

The quality of life of arthritis patients taking biologic arthritis medication

by

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requirements for the degree**

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“It always seems impossible until it's done.”

Nelson Mandela

ABSTRACT

The quality of life of arthritis patients taking biologic arthritis medication

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The goal of the study was to explore and describe how arthritis patients experience the influence of arthritis on their quality of life after commencing with biologic arthritis medication. In order to achieve this goal, a qualitative research approach was adopted in an attempt to understand what the arthritis patients experience their quality of life to be while taking biologic arthritis medication.

To achieve the research goal, the collective case study guided the research. Individual interviews, specifically semi-structured one-to-one interviews, with an interview schedule, were used as method of data collection. The researcher made use of Creswell's (1998) qualitative data analysis process to analyse and to interpret the qualitative data. The trustworthiness of the data interpretation was confirmed through credibility, transferability, dependability and conformability.

An analysis of the literature and transcripts of interviews was undertaken to answer the following research question: What is the influence of biologic arthritis medication on the quality of life of arthritis patients?

The key findings of the study can be stipulated as follows: (1) Several signs and symptoms are associated with an arthritis patient, such as pain and fatigue; (2) Arthritis patients often visit several medical practitioners which can even be over a period of years before an official diagnosis of arthritis can be made; (3) A decrease of arthritis symptoms may be experienced during pregnancy, but increases again after the delivery; (4) Several types of arthritis treatments are available for managing the arthritis condition, ranging from traditional methods, such as anti-inflammatory medication, to biologic medication, such as Adalimumab (Humira); (5) A lack of knowledge pertaining to certain levels of medical doctors causes a mistrust amongst patients towards medical personnel; (6) Quality of life is a variable construct that is influenced by a patient's culture and values; (7) Arthritis affects the patient's ability to perform daily activities, such as washing; (8) Employment is important in making the patient feel human and therefore patients tend to hide their condition or to make adjustments at work, just to keep on working; (9) Biologic medication is seen as a miracle drug, albeit not totally without side effects, as patients are able to do things that were previously impossible; (10) Relationships are important in the life of an arthritis patient to enable coping, whether it be family, friends or the relationship with their medical practitioner; (11) Support provided by patients amongst themselves was also found to be important in

order to facilitate coping with the disease; (12) Arthritis patients are encouraged to participate in physical exercise as it increases joint mobility; and lastly, (13) Biologic medication is quite expensive and patients are reliant on medical aids for funding of the treatment.

In strengthening the role of social workers to assist arthritis patients to manage their disease better, the following recommendations are offered: (1) An awareness campaign facilitated by social workers, with experience in arthritic conditions, in collaboration with other health care workers in order to create awareness at different levels of society; (2) Social workers working in the field of arthritis should continuously strive toward improving the quality of life of arthritis patients they work with by setting up support networks and facilitating programmes that aim toward empowering those living with arthritis; (3) Social workers are encouraged to partner with rheumatology practices during which social workers are able to support newly diagnosed patients from the point of diagnosis. Social work support services could be in the form of counselling, or group support programmes; (4) A “fit for life” programme is recommended that is facilitated by social workers working with patients suffering from arthritic conditions with the goal of providing a safe environment where patients can be encouraged to be physically active. The aim will be to improve the patients’ quality of life experience, but also to create a safe environment for patients to support each other. (5) It is recommended that social workers working in the field of arthritis set up a database of patients that have proved to be involved in support programmes and shared their desire to provide guidance to newly diagnosed arthritis patients. The aim is then to partner a newly diagnosed arthritis patient with a more “senior” patient with a similar diagnosis and characteristics in order to establish a buddy support system. A context can then be created where the “senior” patient can share surviving techniques to the newly diagnosed patient but also provide assistance, for example picking up the children from school. Social workers are encouraged to then work closely with these buddies in order to provide further therapeutic support should it be required (6) Social workers working in the field of arthritis should always seek to advocate for arthritis patients when presenting at conferences and workshops (7) Investigate current, refine, or develop, policy related to the management and treatment of arthritis. Such policy should address aspects, including but not limited to, the employment conditions of people living with arthritis and securing the employment of people once diagnosed with the disease, medical aid and the requirements patients need to comply with in order to receive the full benefit provided to patients by medical aids, and thirdly, aspects related to the pricing (i.e., affordability) of disability insurance (8) The design and implementation of a continuous professional development programme is recommended to enable all health care workers to be continuously up to date with the latest developments related to arthritis research and management, in order to ensure that first line practitioners, for example physio-therapists and general practitioners, be equipped with the necessary skills to identify possible arthritis signs and symptoms which will ensure that patients are referred to specialist intervention as soon as possible. The sooner the patient receives the adequate level of care, the less joint deterioration may be sustained, and the higher the possibility to enjoy a good quality of life

