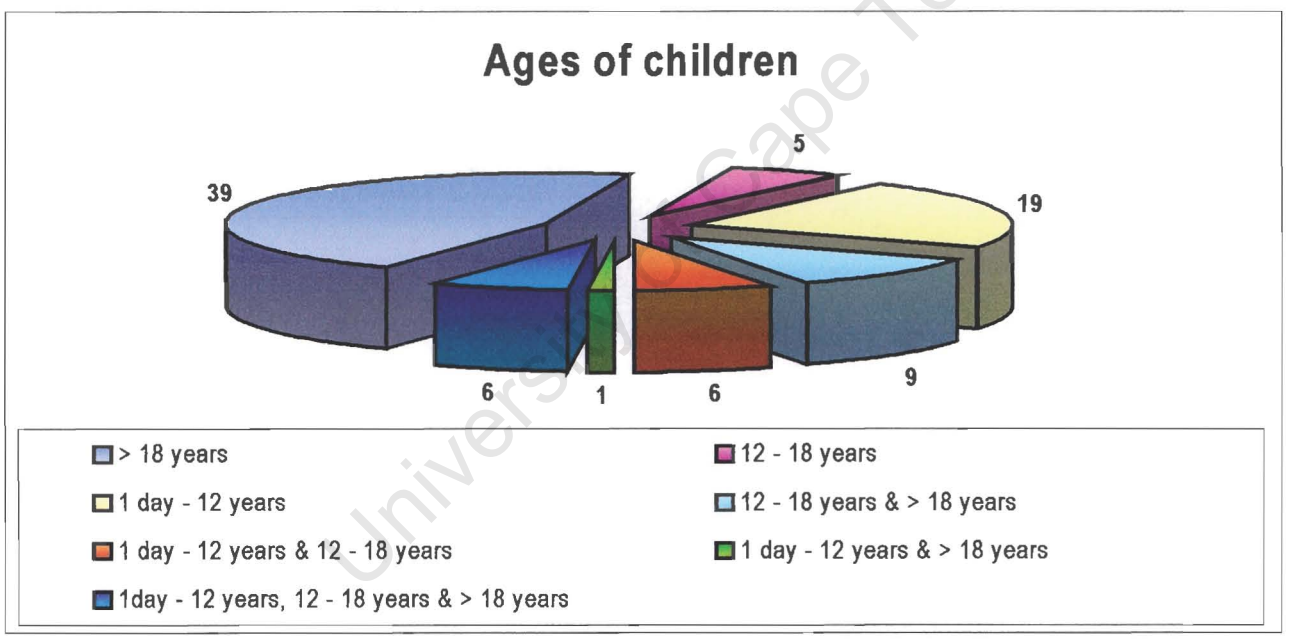
Graph 7.4 Number of children



It was found that the more children individuals had the higher the HAQ score (interval scale) was (p=0,0318).

For statistical purposes, the developmental categories of the children were divided further into three groups, namely age 1 day to 12 years (primary school age), 13 years to 18 years (high school age) and older than 18 years (working age). When considering the ages of the children of the 85 participants that did have children, 39 had children aged older than 18 years, five had children aged 12 to 18 years, and 19 had children aged 1 day to 12 years. Nine had children aged 12 to 18 years as well as children older than 18 years. Six had children aged 1day to 12 years as well as children aged 12 to 18 years, and only one had children aged 1 day to 12 years and children older than 18 years. Six had children in all three of the age groups. The above age distribution can be observed in Graph 7.5.

Graph 7.5 Ages of children



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No association was found when marital status was compared to the number of children, the importance of the participants' employment or the HAQ. There was also no association found between individuals' health status (HAQ score) and pain among those who had no children, those with children older than 18 years, those with children older than 12 years or those with children younger than 12 years. There was, however, an association between the number of children and the individuals' self-perceived health status (HAQ score).

7.1.2 Health profile of the employed individual with rheumatoid arthritis

Of the individuals who participated in the study, 51% had been diagnosed with RA less than five years ago, while 20% had been diagnosed 6 to 10 years ago. In Table 7.10 a breakdown is given of the duration of the disease against the percentage of participants.

Table 7.10 Duration since diagnosed with RA

Years since diagnosed with RA	Frequency	Percentage	Cumulative frequency	Cumulative percentage
< 1 year	12	12,00	12	12,00
1 year 1 day to 3 years	25	25,00	37	37,00
3 years 1 day to 5 years	14	14,00	51	51,00
5 years 1 day to 10 years	20	20,00	71	71,00
10 years 1 day to 15 years	8	8,00	79	79,00
15 years 1 day to 20 years	5	5,00	84	84,00
20 years 1 day to 25 years	9	9,00	93	93,00
25 years 1 day to 30 years	4	4,00	97	97,00
More than 30 years	3	3,00	100	100,00

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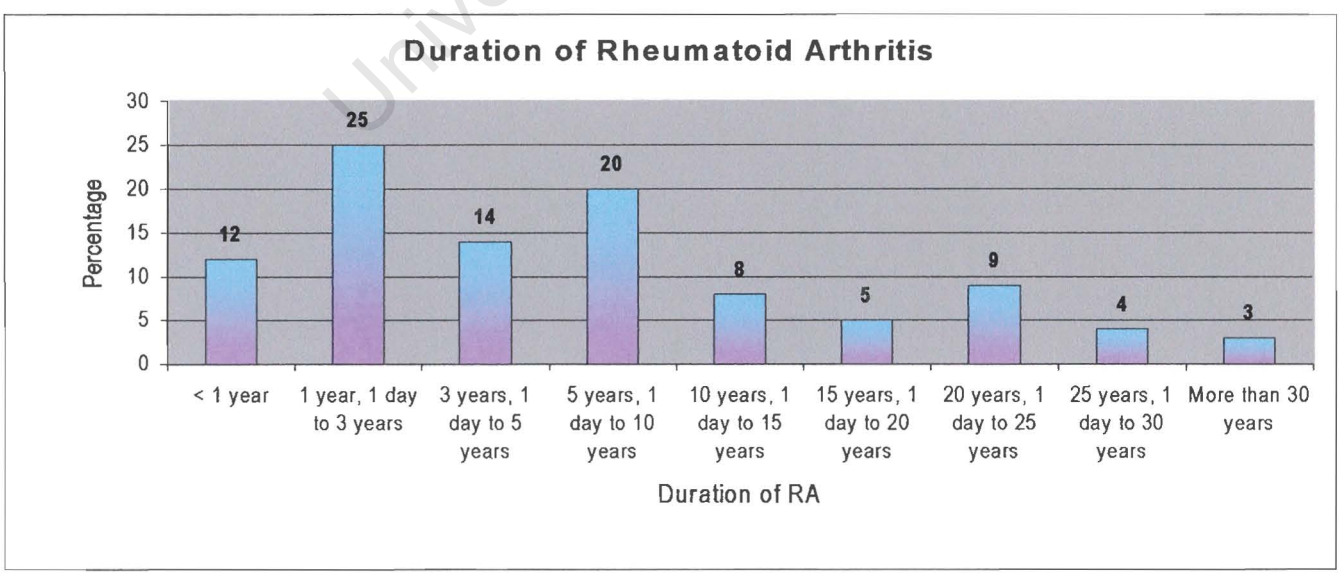
There are fewer individuals with RA employed in the open labour market with longer duration of the disease, as becomes clear in the graph below (Graph 7.6).

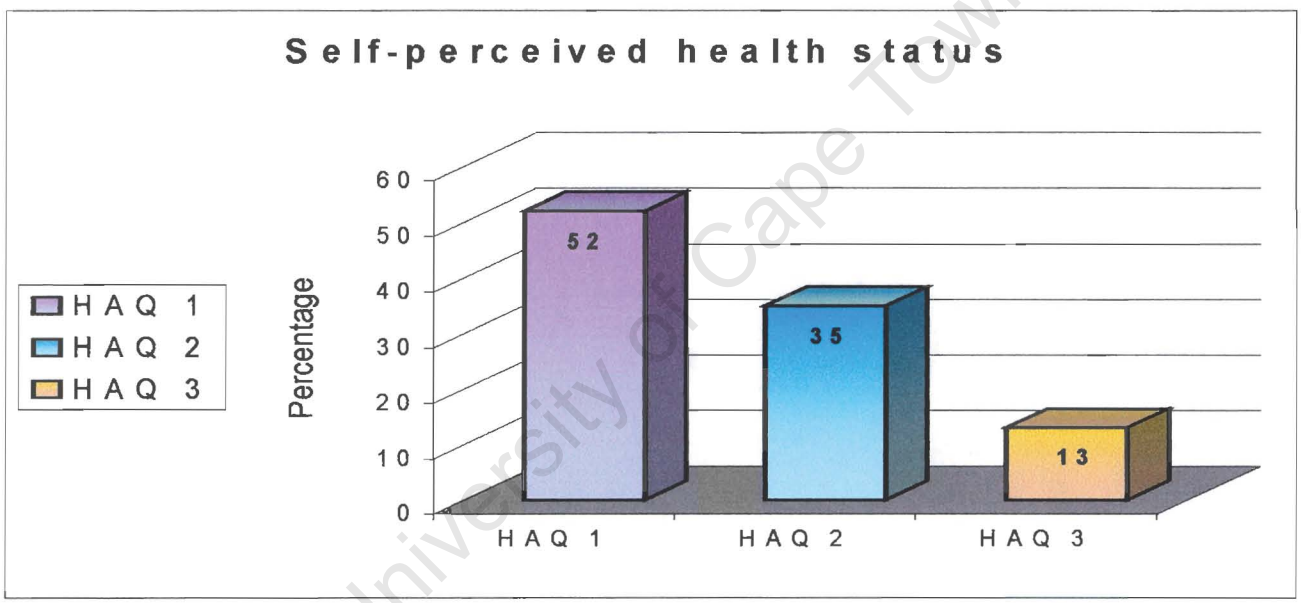
Graph 7.6 Duration of rheumatoid arthritis



Five of the participants had been diagnosed with Juvenile Chronic Arthritis (JCA) before the age of 18 years. There was no association between age at diagnosis and HAQ scores (interval scale).

The mean HAQ score (continuous scale) was 1,035 and the median 1,000. Of the participants, 75% had a HAQ score of < 1,5. The HAQ (interval scale) showed that 52% of the individuals had a good self-perceived health status (HAQ=1), 35% had a fair self-perceived health status (HAQ=2) and 13% had a poor self-perceived health status (HAQ=3). These results are shown in Graph 7.7.

Graph 7.7 Self-perceived health status



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Pain (interval scale) was divided into two categories to make statistical analysis easier, where 1 – 5 indicated no pain to medium pain and 6 – 10 medium to severe pain. Of the participating individuals 60% indicated that they had no pain to medium pain and 40 % indicated that they had medium to severe pain. The mean for pain (continuous scale) was 4,9779 and the median 5,0000.

When comparing HAQ and pain, it was found that there was a significant association/correlation between pain and the HAQ, whether an interval scale (p=0,0007 & r=0,3570) or a continuous scale (p<0,0001 & r=0,56985) was used. The higher the HAQ, the higher was the experience of pain as shown in Table 7.11.

Table 7.11 Association between self-perceived health status and pain

Frequency Percentage		Pain Experience (interval scale)		
		No pain to medium pain	Medium to severe pain	Total
HAQ (interval scale)	1 = **GOOD** self-perceived health status	**38** 38,00	**14** 14,00	**52** 52,00
	2 = **FAIR** self-perceived health status	**20** 20,00	**15** 15,00	**35** 35,00
	3 = **POOR** self-perceived health status	**2** 2,00	**11** 11,00	**13** 13,00
	Total	**60** 60,00	**40** 40,00	**100** 100,00

When comparing the HAQ score (interval scale) with gender, level of education and marital status, no association was found. When the HAQ score was compared to the number of children, it was found that the higher the HAQ (self-perceived health status), the more children the individuals had, versus the lower the HAQ, the less children the individuals had (interval scale, p=0,0467 & continuous scale p=0,0235 & r=0,22643). There was also a marginal association between HAQ score and income, with the lower the income, the higher the HAQ and the higher the income, the lower the HAQ score (HAQ interval scale, p=0,0547 & HAQ continuous scale, p=0,0935 & r=–0,16865).

When comparing HAQ (interval scale) with the type of transport used by the participants, it was found that significantly more individuals with a HAQ score of 1 (in other words *good self-perceived health status*), made use of private transport (p=0,0107). There was no association between the HAQ scores of 2 and 3 (i.e. *fair* and *poor self-perceived health status*), and use of public versus private transport. The analysis of this data is shown in Table 7.12.

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Table 7.12 Self-perceived health status and transport utilisation

Frequency Percentage		Transport		
		Public transport	Private transport	Total
HAQ (interval scale)	1 = **GOOD** self-perceived health status	**14** 14,00	**38** 38,00	**52** 52,00
	2 = **FAIR** self -perceived health status	**19** 19,00	**16** 16,00	**35** 35,00
	3 = **POOR** self-perceived health status	**8** 8,00	**5** 5,00	**13** 13,00
	Total	**41** 41,00	**59** 59,00	**100** 100,00

When comparing HAQ (continuous scale) and pain (continuous scale) with transport it was found that individuals who made use of private transport had a significantly lower HAQ score (p=0,0389) and less pain (p=0,0014) than the individuals who make use of public transport as shown in Table 7.13.

Table 7.13 Self-perceived health status, pain experience and transport utilisation

		Transport	
		Public transport	Private transport
HAQ (continuous scale)	N	41,00	59,00
	Mean	1,22	0,91
	SD	0,77	0,63
	Min	0,00	0,00
	Max	3,00	2,38
	Median	1,25	0,88
Pain (continuous scale)	N	41,00	59,00
	Mean	6,02	4,25
	SD	2,75	2,65
	Min	0,10	0,00
	Max	10,00	10,00
	Median	6,50	4,00

When comparing HAQ (interval scale) with pain (interval scale), the medical facility used by the individual for care and the use of either private or public transport, it was found that there is a significant association between pain experienced and the HAQ score of the individuals who made use of government hospitals and public transport (p=0,0159). On the other hand, individuals who make use of government hospitals, but used private transport, showed only a marginal association between the HAQ score and pain experienced (p=0,0850). No association could be found regarding HAQ scores and pain, and individuals who were private patients and who made use of private transport (p=1,000). It appears that the manner of transport might have an important influence on maintaining a low HAQ score.

When comparing pain (interval scale), gender and marital status with whether an individual made use of public or private transport, the only association was that married women, with less pain made more use of private transport (p=0,0255). Married men with less pain also rather made use of private transport, whereas married men with more pain made use of public transport (p=0,0107).

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No association could be found when comparing HAQ (interval scale) with the type of work, work status or number of jobs that an individual had since being diagnosed with rheumatoid arthritis.

Significant associations were found when HAQ (interval scale) was compared with the following work characteristics, which are believed to affect work ability negatively, namely sitting the whole day, light or medium work tasks, medium to heavy work tasks, tasks that require fine hand functioning, repetitive tasks.

- Between HAQ and light or medium work tasks (p=0,0413), it was found that individuals with a *good* (1) and *fair* (2) HAQ score performed more light or medium tasks than individuals who had a *poor* (3) HAQ score.

- Between HAQ and medium to heavy work tasks (p=0,0097), it was found that individuals with a *poor* (3) HAQ score performed more medium to heavy work tasks than individuals with *fair* (2) and *good* (1) HAQ scores.

- There was marginal association between the HAQ score and tasks that require fine hand functioning (p=0,0645), suggesting that individuals with a *poor* (3) HAQ tend to do more tasks that required fine hand functioning than individuals who had *fair* (2) and *good* (1) HAQ scores.

No association was found between the HAQ scores (interval scale) and whether individuals did repetitive tasks or worked sitting the whole day.

Seeing that an association between HAQ score and pain was found, it was decided to determine whether the association persisted when pain (interval scale), HAQ score (interval scale) and the above work characteristics were compared.

For individuals who did medium to heavy work and not any light to medium work, there was a significant association between HAQ and pain. The higher the HAQ score, the higher the experience of pain (p=0,0017). On the other hand, for individuals who did light to medium work, but no heavy to medium work, no association between HAQ score and pain was found as the pain experience was fairly even in all three HAQ score categories.

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The association between HAQ score and pain persisted whether an individual did fine hand activities (p=0,0308) or not (p=0,0363), so that the higher the HAQ score, the higher the pain experience. This could mean that heavy work causes more pain than medium to light work and thus worse self-perceived health status, or that work requiring fine hand movements did not have any effect on the association between HAQ and pain.

Of the individuals with RA, 14% visited their doctor weekly as a result of their RA, 55% visited their doctor 1 to 3 monthly, 21% visited their doctor 3 to 6 monthly and 10% visited their doctors every 6 months to a year or more. A graphical representation of this information appears in Graph 7.8. Of the 100 participants, 43% indicated that they never took sick leave. As expected, individuals who have had RA for one year or less, visited their doctor more often than individuals who had RA longer than one year (p=0,0470).

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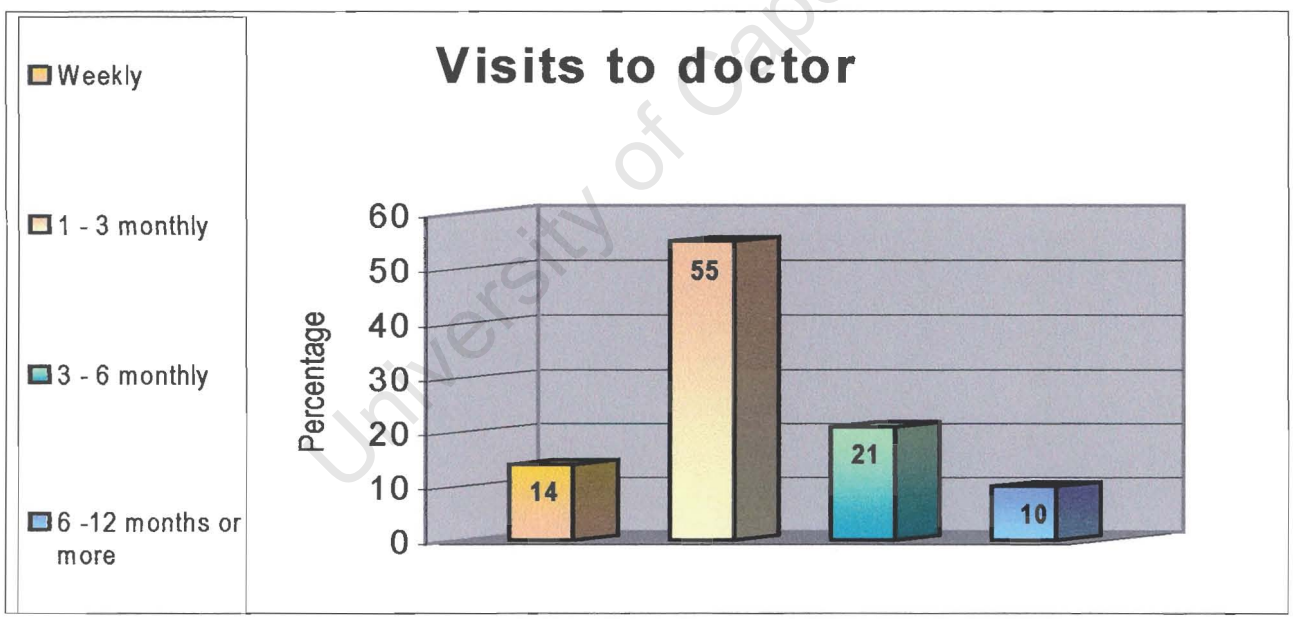
Graph 7.8 Visits to doctor



The distribution of the types of occupation and how often the individual visited their doctor as a result of RA showed a fairly even distribution, with 55% of all the employment categories visiting their doctor as a result of RA every 1 to 3 months.

When the HAQ (interval scale) was compared to frequency of visits to the doctor, how regularly the individuals took sick leave as well as the length of the sick leave, no association was found. When frequency of visits to the doctor, how regularly they took sick leave and the length of their sick leave were compared to how long they have had RA, pain experience (interval scale) and HAQ score (interval scale), a low association was found. Individuals who had RA for longer than 5 years and had a HAQ score of 2, tended to visit their doctor less often than individuals who have had RA for less than 5 years, although they might also have had a HAQ score of 2 (p=0,0057). Individuals who had RA less than 1 year and a HAQ of 3, tended to take sick leave for a longer period than individuals who have had RA longer than 1 year although they also had a HAQ of 3 (p=0,0109). No significant difference was found regarding individuals with a HAQ of 1.

In this study in the Western Cape, 64% of the participants indicated that they were on DMARD. The various responses are tabulated in Table 7.14.

Table 7.14 Disease Modifying Anti- Rheumatic Drugs (DMARD)

		Frequency	Percentage	Cumulative Frequency	Cumulative Percentage
DMARD	Yes	64	64,00	64	64,00
	No	7	7,00	71	71,00
	Do not know	29	29,00	100	100,00

There was also no association found when HAQ (interval scale), pain (interval scale), how often they visited their doctor, how often they took sick leave and how long their sick leave lasted was compared to whether an individual was on DMARD or not or did not know whether he/she was on DMARD.

When comparing whether participants knew whether they were on DMARD or not, it was found that significantly more individuals at the private practices knew whether they were on DMARD or not (p=0,0031). Individuals attending Groote Schuur Hospital, Princess Alice Orthopedic Unit and the private practices indicated more positively that they were on DMARD, while individuals attending Tygerberg Hospital answered that they did not know (p<0,0001).

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There was also a positive association between individuals knowing they were on DMARD and those not knowing. The higher the level of education, the more they answered *yes* or *no* instead of *do not know*. The lower their education, the more individuals answered *do not know* instead of *yes* or *no* (p<0,0001). The various responses are tabulated in Table 7.15.

Table 7.15 DMARD, medical facility and education level

Frequency Percentage		DMARD		Total
		Yes/No	Do not know	
Medical facility	Government Hospitals	**39** 39,00	**25** 25,00	**64** 64.00
	Private	**32** 32,00	**4** 4,00	**36** 36.00
Level of education	≤ grade 7	**7** 7,00	**14** 14,00	**21** 21.00
	Grade 8 – 10	**18** 18,00	**10** 10,00	**28** 28.00
	Grade 11 & 12	**24** 24,00	**3** 3,00	**27** 27.00
	Tertiary Education	**22** 22,00	**2** 2,00	**24** 24.00
Total		**71** 71,00	**29** 29,00	**100** 100.00

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7.1.3 Employment profile of the employed individual with rheumatoid arthritis

As mentioned under demographic information, there were no individuals diagnosed with RA and employed in the employment category of skilled agricultural and fishery workers as indicated in Table 7.16.