Future research could focus on initiating a research study that covers a more extensive geographical area, which is also more representative of the ethnic diversity in South Africa. Such a study could also cover more of the biologic medication used in the treatment of arthritis in order to reach a more holistic picture.

Keywords:

Arthritis

Quality of life

Social Workers

Biologic arthritis medication

Arthritis treatment

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Chapter 1

General introduction

1.1 INTRODUCTION AND CONTEXTUALISATION

Over the past number of years more and more people have been diagnosed with a condition that is silent, not always visible to the eyes of an outsider, but which destroys, disrupts and affects both the life of the patient and those around them. The condition is called arthritis. Society is often of the opinion that it is an “old person’s” disease. The term arthritis originates from the Greek word “Arthro” which means joint and “Itis”, which means inflammation (Arthritis, [sa]). In ‘What is arthritis’ [sa], the author refers to arthritis as a group of conditions that is responsible for causing pain, stiffness and swelling in the joints. Arthritis can also cause serious, life-threatening complications and can even affect parts of the body that may include the muscles, bone and internal organs.

The first signs of arthritis in humans, were noted as far back as 4500BC (Here are some ..., [sa]). Arthritis is thus a condition which has been experienced by people for centuries. *Mosby’s Dictionary of Medicine, Nursing and Health Professions* (2006:143) defines arthritis as any inflammatory condition of the joints; characterised by pain, swelling, heat, redness, and limitation of movement.

Examples of different types of arthritis include: rheumatoid arthritis and ankylosing spondylitis. Ankylosing spondylitis is a systemic chronic inflammatory disease that primarily affects the axial skeleton (Ovayolu, Ovayolu and Karadag, 2011:655). According to *Mosby’s Dictionary of Medicine, Nursing and Health Professions* (2006:109), ankylosing spondylitis, is a chronic inflammatory disease. The exact cause of the disease, however, remains unknown but it has been determined that the disease affects the spine first and then progresses to the neighbouring joints, for example: hips and knees. The common process of the disease is that the affected joints eventually fuse (ankylosing). Rheumatoid arthritis is a chronic progressive inflammatory disease that often effects physical and psychological well-being and is accompanied by pain (Grønning, Rodevand & Steinsbekk, 2010:1317; Nas, Sarac, Gur, Cevik, Altay, Erdal, Ersoy, Kaya, Tekeoglu, Ugur, Durmus, Ardicoglu, Senel,

Baysal, Kamanli, Karatay, Yildirim & Ozgocmen, 2011:95). *Mosby's Dictionary of Medicine, Nursing and Health Professions* (2006:1634) defines rheumatoid arthritis as a chronic, auto-immune, inflammatory disease that causes swelling and, eventually, deformation of the joints.

A patient is a person that is receiving, or is registered to receive, medical care (Oxford dictionaries..., [sa]). From the patients' perspective, arthritis influences their lives in different ways. This includes: continuous pain, difficulty in completing physical activities, fatigue and depression. The extent, in which these factors influence a patient's life, is determined by their health belief and underlying psychological problems (Pollard, Choy & Scott, 2005:43). Due to the activity of the disease, patients may suffer the loss of employment which has an impact on their quality of life. Patients thus find it difficult to participate in social activities and are therefore unable to fulfil various kinds of social roles (Lütze & Archenholtz, 2007:64).

Patient experience can be defined as "...the knowledge and skill that you have gained through doing something for a period of time" (*Oxford Advanced Learner's Dictionary*, 2006:513).

Garip, Eser and Bodur (2011:769) defines quality of life as the satisfaction that is experienced from life, the happiness, and the way people view their situation within their own cultural and value system. Quality of life includes physical, social, emotional, cognitive and spiritual components which thus make it a positive, multi-dimensional and integrative construct. The patients' meaning of quality of life is influenced by individual and social influences, as well as the context they may find themselves in (Gill, Hammond, Reifsteck, Jehu, Williams, Adams, Lange, Becofsky, Rodriguez & Shang, 2013:32).

As arthritis influences the daily functioning of persons, the burden of this disease is referred to as Disability Adjusted Life Years (DALY) (Health statistics, [sa]), which is defined as:

DALYs for a disease or health condition are calculated as the sum of the years of life lost (YLL) due to premature mortality in the population and the years lost due to disability (YLD) for incident cases of the health condition.

Lundkvist, Kastäng and Kobelt (2008:50) see DALY as one year of healthy life lost. During a study, Lundkvist et al. (2008:51) calculated the DALY lost per 100 000 due to rheumatoid arthritis (a type of arthritis) in the Russian federation as 144. In South Africa the DALY lost per 100 000 was found to be 48. An explanation for the huge discrepancy in South African' statistics versus other countries are partly due to difficulties in finding accurate data (Lundkvist et al., 2008:51). The reality however remains that arthritis is a burden on patients and their families and influences their quality of life.

Every patient's definition of quality of life will differ from another and, according to Gill et al. (2013:30) it differs in such a way that cannot always be ascertained by survey measures. A qualitative study can thus provide a vehicle to explore and describe these sensitive issues of daily living.

Although there is no cure for most types of arthritis, different treatment approaches exist and this can include medication, life style changes, counselling, surgery and exercise (Matthee, 2008:11). Chronic medication plays an integral part in an arthritis patient's day to day programme. One of the medical treatment approaches is the new modern biologic medication. Pucino, Harbus and Goldbach-Mandy (2006:16) report that biologic medication has modernised the treatment of, amongst others, rheumatoid arthritis as it reduces both the signs and symptoms of arthritis and reduces the radiographic deterioration of the joints. Access to the more expensive biologic medication is, however, seldom authorised by medical aid funds due to its high cost. Nurmohamed and Dijkmans (2005:661) state the following regarding the United States: "The costs of traditional disease modifying anti-rheumatic drugs are up to \$US3000 per year, whereas for the biologics the yearly drug costs range between \$US16000 and \$US20000". These biologic medicines can vastly improve the daily functioning of patients as well as their quality of life (Nurmohamed & Dijkmans, 2005:661).

In the light of the above, the researcher deemed it appropriate to explore and describe the change in an arthritis patient's quality of life while taking biologic arthritis medication. From the data, recommendations are offered in order to enrich and improve a patient's real life experience by guiding the rheumatologist to know their

patients better, but also to provide data from which support programmes for arthritis patients on biologic medication can be developed.

1.2 RATIONALE AND PROBLEM STATEMENT

The researcher identified that most people lack knowledge regarding the influence of arthritis on a patient's functioning and the gap this leaves in the research environment. Arthritis is a chronic illness that affects not only old people, as is commonly believed, but people of all ages worldwide. It is a debilitating disease affecting the daily functioning of persons living with it. Patients find it difficult to participate in activities and are unable to fulfil various kinds of social roles (Lütze & Archenholtz, 2007:64). Their quality of life is thus adversely affected.

The researcher developed the understanding that pharmaceutical companies market their product based on quantitative medical research around the effectiveness of the drug in terms of combatting the disease process. There is very little focus on the patients' experience regarding their quality of life while taking chronic arthritis medication. During his literature review, the researcher came across quantitative research evaluating the impact of the disease on the patient's quality of life but very little qualitative research addressing the patient's experience surrounding the influence of the medication on their quality of life (Antoni, Krueger, De Vlam, Beutler, Guzzo, Zhou, Dooley & Kavanaugh, 2005:1150-1157; Pollard et al., 2005:43-52).

The following questions arise: how does biologic medication affect arthritis patients' view of life? What can further be done to make life easier for a patient living with arthritis? The researcher is of the opinion that, once research has been conducted on the patients' experiences of quality of life on how the biologic medication is impacting on their quality of life, themes can be identified reflecting how patients are experiencing this disease which can then be used to design social work support programmes. These social work support programmes/services could assist in addressing all spheres of the patients functioning and not just the medical aspect thereof. The research can further assist rheumatologists and professionals, such as social workers working in the field, to have a better understanding of the patient they are treating.

This study attempted to answer the following research question: “What is the influence of biologic arthritis medication on the quality of life of arthritis patients? “

1.3 THEORETICAL FRAMEWORKS

The researcher used a practice model as well as a meta-theory to guide the study. The meta-theory that was used was the general systems theory from which the practice model, the bio-psychosocial framework¹, was developed.