Table 7.16 Occupational categories

Occupational category	Frequency	Percentage
Legislators, senior officials and managers	7	7,00
Professionals	14	14,00
Technicians and associate professionals	10	10,00
Clerks	22	22,00
Service and sales workers	8	8,00
Skilled agricultural and fishery workers	0	0,00
Craft and related trades	9	9,00
Plant and machine operators and assemblers	9	9,00
Elementary occupations	21	21,00
Total	100	100,00

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As discussed before, the occupational categories were grouped together for statistical analysis to form three groups. Legislators, senior officials and managers, professionals and technicians and associate professionals were grouped together, as most of these jobs would have required post-graduate training. This group was called *professionals* for easy identification. Clerks and service and sales workers were grouped together as most of these jobs would have required secondary education. This group was called *clerical workers* for easier identification. Craft and related trades, plant and machine operators and assemblers and elementary occupations were grouped together, as it was decided that these individuals would have had more primary education and some secondary education in order to be part of these occupation categories. For easier identification they were called *labourers*.

There was no association found between the average work autonomy as experienced by the three groups, but there was a significant association between their levels of education as well as between their respective income as shown in Table 7.17. In general the professionals had higher levels of education as well as higher incomes than the clerical workers. Clerical workers, however, had higher levels of education and income than labourers (education p<0,0001 & income p<0,0001).

Table 7.17 Occupation versus autonomy, level of education and monthly income

		Occupation		
		Professionals	Clerical workers	Labourers
Autonomy	N	**31,00**	**30,0**	**39,00**
	Mean	2,09	2,43	2,19
	SD	0,96	0,89	0,77
	Median	2,25	2,25	2,25
Level of education	N	**31,00**	**30,00**	**39,00**
	Mean	12,74	11,07	7,44
	SD	2,07	2,41	3,09
	Median	13,00	11,50	8,00
Monthly income	N	**31,00**	**30,00**	**39,00**
	Mean	8675,00	3378,33	1589,74
	SD	6828,30	2546,49	999,16
	Median	7000,00	3000,00	1250,00

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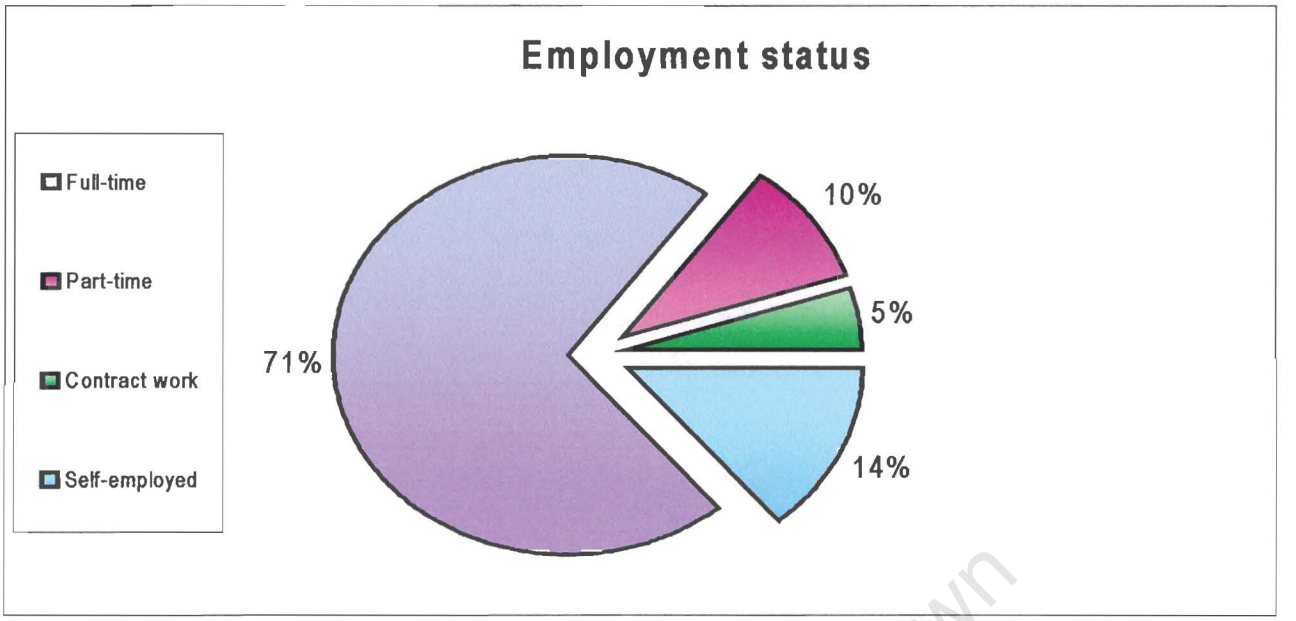
Of the 100 participants, 71% were employed full-time or permanently by someone else, 10% were employed regularly part-time, 5% worked as contract workers and 14% were self-employed, as depicted graphically in Graph 7.9. Regarding the number of times participants changed jobs since being diagnosed, 78% had only one job since being diagnosed, while 16% had two jobs, 1% had three jobs, 2% had five jobs and 3% had six jobs since being diagnosed. Of the 22 individuals who had more than one job since being diagnosed, only 50% of the individuals indicated that they changed their jobs as a result of RA-related reasons, with one of them indicating that she had to change jobs twice due to her RA.

Graph 7.9 Employment status



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Only 10% of the individuals taking part obtained further qualifications after being diagnosed with RA. When compared to the degree of importance with which they regarded their work, only those who believed that their work was very important, obtained further qualifications. Those who obtained further qualifications had mostly been diagnosed with JCA before the age of 18 years, and one would have expected them to obtain further qualifications to enable them to enter the job market.

The only important changes to participants' jobs since being diagnosed with RA were found regarding the time it took them to complete tasks, and in terms of adaptations they or their employers had to make to the workplace. Significantly more individuals who have had RA longer than 5 years felt that the time that they needed to complete tasks have decreased since being diagnosed with RA, when compared to individuals who have had RA less than 5 years (p=0,0630). The more individuals felt that the time necessary to complete tasks had increased, the higher was their HAQ score, whereas the more the time they needed stayed the same, the lower the HAQ score (p=0,0054). The longer individuals have had RA, the more adaptations were necessary regarding their jobs, whereas the less the time had lapsed since the onset of RA, the less adaptations were necessary to the workplace (p=0,0032).

When questioned whether their work was affected during an acute episode, it became clear that only the volume or the amount of work that they could do during such an episode, was markedly affected as can be seen in Table 7.18.

Table 7.18 Adaptation during an acute episode of RA

Adaptations during an acute episode of RA				
	Yes		No	
	Frequency	Percentage	Frequency	Percentage
Adaptations during an acute episode	49	49,00	51	51,00
Neatness during an acute episode	40	40,00	60	60,00
Accuracy during an acute episode	42	42,00	58	58,00
Volume during an acute episode	63	63,00	37	37,00

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When comparing whether their work was affected during an acute episode to their HAQ score (interval scale), pain experience (interval scale) and how long they have had RA, only the group that have had RA for 1 to 5 years showed a significant association between HAQ and pain. In the group with 1 to 5 years since diagnosis, there was found to be an association between HAQ and pain if no adaptations are made to their work (p=0,0114). If adaptations were made to their work during an acute episode, the association between HAQ and pain was found to be only marginal (p=0,0562). A significant association was found between HAQ and pain in individuals who have had RA for 1 to 5 years, that indicated that their work was affected in terms of accuracy and volume or amount during an acute episode (p=0,0026). The data regarding the individuals that answered no to the last two questions were too small to analyse statistically.

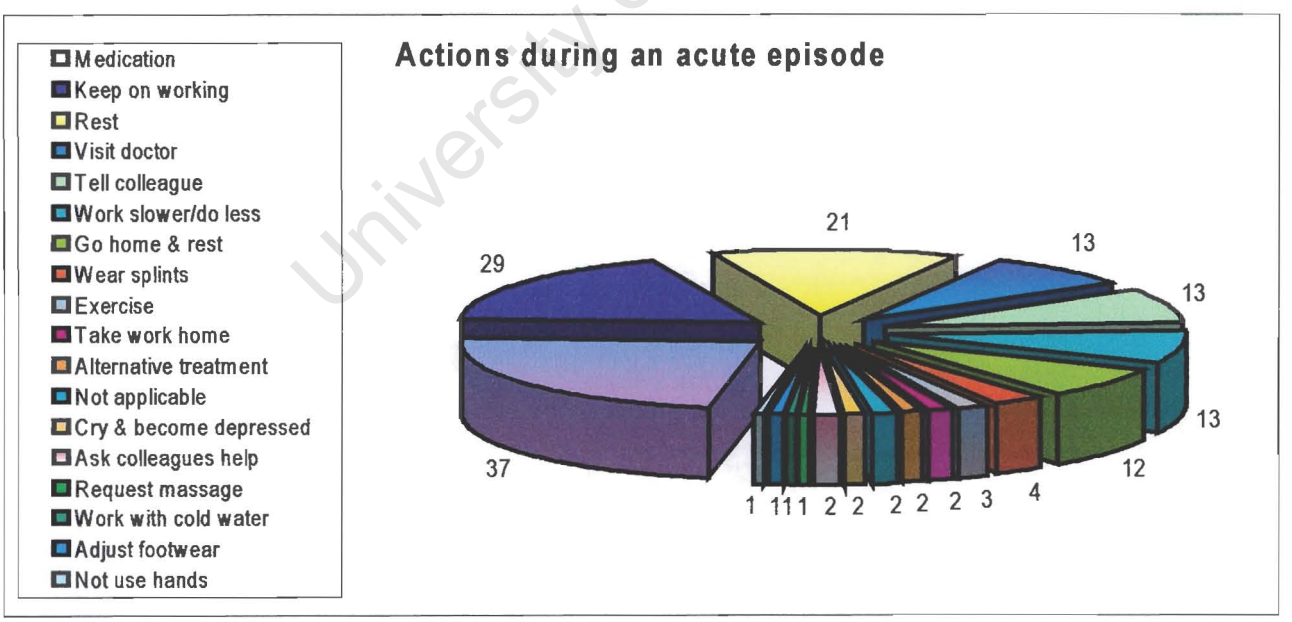
There was no association between the duration since being diagnosed with RA and whether there were any changes to the work done by these individuals during an acute episode.

The actions that the participating individuals took when they became aware of an acute episode while at work, included:

- take some sort of medication = 37%
- keep on working = 29%
- rest = 21%
- visit the doctor = 13%
- tell one of their colleagues = 13%
- work slower or do less work = 13%
- go home and rest = 12%
- wear splints or bandage their joints = 4%
- exercise = 3%
- take work home = 2%
- use some alternative form of treatment or home remedy = 2%
- have not yet experienced an acute episode = 2%
- cry and/or become depressed = 2%
- ask for help from colleagues = 2%
- request a massage = 1%
- work with cold water = 1%
- adjust their footwear = 1%
- try not to use their hands = 1%.

The following pie chart depicts this graphically.

Graph 7.10 Actions during an acute episode



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When comparing the above actions with the individuals' HAQ scores (interval scale), individuals who had a HAQ score of 3 (i.e. *poor self-perceived health status*) would rather take some form of medication, than individuals with a good(1) or fair(2) self-perceived health status (p=0,0263). When comparing the above actions with pain (interval scale), it was found that individuals with little to average pain would rather carry on working (p=0,0450). When comparing the above actions with the duration of RA, it was found that the longer individuals had RA, the more they would be inclined to take medication when feeling an acute episode coming on while at work (p=0,0193).

Of the participating individuals, 88% felt that their jobs were very important to them, thus the score of 8, 9 or 10 when asked to grade the importance of their work. The graphic representation of the respective percentages of individuals' rating of the importance of their jobs is given in Graph 7.11 below.

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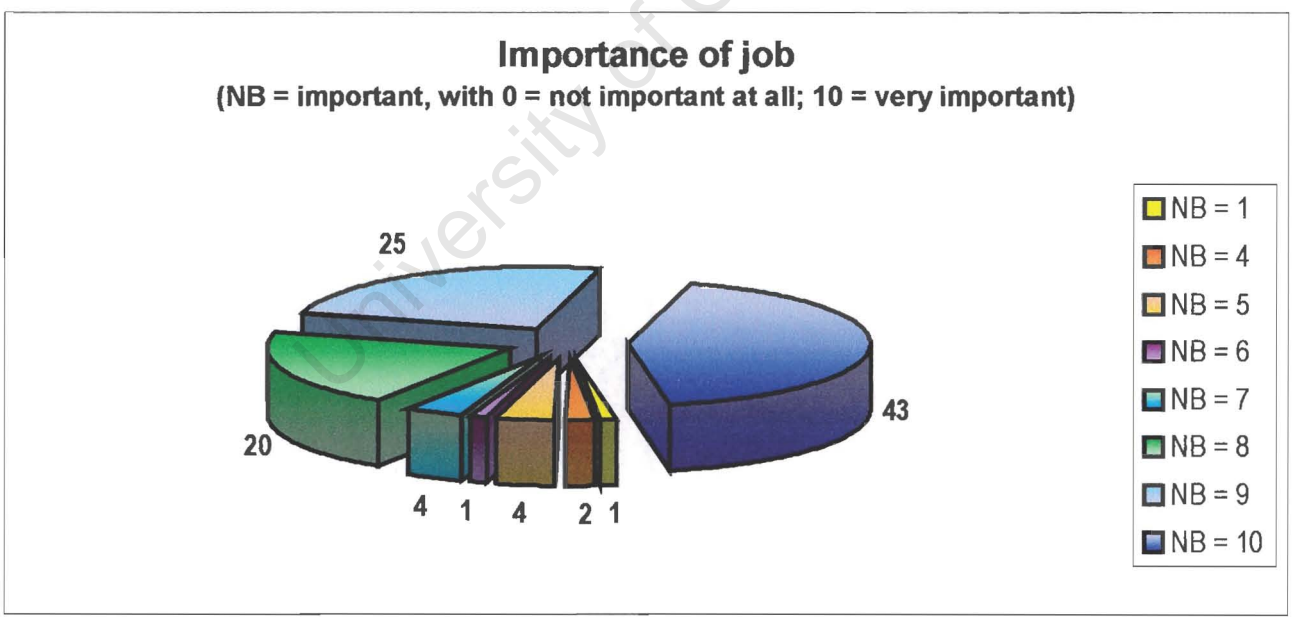
Graph 7.11 Importance of job



When the different occupational categories were compared with how important the participants felt their work was, it was found that in all the categories the overall feeling was that work is very important. Women, more than men, felt that their work was of great importance, even though the difference was not significant.

When workstatus was compared to the importance of the job, it was found that all, except one individual who did part-time/contract work, found their work to be very important to them, while about one third of individuals who were self employed indicated that their work was less important to them. These findings are tabulated below.

Table 7.19 Importance of job and work status

Importance of the job	Frequency Percentage	Work status			
		Permanent/full-time	Part-time/contract	Self-employed	Total
	0 – 7	**6** 6,00	**1** 1,00	**5** 5,00	**12** 12,00
	8 – 10	**65** 65,00	**14** 14,00	**9** 9,00	**88** 88,00
	Total	**71** 71,00	**15** 15,00	**14** 14,00	**100** 100,00

As far as the three occupational groups are concerned, individuals who saw their work as *less important* did not show any association when the importance of their jobs was compared to work status. Of the individuals who saw their work as *very important*, and who were *employed full-time* by someone else, individuals who did clerical work and who were labourers saw their work as more important than the professionals (p=0.0338), as illustrated in Graph 7.12.

Even though there was no association between, how important participants perceived their job to be and average work autonomy, a significant association was found when comparing the above two variables (i.e. the three occupational groups and the importance of the job) with work status. When comparing work autonomy with work status and importance of the job, it was found that the individuals who felt that their work was more important and who were self-employed, had more autonomy than individuals who were part-time employed or contract workers. Individuals who were part-time employed or contract workers however had, more autonomy than individuals who were employed full-time by someone else (p=0,0004). Individuals who rated their work as *less important* and who were self-employed, also felt that they had more work autonomy than individuals who were employed full-time by someone else (p=0,0446).

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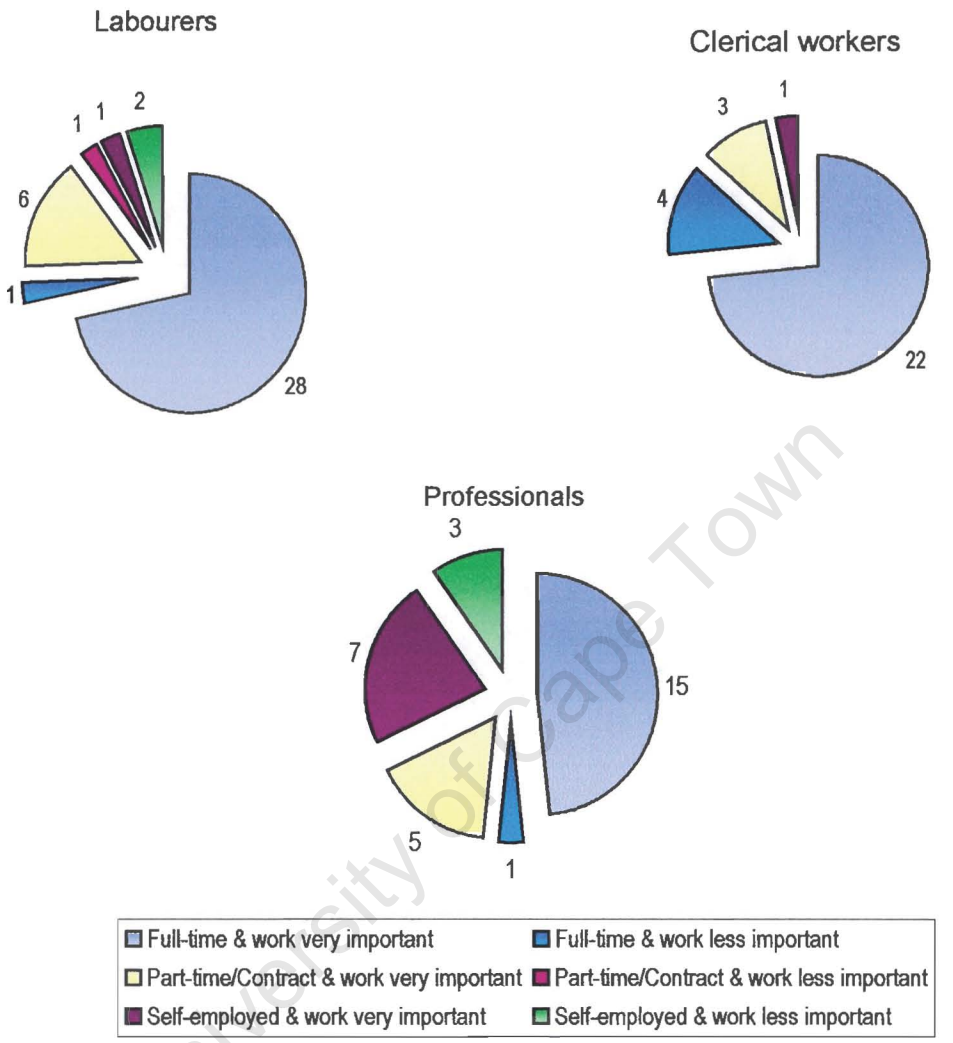
Graph 7.12 Work status and importance of the job



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When comparing importance of the job with the support individuals believed they were receiving at work, it was found that those who had told their employer (p=0,0220) and co-workers (p=0,0795) of their diagnosis, felt that their work was more important to them than those who had not revealed their illness. There was no significant difference regarding work importance between those who did and those who did not inform their direct supervisors at work.

Work support was further explored, and it was found that individuals who informed their employers that they have been diagnosed with RA, felt that they had received sufficient support from their employers (p=0,0045). On the other hand, individuals who had not informed their employer that they have been diagnosed with RA, felt that they did not receive enough employer support (p=0,0436). Individuals who have or have not informed their direct supervisors or co-workers of their diagnosis, showed no significance in terms of receiving sufficient support or not receiving sufficient support from their direct supervisor or co-workers respectively.

Significantly more females, than males felt that they received sufficient support at work (p=0,0016). When comparing gender with work autonomy and income, it was found that there was no association between the amount of autonomy that males and females respectively had or as regards their income, as shown in Table 7.20.

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Table 7.20 Gender, work support, work autonomy and income

		Gender	
		Male	Female
	N	**17**	**83**
Support at work	Mean	4.06	5.98
	SD	3.17	2.54
	Min	0.00	0.00
	Max	9.00	9.00
	Median	4.00	6.00
Work autonomy	Mean	2.00	2.28
	SD	0.94	0.86
	Min	1.00	1.00
	Max	3.75	4.00
	Median	1.75	2.25
Individual monthly income	Mean	7.12	5.92
	SD	2.89	2.70
	Min	4.00	1.00
	Max	13.00	12.00
	Median	6.00	5.00

Males were found to have more work autonomy as well as a higher monthly income, although a statistically significant difference was not found. When comparing level of education to work autonomy and income, it was found that there was an association between level of education and income ($p<0,0001$), but not between level of education and work autonomy. No significant difference was found when average work autonomy was compared to the nine occupational categories. This was further explored by comparing the average autonomy with income and the three occupational groups. A significant association was found between income and autonomy for participants who fell in the professional group ($p=0,0434$), but no association could be found for the other two employment groups. It appeared it was easier for professionals than for clerical workers or labourers to decide independently about time to report for duty. Clerical workers and labourers would rather ask permission or tell their supervisor that they need to report later than usual for duty ($p=0,0409$). Professionals could also decide more independently than the other two groups when to take a week off, while clerical workers or labourers would rather tell someone or ask permission.

Requirements of the work were assessed by means of a questionnaire, where individuals had the option to answer *never*, *almost never*, *sometimes*, *almost always* and *always* regarding specific questions relating to their work. For statistical analysis the categories *never* and *almost never* were grouped together and the categories *always* and *almost always* were grouped together.

When comparing work requirements with work status, it was found that individuals who worked full-time, had to handle more conflicting work demands than individuals who were part-time/contract workers or who were self-employed ($p=0,0497$). Individuals who are employed full-time also felt that they had more often too much work, compared to individuals who were part-time/contract workers or who were self-employed ($p=0,0044$).

For reasons of statistical analysis some of the questions were grouped together. "How often do you have to handle conflicting work demands?", "How often is there insufficient time to complete tasks at work?" and "How often is there too much work?" all pertained to how stressful or challenging participants found their work to be. The two questions relating to *heavy to very heavy work* and *lifting* were also grouped together for statistical analysis.

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When comparing requirements of the job with the importance of the job, it was found that individuals who had possibly more stressful work requirements or more work challenges, felt that their work was of more importance to them (p=0,0067). Individuals who indicated that they did more heavy work also found that their work was more important to them than individuals who indicated that they *never* or *almost never* had to do heavy work (p=0,0432). No association was found between the importance of the job in participants who *always* versus *never* did medium or light work, or in terms of work satisfaction.