It is believed that Ludwig von Bertalanffy (1901-1972) is responsible for initiating the systems theory that is used amongst social workers today. Von Bertalanffy, born in Austria, was a theoretical biologist that came to believe that growth and change in organisms came about not only because of a linear cause and effect process, but that interaction between the organisms could also affect change (Friedman & Downey, 2012:372).

The focus of the general systems theory is on the interactions between the different parts with a special emphasis on its solidarity and the importance within the system (Goldenberg & Goldenberg, 2004:508). According to Flamand [sa] the systems theory is the interdisciplinary study of complicated systems with a special interest on how parts relate to one another and to the whole system. Social workers find this beneficial as it provides guidance in identifying, defining and addressing problems within social systems. This is done by identifying how a system functions, what aspects of the system impacts negatively on people and what can lead to positive change within the system.

Engel (1980:535-543) agreed that the general systems theory was the “new” theory for medicine as it became possible for the medical practitioner to not only focus on studying and treating a patient’s organs, but was also able to acknowledge that there are systemic interactions between the different systems, for example the interactions between a cell, molecule, the patient’s family and society (Short, 2006:128).

¹ This study adopts Engel’s (1980:535-543) conceptualisation, namely that the bio-psychosocial theoretical framework is a framework. Hence, this research report will refer to the bio-psychococial framework.

Engel (1980:535-543) challenged the traditional linear cause and effect of medical conditions, by introducing the bio-psycho-social framework, which was a whole new way of looking at health-illness issues at the time. Friedman and Downey (2012:372) report that Engel practiced from the viewpoint that diseases cannot be adequately treated when the professional believes that the disease manifestation is purely due to biophysical causes isolated from social behaviour. The focus therefore was on the patient as a whole (Friedman & Downey, 2012:372). Within the bio-psycho-social framework, a patient's disease process is influenced by biological, psychological and social factors (Somers, Wren & Shelby, 2012:502), which are interlinked, as are the systems and sub-systems in the systems theory.

The bio-psycho-social framework is thus a way of thinking about clinical care, but also a practical clinical guide. The philosophy surrounding the bio-psycho-social framework is to understand how suffering, disease and illness are affected by so many different aspects from society down to the smallest molecule. Practically, it is a way of understanding that in order to make an accurate diagnosis, achieve an appropriate outcome and provide adequate humane care, the patient's personal experiences, should be taken into consideration (Borrell-Carrio, Suchman & Epstein, 2004:576). Faleiros and Machado (2006:432-424) are of the opinion, that by using the bio-psycho-social framework, all aspects that play a role in a patient's quality of life, are being considered. These include a patient's personal attitude and belief system, social factors like education and community influences, as well as family systems for example, family upbringing.

The researcher is of the professional opinion that, traditionally, medical practitioners are taught to diagnose, treat and measure responses. He has however personally experienced that physicians often forget about the effect of family and social support systems on the outcome of a certain treatment. As a social worker, the researcher is of the opinion that it is his professional duty and responsibility to assist physicians by providing them with feedback on the role that psychological and social aspects play within the medical treatment of a disease. With the assistance of the theoretical framework, the researcher was able to focus on the patients' personal experience surrounding the chronic arthritis treatment and the role that it plays in their quality of life. This enabled the researcher during the data interpretation phase to not only

focus on the physiological outcome, but also to consider the impact of a patients' biological, psychological and social systems on their overall quality of life.

More detail will follow in Chapter 2, Paragraph 2.7.

1.4 GOAL AND OBJECTIVES OF THE RESEARCH STUDY

The goal of the study was to explore and describe how arthritis patients experience the influence of arthritis on their quality of life after commencing with biologic arthritis medication.

The **objectives** of the study were as follows:

- To conceptualise and describe arthritis, the treatment options, including the biologic arthritis medication, and the influence of this disease on the quality of life of patients;
- To explore and describe the quality of life as experienced by arthritis patients while taking the biologic arthritis medication;
- To make conclusions and recommendations in order to enhance the field of social work intervention with arthritis patients.