When comparing the requirements of the job with work autonomy, it was found that participants who had to handle conflicting work demands more often, had a lower autonomy than those who rarely experienced conflicting demands in their work (p=0,0703). Individuals who felt that they often had too much work, were also found to have a lower autonomy at work (p=0,0777). Individuals who always had to do heavy work or lifting, were found to have a lower autonomy than individuals who never or only sometimes had to do heavy work (p=0,0616), or lifting respectively (p=0,0739). Individuals who were never satisfied with the quality of their work (p=0,0648), or the type of work that they did (p=0,0897), were found to have a lower autonomy than individuals who answered *sometimes* or *always*. All of the above showed only a marginal difference. The only work requirement that showed to be significant when compared to work autonomy, was participants who indicated that they *sometimes* had to do sedentary work all day long. They had lower work autonomy than participants who *never* or *always* had to do such work (p=0,0112).

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7.2 Qualitative results

The qualitative part of the research provided four main categories with related sub-categories. The categories and sub-categories explained the factors that participants diagnosed with RA believed helped them to remain employed, as explicated in Table 7.21.

Table 7.21 Qualitative categories

Locus of control • Internal locus of control ★ Motivation ★ Generativity • External locus of control ★ Religion ★ Hope	**Rheumatoid arthritis management** • Diet • Exercise • Medical treatment • Alternative treatment
Self-management • Adaptation ★ Lifestyle ★ Work place • Goal setting • Problem-solving • Positive thinking • Self-efficacy	**Work enablers** • Working for survival • Education of colleagues • Support ★ Family ★ Colleagues ◆ acceptance ◆ acknowledgement • Control over the work ★ Work flexibility ★ Accessibility • Attitude towards work • Work satisfaction

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In RA, as in other illnesses, a unique interaction exists between disease, stages in life, personality and environment. The interaction between these different facets does not only vary from individual to individual, but will vary also for each individual during the course of the disease. The variability of RA means that an individual will be passing from periods of exacerbation to periods of remission and from periods of acute illness to periods of chronic disease. As a result of this, the response of clients have to be flexible to cope with the varying levels of pain, functional ability, deformity and the psychosocial impacts of these variations. The additional problem of feeling controlled by the disease, instead of rather feeling in control of the disease can also arise. A high degree of unpredictability, change and feelings of loss of control can lead to stress and anxiety (Sandles, 1990).

From an occupational therapy framework, the above view of RA links with the Person-Environment Occupational Performance Model. The three elements of the model describe what people do in their daily lives, what motivates them, and how their personal characteristics combine with the situations in which occupations are undertaken to influence successful occupational performance. This model provides a framework for viewing and studying human behaviour and combines knowledge about the impairments that impede performance, the environment that supports performance, and individual needs, preferences, styles and goals of RA sufferers (Christiansen & Baum, 1997).

The four categories and their sub categories found in this study (Table 7.20) are encompassed by this model and will be discussed in the following chapter. It is therefore important to consider that the categories are viewed from an occupational therapy perspective and that the model is viewed as a client-centred model. I believe that a client-centered approach has not always been followed in the literature on RA and the work situation. This may be the reason why work disability has been the focus of research up to now, instead of what it is that assists individuals to maintain their employment status.

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Chapter 8

Discussion of research results

According to Barrett *et al.* (2000) the common factors associated with work disability fall into three main categories. The first relates to the **employment**, more specifically the nature of the job, the level of physical activity required, and the degree of autonomy, particularly as far as the pace of the work is concerned. The second relates to the **employee**, his/her age at the onset of RA, marital status and the level of formal education. The third relates to the **disease**, mainly the time since the onset of RA and the level of disability. Barrett *et al.* (2000) found that the HAQ score regarding self-perceived health status was the only significant indicator of work disability.

The researcher would expect the factors that enabled individuals with RA to stay employed in the open labour market since being diagnosed, to be exactly the opposite of the factors causing work disability.

Educational attainments, autonomy within the workplace, self-employment and the individuals' level of motivation and his/her determination to work, despite significant disease, have all been reported as important predictors of continued employment (Gilworth *et al.* 2001). Chorus *et al.* (2000) also report that other studies have shown that psychosocial as well as work-related factors (such as physical job demands, job autonomy, type of job, and job satisfaction) contribute to the ability of individuals with RA to work. Individuals with RA indicated changing their job or altering their career path, altering their work hours, using more DMARD, using a car service, sleeping more and working at home as the most helpful adaptations they have made in order to remain employed. On the other hand, the same individuals indicated fatigue, not being able to use their hands, not being able to choose rest periods and transportation to and from work as the most important threats facing them in their endeavours to keep their work. (Manusco *et al.*, 2000)

From research we know that a physically demanding job, lack of control over the pace and activities at work, no self-employment status, lack of support by employers and colleagues and also difficulties in commuting are important factors for leaving the labour force (Chorus *et al.*, 2001). Despite this valuable knowledge, it is still not clear which factors

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should be regarded as most important, as some studies indicate that disease-related factors are the most important, whereas others conclude that work factors are the most important predictors of withdrawal from the labour force.

8.1 Demographic variables assisting individuals with RA to stay employed

In South Africa, with its cultural diversity and political background, and more specifically in the Western Cape, whites with RA were found to have higher levels of education, make more use of private treatment facilities and are more likely to use private transport. This also means that they fall in higher income categories, as they tend to work in jobs categorised as *professional*. Coloured and black individuals with RA, on the other hand, tend to have lower levels of education and make more use of tertiary treatment facilities and public transport, possibly as a result of their lower income levels.

There are few explanations as to why so few black individuals participated in the study. According to the 1996 National Census of South Africa, 21% of the people in the Western Cape are black, 21% are white, 1% are Indian and 54% are coloured. A few possibilities could be that individuals with RA are not employed in the open labour market or that less black individuals are diagnosed with RA compared to whites or coloureds. The 1% Indian population in the Western Cape was also not matched. No proof could be found that there are fewer blacks in South Africa with RA compared to the other racial groups, even though early studies suggested that this might be the case (Meyers, 1989).

The fact that the 3:1 female to male ratio as found in RA, was not met in this research project could have negative implications on the study and could cause some skewness of the data. The other factor that may negatively affect the data is that two females were older than 65 years, which is regarded as retirement age in the open labour market. As the males were marginally older than the females, it might have meant that the males with RA and employed in the open labour market were significantly older than the females, had the two female individuals fallen within the 65 years employment age.

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8.1.1 Age at the onset of RA

Numerous studies show that age of onset is an indicator of work disability, with older age negatively affecting work disability (Mau *et al.*, 1996, Fex *et al.*, 1998, Sokka *et al.*, 1999 and Young *et al.*, 2000). Another factor that needs to be kept in mind is the increasing incidence of work disability with age as it might also reflect that the incidence of RA increases with age (Holte *et al.*, 2001). The individuals included in this study and employed in the open labour market showed a wide distribution of age at onset of disease, but they still continue to be employed in the open labour market. There had to be other factors therefore that assisted them to remain employed, even though their age at onset of the disease put them at higher risk of becoming work disabled.

8.1.2 Marital status

Marital status seemed to have an influence on the work as well as the health status of the individuals included in this research. There were significantly more females in single relationships, and single females had a lower income than married males and females. It could therefore be expected that single females would have to work while married individuals (males and females), especially females, could have an option whether they wanted to work or not. Married individuals (male and female) also seemed to experience significantly less pain than single individuals (male and female), but only marginally less pain than single females. This may be because it was found that married individuals (male and female) make more use of private transport. Some of the other reasons not assessed in this study, are the level of support that individuals with RA receive from their family and level of depression.

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According to Reisine (1993) the rates of progression in disability are higher in unmarried individuals (male and female) with RA than in married individuals (male and female) and the rate of progression varies in time according to marital status. It is also important to keep the social support in the marital relationship in mind as it was found that absence of support in the home accounts for higher depression scores in working women with RA. Apparently a supportive relationship seems to foster better coping strategies, which leads to better psychological adjustment. Reisine and Fifield (1995) found that married individuals feel more needed by others than individuals who are not married, and could be one of the critical aspects that help arthritis patients to maintain higher levels of social and

psychological functioning in order to meet the expectations of the significant other. This was supported in studies by De Roos and Callahan (1999), Williamson *et al.* (1997), Fitzpatrick *et al.* (1991), Manne and Zautra (1989), Reisine *et al.* (1989) and Yelin *et al.* (1980).

Even though it was found that single individuals seem to have significantly more pain, there was no marked difference found between the HAQ scores or self-perceived health status of married individuals and those of single individuals. The fact that individuals are single could be the reason why they experience more pain, as pain is linked with depression, and the literature shows that single individuals with RA tend to be more depressed than married individuals (Reisine & Fifield, 1995 and Fifield *et al.*, 1991). Marital status in working individuals with RA therefore does have an effect on pain experience, but not on self-perceived health status. It could also mean that married individuals have a dual income, which places them as a family into an income category where they can afford their own car, as transport difficulties have been shown to contribute to work disability (Manusco *et al.*, 2000).

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8.1.3 Level of formal education

Females in this study had a higher level of education than males. This could be the reason why significantly more males are employed in craft and related trades, as plant and machine operators and assemblers and in the elementary occupations. Individuals with a higher level of education also made more use of private transport, as they had a higher level of income. There was once again no association between the HAQ scores or self-perceived health status and the level of education. Individuals with an HAQ score of 1 had a mean level of education 10,56 years, those with an HAQ score of 2 had a mean level of education of 9,43 years and those with an HAQ score of 3 had an mean level of education of 10,62 years. The other important factor to keep in mind is that there was an association between the level of education, income, use of private versus government facilities for medical care and use of private versus public transport.

Leigh and Fries (1991) found a smooth, inverse association between the disability score and schooling for men, but conflicting results were found for women. These authors came

to the conclusion that higher education would enable individuals to do work where they would be able to do more light to medium work instead of heavy work.

Extensive work on the effect of level of education on work disability was done by Chorus *et al.* (2000). They compared individuals with RA to the general population and found that labour force participation in individuals (male and female) with RA and with primary levels of education was significantly reduced only for males in the age categories 20 – 29, 40 – 49 and 50 – 59. In the case of both male and female individuals with RA and with secondary levels of education labour force participation was only significantly reduced for the highest age category of 50 – 59 years. For individuals with RA and with a high level of education labour force participation was significantly reduced only for females in the age categories 40 – 49 years and 50 – 59 years.

Another factor that needs to be taken into account regarding the effect that the level of education could have on health status, was individuals' knowledge about their medical management. There was a significant association between the level of education and whether individuals knew or did not know whether they were using DMARD. The lower the education, the more individuals did not know whether they were using DMARD, while the higher the education, the more individuals knew whether they were or were not using DMARD. It is interesting that the study by Barrett *et al.* (2000) showed that DMARD did not lessen the chances of work disability. The fact however that an individual has knowledge regarding his/her disease and its management, could have a direct impact on how he/she copes with RA (Lorig & Fries, 1996; Lorig & Holman, 1993). It may also be that DMARD use is associated with better control of the RA.

In this South African study the individuals employed in the open labour market had a wide distribution of levels of education, with the males having a lower level of education than the females. This would imply that men would be required to do jobs which could be physically more demanding, as these jobs fall in the labourer type jobs. Males did not have a lower HAQ score than females. There was also no association found between HAQ score and the level of education, even though the HAQ score has been found to be one of the only persistent indicators of work disability in other studies (Reisine *et al.*, 1989; Doeglas *et al.*, 1995; Fex *et al.*, 1998; Jäntti *et al.*, 1999; Young *et al.*, 2000).

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Even though level of education is an indicator of work disability, it seems that in individuals with RA and employed in the open labour market, there are other factors that assisted them to stay employed.

8.1.4 Other demographic factors

Other demographic factors that seemed to have an effect on individual HAQ scores included the number of children. The more children individuals had the higher were the HAQ scores, which are considered to be an indicator of work disability.

With the above in mind, one would expect that the age of the children would have an effect on pain experience or HAQ score. No association was found when individuals who had no children were compared to individuals who had children older than 18 years, older than 12 years and those who had children aged 1 day to 12 years.

From this research on employed individuals with RA in the Western Cape, it seems that individuals who are categorised as coloured/black tend to have a lower level of education, and therefore a lower income. This in turn led to individuals making use of public transport. If the individuals were single as well, it could further predispose them to work disability, due to increased pain experience.

Some of the individuals with RA, taking part in this research were employed in the open labour market for longer than 10 years since diagnosis, even though they were single with a primary level of education. This indicates that there are other factors that assisted them to stay employed once diagnosed with RA, and which need to be taken into account.

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8.2 Health factors enabling individuals with RA to stay employed in the open labour market

According to Young *et al.* (2000) the clinical profiles of RA patients in their study and who were treated with conventional drug therapy during the first five years of the study show that 40% of patients did relatively well, (of whom 13% were in clinical remission), 44% followed a relapsing remitting course with variable, but definite functional impairment, in comparison with a small proportion (around 16%) who did badly in terms of the effects of RA on functional disability and life events.

8.2.1 Time since the onset of RA

The time since RA diagnosis was found to be an indicator of work disability in individuals with RA, according to Callahan *et al.* (1992), Allaire *et al.* (1996) and De Roos & Callahan (1999). It was found that the longer the duration of the disease, the fewer individuals still worked. In our study, 51% of individuals fell into the 1 day to 5 year category, 71% in the 1 day to 10 year category and 79% in the 1 day to 15 year category. It became progressively less, with only three individuals still being employed more than 30 years after diagnosis. There was no significant association between HAQ scores and the duration of disease in the individuals diagnosed with RA employed in the open labour market.

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8.2.2 Level of disability

In this study the level of disability was assessed with the HAQ, as it was regarded as a self-perceived indicator of health status and found to be one of the only significant indicators of work disability in other studies (Reisine *et al.*, 1989; Doeglas *et al.*, 1995; Fex *et al.*, 1998; Jäntti *et al.*, 1999; Young *et al.*, 2000). Barrett *et al.* (2000) determined that with a HAQ score of over 1,5 an individual's chance of becoming work disabled increased threefold and these authors found the HAQ to be the only significant indicator of work disability in early RA.

Overall, the HAQ scores (interval scale) varied, with 52% having an HAQ score of 1/good self-perceived health status; 35% an HAQ score of 2/fair-self perceived health status and 13% with an HAQ score of 3/poor self-perceived health status. Of the participants, 75%

had a HAQ score (continuous scale) of ≤ 1,5. From this data it seems that individuals with RA and employed in the open labour market in the Western Cape tend to have a good to fair self-perceived health status, instead of a poor self-perceived health status, with a mean HAQ score (continuous scale) of 1,035. In this study, 52% of the participants had an HAQ score ≤ 1 and 48% had an HAQ score > 1 (interval scale).

Chorus *et al.* (2000) found a mean HAQ score of 0,7 for working individuals and 1,3 for non-working individuals, while Wolfe & Hawley (1998) found that the average adjusted HAQ score for work-disabled patients was 1,49 and for non-work-disabled patients 0,86. Young *et al.* (2000) found that of the 732 participants in their study with early RA (employed and unemployed) 51,6% had an HAQ score ≤ 1 and 48,4% had an HAQ score > 1 at onset. This last study compared better with what was found in this South African study of 100 employed individuals with RA, even though 49% of the participants have had RA for longer than 5 years.

Pain was also identified in this study as a variable to determine health status, even though it was not found to be an indicator of work disability in other studies. In the South African study there was found to be a significant association between pain and self-perceived health status, as measured by the HAQ (interval scale as well as continuous scale). The higher the HAQ scores the higher was the individual's experience of pain. In a study by Van Lankveld *et al.*, 1999 these authors identified pain as one of the main stressors in RA and found that the different stressors may lead to disability. Pain management can also be linked to coping strategies and a sense of self-efficacy, according to Strahl *et al.* 2000.

During the research in the Western Cape it became clear that individuals with a good HAQ use more private transport and individuals that use private transport fall into a higher income level. This could be one of the reasons why individuals with a poor HAQ experienced more pain than individuals with good or fair HAQ, even though there was no association between HAQ score and education level.

In general it seems that individuals with a poor HAQ also tend to do more heavy work and tasks consisting of fine hand motion and less medium to light work than individuals with a fair to good HAQ. As heavy work and tasks that require fine hand motion could pre-dispose individuals with RA to become work disabled, it could be a reason for them to experience a poor HAQ. On the other hand, individuals who did heavy to very heavy work

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felt that their work is more important than individuals who sometimes or never did such work. This could be the reason why individuals with a poor HAQ and doing heavy labour were still employed in the open labour market.

Whether individuals in the case of the study in the Western Cape had poor, fair or good self-perceived health status, did not affect how often they visited their doctor, how regularly they took sick leave or what the duration of the sick leave was. The only significant finding was that regarding individuals with a fair self-perceived health status, who have had RA for more than 5 years and who visited their doctor less than individuals with RA for less than 5 years. One would presume that they have adapted well to their disease after 5 years since diagnosis and that their disease was fairly well under control at that stage. Individuals with a HAQ of 3 and RA less than one year also tended to take sick leave for longer than three days at a time compared to individuals who have had RA for longer than one year. This could be expected, as the disease is often not yet well controlled within the first year since diagnosis. A high percentage of individuals also tended to leave the work force within their first year of disease. This could be the result of them losing too many work days due to sick leave, or while they were still struggling to come to grips with their diagnosis they saw it as the only way out.

Jäntti *et al.* (1999) found that of the patients of working age 31% had already stopped working due to RA one year after the onset of the disease. The cumulative work disability rate gradually increased, and after 20 years had reached 80%.

The recent move to more aggressive treatment and use of DMARD has had no effect on the rates of work disability (Barrett *et al.*, 2000). This finding links with the findings of the research done in the Western Cape, namely that there is no association between the use of DMARD and HAQ or pain scores.

The individuals participating in the study in the Western Cape had a higher mean HAQ than individuals diagnosed with RA and employed in the open labour market in other studies. The mean HAQ score of the participants in the study in the Western Cape, compared better to individuals who were work-disabled or at an early onset, before the introduction of DMARD. If an HAQ of 3 defined the individuals that do badly, then the 13% in the Western Cape study compared well with the 16% as determined by Young *et al.*, 2000. Similarly our finding of 52% in the Western Cape study with a HAQ of 1 would

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compare fairly well with the 40% that did relatively well over the first 5 years. HAQ and pain were seen to be associated with heavy work, but there seemed to be other factors that also needed to be taken into account, e.g. importance of the job to the individual, whether for financial reasons or for the satisfaction derived from the job itself.

8.2.3 Other qualitative health related factors

Other health-related factors (see Table 8.1) that assisted individuals to stay employed, as found in the qualitative part of the research, were grouped into the category **RA Management**. *Rheumatoid Arthritis management* refers to direct intervention, whether by other people or by the individuals themselves, in order to try and control their RA. Intervention by others include the use of **medical** (medication, splints, hydrotherapy) and **alternative treatment** (acupuncture, vitamins, reflexology, use of the APS pain machine, hypnotherapy, visiting a sangoma). Interventions, which the individuals were able to control themselves, were their **diet** and **exercise**. Being able to control their disease links with having an internal locus of control as discussed later as well as a sense of self-efficacy.

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Table 8.1 Rheumatoid arthritis management

	Rheumatoid Arthritis Management
	• Diet • Exercise • Medical treatment • Alternative treatment

As all the individuals who participated in the study were receiving medical treatment one would have expected them to believe that this was one of the major factors that helped them to stay employed. Only 2 of the 6 individuals who participated in the qualitative part of the research believed that medication played a major part in their ability to remain employed. One individual had even turned to alternative treatment as she felt that the medication did not agree with her.

"And not to live with arthritis, but to live a better life with medication. And that has proved hmm, that point in my life. And I believe that hmm, people shouldn't go and sit and not attend the hospital or not take medication. Hmm, and that is why I am being living with arth.., rheumatoid arthritis for so long. Because I've been on medication for that long."

"Ek dink dit is maar die medikasie eintlik, want ek dink as ek nie die medikasie gehad het nie, sou ek waarskynlik nie uit die bed kon opgestaan het in die oggende nie en baie moeilik by die werk ook rondbeweeg het en in die motor in en uitgeklim het en sulke goed. So, ek moet rerig sê medikasie hou my aan die gang. Jy weet ek's nie mal oor medikasie gebruik nie, soos ek dink enige iemand maar is, maar wat kan 'n ou nou doen. Jy weet ek het nie 'n keuse nie, jy, ek moet maar. So dit gaan aan." (See Appendix F)

At the time of the interview the individual who sought alternative treatment was not taking any medication, except pain medication.

"I always try to sought alternative treatments. And I've never ever relied on, on the medicines that the hospital has given me, because of most of the time after a few months, the tablets and things didn't agree with me. There would always be certain complications. I've been on most of the arthritis drugs and, hmm, I think it's the fact that I sought alternative treatment."

After discussing all the different types of alternative treatment that she had already tried out and the merits of each, she said that she still felt it was worth it, although alternative treatment was very expensive and most medical aids did not pay for it.

"But, I suppose its worth it in the end if I can still continue working then all the little bits add and all helps. It helps me not to be hmm, crippled and at home sitting and, you know, on a disability grant and so on."

She also ended her interview by saying that she wished there was someone at the hospital that could discuss the merits of all the different alternative treatments with the patients. This could be an aspect to explore, as the use of alternative treatment is progressively becoming more acceptable in the medical world. If it can make the life of an individual with RA more bearable and therefore improves his/her health status, it should be worth investigating.

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One other individual also mentioned that hydrotherapy and resting hand splints helped with pain management and thus enabled her to continue working. She also concluded that support by medical personnel and having to "answer to someone" assisted her in maintaining her work.

Two individuals felt that diet played a major role in keeping their RA under control. A healthy diet cannot cure RA, but promotes a sense of well-being and gives individuals with RA some control over their disease, as it is something that they can do for themselves and is not something that is done for them, or to them. This links with their locus of control and self-efficacy as discussed later.

"En as jy op 'n dieët kan gaan, gaan op 'n dieët, want in die jaar 1999 het ek op 'n rou dieët gegaan waar ek baie dinge moes prysgee en ek het uitgevind in die ses maande tyd wat ek dit gedoen het, het – was daar groot verligting en ek voel dat mense dit kan doen. Jy kan op so 'n dieët gaan om jouself te help, want daardeur kan jy self in jou ligaam voel dat jy, hmm, hmm, oorwinner – die oorwinnaar is van jou liggaam." (See Appendix F)

"Hmm, I suppose it's mostly the diets – I would say ja, it's mostly the diets, because there was a stage when I just developed arthritis the first year, I didn't want to know anything about the disease, because I thought that if hmm, I – I didn't know anything, it wouldn't effect me. It wouldn't – what I didn't know, can't harm me. That kind of attitude. I also merrily going along eating whatever, all acidic things and so on and that was possibly the worst year of my life. I was the sickest of in all the years that I've had the disease. Hmm, so I think diet has played a major role in being able to work and just continue from year to year and day to day."