1.5 OVERVIEW OF RESEARCH METHODOLOGY

The research approach utilised in the study was qualitative research. The qualitative research approach was identified for the study in order for the researcher to strive towards understanding how the arthritis patient experiences their quality of life while taking biologic arthritis medication (Ong & Richardson, 2006:369). Bansal and Corley (2011:235) further guided the researcher into using the qualitative research approach as this allows society to change its way of thinking, and start to talk more, about a certain phenomenon and in this case, arthritis.

In order for the researcher to obtain more insight into the experience of arthritis patients on their quality of life, while taking biologic arthritis medication, applied research was considered the most appropriate. Jupp (2008:8) describes that the purpose of applied research is to gain insight into the patient's experience regarding

the quality of life while taking biologic arthritis medication. Based on the research findings, social work support programmes/services could be recommended, which could help to address all spheres of the patient's functioning, for example the medical, social and psychological and not just the medical aspect thereof.

The collective case study was the research design which guided the study. The collective case study was utilised in order to compare cases and concepts amongst different arthritis patients with the view of developing a broader understanding of a particular issue (Crowe, Cresswell, Robertson, Huby, Avery, Sheikh, 2011). The advantage of a case study, according to Fouché and Schurink (2011:320), is that it allows the researcher to engage with a single person or a small number of people who remain busy with their activities. The researcher thus became familiar with the participants' social world and was able to identify patterns in the participants' lives, words and actions in relation to their quality of life while using biologic medication.

Individual interviews, and specifically semi-structured one-to-one interviews, were used as the method of data collection. The interviews were guided by questions contained in an interview schedule (see Appendix C). Eleven interviews of approximately an hour each were held. Hesse-Biber and Leavy (2011:352) report that semi-structured one-to-one interviews are suitable when the interviewer is interested in complexity or process, or when an issue is controversial or personal. The researcher made use of Cresswell's (1998) data analysis spiral when the raw data were analysed (Schurink, Fouché & De Vos, 2011:403). This was done through open coding and a process of thematic analysis.

In order to ensure trustworthiness during the study, the researcher made use of Lincoln and Guba (1999) to address four constructs (Schurink, Fouché & De Vos, 2011:419-421), namely credibility/authenticity, transferability, dependability and conformability.

The population of the present study was drawn from patients, who reside in the Gauteng Province, who all attended a rheumatology practice in Muckleneuk Pretoria and used a chronic biologic medication to manage their arthritis. There were 11

participants, recruited through non-probability sampling, which also represents the point of data saturation that participated in the study.

Several ethical issues were taken into consideration during the research study. Aspects of confidentiality and anonymity were discussed before the start of the interviews. The researcher requested permission, and through signing of the informed consent, the participants provided permission for digital recording of the individual interviews to be made. The informed consent (see Appendix B) further protected the participants from harm as they knew what they were participating in (Hargreaves, 2006:264). Each participant thus had the opportunity beforehand to make an informed decision as to whether they wanted to participate in the study or not (Strydom, 2011a:115).

Before the start of the empirical study, ethical clearance was obtained from the Research Ethics Committee of the Faculty of Humanities at the University of Pretoria (see Appendix A). For a more detailed discussion of the research methodology and ethical considerations applicable to the study, see Chapter 3, section 1.

1.6 LIMITATIONS

The following limitations of this study should be considered while interpreting the research report:

- Only one medical practice was used during the study, and the study is therefore not representative of all rheumatology practices in South Africa.
- Only patients residing in Gauteng were selected, and the study is therefore not representative of all provinces in South Africa.
- Although it was not intended, participants did not reflect the cultural diversity in South Africa.
- Although it was not intended, biologic medication used by participants in the study did not represent all biologic medications that are available in the treatment of arthritis.

1.7 OUTLINE OF THE RESEARCH REPORT

The remainder of the research report is structured as follows:

Chapter 2: Arthritis and quality of life: a social work perspective

An in depth review of the literature on arthritis will cover aspects such as causes, symptoms, treatment and influences on quality of life with a specific focus on biologic medication.

Chapter 3: Research methodology, researching findings and interpretation

The research methodology will be discussed briefly followed by the ethical considerations. The research findings will be presented in the form of a thematic analysis of themes and sub-themes supported with verbatim quotes and substantiated with literature.

Chapter 4: Conclusions and recommendations

This chapter will provide the reader with the key findings emanating from the study, the conclusions and concomitant recommendations.

Chapter 2:

Arthritis and quality of life: a social work perspective

2.1 INTRODUCTION

Over the past number of years more and more people have been diagnosed with a condition that is silent, not always visible to the eyes of an outsider, but destroys, disrupts and affects both the patient's (quality of) life and that of those around them. The condition is called arthritis. The first signs of arthritis in humans were noted as far back as 4500BC (Here are some ..., [sa]).

This chapter will focus on defining the medical condition, arthritis, its causes and the effects on a patient's quality of life. Special focus will be on the more modern arthritis medication available to patients who have shown unsatisfactory improvement on traditional arthritis medication. The chapter ends with a consideration of social work services to patients living with arthritis, as well as the theoretical frameworks that underpin the study.

2.2 GENERAL CAUSES OF ARTHRITIS

Through the years, several factors have been identified that increase the risk for the development of arthritis (Risk factors, [sa]). Arthritis can be caused by infection, degenerative changes, trauma, injury or metabolic disturbances (Diseases..., [sa]). Several viruses can cause arthritis post an infection which is also called post-infectious arthritis. Some of these viruses include: alpha virus, rubella virus, human parvovirus B19, hepatitis B virus, hepatitis B and C viruses and the Epstein-Barr virus (Franssila & Hedman, 2006:1139). An infection during critical periods of human development can lead to permanent and possibly damaging changes in the functioning of the immune system. This together with genetic makeup and other environmental factors may lead to the development of the disease (Edwards & Cooper, 2005:3).

The Centers of Disease Control and Prevention in the United States of America have identified that overweight patients have an increased risk of developing arthritis due to the impact the weight has on the joints. A further risk factor for developing arthritis is occupations where the patient has to do excessive knee bending and squatting. This repetitive motion puts extreme tension on the joint which can later lead to the development of arthritis (Risk factors, [sa]).

Stojanovich and Marisavljevich (2008:209) report that physical and psychological stress can play a part in the development of auto-immune diseases. It is further a two way process. As much as the stress plays a role in the cause of the disease, the disease itself causes a level of stress and anxiety to the patient. The exact mechanism, in which the process occurs, currently remains unknown (Stojanovich & Marisavljevich, 2008:209).

From the above it is evident that there are several opinions regarding the causes related to the development of arthritis.

Arthritis is a complex family of musculoskeletal disorders that consists of more than a 100 different diseases that can affect people of all different races, ages and genders (Understanding..., [sa]). The focus of the study is specifically on a biologic medication designed to manage a certain group of arthritic conditions. In the next section of this chapter, the focus will be on the five types of arthritic conditions and an inflammatory bowel disease which are specifically treated with biologic medication.

2.3 TYPES OF ARTHRITIS

Juvenile idiopathic arthritis is the first type of arthritis that will be discussed.

2.3.1 Juvenile idiopathic arthritis

Juvenile idiopathic arthritis is a type of arthritis that, starts before the patient reaches 16 years of age, lasts longer than six weeks and its exact cause remains unknown (Bell, 2009:17). It is evident that juvenile idiopathic arthritis is not just one disease

but a group of diseases characterised by chronic inflammatory arthritis (Berkun & Padeh, 2010:319). Berkun and Padeh (2010:323) are of the opinion that there are several factors, for example, stressful life episodes and maternal smoking that can contribute to the development of juvenile idiopathic arthritis, but the exact process is yet to be determined. Research has also shown that, even though many patients experience their disease to go into remission before they reach adulthood, others will continue experiencing symptoms even as an adult (Bell, 2009:17).

The industry has referred to juvenile idiopathic arthritis as juvenile rheumatoid arthritis for over 60 years (Bell, 2009:17). Bell (2009:17) reports that, not all scientists accept the term “rheumatoid” in children as it may appear that reference is made to a condition that has the same presentation in both children and adults, which is not the case as arthritis in children covers more than one type of arthritis and rheumatoid arthritis in adults refers to one. Juvenile idiopathic arthritis (JIA) was previously known as juvenile rheumatoid arthritis and refers to arthritis that occurs in children and adolescents under 16 years of age.

The American College of Rheumatology differentiates between five different sub-groups of juvenile idiopathic arthritis (Arthritis in Children, [sa]). Each category has its own clinical signs and symptoms (Ravelli & Martini, 2007:767). These are discussed in the paragraphs that follow.

The first sub-type is that of systemic onset juvenile idiopathic arthritis.