Four of the individuals with RA found exercise to be beneficial and in a way something that they could do to outwit the disease. Again, this was something that allowed the individuals to be in control of the disease.

"As daar oefeninge is wat gedoen moet word, dan moet jy die oefeninge doen, want oefeninge glo ek stellig dat dit baie help. Ja, oefeninge help baie. Ek het elke oggend vyf uur in die more, het ek opgestaan en ek het elke dag die oefening gedoen. Vyf uur namiddag het ek weer oefeninge gedoen en ek het uitgevind dat die liggaam, die oomblik dat ek oefening doen, voel ek altyd net beter en beter en beter." (See Appendix F)

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"...die oefeninge doen en self vir my iets te doen. So ek glo vorentoe al raak ek 70 jaar oud, sal ek nog vir myself kan... Ek sal vir my nog self iets kan doen. En ek voel die pasiënte wat by die hospitale – hulle moet – hulle moenie net die pille neem nie, hulle moet oefeninge doen. Hulle moet oefeninge doen, hulle moet iets self vir hulle self doen." (See to Appendix F)

Two of the individuals with RA had built their exercise into their daily work schedule in order to prevent joint stiffness and the pain that goes with it. Both of them worked in situations were they had to sit for long periods of time. This may link with coping skills used by individuals, as it is, in a way, an adaptation made to their work schedule which allowed them to be more in control of their job, as discussed later.

"I too concentrate on exercising while I'm sitting, exercising my legs, and then every, say every hour I would get up and just go to the ladies room just for a bit of exercise and not just sitting the whole day."

"Nou dikwels sit 'n ou in vergaderings en hmm, nou ja in 'n vergadering kan jy mos nou nie eintlik vrylik rondbeweeg nie. Maar so ek het nou al geleer om by 'n vergadering, veral met my linker knie wat my so opkeil. Ek sit altyd so dat ek, my been het ruimte, ek kan hom reguit maak, ek kan hom buig en onder die tafel kan niemand nou nie eintlik sien wat jy doen nie. So ek beweeg hom maar so gereeld as wat ek nou daaraan kan dink of kan onthou en hmm, dit werk eintlik vir my." (See Appendix F)

Sokka *et al.* (1999) found that after an average of 10 years from the onset of the disease, the work disabled patients were physically much more disabled than the others, despite more intensive DMARD and surgical therapy. On the other hand, Wolfe & Hawley (1998) conclude that while their study enumerated factors associated with work disability, it did not examine why some patients with severe nodular and erosive disease would continue working in physically demanding jobs. There were many patients who would just not admit defeat despite poor prognostic indicators, such as ESR, rheumatoid factor and level of education.

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8.3 Work factors enabling individuals with RA to stay employed in the open labour market

According to Manusco *et al.* (2000) the most important job characteristics identified by individuals employed in the open labour market that helped them to stay employed are:

- controlling the pace of the work;
- having flexible working hours;
- having light physical demands, especially with regards walking and hand activities;
- being able to sit down most of the time;
- having a sympathetic employer;
- commuting easily;
- having no repetitive physical motions; and
- not having to work overtime.

Albers et al. (1999) found that early after diagnosis RA already had a huge impact on patients' socio-economic well-being, with work disability seven times higher in RA patients than in the Dutch working population in general.

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8.3.1 The level of physical activity required

Not a single individual with RA who participated in the study fell in the category of skilled agricultural and fishery workers. The work is defined as *people who grow crops, breed or hunt animals, breed or catch fish or cultivate or harvest forests.* Examples given are farmers, crop growers, fishermen, horticulturists and forestry workers. One would assume that the above types of jobs would require heavier work in which employees are often subjected to elements of nature. As mentioned by Leigh and Fries (1991), occupations that involve bending, lifting, stretching and outdoor work in cold damp weather could hasten the progression of RA. Barrett *et al.* (2000) also found that manual workers are more at risk of becoming work disabled. According to Hilde *et al.* (2001) the association between work disability and manual work in men probably reflects that it is more difficult for a manual worker with RA to remain employed than for a professional. Also that the work environment of professionals can be modified easier than for manual workers, so that patients with RA can remain employed even with significant physical incapacity. Hilde *et*

al. (2001) also found that manual work predicted work disability for men in all age groups, but not for women.

Work requirement was divided into the following categories: requirement that might increase stress or which prove to be challenging, heavy work requirements, medium work requirements and light work requirements.

Individuals taking part in the research in the Western Cape and who were working full-time for someone else, seemed to handle more conflicting work demands and felt that they often had too much work. On the other hand those individuals who felt their work to be very stressful and challenging perceived their work as more important to them than individuals who did not perceive their work to be stressful and challenging, even though they had lower work autonomy. Individuals who did physically heavy work also indicated that their work was more important to them than individuals who indicated that they never did any physically hard work, even though they were found to have lower autonomy. If it is taken into account that individuals who work for someone else have less autonomy than someone who is self-employed, it is easy to see why perceived importance of the job is an important reason why individuals with RA stay employed. The reason why individuals who only *sometimes* did sedentary work the whole day had lower autonomy, instead of *always* or *never*, may indicate individuals who have less control over the scheduling of their work.

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8.3.2 The degree of autonomy

There was no difference found between the three occupational groups' level of autonomy at work, even though there was a significant difference in their level of education as well as level of income. A significant association was found between income and autonomy for individuals who fall in the professional group, but no association was found in either the labourer group or the clerical group. The higher the income of the professional group, the higher was their autonomy. Individuals who worked full-time for someone else and who fell in the labourer group or the clerical group, found their work to be more important than individuals who worked full-time as professionals for someone else.

The assumption can therefore be made that individuals who were employed full-time by someone else and who worked as professionals, stayed employed because their level of autonomy was linked to their income in the first place. This meant that the higher the income, the higher the autonomy and vice versa in the professional group. On the other hand individuals who worked as labourers and did clerical work, stayed employed because their work was important to them, regardless of whether for financial, personal or other work related reasons.

Individuals who were self-employed also had a much higher autonomy than individuals who were employed by someone else. The individuals who were self-employed and believed their work to be important, had more autonomy than individuals who were part-time or contract workers. Part-time or contract workers however had more autonomy than individuals who worked full-time for someone else. Of the individuals who rated their work as less important, it was found that those who were self-employed also felt that they had more autonomy than individuals who were employed full-time by someone else. As the sample size was relatively small and none of the part-time workers or contract workers saw their work as less important, it was difficult to make assumptions.

Males were also found to have a higher level of autonomy than women and a higher income, though the difference was not statistically significant. A higher level of autonomy and income for men than women could be as a result of the historical nature of the gender worker role and the power that is linked to employment. (Statt, 1994)

Autonomy has also been found to be closely linked to the degree of importance which individuals attached to their work. Individuals' personal perception of the importance of their work is an important factor that has been overlooked in other studies. The reason why work is seen as important has not yet been established.

As mentioned before, individuals who do heavy work, felt that their work was more important than individuals who indicated that they do not do any heavy work. This could be a reason why these individuals are employed in the open labour market even though they had a significantly poorer HAQ, and even though it is known that manual labour is detrimental for individuals with RA.

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Individuals who fell in the labourer and clerical groups also indicated that they believed their work was of more importance than the individuals who were in the professional category, but as mentioned before, there was no difference found between the three groups' levels of autonomy.

This links with the findings by Barrett *et al.* (2000) that individuals who are self-employed and have a high work autonomy have less chances of becoming work disabled.

8.3.3 The nature of the job

The amount of support that individuals felt they were receiving at work and work satisfaction are important in maintaining employment status (Barrett *et al.*, 2000; Chorus *et al.*, 2000). Women felt that they received more support than men at work. This could be one of the reasons why so many women with RA were found to be employed in the open labour market.

The individuals who participated in the study by Manusco *et al.* (2000) indicated that accommodation by supervisors helped them to stay employed, e.g. flexible working hours, fewer telephone answering responsibilities, writing memos by hand instead of typing them, less travelling and the fact that supervisors bought special equipment or obtained an ergonomic evaluation if necessary. Co-workers supported the individuals with RA and employed in the open labour market by helping with physical aspects of the job such as lifting, reaching and typing and also by providing emotional support.

In the research done in the Western Cape individuals who told their employer that they had been diagnosed with RA felt that they received more support from their employer than individuals who did not disclose this information to their employer. Individuals who told both their employer and direct supervisor felt that both respectively understood what it meant to be diagnosed with RA, when compared to individuals who did not inform their employers or direct supervisors of their diagnosis. Individuals who told their employer and co-workers that they were diagnosed with RA also indicated that their work was more important to them than individuals who did not disclose such information to their employer or co-workers. The fact that their work was important to them could be the reason why

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individuals told their colleagues of their diagnosis. This assumption was supported by the qualitative part of the research that will be discussed later.

According to McGlone and Chenoweth (2001) job satisfaction had been explained in terms of the interaction between the demands of an occupation and the job discretion associated with the occupation. Job stress only occurs in high demand jobs when combined with low levels of control, and therefore high job demands alone is not responsible for job stress. In contrast to this, no association could be found during the research in the Western Cape between how satisfied individuals with RA were with the type of work that they were doing and the importance of their jobs or job autonomy.

According to Chorus *et al.* (2000) paid employment has an important role in daily life. Work provides social status and income, but is also valued for its social support and social distraction. Having a paid job can have positive effects on well-being and quality of life. In the general population work in the open labour market has been directly related to health, whereas house work, on the other hand, was found to have negative effects on health.

8.3.4 Other qualitative work related factors

The qualitative data was used as an attempt to clarify why individuals see their work as important, as well as to provide more insight into the support of colleagues and what it means to have control over work.

Work is traditionally defined as *activity required for subsistence*. In the field of occupational therapy literature the term *productivity* is being used as a more useful alternative for *work.* Productivity is defined as *those activities and tasks which are done to enable the person to provide support to the self, family and society through the production of goods and services.*

Factors at work that enabled individuals to stay employed, link well with existing knowledge about what causes work disability in RA, as well as what enables individuals in general to stay employed. Humans are viewed as having an occupational nature, which can be compromised by a medical condition and/or overwhelming environmental demands (Christiansen & Baum, 1997).

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According to Westmorland *et al.* (1998), there are three major factors that contribute to a positive working environment for women with disabilities. As three quarters of the RA population are female and 83% of the study population in the Western Cape were female, this would pertain to individuals diagnosed with RA and employed in the open labour market. The three factors are: *organisational and social factors*, *individual characteristics* and *social support*. Organisational and social factors were further broken down into: *employment flexibility*, *supervisor and co-worker support* and *control over work tasks*.

Work enablement was found to be much more inclusive than just the work environment. A summary of the work-enabling factors appears below.

Table 8.2 Work enablers

	Work Enablers • Working for survival • Education of colleagues • Support ★ Family ★ Colleagues ◆ acceptance ◆ acknowledgement • Control over the work ★ Work flexibility ★ Accessibility • Attitude towards work • Work satisfaction

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All the individuals with RA who participated in the qualitative part of the research in the Western Cape reported that they have to **work for survival**, which links with the definitions of work as well as productivity.

"Hmm, I also at the time was a single parent and of course my drive to provide for my family and that I could overcome what hmm, ah the rheumatoid arthritis crippling my body."

"...as I've said I'm also a single parent is that my daughters, the one is working permanently but she's still in the, she's still at home and hmm, my youngest daughter

she's at University second year, and that is, that's one of the reasons I would like to work is to let them finish their career, their education…"

"…ek dink om 'n lewe te kan hê. Jy weet om 'n voortbestaan te kan hê. Ook goed na te strewe, hmm, ja, dit, dit jy weet, maak ook dat jy wil lewe, net die feit om te kan lewe, geld in te bring hmm maak dit, dat 'n mens aanhou."
"Hmm, ja so ek, ek hmm, dit en 'n ou moet die pot aan die kook hou so, so jy moet maar opstaan." (See Appendix F)

Support from the family and especially from colleagues, regardless of whether it was their employer, direct supervisor, or co-workers was found to be important for individuals to stay employed.

"And I know that hmm, even now at this stage my children is good, I reared them and they are giving back to me what I gave them. Oh yes, I get a lot of support from my family and that enables me to live with arthritis, rheumatoid arthritis. Ja, and I must say that hmm that my family is great."

"Hmm, my family supported me. Hmm, my colleagues, my, myself. They've been great."

"Hmm, maybe socially, the staff was very supportive of me. I'm the youngest person working here and I think we get along very well and they are very understanding about my condition and so and sometimes the male staff members carry me up and down the stairs if I can't manage. It's quite embarrassing, but they don't mind."

"Tee gemaak en koppies gewas en altyd uitge... en – wat ek ook – wat hulle ook vir my baie by gevra het wanneer ek moes kom help wanneer hulle meetings gehad het, dan het ek daar gehelp. Die heel eerste keer was hulle altyd versigtig om vir my te vra, want hulle het nooit geweet sal ek dit kan doen nie. En toe hulle uitvind dat ek ywerig is om dit te doen, toe het hulle meer nog vir my gehelp. Hulle het altyd vir my betrek in die werk. Hulle het nooit as ek miskien nie lekker gevoel het nie, hulle't nooit vir my ge-force om iets te doen nie. Hulle't altyd net gesê kom en kom help. As jy nie kan nie, dan is – verstaan ons. Maar ek het altyd het ek maar ja gesê en hulle't baie bygedra ook want hulle het altyd as ek miskien by 'n plek moet wees, dan sou hulle altyd vir my gesê dis all right, jy kan maar gaan. En so 'n tyd kan jy terug wees of as jy dit nie kan maak nie, kan jy maar

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bly, kan jy maar huis toe gaan. Hulle't – hulle het baie – die – my, hmm fore-vrou het baie ondersteuning gegee. Hulle't altyd seker gemaak dat ek kan op iemand anders se plek loop werk as ek nie presies kon nie, dan het hulle gesê laat staan. Maar ek het altyd ja gesê en so het hulle altyd vir my gehelp en gehelp. En hulle was bereid om vir my – om aangewings te maak sodat ek vir hulle kan help." (See Appendix F)

"Wat vir my gehelp werk is dit dat baie van ons is vriende bymekaar, goeie vriende. Spoor mens ook aan en baie liefde ook, die gesindheid wat 'n mens teenoor mekaar het daar by die werk. Dit gee vir my ook 'n fisiese ding en wat ook is as ons saam werk as 'n span die einde van die week, dan kry jy 'n bonus. Ja, jy werk vir 'n target saam en jy daai vier spanne, werk saam vir 'n bonus en omdat jy dan bonus verdeel tussen ons vier, dan sien jy ook wat jy gedoen het, nou fisies kan jy ook dink en alle dinge doen met jou hande en jy kan werk." (See Appendix F)

On the other hand, individuals also felt that they also had to perform their work tasks to the best of their ability, in order to make up for the days when they were not able to perform their work as well as usual. This implied being responsible and not hiding behind their RA. (This links with their attitude to their job, which will be discussed later.)

"And that, hmm, they, my colleagues support me a lot as I said and hmm, hmm, my situation is, there were times that I was also hmm, not sick but, my, the, the , the disease flared up. And then he would understand, and then he'd say just relax today and don't do too much, because he knows the next time when I'm feeling okay, which is most of the times then I would give a hundred and.., over a hundred percent"

"Hulle moet verstaan hmm, en hmm, weet, want dis nie altyd so 'n probleem nie. Gister moes ek vir training gegaan het hier bo vir iets. Dit was 'n eerste kursus wat ek nou bietjie voice assessment gaan doen, maar as ek die eerste keer na 'n plek gaan en ek weet dit gaan nie toeganklik wees nie en toe het die bestruurderes van 'n ander afdeling, ag ons werk almal baie goed saam, toe het sy nou gesê nee een van haar, Colleen, een van die meisies daar, sal vir my vat die eerste keer en hmm, so nou weet ons dat daar's twee trappe daar, daar moes ek geparkeer het. Die hysbak, nee ek kan nie die hysbak gebruik het nie, want die knoppies is te hoog. Hmm, so ek sou nie op my eie die eerste keer gecope het nie, verstaan jy. So hmm, en hulle is, geniet dit tog om iets te doen. Nou sê vir my, kyk ek het al vir, van die straat sekuritiet het al by die gebou die trappe op dra by

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trappe, so as sy byvoorbeeld nie vir my kon vat nie, sal dit my nie verhoed het om te gaan het nie. My streslevel sou so 'n bietjie hoer gewees het omdat dit is daai unknown factor, gelukkig was die sekuritiet en so aan, en hy't my op die einde opgedra het. Vrouens kan my nie dra nie, ek is 'n dooie gewig. So ek sou nog steeds dit gedoen het, maar dit maak dit net makliker. Maar dit sou my beslis nie verhoed het nie, want om daar te kom… Ja, maar jou, ja dit is beter as jy daai hmm, support het en dit maak dit vir jou makliker. Dit help." (See Appendix F)

As part of the support, **acceptance** and **acknowledgement** by colleagues were seen as important aspects of support. To be part of a team was important, as one individual mentioned, because with the job came friendship and understanding. This seemed to make it easier for them to do their work as expected.

"First of all I must say that people don't see me as having rheumatoid arthritis. First of all my immediate colleague, my supervisor, hmm working is first of all something I must remind you, you use your brain and then the physical. I see, they don't see me, I think that's an encouragement, because if I do something, I must do something, I'm here in that situation to work. I mustn't think, oh because I have arthritis I cant do this and I cant do that. If it is now really that I cant do it, they do support me, but they don't see me as handicapped."

"And that, it's a give and take situation, but I must say hmm, and the rest of my colleagues they don't also hmm, judge me on having arthritis. If we've got to do something all of us, or if we've got to go somewhere hmm, then I just part of the crowd, I'm part of the rest of them. And I hmm, appreciate that, because I don't like to be singled out for my hmm, condition."

"Ek sien my nie veel anderster as ander mense nie en, hmm my kollegas ek is ook deel van hulle. Ek raak altyd vies vir hulle want as hulle goed bespreek soos uiteet of dit of dit, hulle vergeet so bietjie, (lag) is die plekke toeganklik. Maar dit wys jou net weer, hulle, hulle aan die einde van die dag kom hulle nie eers die verskil agter nie, omdat jy doen dieslefde as hulle. Jy doen dit, hulle sien dit nie meer as dat jy dit anders doen nie noodwendig as hulle nie." (See Appendix F)

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Acknowledgment, on the other hand, is the feeling that, as working individuals, they are seen as important and not as different from their colleagues. Their work was also deemed as important and of similar worth as that of their colleagues.

"Hulle is bly om vir my in die oggend te sien. Hulle waardeer – en die waardering omdat hulle weet ek het 'n probleem, is dit vir my so lekker as hulle altyd vir my sê, baie dankie, antie, antie vandag was die tee weer lekker. As ek eendag weggebly het, antie, hoekom het jy weggebly, jy weet die tee word nie so lekker gemaak nie wat jy dit maak. En dis wat vir my so lekker is. Dis wat vir my so lekker is." (See Appendix F)

"...ek dink net om, om die beste te gee in my werk. Jy, jy weet dis lekker as jy weet jy doen goed, mense wil jou he omdat jy goed is en omdat jy die , die daar is." (See Appendix F)

Individuals also felt that, in order to receive support, it is their responsibility to inform their colleagues of their diagnosis and to **educate** them if need be in order to receive the necessary support, acceptance and acknowledgment. The individual with RA could not expect to receive support from colleagues if they have not disclosed, first of all that they had RA, but secondly also specifically which problems they experienced in performing their work. Their own attitude was important as they had to see themselves not as different from others or entitled to special treatment.

In the study by Manusco *et al.* (2000) patients stated that they felt caught in a dilemma as far as their supervisor and co-workers were concerned. Although they wanted their co-workers and supervisors to know they had RA, they did not want them *to dwell on it, or even think about it.* Their reasons were that they wanted others to perceive them as competent for the job and in no way as seeking excuses not to do their work. Patients indicated that this is what made them reluctant to ask for modifications or assistance. This was not the case in the study in the Western Cape and participants found this to be a very important aspect of staying employed with RA.

"The rest of the, of my colleagues know as well that hmm I, I, I've spoken to them about that self-help hmm course I did, and, and I've asked my supervisor if I could do that, could do everything or put the, the files and things so that it is comfortable or suitable for myself. So he is in agreement as long as he gets his work out."

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"Dit is belangrik dat persone met arthritis ook hmm, verantwoordelikheid neem. As hulle kan sê goed dit is my probleme, ek wil lae, ag jy weet wat sy hoogte kassies hul wil he, dan, kan, kan dit vir my gedoen word, of wat die geval ook al is. So hulle moet ook disclose, dit is belangrik om ook te disclose aan bestuur. Dit help nie jy sit en jy sê niks nie. Want elke, as jy twee persone met arthritis het, dit gaan hemelsbreed verskil en dit is so, ek sê altyd, vir my is dit belangrik die persoon met die gestremdheid, jy kan hoeveel assesserings laat doen, daardie goed help op die ou end van die dag, maar die kandidaat is die beste ou wat hmm, om sonder om dit baie kompleks te maak hmm, wat kan sê hoe, ja wat, hulle gemaklik te maak, sodat hulle die werk wat hulle moet doen kan beheer." (See Appendix F)

"Ek het, ek persoonlik het nog nooit hmm, mense teegekom wat snaaks is nie oor my nie, maar ek dink ook jy as 'n persoon wat anderster is, jou gesindheid bepaal grootliks hoe mense om jou gaan reageer, want hulle kan negatief wees. Ek dink nogal die grootste verantwoordelikheid rus op die persoon met die siekte om 'n verskil te maak en om hulle sommer te vertel. Ek vertel altyd, as ek sien hulle wonder, ek het arthritis of wat ook al en dan weet hulle en dan, dan pla dit hulle nie meer nie. So 'n mens se kolllegas, bestuur dit is baie belangrik dat hulle weet, ook hulle support gee." (See Appendix F)

Support, acceptance, acknowledgement and also the fact that the individuals took responsibility for their role as worker, would then lead to control over their work. **Control over work** was attained through the type of work that they did, especially flexibility and the accessibility of the workplace.

"I think it's possibly the fact that I'm in control of the job itself. I'm in control of the creative aspect of the job, because when I came to work here, this woman, she just dump me in at the deep end and I was a bit resentful at the beginning. Then I realized that maybe this is good thing, I must make it work for me. I didn't have somebody watching over my shoulder all the time. I could do my own thing. I could be as creative as I wanted to be. I could design the course according to what I wanted in it, you know. And I think it's the fact that I'm in control of, of – I don't have somebody watching me. I don't have a boss. My colleague and I are both the co-originators of the course. And we just liaise with one another, or with each other and I think that is what. This is actually the best job I've ever had. And this is what I dreamt about for the last ten years and it's finally – I finally got it."

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The type of work itself and how flexible the job is, have an effect on whether an individual with RA can manage to perform his/her job, as seen in the study by Mancuso *et al.* (2000). These authors found that, even though the physical demands were light, typing, writing, walking, standing for prolonged periods, travelling for business, commuting, handling files and holding a telephone can be challenging tasks for individuals with RA.

"So, maar die tipe werk wat ek doen, ek sit maar meeste van die dag in elk geval, so behalwe vir hande wat ek maar gebruik vir die rekenaar en om te skryf en gelukkig lyk dit vir my arthritis tas nie die brein aan nie (lag), dit lyk my werk nog goed." (See Appendix F)

"Ja ek dink as ek met pik en graaf moes gewerk het, sou ek rerig nie lekker gewerk het nie." (See Appendix F)

Work status, especially whether one is self-employed, seemed to be important to one individual. This allowed him a very high degree of autonomy over the pace as well as the scheduling of his job and thus flexibility.

"Ek het vier jaar gelede my eie maatskappy begin en hmm die laaste ding waaraan ek gedink het was hmm, ek kan nie die maatskappy begin nie, want ek het artritis. Ek het rerig nie daaraan gedink nie, hmm, maar daar kom mos maar tye wat jy nie so wonderlik voel nie, wat die ding maar so opvlam. Maar ek is gelukkig in die posisie dat ek hmm, dat ek nou dink ag dit is nie so lekker vir my nie, dan gaan ek huistoe, dan gaan ek, slaap ek as ek wil slaap of gaan lê op die bed of whatever."
"Ek het die vryheid van beweging ja, ja en dit was een van die, nie oor die siekte nie, een van die redes hoekom ek van die ander maatskappy waar ek hmm waar ek die senior pos beklee het of sewe, agthonderd mense, waar jy nie hmm, jy weet jy nie die vryheid van beweging het as wanneer jy 'n klein maatskappytjie het wat aan jouself behoort nie. So daar is jy maar altyd onder die oë." (See Appendix F)

"...en ek wil vir jouself so sê as ek nou in 'n situasie moet kom waar ek nie nie meer maklik, so gemaklik kan beweeg om werk toe te kom nie, kan ek altyd van die huis af werk." (See Appendix F)

One of the participants, a female on crutches, felt that **accessibility** was of great importance to her in performing her work.

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"So fisiese dink ek net as dat my werksomgewing moet vir my toegankilik wees en ek moet regkom waar ek werk, so hm, ek sal nie aansoek doen vir iets waar ek weet ek nie kan regkom nie, byvoorbeeld as dit 'n advertensie is en ek ken nie die plek nie sal ek bel en hoor wat is julle toeganklikhied. Want dit is vir my sinneloos om deur alles te gaan en aan die einde van die dag kan ek nie eers in die gebou kom nie, so hm, so die eerste punt is om ja my werksplek moet vir my toegankilik wees, in terme van hysbakke en ramps en so ensovoorts. My huidige is toeganklik. Parkering in die gebou is belangrik, veral in die stad..." (See Appendix F)

A **worker's attitude** to his/her job is essential for job satisfaction, according to Statt (1994). Having a positive attitude towards work implies not staying away from work unnecessarily as a result of RA. RA is a disease one has to live with and not some unknown mysterious condition that rules the life of the individual affected by it, and this in a way is linked to self-efficacy.

"Maar ek het nooit weggebly van die werk af nie. Ek het geglo as ek vandag wegbly van die werk af, more sal ek wegbly, oormore sal ek wegbly, later sal ek sê dokter, sit my af. En ek wou dit nie hê nie. Ek wou dit nie hê nie. Ek wou aanhou, ek wou vir myself bewys, ek wou vir die mense daar buitekante gewys het dat jy kan werk." (See Appendix F)

"And the amazing thing is with all this pains and aches that I never stay absent, I've only been absent last year hmm, when I was in hospital. If I am really stiff and sick and I just pump myself full of panados and go back to work."

In order to be employable in the open labour market, individuals with RA and taking part in this research project in the Western Cape felt that it was important to keep up with change, but also to know what was available in terms of employment in the market place. This can be regarded as a positive attitude to their role as worker.

"Nog 'n strategie is sou ek sê is maar net om op hoogte van sake te bly, wat gaan aan in die arbeidsmark, dat ek kan deel bly van dit..." (See Appendix F)

"Ja maar ek het gesê van die hmm, en dinge by die huis, ambisiues en op top bly van alles, weet wat gaan aan, hmm selfs nou nog sal ek die, die koerante scan en net altyd

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bewus wees, wat doen ek, hoe en waar pas ek in, wat is daar en waarvoor is ek marketable." (See Appendix F)

All of the above leads to **work satisfaction**, which was another factor that allowed individuals to stay employed since being diagnosed. Individuals in this study seemed to enjoy their jobs and the challenge of their jobs and it prevented them from sitting at home, focusing on their pain. Mottaz (1981) and Baxter (1990) found that control over work increased job satisfaction. The sense of control at work can also be associated with positive outcomes, such as emotional well-being, coping with stress, good health and improved performance (Thompson and Spacapan, 1991). Job satisfaction thus links with the self-management strategies that individuals use to stay employed, as will be discussed later.

"So I think that's what helps me – keeps me going, cause I had a tough time at school when I never ever wanted to, to, to be, in a learner situation where I was going to be subordinate or inferior and so on. So we really try and build the students up and that's what I enjoy a lot about my job. It's not just about the teaching, it's about giving them counseling, it's find jobs for people and just see this person develop and blossom in front of me and that's what really – it's the thrill for me."

"I'm not one for staying at home. I must honestly tell you I prefer working in the workplace than to do housework. I'm one, I love going to shopping malls, I like being with the ladies and it's better for me to get out. So that as well, that's why I like to work, like to work till whenever I can. Sometimes I do feel I must stop now, but then when I think I should be at home for just a week I would like, I would want to go back to work again. Because I've been working all my life and I like working."

"...maar ek, ek dink eintlik is ek 'n career tipe van mens. En ek dink al het ek nie die siekte gehad nie, ek hou nie van huiswerk nie, punt. Nou kan ek ook nie die goed doen nie omdat 'n mens maar moet buk en dit, maar die hele ding is al kon ek dit doen is dit nie, ek hou van 'n huis moet mooi wees en ek sal sê sit dit daar en so aan. Huiswerk, daar is vir my niks waarde nie, so ek dink ek is net 'n carreer type person om dit so te stel. Moontlik ambisieus. Ek wou altyd vir my 'n carreer gemaak het en dit is hoekom ek op 28 gaan swot ook, gaan swot het hm, omdat ek besef het as daar werklike hm verandering

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teweeg gebring in die saak van die gestremde het ek gevoel ek moet 'n kwalifikasie agter my rug kry. En ook net wat vir my daai werelde oop maak" (See Appendix F)

"Natuurlik ek het 'n baie lekker werk hmm, hmm, ons hmm, die tipe goed wat ons doen is nie vervelig nie. Hmm, ons beplan maar elke dag om dit en dit en dit te doen en nege uit tien dae werk dit nie so nie, dinge gebeur en dit is deel van die fun. Ja, ek dink 'n ou moet hmm, as nie dit het nie dink ek is dit ook maar vervelig, terwyl 'n ou, somtyds as jy die klein krissise het, hmm dan sê jy jislaaik het ek nog rerig lus hiervoor, maar hmm, ek dink dis deel daarvan, hoe, 'n mens het dit nodig." (See Appendix F)

8.4 Psychological factors assisting individuals with RA to stay employed in the open labour market

The psychological factors that assisted the individuals with RA in the study in the Western Cape to stay employed were only assessed in the qualitative part of the research, as feelings and the meaning of work cannot be adequately expressed with quantitative research.

As mentioned by Wolfe and Hawley (1998), there are many patients who just do not admit defeat, despite the severity of their disease and positive prognostic indicators pointing to work disability. This is the question that seem to puzzle researchers over the years and which could possibly be linked to the personalities of individuals with RA and how important these individuals regard their work to be.

The psychological factors that enabled individuals with RA to stay employed, were called **locus of control**. According to Rotter (1966) (in Christiansen & Baum, 1997), locus of control is the perceptions individuals have of what it is that causes things to happen. Some people believe that events are mostly the result of chance, fate, luck or circumstances outside human control and so these individuals are said to have an *external* locus of control. Others perceive that events are influenced by their own actions, and individuals in this category are said to have an *internal* locus of control. A summary of the locus of control category appears below.

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Table 8.3 Locus of control

Locus of control	
• Internal locus of control ★ Motivation ★ Generativity • External locus of control ★ Religion ★ Hope	

Considering the responses individuals in the study in the Western Cape offered when asked what they believe has enabled them to stay employed since being diagnosed with RA, **religion** and **hope** were classified as perceptions of an external locus of control, and **motivation** and **generativity** as perceptions of an internal locus of control, as shown in Table 8.3.

Although **religion** if often seen as the core of spirituality, it forms actually only a very small part of it. Being able to believe in a higher hand that is in control or being able to pray for assistance, were factors that assisted individuals to stay employed.

"Ek sal sê my geloof. Ek het baie vertrou aan die Here, want u sien, my siekte is God siekte en so ver my is as ek bid, ek bly biddend op my knieë en hmm, ek kom tot op daai punt wat jy die Here in jou lewe wil aanneem en dat hy jou verder sal help deur die siekte. Maar wat ek kan sê is, jou geloof moet sterk wees. Jy moet hmm, in glo ook en as jou geloof is sterk is dan help hy vir jou deur die tye van moeilikheid en jou siekte en alles. So vir my is dit, dis basies jou moet 'n sterk mens wees vir al die tipe goed wat jy doen en hmm, volgens my is dit as jy die Here in jou lewe aangeneem het, dan word jy 'n sterk mens en hy help jou deur die dinge." (See Appendix F)

"Hy het twee keer vir my kom gebid en een keer vir my gesalf en gesê ek moet glo dat God my sal gesond maak. As ek nie glo nie en ek nie vra nie, sal ek nie beter – en ek glo vas wat ek bereik het, was deur God. God het my die krag en die ondersteuning gegee omdat ek geglo het en omdat ek gevra het. En ek glo dat die Here sal vir my help tot ek 65 is om te werk." (See Appendix F)

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Participants used **hope** in conjunction with religion, but also regarding other forms of treatment and regarding trying out different types of remedies in order to stay employed.

According to Neuhaus (1997), most literature on hope has incorporated the structures of Stotland or Dufault and Martocchio. Dufault and Martocchio (1985), (in Neuhaus, 1997) defined hope as:

A multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant. Hope has implications for action and for interpersonal relatedness.

Dufault and Martocchio identified two dimensions of hope: **generalised** hope *...casting a positive glow on life...* and **particularised** hope concerned with a *...valued outcome, good or state of being.* Particularised hope encourages commitment to a specific goal towards which the energies of both the hoping person and other can be directed and further characterised hope as a source for constructive coping with obstacles. If hope is viewed as particularised, it tends to link with an individual's internal locus of control.

"Maar soos ek sê, hoop en daai, het my nog altyd die krag gegee om, om te werk. So vir my is dit die belangrikste." (See Appendix F)

"It's the fact that I haven't given up hope. That's the main thing. I haven't given up hope."

"So I think it's really helped me a lot. All these little treatments and all the searching for and never giving up hope."

On the other hand, according to Burke (1977), the helplessness associated with chronic disability and the hopelessness of the disadvantaged and deprived are very often extreme instances where individuals manifest a lack of motivation. The feelings of powerlessness result not from a lack of appropriate values and aspirations, but rather from the inability to conquer obstacles. **Motivation** is therefore linked to the internal locus of control as the effect of their actions on the environment.

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Motivation describes the drive towards action. In general, motivation is related to the individual's wish for well-being. Whether motivation is an internal or external process, it still leads the individual to interact with his/her environment. Persons need the motivational system not only to initiate, but also to sustain behaviour. The fact that an individual has something to believe in order to keep his/her hope alive helps him/her to keep going on (Christiansen & Baum, 1997).

"Motivering. Ek het alles ingesit het wat ek moes, want ek het geweet ek - as ek nie probeer nie, dan sal ek nie daar kom nie. Ek het na die dokter geluister en die dokter het gevra, het vir my gesê ek moet – hy dink hy moet my afsit van die werk af en ek het gesê nee en ek het net hmm, huis toegekom en self kom probeer." (See Appendix F)

"Jou vraag wat jy vra, wat maak my werk ten spyte van my siekte is net ek moet se my wilskrag. Miskien is dit deel van my geaardheid. Hm, of ja, my interne lokus van kontrole..." (See Appendix F)

"Ek kon maklik kommunikeer – ek – toe ek die arthiritis het, was ek altyd teruggetrokke. Ek was nommer een – ek was skaam vir my hande. Ek kon nie maklik vat nie. Maar toe ek met die salads beginne, het ek – ek het daarie motivering gekry. Ek kon mense serve, ek hoef nie bang gewees het nie ek gaan goed gelaat drop het soos ek altyd in die verlede gedoen het nie. Dit was vir my net lekker." (See Appendix F)

For some individuals, helping others made them feel that they were able to feel good about themselves and to build up a sense of self-worth. Being able to give back to others became another reason not to give up their work. According to Erikson (1982) (in Newman & Newman, 1999), **generativity** encompasses *procreativity, productivity and creativity, and thus the generation of new beings, as well as of new products and new ideas, including a kind of self-generation concerned with future identity development*. At some point, all adult members of society begin to feel an obligation to contribute their resources, skills and creativity to improving the quality of life of the young. Across all age groups it has been found that, generative concern was significantly related with happiness and life satisfaction (Newman & Newman, 1999).

"Ek kon ook mense leer om gesond te eet, want daar was niks, geen ongesonde kosse by. Dit was net salads wat hulle geniet het. En ek het dit op 'n Maandag gedoen en op 'n

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Maandag en 'n Vrydag. Toe verander ek dit, toe vind ek uit Maandae bring die mense hulle eie kos. Van Sondag, toe sê ek Dinsdag en Vrydag. En omdat ek geld gemaak het, omdat mense kon gesondsheidskosse geëet het, het ek in dieselfde tyd geld gemaak en dit het vir my baie lekker laat voel. Want ek het geld gemaak en ander mense geleer om gesond te eet." (See Appendix F)

"En die mense in die omgewing – die mense wat vir my ken, die mense by die kerk. Even nou – drie weke gelede het ek 20 koeke gebak vir die kerk. Ek het 20 koeke – dit was vir my lekker want ek het geweet, hulle weet Sarah het 'n probleem. Sy't probleem om te staan met haar knieë, dit swel baie, maar vir my was dit net lekker om te sien hoe die mense my koeke verkoop. Hoe hulle dit koop, vir my was – dis vir my 'n aansporing om te weet ek kan iets vir die gemeenskap doen." (See Appendix F)

"En hier is 'n paar pragtige jong mense en ek wil graag hê hulle moet eendag almal lekker lewe en in groot Mercedese rondry, whatever so dit sal vir my lekker wees as hulle ook erens kom. Ek, ek voel ook 'n verantwoordelikheid jeens hulle. Ja, ja baie van hulle kom al van die vorige werk saam met my. Omtrent die helfte. So, daar is nou 'n paar nuwes by, nuwes, dit is ook nou al amper vyf jaar,maar hmm, so ek, ons is 'n klein familietjie en ek is baie gelukkig." (See Appendix F)

"Hmm, jy weet hmm, miskien raak ek nou te filosofies maar ek dink as 'n ou nou kom by vyftig dan, ek, ek dink ek het baie uit die lewe uitgekry dat dit is nou tyd om vir my ook bietjie terug te gee." (See Appendix F)

"Ja terug te gee is seker die lekkerste ding om te doen is om te gee. En hmm, as 'n ou nou in 'n posisie is om dit te kan doen dan hoekom nie. Dit laat 'n mens lekker voel." (See Appendix F)

According to Janelle (1992), numerous studies strongly support the hypothesis that individuals with an internal locus of control (a) are more alert to those aspects of the environment which provide useful information for their future behaviour, (b) take steps to improve their environmental condition, (c) place greater value on skill or achievement reinforcements and are generally more concerned with their ability, particularly their failures, and (d) are resistive to subtle attempts to influence them. With this in mind one

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can presume that the individuals with a strong internal locus of control would be the ones that, even though he/she has RA, refuses to give up and to become work disabled.

8.5 Personal strategies used by individuals with RA to stay employed in the open labour market

Individuals with RA and employed in the open labour market who were involved in the study by Mancuso *et al.* (2000) had this advice for other individuals with RA who wanted to stay employed:

- have a determined and persistent outlook;
- be practical and ready to adapt;
- improve yourself constantly(e.g. attend classes) to broaden your options;
- follow your physician's medical advice;
- know your limitations and change to part-time if necessary;
- conserve energy every way possible, including by modifying home life; and most importantly
- stick to your current employment.

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Individuals with RA make use of various strategies to enable them to stay employed. This should not be seen as a negative factor, something that only individuals with disabilities should do, as it is used by most employed individuals in everyday life. Whether it is an ergonomic chair to prevent backache, or not going out on a weeknight as a result of a hectic work week, such sacrifices are not only made by disabled individuals.

According to Chorus *et al.* (2001) another explanation for differences in work disability in RA among otherwise comparable patients might be the way in which some individuals deal with the biological consequences of their disease. Chorus and colleagues report that coping (by individuals with RA) has been investigated extensively and it is generally found that what individuals do in relation to the stresses of the disease, has potentially important implications for their levels of disability and psychological well-being. Pain, limitations and dependency are identified as the most important stressors of RA (Van Lankveld *et al.*, 1993). Limiting the levels of activity when faced with the stressors of the disease, could have negative effects on future physical functioning (Van Lankveld *et al.*, 1999 & 2000).

When at work, an individual's behavioral reaction to these stressors could also be an important factor in determining his/her work capacity. According to Chorus *et al.* (2001) both work factors and coping skills are potentially modifiable and could be used to construct vocational interventions to prevent early withdrawal from the labour force.
Individuals make use of various strategies when becoming aware of an acute episode at work. Some actions could be medical in nature, like taking medication or visiting their doctor. Others could be work-related, like keeping on working, working slower and doing less work or even taking rest breaks. Some would tell one of their colleagues and ask for help, while others would go home to rest. Individuals with poor self-reported health status would rather take medication, while the individuals with less pain would be the ones who continue working.

In order to cope with limitations, pacing (i.e. adapting ones level of activity) and diverting attention was found to be negative coping skills, as patients who used these skills were more likely to stop working. According to Strahl (2000), passive coping is inversely related to physical functioning. This author found that the greater the use of withdrawal and avoidant-like coping strategies, the poorer the physical functioning, whereas active coping was found to be directly associated with increased social interaction. Active coping, being a rather global construct, is most likely composed of several different strategies, each of which may relate to different pain-related functions. Strahl (2000) suggested that treatment or management programmes for patients with RA should continue to focus on enhancing self-efficacy and decreasing the use of passive and related coping strategies. As one individual commented:

"And hmm, ja, organizing myself to suit my needs..."

Self-management refers to the way individuals organise those abilities that enable them to accomplish their goals, despite stressors. The researcher used the term to describe all the coping or self-help skills that individuals used to stay employed. This links with the Arthritis Self-Management Program (Lorig & Holman, 1993) that uses social learning theory to enable people to feel more in control of their symptoms. This programme promotes self-efficacy through group sessions. Results indicated that improvements in health was strongly associated with improved self-efficacy, while a change in health behaviour, such as increased exercise, had a weaker link with improved health status. For information regarding the category self-management, refer to Table 8.4.

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The self-management skills used by the 6 individuals who participated in the qualitative part of the research were: positive thinking, setting goals for oneself, adapting ones lifestyle and workplace and problem-solving as all these lead to a sense of self-efficacy. Self-efficacy was used to describe the individuals' belief in themselves as well as regarding the importance ascribed to doing things for themselves.

Table 8.4 Self-management

Self-Management • Adaptation ★ Lifestyle ★ Work place • Goal setting • Problem-solving • Positive thinking • Self-efficacy	

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Bandura (1977, 1986) according to Christiansen & Baum (1997), used the term self-efficacy to describe individuals' views of themselves as competent. Research has shown that people who perceive themselves as *competent* tend to view their overall well-being as more favourable and they are more likely to continue working on tasks despite early setbacks (Gage & Polatajko, 1994 in Christiansen & Baum, 1997).

Positive thinking is one of the strategies that individuals use to manage pain or just the everyday difficulties that they encounter. Some call it *mind over matter.* Positive thinking links with the beliefs in cognitive behavioural therapy. It suggests that people have automatic thoughts – things they tell themselves about themselves and the world around them. *Automatic thoughts* are usually highly abbreviated forms of internal speech that reflect habitual forms of thinking. Placing *mind over matter* by thinking positively about life events and their own abilities, assisted individuals with RA in staying employed.

"Dit is – daar is nog baie pyn. Ek sal nie sê daar is nie pyn nie, daar is pyn, maar jy moenie loop lê omdat daar pyn is nie. En as ek sê le, jy moenie bedleênd wees nie. Jy kan nog 'n bietjie loop rus, jy kan 'n pynpil vat, loop lê en as jy voel jy kan opstaan en iets

doen, doen iets. Skil die artappels, moenie lat jy vir jou …Moenie lat jy vir jouself sê ek kan nie artappels skil nie. Jy kan artappels skil. Jy kan dit doen as jy net wil. Dan kan jy. Dis al – dis al wat jy moet doen, net jy moet net dit kan doen." (See Appendix F)

"And then lunch times I do go out with the ladies. Not every day but hmm, a few times, hmm just to, even if I'm not feeling that well, just to get out of the building. That helps and take my mind of my situation."

"First of all I am a person with a very positive mind. But I hmm, as I've said I'm a positive person and I wanted to work and I wanted to hmm, hmm do that. Hmm, I wasn't prepared to sit back and just accept my circumstances."

"Ek het nooit die siekte beskou as 'n rede om nie te werk nie. Dit was nooit, van kindsdae af, so ek weet nie of dit deel van die gene of wat dit is nie, maar hm selfs op skool, ek het in die laerskool het ek skool in die hospitaal skool gegaan, maar ek het my standerd gemaak. In die hoerskool het ek na 'n gewone skool gegaan en die kinders het my op en af gedra. Jy weet so, ek het nie na, ek het geweier om na 'n spesiale skool te gaan en na matriek, ek het net altyd ge, die passie gehad om te wil werk." (See Appendix F)

"Ek is baie positief ingesteld in die lewe, so niks, ek laat niks toe om my onder te kry nie. Ek se altyd, my mind rules my body, en hoe ek deur elke, want ek kry set backs." (See Appendix F)

Setting goals for themselves in terms of their work or having personal long-term goals have assisted individuals in the study in the Western Cape to stay employed. Among other things it implied having a long-term goal towards which the individual could work. Actions linked to longer-term goals and purposes are more likely to be maintained and to contribute to one's self-concept. Goals that were more abstract tended to have a greater influence on overall well-being than goals that were more concrete, and thus likely to be shorter-term. Goals become effective motivators and regulators of behaviour because they are part of one's image of *possible selves* (Christiansen & Baum, 1997).

"Hmm, I've tried to continue studying. I tried to do something at least maybe every two years to improve my, my qualifications and just, just to improve my own personal development. Hmm, since, since I left university with my degree I didn't, I couldn't, didn't

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find a job anywhere, because I also made the mistake, I thought I was like highly qualified when I had one degree, and meantime I had no experience, no skills, so the first things I did was I went to do a secretarial course and a computer based course where I learned, my first computer skills and typing and so on and that helped me to get a job and I – that was possibly the most valuable thing that I have of all the things that I studied, because it's really helped me in almost every job that I've had I can continually go back to that. And you know those skills have pulled me through most of the jobs that I had. And then after I've completed that, I went back to university and I did a part time adult education diploma, because I realize I don't have a professional qualification and I thought I thought I must do this, so I took that. It's equivalent to a teaching qualification. Then after that I decided to go overseas, to work overseas, so I did a language course, hmm, teaching English as a foreign language course. I did that, but then due to the operations I had I couldn't go and I just canned the whole idea. And that was in 1998. I haven't studied since then, but I am going to study from next month onwards. I going to do a writing course through correspondence place in England in Manchester, it's a ten-month writing course, so I should do that. Hopefully try earn some money from work that can be published afterwards. Ja, cause I'm also preparing myself cause I don't' know for how long I would be able to maintain, care for myself. For how long I would be able to come to work everyday, cause my joints are obviously – I mean I have to face reality, my joints are obviously deteriorating. As you get older arthritis gets worse and worse, so I need to equip myself so that I can then maybe work from home. And I need also to do not physical work. So that's why I'm doing that. Something like more intellectual, brain powered work."

"Ek sou nie kon bereik het dink ek wat ek wou bereik het, en waar ek op pad is na, want ek is beslis nog nie by my peak nie. Ek het groot planne voor my, ja binne die volgende drie jaar." (See Appendix F)

Adaptations are made in terms of changes to the participant's **lifestyle** as well as to the **workplace** in order to allow him/her to stay employed. The terms *coping* and *adaptation* are often used interchangeably, but *adaptation* should be seen as more encompassing than *coping*. *Coping* implies specific reactions to specific situations, whereas *adaptation* is the broader conceptualisation of the fit between the individual's capacities and the demands for performance. Adaptation also requires the satisfactory adjustment of individuals within their environment over time.

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Lifestyle changes often require support and understanding by family, as it could influence the family as a whole. *Lifestyle* is defined as a distinctive, selected mode of living with continuity over time that is both observable and recognisable, and through which an individual expresses his or her self-identity. The routine or established way of dealing with personal needs and the demands of the environment, as well as an established and consistent pattern of involvement in a particular type of behaviour, is also an important characteristic of lifestyle (Christiansen & Baum, 1997).

According to Reisine and Fifield (1995), family members attempt to find the most appropriate ways to sustain a stable social environment, when stressful situations occur, modifying behaviour patterns and developing *coping strategies* that have the greatest benefit for the total family. Cohesiveness and organisation, two family social environment concepts, have been shown to be essential for stable family functioning in individuals with RA (Whitley *et al.* 1999). *Cohesiveness* refers to the amount of commitment, help and support family members give to one another, whereas *organisation* is the degree of importance given to clear organization and structure in planning family activities and responsibilities.

"Ek en; my man help my baie in die huis en ek se reguit vir mense, ek, in die week gaan ek teen die spoed van tweehonderd, maar dan naweke is ek net half flou, maar dan gebruik ek dit om te rus. Hmm, so ons gaan minder uit as wat ons uitgegaan het, hmm, en ons doen net meer goed wat aan..." (See Appendix F)

"Hmm, well it's to plan my life. To plan my, starting from early in the morning, hmm getting up very early because I'm slower than the normal person, hmm and I don't rush because that flares up you know the adrenaline, hmm going very fast can also be a, have a negative effect. So I plan my day the way, I plan the morning slowly and by the time, I even have breakfast at home. Before I never used to have breakfast at home, I'd have breakfast when we have our tea at work. I'd, I have my breakfast at home so that I can take my medication before I go to work. By the time I get to work, I do drive to work, but that is only now for the last ah, three years."

"...en my styfheid en dit, ag ek het so bietjie styf in die oggend, maar jy weet jy gaan maar net aan, ek weet deur die dag, dan kom dit reg, dan vat ek 'n warm bad, so jy pas maar jou lewenstyl aan en jy weet nou al wat jy moet doen. En, en een keer in ses maande vat

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ek 'n dag af en slaap ek net die dag, vir vier en twintig uur. Ek doen dit. Ek doen dit, ek kan nie vir jou sê hoe demanding ons werk is nie. Van vieruur tot halfag werk ons, ek doen standby. Ek slaap saans vroeg en ek dink dit is my behoud. My, dis weer een van my dinge wat ek doen, my, sodat ek my hectic lifestyle kan volhou, is ek slaap baie. Letterlik, naweke sorg ek dat ek my rus inkry. So ek pas maar my lewensonstandighede aan, wat dit vir my makliker gemaak om te kan werk en hm, om dit te kan doen wat ek wel doen, want ek het bereik (lag)." (See Appendix F)

On the other hand **adaptations to the workplace** require support and understanding by both the individual's employer and co-workers.

"Then hmm, the attitude at work I hmm, as I said, I also plan I set out hmm, hmm I do things for my comfort."

"Where I hmm, I did hmm, I don't know what time that courses, many years ago with hmm, ...Sr. Brown, Sr. Brown how to set out your life to make your life easy. Self-help groups, yes and hmm, I set out my desk and even at home, and even at home I set out my desk where everything is situated to my convenience. I even had the workshop hmm, at the, at the, my company getting a special chair and hmm, rolling the chair up to the level I wanted it and then I, if there's things for instance, pressing the punch, I have, I hmm, I would put something soft on, hmm, on the, not the punch, the stapler. I've put something soft on the stapler, because I press it down with my elbow, and because my wrist's are weaker than my elbow's and then I've put something on top to, not to harm my joints."

Another strategy individuals use to maintain independence is **problem solving**. *Problem solving* entails making plans in order to perform tasks at work, as well as at home, that will enable individuals to attend work independently. Problem solving is seen as one of the five major dimensions of personality traits that influence human behaviour. Personality traits help to explain purposeful behaviour, by indicating the reasons that motivate actions. It thus links with motivation as part of the internal locus of control over the environment (Christiansen & Baum, 1997).

"Toe iemand vir my sê jy gaan in 'n rystoel beland. Het ek net gebesluit, ek sal nie in 'n rystoel beland nie. Ek was ook kwaad omdat ek nie vir myself kan aangetrek nie. Ek moes wag laat hulle vir my help altyd en dit het my meer desperaat gemaak dat ek moet,

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ek moet – ek kon nie my eie bed opmaak nie. Die was ook frustrerend. Ek, ek kon nie – ek kon dit nie hanteer dat ek nie kan die kraan opmaak nie en met die hulp van die sleutel en tandeborsel – al daai goed het ek gebruik – ek het gebruik gemaak van dit en toe het ek uitgevind eendag en kan my bed opmaak, nie soos dit – soos – soos al die ander mense die bed opmaak nie, ek het die lakens oorgevou en gevou en van daai dag af het ek geweet ek kan my eie bed opmaak. Ek kon in die bad inklim, sonder my ma se hulp, sonder my suster se hulp. Dit was 'n gesukkel om uit te klim. Maar toe ek uitklim – die eerste keer wat ek uitklim, toe sê ek nou gaan julle my nie weer help nie. Toe ek uitvind ek kan my bra self vasmaak en ek kan my hmm, hmm hemp aantrek, ook met 'n gesukkel, toe weet ek Elenor, van vandag af trek jy nie meer vir antie Sarah aan nie, antie Sarah sal vir haarself aantrek. En dis wat dit vir my gehelp het by die werk. Iemand anders het altyd vir my die water ingegooi in die urn. En op 'n dag het ek gebesluit, as ek die emmer vat en klein bietjies water ingooi in die urn in, dan sal ek my arm kan opgelig kry, want altyd het ek geweet daar is iemand wat vir my water ingegooi en wanneer daar iemand is wat vir jou water ingooi en vir jou jou klere aantrek, dan, waarvoor het jy nodig om gehelp te word. Maar as jy self insit en self jou water ingooi, self jou klere aantrek, dan kom jy bo uit soos ek vandag bo uit gekom het. Ek glo ek is bo uit." (See Appendix F)

"Sy't altyd die deur oopgemaak vir my, dat ek inklim en ook op 'n dag het ek net gebesluit ek moet self probeer. En ek het self leer om die pot van die stoof af te haal en toe ek onthou jy't gesê as ek die pot nie kan optel nie, moet ek dit skuif en dit het ek gedoen en so het ek beginne kom om die potte te skuif. Om die potte te skuif. En dis wat – sy het ook vir my baie gehelp. Sy het altyd vir my gesê probeer om, om die trappe te klim, want vir my was dit baie swaar. Die huis het baie trappe. En dan't sy altyd gesê hou vas aan die reëling en so sal jy die trappe opkom en ek het uigevinne, dit is waar. Ek het die trappe uitgeklim, later toe hardloop ek die trappe uit." (See Appendix F)

Individuals with RA also seem to believe that it is important to help themselves in order to strive for independence. If they always rely on others, they feel as if they would become more dependent. **Self-efficacy** is the view of ourselves as competent. Individuals who perceive themselves to be competent, tend to view their overall well-being as more favourable and they are more likely to continue working on tasks, despite early setbacks.

According to Strahl *et al.* (2000) coping strategies and self-efficacy have been found to be associated with the experience of chronic pain and are predictive of the level of pain and

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functional impairment in RA. *Arthritis self-efficacy* refers to the belief individuals have that they can effect change in some specific domain such as their functioning, performance, pain level, or other illness-related area. The way in which patients with chronic pain cope or adjust to their illness, is also central to understanding the great variability in the ability of different patients to function with their illness and to maintain a good quality of life. Coping with illness and pain has been conceptualised in several ways. Brown and Nicassio (1987) described *coping* as consisting of *passive strategies*, including bed rest and restricting activity to reduce pain. These strategies are typically associated with poorer overall adjustment, increased depression and functional impairment. *Active coping*, e.g. attempting to maintain activities despite pain, on the other hand, is associated with more favourable adjustment to illness in individuals diagnosed with RA. (Strahl *et al.*, 2000)

"...jy moet net vir jouself help. Om aan te gaan. Jy moet aangaan. Jy moet vir jouself kan help. Jy moenie net stil sit nie, want as jy stilsit, dan gaan jy net by een plek bly. Want soos hulle sê 'n voël wat nie vlieg nie, kan nie eet nie. So ek het gebesluit ek moet vlieg en so sal ek kan eet. En dis wat dit is wat dit vir my gemaak het, wat ek is vandag." (See Appendix F)

"Ek het vir myself gesê, hier is iets wat ek moet vir myself doen. Toe ek met die salads begin het ek agtergekom dat ek is ywerig om dit te doen. Dit is vir my lekker om te weet ek kan my twee hande gebruik." (See Appendix F)

"Hulle moet nie wag dat ander vir hulle iets doen nie. Want as jy wag dat iemand anders vir jou doen, sal jy altyd gedurig wag vir die bediende. Dan maak jy ander bediende – jou familie sal jy bediendes maak, want jy wil dit nie vir jouself doen nie. Jy dink waarvoor sal ek dit doen, ek het mense wat dit kan doen. Dit werk nie so nie. Die lewe is – jy moet vorentoe kan gaan. Jy moet jou voet kan optel en bo-op die trapppie sit, dis hoe jy jouself gaan help. Dis, dis al, dis al wat ek kan vir die pasiënte sê. Hulle moet hulle self kan help, die mense wat vir hulle help, moet ook vir hulle sê, help jouself, andere kan nie vir jou help nie. Ons kan vir jou die pille in jou hand gee, ons kan dit nie vir jou maak drink nie. Ons kan vir jou sê jy moet die oefeninge doen, ons kan dit nie vir jou doen nie, jy moet dit self doen. Dit hang net van jou af. En ek glo dat arthritis kan nie vir ons doodmaak nie. As ons vir onsself help ne, ons moet vir onsself help." (See Appendix F)

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"Vir my is dit belangrik as gevolg van, ek het nie 'n inkomstes wat ek nou vir mense kan vra om vir my 'n werkie of 'n ding te doen nie, vir my is dit belangrik om my eie werk te doen. En so weet ek ek het arthiritis hande, hou dit my fiks. Dit gee vir my krag, dit hou my laat ek aangaan met hierdie lewe, dat ek nie kan sit op my agterste, of op my kniee of sit en wag vir iemand anders om dit te doen nie. Ek doen dit self, dis hoekom ek daarvan hou en dis belangrik vir my om my eie werk te doen. Ek sien dit, dit help my. Ja, dit het baie gehelp. Vir my is dit belangrik." (See Appendix F)

"I do, I do it everyday. If I need to change the paper in a printer then I've got to bend down my way, and I also don't want to ask because I have my dignity."

Believing in oneself is another aspect of self-efficacy. If individuals with RA believe in their own abilities, it is easier for them to do things independently.

In an article by Reed (1999), Bandura stated that one's perceived self-efficacy to perform a behaviour or task leads to one's willingness to perform that behaviour or task. Bandura argues that a person's perceived self-efficacy is influenced by four sources of information: (a) past performance accomplishments, (b) vicarious learning, (c) verbal persuasion from others, and (d) emotional arousal. In turn, one's self-efficacy influences (a) whether one chooses to approach or avoid a behavior, (b) if one chooses to perform the behaviour at all, and (c) how persistently one will perform a behavior.

"I don't like people to, the reason being, I don't like people to underestimate my abilities. As I've said I'm a positive person and I, I'll, my abilities to me, I'm not, I'm not disabled. I'm not disabled, not at all."

"Hmm, ek dink, ag ek weet nie ek dink net soos ek vir jou voorheen gesê het ek hmm soos ek vir een MD een dag gese het, "Even if you have got a flight of stairs and someone has to carry me up their, then I'll do it", so ek dink weereens is dit maar net my hmm, my vreeslike, seker maar my geloof, my geloof in myself dat ek kan dit doen." (See Appendix F)

A sense of self-efficacy is what motivates an individual to use the different self-management skills in order to adapt his/her life in such a way as to stay employed in the open labour market.

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The qualitative data support the quantitative data in that it gave us an understanding of the perceptions regarding individuals with RA. There are more factors than merely those related to demographic, disease and work that help individuals to stay employed. The will to survive and to carry on with life are often major factors that cannot be ignored when work disability and enablement are considered.

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Chapter 9

Conclusion

As health care professionals occupational therapists need to know not only what causes work disability, but also how to assist people in staying employed. Even with this knowledge occupational therapists may not be able to change the factors that cause work disability as these might be directly related to the disease or the demographics, for example the level of education or marital status. It is important to realise that the presence of the factors causing work disability in RA may pre-dispose an individual with RA to become work disabled. On the other hand, enabling factors may assist an individual with RA in staying employed, even though these individuals are predisposed by the risk factors to become work disabled. This interplay between disabling and enabling factors is what causes or prevents work disability. As health care professionals, occupational therapists should rather focus on what they can change in an effort to keep individuals employed for longer, so that these individuals will be able to take control of their disease and their work situation, in order to maintain their employment status.

From the literature we know that factors like age at the onset of the disease, marital status, level of education, baseline HAQ, duration of the disease, work autonomy, type of work and the physical nature of the job can affect work positively or negatively (Barrett *et al.*, 2000; Chorus *et al.*, 2000). In the study in the Western Cape we found that there are also other factors that assist individuals in staying employed in the open labour market once they have been diagnosed with RA.

From the quantitative part of the study in the Western Cape, it is clear that the perceived importance of work has a major impact on whether an individual stays employed, even though there is more than one factor predisposing them to work disability. As found in other studies, autonomy over the pace and scheduling and especially being self-employed, are important factors that allow an individual to stay employed once diagnosed with RA. Self-employed individuals have significantly higher autonomy than individuals employed by someone else. Individuals working part-time or as contract workers for someone else also had higher autonomy than individuals working full-time for someone else.

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Whether individuals perceive that they receive support and understanding from colleagues and employers or not, was found to be closely linked to disclosure of the diagnosis in order to receive support. This was reinforced by the qualitative part of the study. Individuals with RA cannot expect to receive help and understanding if he/she does not take the responsibility to educate their employers and colleagues about the diagnosis and specific needs. Being married also had a positive effect on the experience of pain, though pain was not linked to work disability. Depression and family support in the case of the individual with RA is linked to pain. Depression and family support were however not assessed in the study in the Western Cape.

Medical management, regardless of whether in the form of medication or support from medical personnel, was found to be of value, even though there was no association between the use of DMARD and self-perceived health status (HAQ score). More important was the finding that individuals, in their search for control over the disease and due to self-efficacy, made use of diet, exercise and alternative treatment in order to manage their RA.

Self-management strategies in the form of problem solving, adaptation, goal setting and positive thinking, which are interlinked with individuals' perceived self-efficacy, were used to stay employed. These can be classified as *active coping strategies* as they are linked to whether individuals can change the environment or not. Regardless of whether they were taught by health care professionals or self taught, self-management strategies formed an essential part of the factors that help individuals to stay employed. Participation in self-help groups is therefore essential for individuals with RA in order to learn in a group setting and together with other individuals with RA how to take control of the disease.

Locus of control, whether internal or external, links with whether individuals use active or passive coping strategies. In a way, locus of control answers some of the questions regarding why some individuals with RA, despite negative prognostic factors, stay employed. It might also be one of the answers as to why individuals perceive their work to be of importance.

A concern is whether health care professionals know when and how to handle the work related problems of individuals with RA. This matter was not investigated during the study in the Western Cape, but could result from the findings of this study. In the study by

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Gilworth *et al.* (2001) these authors mention that probably the most important finding is that rheumatologists and hospital-based therapists in the United States of America did not appear to recognise which of their patients could benefit from referral to a Disability Employment Advisor (DEA) and the subsequent support that could be offered to the patients in the workplace. In South Africa there are no DEA's at the moment, but occupational therapists act as liaison between the hospital and the employer, or often linking with the Human Resource Manager, if one is available.

It remains an open question whether South African rheumatologists and occupational therapists really know when and how to handle the work related problems of individuals with RA.

The study objectives, as set out in Section 2.3, have been met partially. A profile of the working individual with RA in South Africa has been drawn up. The use of public versus private transport and whether individuals with RA experience any problems with either, need to be investigated further.

The physical, psychological and social support experienced by individuals with RA in the workplace was determined, but the effect of depression and family support needs to be investigated. Whether all individuals with RA employed in the open labour market receive sufficient support from their family and whether individuals with RA in general are depressed needs to be assessed.

The personal strategies used by individuals with RA to stay employed, were also determined. This need to be investigated further to ensure trustworthiness through the use of triangulation, so that the findings can be further generalised to the South African working population with RA.

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Chapter 10

Recommendations

Health professionals need to be educated regarding what specifically causes work disability in individuals diagnosed with RA, but also what enables some individuals with RA to stay employed, so that effective intervention can be implemented.

Rheumatologists need to refer patients at the first diagnosis of RA for intervention in terms of work, whether they experience any problems at that stage or not. Health care professionals need to be able to identify whether an individual experiences problems or not, instead of only focusing on disease progression and the medical management of the disease.

Research needs to be undertaken to determine why individuals with RA see their work as important, when they rate it as an 8, 9 or 10 on the VAS. Even though this was partially determined through the qualitative part of this study, individuals need to be questioned why they perceive their work as important.

A larger qualitative study is necessary to determine what it is that enables individuals with RA to stay employed in the open labour market in South Africa in order to determine whether there are any other factors that can be taken care of by health professionals when assisting individuals to stay employed. It is important to continue with the qualitative process until saturation is achieved and no new themes emerge. The possibility of a framework of work enablement for individuals with RA can also be explored in this way.

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Rumatoïede Artritis Vraelys

Hierdie vraelys is deur Ancil Prinsloo, as deel van haar Magister Graad in Arbeidsterapie by die Universiteit van Kaapstad opgestel. Dit behoort u ongeveer 15 minute te neem om te voltooi.

Die doel met die vraelys is om vas te stel watter faktore u gehelp het om te bly werk, vandat u met rumatoïede artritis gediagnoseer is. Hierdie informasie sal die mediese beroep inlig oor spesifieke stappe wat gevolg kan word, voordat 'n persoon met rumatoïede artritis sy werk verloor. Die nuwe arbeidswetgewing bevat wetlike stappe wat eers deur die werkgewer geneem moet word, voordat 'n persoon met rumatoïede artritis medies ongeskik vir werk verklaar kan word.

Alle informasie wat ingesamel word sal konfidensieel behandel word. Die voltooide vraelyste sal aan die einde van die studie vernietig word.

Indien u enige vrae het is u welkom om my by (021) 938 9291 te skakel.

Vul asseblief die vraelys volledig in, aangesien u inset baie waardevol is.

Afdeling 1 **Datum**_____

Voltooi asseblief hierdie afdeling in drukskrif.

1. Van_____ A1☐
2. Naam_____ A2☐
3. Geboorte Datum*_____ A3☐
4. Lêer Nommer GSH1 _____ A4☐
   PAOH2 _____
   TGB3 _____
   Privaat4 _____
5. Adres (slegs woonarea en poskode)_____ A5☐☐☐☐
6. Opleidings Vlak* Hoogste Standerd Deurgekom_____ A6☐
   Tersiêre Opleiding_____ A7☐
   _____
7. Kinders Hoeveelheid _____ A8☐
   Ouderdomme* _____ A9☐☐☐☐☐☐☐☐

Voltooi asseblief hierdie afdeling deur 'n ✓ in die toepaslike spasie te maak.

8. Ras Kleurling1 _____ Wit2 _____ A10☐
   Asiaties3 _____ Swart4_____
9. Geslag Manlik1 _____ Vroulik2_____ A11☐
10. Huwelik Status Getroud1 _____ Enkel2 _____ A12☐
    Geskei3 _____ Verwyderd4 _____
    Wedewee/Wewenaar5 _____
11. Vervoer Het u toegang en/of maak u gebruik van: A13☐
    Publieke Vervoer1_____ Privaat Vervoer2_____

Voltooi asseblief hierdie afdeling in drukskrif.

12. Datum van aanvang van Rumatoïede Artritis*_____ A14☐

* sien kode lys

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Afdeling 2 - Ernstigheid van die Siekte

(Hierdie afdeling is in Engels aangesien die vraelys internasionaal gebruik word en tot op datum nie in Afrikaans beskikbaar is nie)

13. Stanford Health Assessment Questionnaire - Functional Ability Measure*

We are interested in learning how your illness affects your ability to function in daily life. Please feel free to add any comments at the end of this form.

Please tick the one response which best describes your usual abilities over the past week:

	Without **ANY** difficulty	With **SOME** difficulty	With **MUCH** difficulty	Unable to do
1. Dressing and Grooming				
Are you able to:				
• Dress yourself, including tying shoelaces and doing buttons?				
• Shampoo your hair?				
2. Rising				
Are you able to:				
• Stand up from an armless straight chair?				
• Get in and out of bed?				
3. Eating				
Are you able to:				
• Cut your meat?				
• Lift a full cup or glass to your mouth?				
• Open a new carton of milk (or soap powder)?				
4. Walking				
Are you able to:				
• Walk outdoors on flat ground?				
• Climb up five steps?				

Please tick any aids or devices that you usually use for any of these activities:

Cane_____ Walking Frame_____ Crutches_____ Wheelchair_____

Devices used for dressing (button hook, zipper pull, long handled shoe horn, etc.)_____

Built-up special utensils_____ Special or built up chair_____

Other (specify)_____

_____

_____

_____

Please tick any categories for which you usually need help from another person:

Dressing and grooming_____ Eating_____ Rising_____ Walking_____

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* sien kode lys

Please tick the one response which best describes your usual abilities over the past week:

	Without **ANY** difficulty	With **SOME** difficulty	With **MUCH** difficulty	Unable to do
5. Hygiene Are you able to:				
▪ Wash and dry your entire body?				
▪ Take a bath?				
▪ Get on and off the toilet?				
6. Reach Are you able to:				
▪ Reach and get down a 5lb object (e.g. a bag of potatoes) from just above your head?				
▪ Bend down to pick up clothing from the floor?				
7. Grip Are you able to:				
▪ Open car doors?				
▪ Open jars, which have been previously opened?				
▪ Turn taps on and off?				
8. Activities Are you able to:				
▪ Run errands and shop?				
▪ Get in and out of a car?				
▪ Do chores such as vacuuming, housework or light gardening?				

Please tick any aid or devices that you usually use for any of these activities:

Raised toilet seat_____ Bath rail_____ Bath seat_____

Long handle appliances_____ Jar opener (for jars previously opened)_____

Other (specify)_____

Please tick any categories for which you usually need help from another person:

Hygiene_____ Gripping and opening things_____ Reach_____ Errands and housework____

B1☐

14. Pyn Skaal

Beoordeel asseblief u pyn in die <u>vorige week</u> op 'n skaal van 1 tot 10 deur 'n ✓ te gebruik, waar 1 geen pyn voorstel en 10 die meeste pyn moontlik voorstel.

1_____10 B2☐

geen pyn die meeste moontlike pyn

* sien kode lys

University of Cape Town

Afdeling 3
Werkgeskiedenis

15. Huidige Werk in die Ope Arbeismark Tipe*_____ C1☐
(Voltooi asseblief in drukskrif)

- Voltyds/Permanent1 _____ Gereeld Deeltyds2 _____ C2☐
  Kontrak Werker3 _____ In eie diens4 _____
  (Merk asseblief een met 'n ✓)

16. Werkgeskiedenis (vanaf diagnose met rumatoïede artritis/RA)

Werk/pos tydens diagnose met RA	**Totale jare in die werk/pos werksaam**	**Beskrywing van werks aktiwiteite** (Merk asseblief al die toepaslik met 'n ✓)					**Rede waarom die betrokke werk verander is** Voltooi asseblief hierdie afdeling deur 'n ✓ in die toepaslike spasie te maak		
(Voltooi asseblief in drukskrif)	(Voltooi asseblief in drukskrif)	Sit heeldag	Ligte tot medium take	Medium tot swaar take	Verys fyn handfunksie	Vereis herhalende take	**Stop as gevolg van RA** 1	**Stop as gevolg van nie RA verwante oorsake** 2	**Steeds werksaam in dieselfde werk** 3
1		1	2	3	4	5			

Indien u steeds in dieselfde werk/pos werksaam is as tydens u diagnose met RA, gaan direk na no. 17.

Werk vanaf diagnose met RA (In orde)	**Jare in elke werk werksaam**	**Beskrywing van werks aktiwiteite** (Merk asseblief al die toepaslik met 'n ✓)					**Rede waarom die betrokke werk verander is** Voltooi hierdie afdeling deur 'n ✓ in die toepaslike spasie te maak		
(Voltooi asseblief in drukskrif)	(Voltooi asseblief in drukskrif)	Sit heeldag	Ligte tot medium take	Medium tot swaar take	Vereis fyn handfunksie	Vereis herhalende take	**Verander as gevolg van RA** 1	**Verander as gevolg van nie RA verwante oorsake** 2	**Steeds werksaam in dieselfde werk** 3
2									
3									
4									
5									
6									
7									
8									
9									
10		1	2	3	4	5			

C3☐ C4☐☐☐☐☐☐☐☐☐☐ C5☐☐☐☐☐ C6☐☐☐
1 2 3 4 5 6 7 8 9 10 1 2 3 4 5 1 2 3

* sien kode lys

University of Cape Town

17. Wat het in u werk verander vandat u met rumatoïede artritis gediagnoseer is?
(Merk asseblief een respons by elk met 'n ✓ waar van toepassing op u)

		Vermeerder1	Dieselfde2	Verminder3
• Sittende Werk	A			
• Ligte Werk	B			
• Swaar Werk	C			
• Fyn Handtake	D			
• Tyd om take te voltooi	E			
• Funksionele Aanpassings	F			
• Salaris	G			
• Werksverantwoordelikheid	H			
• Werksoutonomie	I			
• Siekteverlof	J			

C7 A☐B☐C☐D☐E☐F☐G☐H☐I☐J☐

18. Hoe gereeld besoek u, u dokter as gevolg van u RA? **(Merk asseblief een met 'n ✓)**

Weekliks	Maandeliks	1-3 Maandeliks	3-6 Maandeliks	6-9 Maandeliks	9-12 Maandeliks	1-5 Jaarliks
1	2	3	4	5	6	7

C8☐

19. Hoe gereeld neem u siekteverlof as gevolg van u RA? **(Merk asseblief een met 'n ✓)**

Nooit	Weekliks	Maandeliks	1-3 Maandeliks	3-6 Maandeliks	6-9 Maandeliks	9-12 Maandeliks
1	2	3	4	5	6	7

C9☐

20. Hoe lank duur u siekte verlof as gevolg van u RA gewoonlik? **(Merk asseblief een met 'n ✓)**

Nie van toepassing	1-3 dae	3-5 dae	5-7dae	1-2 weke	2-3 weke	3-4 weke	1-3 maande	3 maande of langer
1	2	3	4	5	6	7	8	9

C10☐

21. Is u op enige siekte veranderende medikasie (disease modifying drugs) vir u RA? **(Merk asseblief een met 'n ✓)**

Ja_____1 Nee_____2 Weet nie_____3 C11☐

22. Veranderinge aan u werk tydens 'n akute RA episode **(Merk asseblief ja of nee met 'n ✓)**

	Ja1	Nee2
• Word daar enige aanpassings aan u werk gedoen tydens 'n akute episode? A		
• Word u werk geaffekteer ten opsigte van netheid tydens 'n akute episode? B		
• Word u werk geaffekteer ten opsigte van akkuraatheid tydens 'n akute episode? C		
• Word u werk geaffekteer ten opsigte van volume tydens 'n akute episode? D		

C12 A☐B☐C☐D☐

23. Watter aksies neem u ten opsigte van u werk as u die vroeë simptome van 'n akute episode herken?

_____

_____

_____

C13☐

* sien kode lys

University of Cape Town

24. **Beoordeel asseblief hoe belangrik u werk vir u is op 'n skaal van 1 tot 10 deur 'n ✓ te gebruik, waar 1 glad nie belangrik en 10 baie belangrik, voorstel.**

1_____10 C14☐

glad nie belangrik **baie belangrik**

25. Werksondersteuning **(Merk asseblief ja, nee of nie van toepassing (NVT) met 'n ✓)**

	Ja1	Nee2	Onseker3	NVT4
• Weet u werkgewer dat u met rumatoiede artritis gediagnoseer is? A				
• Weet u direkte toesighouer dat u met rumatoiede artritis gediagnoseer is? B				
• Weet u medewerkers dat u met rumatoiede artritis gediagnoseer is? C				
• Voel u dat u genoegsame ondersteuning van u werkgewer ontvang? D				
• Voel u dat u genoegsame ondersteuning van u direkte toesighouer ontvang? E				
• Voel u dat u genoegsame ondersteuning van u medewerkers ontvang? F				
• Dink u dat u werkgewer verstaan wat dit behels om met rumatoiede artritis gediagnoseer te wees? G				
• Dink u dat u direkte toesighouer verstaan wat dit behels om met rumatoiede artritis gediagnoseer te wees? H				
• Dink u dat u medewerkers verstaan wat dit behels om met rumatoiede artritis gediagnoseer te wees? I				

C15 A☐B☐C☐D☐E☐F☐G☐H☐I☐

26. Het u enige ander kwalifikasies verwerf vandat u met rumatoïede artritis gediagnoseer is?
(Kies asseblief een en gebruik 'n ✓ om te voltooi)

Ja1_____ **Nee2**_____ C16☐

27. Indien ja, watter kwalifikasie het u verwerf?* **(Voltooi asseblief in drukskrif)**

_____C17☐

28. Indien ja, hoekom het u die kwalifikasies verwerf?* **(Voltooi asseblief in drukskrif)**

_____C18☐

29. Werkoutonomie **(Merk asseblief een respons met 'n ✓ waar vir u toepaslik)**

	Kan onafhanklik gedoen word	Kan gedoen word deur 'n toesighouer te vertel	Kan gedoen word deur toestemming te vra	Kan glad nie gedoen word nie
• Hoeveel vryheid het u om te besluit wanneer om in te kom werk toe? A	1	2	3	4
• Hoeveel vryheid het u om te besluit wanneer om 'n rus kans te neem? B	1	2	3	4
• Hoeveel vryheid het u om te besluit wanneer om tyd te neem om die dokter te besoek? C	1	2	3	4
• Hoeveel vryheid het u om te besluit om 'n week af te neem? D	1	2	3	4

C19 A☐B☐C☐D☐

* sien kode lys

University of Cape Town

30. Individuele Maandelikse Inkomste Vlak **(Merk asseblief een deur 'n ✓ te gebruik)**

R 1 - R 200	1	R 4501 - R 6000	8
R 201 - R 500	2	R 6001 - R 8000	9
R 501 - R 1000	3	R 8001 - R11000	10
R 1001 - R 1500	4	R11001 - R16000	11
R 1501 - R 2500	5	R16001 - R30000	12
R 2501 - R 3500	6	R30001 of meer	13
R 3501 - R 4500	7		

C20☐

31. Vereistes van die Werk
(Merk asseblief een respons by elke vraag met 'n ✓ waar vir u toepaslik)

	Nooit	Amper Nooit	Partykeer	Amper Altyd	Altyd
▪ Hoe gereeld moet u botsende werksvereistes hanteer? A	1	2	3	4	5
• Hoe gereeld is daar nie genoeg tyd om take by die werk te voltooi nie? B	1	2	3	4	5
• Hoe gereeld is daar te veel werk? C	1	2	3	4	5
Fisiese Werkslading					
• Hoe gereeld moet u swaar tot baie swaar voorwerpe optel? D	1	2	3	4	5
• Hoe gereeld doen u fisiese swaar tot baie swaar werk ? E	1	2	3	4	5
• Hoe gereeld moet u medium tot ligte voorwerpe optel? F	1	2	3	4	5
• Hoe gereeld doen u fisiese medium tot ligte werk? G	1	2	3	4	5
• Hoe gereeld moet u herhaaldelike buig en buk werk doen? H	1	2	3	4	5
• Hoe gereeld doen u ligte, sittende werk? I	1	2	3	4	5
• Hoe gereeld doen u sittende werk die hele dag deur? J	1	2	3	4	5
• Hoe gereeld moet u werk doen wat fyn handbewegings vereis? K	1	2	3	4	5
• Hoe tevrede is u met die gehalte van u werk? L	1	2	3	4	5
• Hoe tevrede is u met die tipe werk wat u doen? M	1	2	3	4	5

C21 A☐B☐C☐D☐E☐F☐G☐H☐I☐J☐K☐L☐M☐

* sien kode lys

University of Cape Town

Ek benodig 6 mense vir 'n onderhoud. Hulle sal ewekansig gekies word van die individue, wat in die studie deelneem, wat aandui dat hulle belangstel om in die onderhoud deel te neem.
As u bereid is om vir een uur aan 'n onderhoud deel te neem, om meer in diepte inligting ten opsigte van wat u gehelp het om u werk te behou, te verskaf, skryf asseblief u telefoon nommer in die onderstaande spasie.

Telefoon nommer _____

Dankie dat u die vraelys voltooi het.

Ancil Prinsloo
Arbeidsterapeut
Tel. No.: (021) 938 9291

University of Cape Town

* sien kode lys

Rheumatoid Arthritis Questionnaire

This questionnaire has been set up by Ancil Prinsloo, as part of a Masters Degree Study in Occupational Therapy at the University of Cape Town. It should take approximately 15 minutes to complete.

The goal of the questionnaire is to determine which factors have helped you to maintain your employment status, once you have been diagnosed with rheumatoid arthritis. This information will help to inform medical practice in order to ensure that specific measures are taken before an individual with rheumatoid arthritis is boarded. With the new labour laws there are certain measures that legally should be taken by the employer before an individual with rheumatoid arthritis can be boarded or retrenched.

All information obtained would be handled as confidential. The completed questionnaires would be destroyed at the end of the study.

If you have any questions you are welcome to contact me at (021) 938 9291.

Please complete this questionnaire <u>in full</u>, as your input is very valuable.

Section 1 **Date**_____

Please complete this section <u>in print</u>.

1. Surname_____ A1☐
2. Name_____ A2☐
3. Date of Birth*_____ A3☐
4. Folder Number GSH1 _____ A4☐
   PAOH2 _____
   TGB3 _____
   Private4 _____
5. Address (only suburb and postal code)_____ A5☐☐☐☐
6. Education Level* Highest Standard Passed_____ A6☐
   Tertiary Education_____ A7☐
   _____
7. Children Number _____ A8☐
   Ages*_____ A9☐☐☐☐☐☐☐☐
   1 2 3 4 5 6 7 8

Please complete this section by making an ✓ in the space indicated.

8. Race Coloured1 _____ White2 _____ A10☐
   Asiatic3 _____ Black4 _____
9. Gender/Sex Male1 _____ Female2 _____ A11☐
10. Marital Status Married1 _____ Single2 _____ A12☐
    Divorced3 _____ Separated4 _____
    Widowed5 _____
11. Transport Do you have access to and/or make use of: A13☐
    Public Transport1_____ Private Transport2_____

Please complete this section <u>in print</u>.

12. Date of onset of Rheumatoid Arthritis* _____ A14☐

* see code list

University of Cape Town

Section 2 - Disease Severity

13. Stanford Health Assessment Questionnaire - Functional Ability Measure*

We are interested in learning how your illness affects your ability to function in daily life. Please feel free to add any comments at the end of this form.

Please tick the one response which best describes your usual abilities over the past week:

	Without **ANY** difficulty	With **SOME** difficulty	With **MUCH** difficulty	Unable to do
1. Dressing and Grooming Are you able to:				
• Dress yourself, including tying shoelaces and doing buttons?				
• Shampoo your hair?				
2. Rising Are you able to:				
• Stand up from an armless straight chair?				
• Get in and out of bed?				
3. Eating Are you able to:				
• Cut your meat?				
• Lift a full cup or glass to your mouth?				
• Open a new carton of milk (or soap powder)?				
4. Walking Are you able to:				
• Walk outdoors on flat ground?				
• Climb up five steps?				

Please tick any aids or devices that you usually use for any of these activities:

Cane_____ Walking Frame_____ Crutches_____ Wheelchair_____

Devices used for dressing (button hook, zipper pull, long handled shoe horn, etc.)_____

Built-up special utensils_____ Special or built up chair_____

Other (specify)_____

_____

_____

_____

Please tick any categories for which you usually need help from another person:

Dressing and grooming_____ Eating_____ Rising_____ Walking_____

University of Cape Town

* see code list

Appendix B

Please tick the one response which best describes your usual abilities over the past week:

	Without **ANY** difficulty	With **SOME** difficulty	With **MUCH** difficulty	Unable to do
5. Hygiene				
Are you able to:				
▪ Wash and dry your entire body?				
▪ Take a bath?				
▪ Get on and off the toilet?				
6. Reach				
Are you able to:				
▪ Reach and get down a 5lb object (e.g. a bag of potatoes) from just above your head?				
▪ Bend down to pick up clothing from the floor?				
7. Grip				
Are you able to:				
▪ Open car doors?				
▪ Open jars, which have been previously opened?				
▪ Turn taps on and off?				
8. Activities				
Are you able to:				
▪ Run errands and shop?				
▪ Get in and out of a car?				
▪ Do chores such as vacuuming, housework or light gardening?				

Please tick any aid or devices that you usually use for any of these activities:

Raised toilet seat_____ Bath rail_____ Bath seat_____

Long handle appliances_____ Jar opener (for jars previously opened)_____

Other (specify)_____

Please tick any categories for which you usually need help from another person:

Hygiene_____ Gripping and opening things_____ Reach_____ Errands and housework_____

B1☐

14. Pain Scale

Please rate your pain in the previous week on a scale from 1 to 10 by using an ✓, where 1 represents no pain at all and 10 represents the most pain possible.

1_____10 B2☐

no pain the most pain possible

* see code list

University of Cape Town

Appendix B

Section 3
Occupational History

15. Current Occupation in the Open Labour Market Type*_____ C1☐
(Please complete in print)

- Full-Time/Permanent1 _____ Regular Part-Time2 _____ C2☐
  Contract Worker3 _____ Self-Employed4 _____
  (Please mark one, using a ✓)

16. Occupational History (since diagnosed with rheumatoid arthritis/RA)*

Job/post when diagnosed with RA	**Total of years employed in the job/post**	**Description of job activities** (Please mark all those applicable with an ✓)					**Reason the job was changed** Please complete this section by making an ✓ in the space indicated, where applicable to you		
(Please complete in print)	(Please complete in print)	Sitting all day	Light to medium tasks	Medium to heavy tasks	Require fine handfunction	Require repetitiv tasks	**Changed because of RA** 1	**Changed for non-RA related reasons** 2	**Currently employed in the same job** 3
1		1	2	3	4	5			

If you are still employed in the same job/post since being diagnosed with RA, move on directly to no. 17.

Job's since diagnosed with RA (In order)	**Years employed in each job**	**Description of job activities** (Please mark all those applicable with a ✓)					**Reason the job was changed** Please complete this section by making an ✓ in the space indicated, where applicable to you		
(Please complete in print)	(Please complete in print)	Sitting all day	Light to medium tasks	Medium to heavy tasks	Require fine handfunction	Require repetitiv tasks	**Changed because of RA** 1	**Changed for non-RA related reasons** 2	**Currently employed in the same job** 3
2									
3									
4									
5									
6									
7									
8									
9									
10		1	2	3	4	5			

C3☐ C4☐☐☐☐☐☐☐☐☐☐ C5☐☐☐☐☐ C6☐☐☐
1 2 3 4 5 6 7 8 9 10 1 2 3 4 5 1 2 3

* see code list

University of Otago

17. What has changed about your job since you have been diagnosed with rheumatoid arthritis?
(Please mark one response under each with a ✓, where applicable to you)

	Increased1	Remained the Same2	Decreased3
• Sedentary Work A			
• Light Work B			
• Heavy Work C			
• Fine Hand Tasks D			
• Time to Complete Work Tasks E			
• Functional Adaptations F			
• Salary G			
• Work Responsibility H			
• Work Autonomy I			
• Sick leave J			

C7 A☐B☐C☐D☐E☐F☐G☐H☐I☐J☐

18. How often do you visit your doctor as a result of your RA? **(Please mark one with a ✓)**

Weekly	Monthly	1-3 Monthly	3-6 Monthly	6-9 Monthly	9-12 Monthly	1-5 Yearly
1	2	3	4	5	6	7

C8☐

19. How regularly do you take sick leave as a result of your RA? **(Please mark one with a ✓)**

Never	Weekly	Monthly	1-3 Monthly	3-6 Monthly	6-9 Monthly	9-12 Monthly
1	2	3	4	5	6	7

C9☐

20. How long do you usually take sick leave as a result of your RA? **(Please mark one with a ✓)**

Not Applicable	1-3 days	3-5 days	5-7 days	1-2 weeks	2-3 weeks	3-4 weeks	1-3 months	3 months or longer
1	2	3	4	5	6	7	8	9

C10☐

21. Are you on any disease modifying drugs for your RA? **(Please mark one with a ✓)**

Yes_____1 No_____2 Do not know_____3 C11☐

22. Changes in your work during an acute RA episode. **(Please mark yes or no with a ✓)**

	Yes1	No2
• **Are there any adaptations to your work during an acute episode?** A		
• **Are your work affected in terms of neatness during an acute episode?** B		
• **Are your work affected in terms of accuracy during an acute episode?** C		
• **Are your work affected in terms of volume during an acute episode?** D		

C12 A☐B☐C☐D☐

23. Which actions in terms of your work do you take when you recognize the early symptoms of an acute episode?

_____

_____

_____

_____

_____

C13☐

University of Cape Town

* see code list

24. Please rate the importance of your work on a scale form 1 to 10 by using a ✓, where 1 represents not important at all and 10 represents very important.

1_____10 C14☐

not important at all **very important**

25. Work Support **(Please mark yes, no or not applicable (NA) with a ✓)**

	Yes1	No2	Uncertain3	NA4
• Does your employer know that you have been diagnosed with rheumatoid arthritis? A				
• Does your direct supervisor know that you have been diagnosed with rheumatoid arthritis? B				
• Does your co-workers know that you have been diagnosed with rheumatoid arthritis? C				
• Does you feel that you receive enough support from your employer? D				
• Does you feel that you receive enough support from your direct supervisor? E				
• Does you feel that you receive enough support from your co-workers? F				
• Does you think that your employer understands what it means to be diagnosed with rheumatoid arthritis? G				
• Does you think that your direct supervisor understands what it means to be diagnosed with rheumatoid arthritis? H				
• Does you think that your co-workers understand what it means to be diagnosed with rheumatoid arthritis? I				

C15 A☐B☐C☐D☐E☐F☐G☐H☐I☐

26. Have you obtained any other qualifications since you have been diagnosed with rheumatoid arthritis? **(Please choose one, using a ✓ to complete)**

Yes1_____ **No2**_____ C16☐

27. If yes, what qualifications have you obtained?* **(Please complete in print)**

_____C17☐

28. If yes, why have you obtained the qualifications?* **(Please complete in print)**

_____C18☐

29. Occupational Autonomy **(Please mark each question with a ✓, where applicable to you)**

	Can be done independently	Can be done by telling a supervisor	Can be done by asking permission	Cannot be done at all
▪ How much freedom do you have in deciding when to come in to work? A	1	2	3	4
▪ How much freedom do you have in deciding when to take a rest break? B	1	2	3	4
▪ How much freedom do you have in deciding when to take time for a doctor's visit? C	1	2	3	4
▪ How much freedom do you have in deciding when to take a week off? D	1	2	3	4

C19 A☐B☐C☐D☐

* see code list

University of Cape Town

30. Your Individual Monthly Income Level

(Please mark one with a ✓, where applicable to you)

R 1 - R 200	____1	R 4501 - R 6000	____8
R 201 - R 500	____2	R 6001 - R 8000	____9
R 501 - R 1000	____3	R 8001 - R11000	____10
R 1001 - R 1500	____4	R11001 - R16000	____11
R 1501 - R 2500	____5	R16001 - R30000	____12
R 2501 - R 3500	____6	R30001 or more	____13
R 3501 - R 4500	____7		

C20☐

31. Demands of the Occupation

(Please mark each question with a ✓, where applicable to you)

	Never	Almost Never	Sometimes	Almost Always	Always
▪ How often do you have to handle conflicting work demands A	1	2	3	4	5
▪ How often is there insufficient time to complete tasks at work? B	1	2	3	4	5
▪ How often is there too much work? C	1	2	3	4	5
Physical Workload					
• How often do you do heavy to very heavy lifting? D	1	2	3	4	5
• How often do you have to do physical heavy to very heavy work? E	1	2	3	4	5
• How often do medium to light lifting? F	1	2	3	4	5
• How often do you do physical medium to light work? G	1	2	3	4	5
• How often do you do repeated bending and stooping? H	1	2	3	4	5
• How often do you do light, sedentary work? I	1	2	3	4	5
• How often do you sit at work all day? J	1	2	3	4	5
• How often do you do work requiring fine hand movements? K	1	2	3	4	5
• How satisfied are you with the quality of your work? L	1	2	3	4	5
• How satisfied are you with the type of work that you do? M	1	2	3	4	5

C21 A☐B☐C☐D☐E☐F☐G☐H☐I☐J☐K☐L☐M☐

University of Cape Town

* see code list

I require 6 people for an interview. They will be randomly selected from the individuals, participating in this study, that volunteers.
If you are willing to be interviewed for an hour in order to provide more in depth information in terms of what assisted you to maintain your employment status, please write your telephone number in the space below.

Telephone number _____

Thank you for completing the questionnaire.

Ancil Prinsloo
Occupational Therapist
Tel. No.: (021) 938 9291

University of Cape Town

* see code list

Letter of Consent
Rheumatoid Arthritis Questionnaire

Hereby I, _____

(Name and Surname)

Acknowledge that I volunteer to participate in the Rheumatoid Arthritis Research Study.

The goal of the study has been explained to me and I understand that all information would be confidential.

Signature _____

(Participant)

Signature _____

(Researcher)

University of Cape Town

Letter of Consent
Rheumatoid Arthritis Interview

Hereby I, _____

(Name & Surname)

Acknowledge that I volunteer to participate in the Rheumatoid Arthritis Interview.

The goal of the study has been explained to me and I understand that all information would be confidential.

Signature _____

(Participant)

Signature _____

(Researcher)

University of Cape Town

Codes

3. **Date of Birth**

People between 18 and 60 years would be included in the study. Age group would be classified in terms of Eriksons Developmental Stages as adapted by Newman and Newman.

- Later Adolescence (18-22 years) 1
- Early Adulthood (22-34 years) 2
- Middle Adulthood (34-60 years) 3

A3☐

6. **Education Level - Highest** grade passed

Classified in terms of Grade 1 to 12 or Sub A & B to Grade 10, thus 12 categories. Codes thus from 1 to 12.

A6☐

6. **Education Level - Tertiary** Education

Classified as:		
	None	0
	Diploma	1
	Bachelors Degree	2
	Masters Degree	3
	Doctorate	4

A7☐

7. **Children** - Ages

Classified in terms of developmental stage as adapted by Newman and Newman. The amount of children in each group will be written in each block.

- Infancy (birth to 2 years) 1
- Toddlerhood (2 to 4 years) 2
- Early school age (4 to 6 years) 3
- Middle school age (6 to 12 years) 4
- Early adolescence (12 to 18 years) 5
- Later adolescence (18 to 22 years) 6
- Early adulthood (22 to 34 years) 7
- Middle adulthood (34 to 60 years) 8

A9☐☐☐☐☐☐☐☐
1 2 3 4 5 6 7 8

University of Cape Town

11. **Date of onset of Rheumatoid Arthritis**
Classified in terms of groups:

- 1 day to 1 year 1
- 1 year, 1 day to 3 years 2
- 3 years, 1 day to 5 years 3
- 5 years, 1 day to 10 years 4
- 10 years, 1 day to 15 years 5
- 15 years, 1 day to 2o years 6
- 20 years, 1 day to 25 years 7
- 25 years, 1 day to 30 years 8
- more than 30 years 9

A14☐

13. **Stanford Health Assessment Questionnaire** - Functional Ability Measure
The HAQ functional disability questionnaire asks 3 questions in each of 8 areas of activities of daily living (ADL). For each area a score of 0 = no difficulty, 1 = some difficulty, 2 = much difficulty or with assistance, and 3 = unable to perform. Any activity that requires assistance from another individual or requires the use of an assistive device receives a score of 2. The highest score for each of the 8 areas is summed (range = 0-28) and divided by 8 to yield, on a continuous scale, a 0-3 functional disability index (FDI), where 0 stands for no disability and 3 for complete dependence on others. The FDI index is coded as follows:

0 - 1,0 1
1,1 - 2,0 2
2.1 - 3,0 3

B1☐

15. **Current Occupation** - Type
This will be coded in 9 different categories as according to the South African Employment Equity Act 55, 1998. This is also used by the Department of Labour as a guideline in preparing an Employment Equity Plan. The complete guideline to occupational categories may be obtained from Statistics SA.

- Legislators, Senior Officials and Managers 1
- Professionals 2
- Technicians and Associate Professionals 3
- Clerks 4
- Service and Sales Workers 5
- Skilled Agricultural and Fishery Workers 6
- Craft and Related Trades 7
- Plant and Machine Operators and Assemblers 8
- Elementary Occupations 9

C1☐

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16. **Occupational History**

- This will be coded in terms of the amount of jobs that the person had since being diagnosed with RA, e.g. 1 to 10.

C3☐

- The years employed in each job will be coded in terms of the amount of years in each job.

C4☐☐☐☐☐☐☐☐☐☐
1 2 3 4 5 6 7 8 9 10

- The description of the job activities will be coded in terms of the total amount of times that the person did work sitting still, did light to medium work, did medium to heavy work, did work requiring fine handfunction and did work requiring repetition.

C5☐☐☐☐☐
1 2 3 4 5

- The reason the job was stopped will be coded in the amount of times that the job was changed or stopped due to RA related reasons or not or whether they are still employed in the same job.

C6☐☐☐

23. Actions taken when early symptoms were recognized will be coded in terms of responses obtained, e.g. "go to the docter"1, "take medication"2, etc.

C13☐

27. **Further qualifications**

Classified as:	Diploma	1
	Bachelors Degree	2
	Masters Degree	3
	Doctorate	4

C17☐

28. The reason the further qualifications were obtained will be coded in terms of the responses obtained, e.g. "to earn a larger income"1,, "to do lighter work"2, etc.

C18☐

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Translation of interview

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"I think it is actually the medication. I think that if I did not have the medication I would not have been able to get up out of bed in the mornings. I would have had a lot of trouble moving around at work and getting in and out of the car. So I must really say that the medication keep me going. You know, I am not crazy about the use of medication, like most other people, but what can one do. You know, I do not have a choice. So it goes on."

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"And if you can go on a diet, go on a diet, because in the year 1999 I went on a raw diet where I had to give up a lot of things and I found out that in the six months that I did it, there was a lot of relief and I feel that people can do it. You can go on a diet to help yourself, because through that you can feel in your body that you are a conqueror - the conqueror of your body."

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"If there are exercises that needs to be done, then you must do the exercises, because exercises, I believe helps. Yes, exercise helps a lot. I got up every morning at five o' clock and did the exercises every day. Five o' clock in the afternoons I did the exercises again and I found out that the body, as soon as I do the exercises, I feel better and better and better."

"...do the exercises and do something for myself. So I believe in future, even if I am 70 years old, I would still be able to do for myself. I would still be able to do things for myself. And I feel that patients at the hospitals – they must – they mustn't just take medicine, they must do exercise. They must do exercise, they must do exercise for themselves."

"Now often a person sits in meetings, at a meeting you cannot move around freely. So I have learnt at a meeting with my left knee that gives me so much trouble. I always sits with my leg so that it has space, I can extend it en bend it under the table, without anybody really seeing what I am doing. So I move it as much as I can think about it or can remember and it actually works for me."

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"...I think to be able to have a life. You know to have the ability to survive. Also be able to strive for things, also makes one want to live, just the fact to live, and be able to earn money makes me want to carry on."

"Yes, I, a person needs to keep the pot boiling, so you have to get up."

"Made tea and washed cups and always, ... and whatever they asked me to help, when they had meetings, then I helped. The first time they were careful to ask me, because they were not so sure whether I would be able to do it. When they found out that I am eager to do it, they even helped me more. They always made me part of work. They never forced me to do something when I did not feel well. They always just said come and help. If you are not able to them we understand. But I always said yes, and they also contributed by telling me I may go if I had to be some place. You can be back at such a time and if you cannot make it you can stay or go home. My direct supervisor gave me a lot of support. They always said that I could work in someone else's place and if I cannot, to leave it. But I always said yes and they always helped me. And they were willing to make special considerations for me so that I could help them."

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"What helped me to work is that a lot of us are friends, good friends. The encouragement and love, the attitude towards each other at work also helps. It also gives me a physical thing and what it also is when we work together as a team that at the end of the week you get a bonus. Yes, you work together for a target and you, the four teams work together for a bonus and because you share the bonus between the four, then you also see what you have achieved. So physical you are able to think and do all these things with your hands and you can work."

"They must understand, know, because it is not such a big problem. Yesterday I had to go for training up here for something. This was the first course in which I had to do a little bit of voice assessment, but if it is the first time that I go to a place and I know it is not going to be accessible – the manageress of another area, we all work well together, said no, one of her, Colleen, one of her girls would take me the first time, so now we know there are two steps,

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where I had to park. The lift, no I could not use the lift because the knobs are too high. So, you understand, I would not have been able to cope the first time. So, and they are, enjoy it to do something. Now you tell me, see I have, some of the street security carried me up the steps into the building before, so if she for example could not take me, it would not have prevented from going. My stresslevel would have been a bit higher, because there is that unknown factor, luckily there was security and so on, and he carried me up in the end. Females can not carry me; I am a dead weight. So I would still have done it, but it only made it easier. But it would definitely not have stopped me, because to get there... Yes, it is better if you have support and it makes things easier for you. It helps."

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" I do not see myself much different from other people, and my colleagues, I am also part of them. I always become annoyed with them, because when they discuss things like going out to eat and such, they forget that the places are not accessible. Again it only shows you that they at the end of the day do not realize the difference, because you do the same things that they are doing. You do it, and they do not see that you are doing things different than they are doing."

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"They are glad to see me in the mornings. They appreciate – and the appreciation because they know I have a problem. It is so nice when they say thank you antie, today the tea was delicious. If I stay away one day, they say anti, why did you stay away, you know nobody else makes the tea as tasty. And that is what makes me feel so happy. This is what is so nice for me."

"I think just to give my best in my work. You know it is nice if you know you do your best, people want you because you do your best and because you are there."

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"It is important that people with arthritis also takes responsibility. If they can say, okay, this is my problem, I want low, you know the height of cupboards they want, then, would it be possible to do this for me, or whatever. So they need to disclose, it is important that they also disclose to management. It doesn't help if you sit and say nothing. Every, if you take two people with arthritis they are going to differ widely. I always say that it is important that the person wit the disability, you can do numerous assessments, it helps in the end, but the candidate is the best person, without making it very complex, who can say how and what makes him comfortable, so that they can control the work that they must do."

I have, I personally have not ever encountered people who acts strange towards me. I also think that you as person, who is different, your disposition determine how other people would act, because they can also be negative. I think the biggest responsibility lies with the person with the disease to make the difference and to tell people. I always tell people if I see that they wonder that I have arthritis or whatever and then they know, then it doesn't worry them anymore. So your colleagues, and management, it is important that they know and also give their support."

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"So the type of work that I do, I sit most of the day anyway, so except for my hands which I use on the computer and to write, and luckily it doesn't seem that arthritis affects the brain, is seems to still work well."

"Yes, I think if I had to work with a pick and shovel, I would not have enjoyed my work very much."

"I started my own company four years ago, and the last thing I thought was that I cannot start my company, because I have arthritis. I really did not think about it, but there are times when you do not feel well, when the thing flare. I am luckily in the position that if I think that this isn't very nice for me anymore, then I go home, then I go and sleep or lie on my bed or whatever."

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"I have the freedom of movement, yes and that was one of the, not because of the disease, one of the reasons why I left the other company where I had a senior position over seven, eight hundred people, where you do not, you know, have the freedom as when you have a small company which belongs to yourself. So there you are always under constant supervision."

"...I want to tell you that if I am in the situation where I cannot move around so easily anymore to go to work, I can always work from home."

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" So physically I think my work environment needs to be accessible and I have to cope where I work. I would not apply for a job where I know I would not cope, for example if it is an advertisement and I do not know the place, I would first phone and find out what is their accessibility like. It is senseless for me to go through everything, and at the end of the day I cannot even enter the building, so yes the first thing is that my place of work needs to be accessible, in terms of lifts and ramps etceteras. My current is accessible. Parking in the building is important, especially in the city."

"I have never stayed away from work. I believed that if I stay away from work today, I would stay away tomorrow and the day after tomorrow, and later I would tell the doctor to board me. I did not want it. I did not want that. I wanted to continue, I wanted to prove to myself and I wanted to show the people outside that you can still work."

"Another strategy I would say is to stay abreast of things, what is happening in the job market, so that I can stay part of it..."

"Yes, but I said about the things at home, ambitious and to stay on top of everything, know what is happening. Even now I would scan the newspapers and just always be aware of what I am doing, how and where do I fit, what is available and for what am I marketable."

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"...but I, I think I am actually a career type of person. I think that even if I did not have the disease, I do not like housework, fullstop. I also cannot do the thins as you have to bend and such, but even if I were able to do it, it is not, I prefer a pretty house and I would tell others were to put things. Housework to me has no worth, so I think I am just a career type person. Probably ambitious. I have always wanted a career, and that is why I went to study at the age of 28, I went to study as I realized that if there really is going to be changes made in the plight of the disabled I need a career behind my back. Also just to open up worlds for me."

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"Naturally I have a very nice job, the type of thins that we do is not boring. We plan each day to do this and that and nine out of ten is doesn't work out, thins happen and it is part of the fun. Yes, I think a person must, if you don't have it, it would be boring, while a person, sometimes when you have the small crises, then you ask yourself whether you are really still in the mood for this. ZI think it is part of it, how, a person needs it."

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"I would say my faith. I trust the Lord, because my disease is the Lords disease and if I pray, I stay in prayer on my knees, I get to the point where you want to make the Lord part of your life and then He would help you further on with your disease. What I can say is that your faith has to be strong. You have to believe and if your faith is strong than He helps you through times of need and your disease and everything. So, for me it is basically that you have to be a strong person in all the things that you do and according to me, if you take the Lord into your life, you become a strong person and he helps you through things."

"He prayed for me twice and anointed me once and said that I must believe that God would heal me. If I do not believe and do not ask, I would not get any better., and I believe strongly that what I achieved was through the Lord. God gave me the strength and support, because I believed and asked. And I believe that the Lord would help me to stay employed until I am 65 years old."

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"But as I said, hope and those, has always provided me with the strength to stay employed. So for me it is the most important."

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"Motivation. I have put in everything that I had to, as I knew that if I did not try, them I would not achieve. I listened to the doctor, and the doctor asked, told me I have to, he thinks I should be boarded, and I said no, and I just went home and tried myself."

"Your question that you asked, what helps me to stay employed even though I have the disease, is my drive. Maybe it is part of my personality. Yes or my internal locus of control..."

"I could communicate easily, I, when I had arthritis was always uncommunicative. I was number one, I was ashamed of my hands. I had problems with grasping. I started with the salads, and suddenly I had all the motivation. I could serve people and I wasn't scared that I am going to drop things as in the past. I really enjoyed it."

"I could teach people to eat healthily, because there was nothing, no unhealthy foods included. It was only salads that they enjoyed. I did it on a Monday, on a Monday and Friday. I then changed it, I found out that on Mondays the people bring their own food, from Sunday, so I said then Tuesday and Friday. And because I made money, and because the people could eat health food, I made money at the same time, and it made me feel good. I made money and taught other people how to eat healthily."

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"The people in the community, and the people that know me, the people at church. Even now, three weeks ago I baked 20 cakes for the church. I baked 20 cakes and I enjoyed it, because I knew that they knew Sarah has a problem. She has a problem standing with her knees, as they swell a lot, but it was such a thrill to see how the people sell my cakes. How they buy it, it was an encouragement to know I could do something for the community."

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There are a few lovely young people here and I would want them to have a good life and to drive around in big Mercedes', whatever, I would enjoy it if they achieve something in life. I also feel a responsibility towards them. A lot of them came with me from my previous job. About half of them. There is a few new ones, it is now nearly five years, but I, we are a small family and we are very happy."

"You know, maybe I am being too philosophical, but I think when you get to the age of fifty, then, I think I got a lot out of life and it is now my turn to give a little bit back."

"Yes, to give back is maybe the best thing to do. If you are in the position to do so, why not? It makes a person feel good."

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"It is, there is still pain. I wouldn't say there is no pain, there is pain, but you mustn't lie down because there is pain. If I say lie down, I mean that you mustn't be bedbound. You can still go and rest, you can take a pain pill and go and lie down, and when you feel that you can get up and do something, do something. Peel potatoes, don't tell yourself...don't tell yourself that you are not able to peel potatoes. You can peel potatoes. You can do it if only you want to. Then you would be able to. That's all, that's all that you must do, only you can do it."

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"I have never considered the disease as a reason not to work. It was never, from childhood, so I do not know whether it is part of my genes or whatever, but even at school, I attend primary school in hospital, but I still completed all my standards. In high school I went to a normal school and the children carried me up and down. You know I, I refused to go to a special school, and after matric I had the passion to work."

"I have a very positive attitude to life, so nothing, I do not allow anything to subdue me. I always say, my mind rules my body, and how I through every, because I do get setbacks."

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"I don't think I would have achieved, what I wanted to achieve, and where I am under way, as I have definitely not yet reached my peak. I have big plans ahead in the next three years."

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"Me and, my husband helps me a lot inside the house and I tell people openly, that I go at the speed of two hundred during the week, but then on weekends I am dog-tired and then use it to rest. So we go out less than we used to and we do more things that..."

"...and my stiffness and that, I am a bit stiff in the mornings, but you know, a person just carries on. I know that it gets better during the day, I take a warm bath, you adapt your lifestyle and by now you know what to do. Once a month a take a day of and sleep the whole day, for twenty four hours. I do it. I do it, and I can't tell you how demanding our work is. We work from four till half past seven as I do standby. I go to bed early, and I think that it is my preservation. My, it is once again one of the things that I do in order to maintain my hectic lifestyle, I sleep a lot. I literally ensure that I get enough rest over weekends. So I adapt my life situation, as it makes it easier for me to work, to be able to do what I am doing, what I have achieved (laughter)."

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"When someone told me that I am going to end up in a wheelchair, I just decided that it won't happen to me. I was also upset because I could not dress myself. I had to wait that they always assist me and it made me more desperate that I must, I must – I was unable to make my own bed. It was also frustrating. I, I could not – I could not handle it that I could not open the tap and with the help of the key an toothbrush – I used all those things – I used it and then one day I found out that I could make my bed, not like all the other people make beds, I folded the sheets over and over and from that day onwards I knew that I was going to make my own bed. I was unable to get in the bath with out my mother or sisters assistance. I struggled to get out. But when I got out – the first time that I got out of the bath, I said that from now on you are not going to help me again. When I realized that I can fasten my bra independently and I can put my shirt on, with a struggle, I knew that Eleanor, from this day forward you are not going to dress antie Sarah again, antie Sarah would dress herself. It also helped me at work. Someone always poured the water into the urn for me. One day I decided that if I take the pail and add little bits of water at a time into the urn, I would be able to lift my arm. Because I always knew that there is someone to pour the water into the urn for me and when there is someone pouring the water into the urn for you and that dresses you, then why do you need to be helped? But if you try yourself, and pour the water yourself, and dress yourself, then you would achieve as I have achieved today. I believe that I have achieved."

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"She always opened the door for me so that I could get in and one day I decided that I have to try myself. I and learnt how to remove the pot from the stove when I remembered that you told me to shift the pot when I cannot lift it and that is what I did and thus started to shift the pots. To shift the pots. And that is what – she also assisted me a lot. She always told me to try and climb the stairs; it was very hard. The house had a lot of stairs. And then she always told me to hold onto the railing and I found that it is true. I climbed the stairs and later I even ran up the stairs."

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"...you must help yourself to carry on. You have to carry on. You have to help yourself. You mustn't sit still, if you sit still you would stay in one place. As they say, a bird that doesn't fly cannot eat. So I decided that I have to fly so that I may eat. And that is what made me what I am today."

"I told myself, this is something which I must do for myself. When I started with the salads I realized that I am industrious. It is a thrill to know that I am able to use my two hands."

"They mustn't wait that other do things for them. If you wait for others do things for you, you would constantly wait for a servant. Then you make others your servant – your family would become your servants, because you do not want to do things for yourself. You think to yourself, why should I do it if I have others doing it for me. It doesn't work like that. Life is – you need to be able to move forwards. You have to be able to lift your foot and place it on the steps, that are how you are going to help yourself. That is all, that is all that I can tell the patients. They have to help themselves, and the people that help them also need to tell them to help themselves, others can not help you. We can place the medication in your hand, but we cannot make you drink it. We can tell you to do exercises, but we cannot make you do them, you have to do them yourself. It all depends on you. I believe that arthritis doesn't kill us. If we help ourselves, we have to help ourselves."

"For me it is important, because I do not have the type of income where I can ask other people do things for me, it is important to me to do my own work. I know I have arthritis in my hands and it keeps me fit. It gives me strength and helps me to carry on with life, that I don't sit back and wait for others to do things for me. I do things for myself, that is why I like it and it is important to do things for myself. I can see that it helps me. Yes it helped me a lot. It is important to me.'

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"I think, I don't know, I think like I mentioned before, like I told the one MD one day, "Even if you have got a flight of stairs and someone has to carry me up their then I'll do it". So I think once again it is just my terrible, probably my faith, my faith in myself that I would be able to do it."

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