2.3.1.1 Systemic onset juvenile idiopathic arthritis

First symptoms include repeating fevers of 39.4°C or higher and are often accompanied with a salmon-colour rash that appears and disappears (Arthritis in Children, [sa]). Cellucci, Huber, Levin, McGrath, Schanberg, Spiegel, Stinson and Tucker [2009c] call this sub-type of juvenile idiopathic arthritis ‘systemic arthritis’ and reports that the ‘systemic’ refers to the fact that the disease can affect many parts of the body and not just the joints. Systemic onset juvenile idiopathic arthritis may lead to joint and internal organ inflammation but joint swelling may not appear for months or even years after the onset of the fevers (Arthritis in Children, [sa]). Even when the

fevers and other symptoms have disappeared the arthritis may still be present (Arthritis in Children, [sa]). Together with the fevers, the patient may present with a rash of pale pink-red spots on the chest, upper arms, thighs and other parts of the body. The rash may appear and disappear together with the fevers. Patients may further experience the presence of swollen glands and their liver and spleen may become larger than normal (Cellucci et al., 2009c). Cellucci et al. (2009c) report that teenagers with a diagnosis of systemic arthritis may have inflammation around the heart, lungs or bowels and may experience a situation where the immune system starts to destroy the blood cells.

‘Systemic’ refers to a whole system and in systemic arthritis it refers to the whole body. In a patient with a diagnosis of systemic arthritis it indicates that not just the joints but other systems within the body system are affected. Patients often experience episodes of pyrexia (high fevers) that come and go. This fever is often accompanied by a type of pink rash that may appear and disappear like the fevers. Other systems that can be affected include the liver and spleen that may undergo enlargement.

Oligoarthritis is the second sub-type of juvenile idiopathic arthritis.

2.3.1.2 Oligoarthritis

Oligoarthritis is described as a sub-type of juvenile idiopathic arthritis that affects four or less joints during the first six months of disease duration. Oligoarthritis affects mostly the legs and then the ankles (Ravelli & Martini, 2007:767). Oligoarthritis is an asymmetrical arthritis where, for example, one of the knee joints is affected. It is more common amongst females (Ravelli & Martini, 2007:769).

The third sub-type of juvenile idiopathic arthritis is polyarticular juvenile idiopathic arthritis.

2.3.1.3 Polyarticular juvenile idiopathic arthritis

Polyarticular juvenile idiopathic arthritis can begin at any stage and involves more than five joints within the first six months of having the disease (Arthritis in Children, [sa]). There are two types of polyarticular juvenile idiopathic arthritis. In the first type the patient tests positive for rheumatoid factor and in the second the patient tests negative for rheumatoid factor (Cellucci et al., 2009b). Children, who are diagnosed with the condition during their teens, may have the adult form of rheumatoid arthritis at an earlier than normal age (Arthritis in Children, [sa]).

In polyarticular arthritis more than four joints are involved during the initial six months of disease duration. Two types of polyarticular arthritis have been identified; one with and another without rheumatoid factor.

The fourth sub-type of juvenile idiopathic arthritis is psoriatic arthritis.

2.3.1.4 Psoriatic arthritis

Children diagnosed with psoriatic arthritis have both arthritis and a skin condition, called 'psoriasis', or have a family member (parent or sibling) that suffers from psoriasis (Arthritis in Children, [sa]). Psoriasis is a skin disease that consists of a scaly red rash that can usually be found: on the scalp, behind the ears, on the eyelids, elbows, knees, or buttocks or inside the belly button (Cellucci et al., 2009e). Those patients who have both psoriasis and psoriatic arthritis are diagnosed with psoriatic arthritis (Cellucci et al., 2009e). Psoriatic arthritis symptoms can include changes in the patient's nails and widespread swelling of a finger or a toe which are called dactylitis (Arthritis in Children, [sa]).

Psoriasis is a skin condition that is identified by a scaly red rash that is often found: behind a child or adolescent's ears, on their eyelids, elbows, knees, buttocks or inside their belly button. When a child or adolescent experience these symptoms, together with arthritis symptoms in the joints, a diagnosis of psoriatic arthritis is made.

The fifth sub-type of juvenile idiopathic arthritis is enthesitis-related arthritis.

2.3.1.5 Enthesitis-related arthritis

Enthesitis related arthritis often involves a process where the ligaments as well as the spine undergo attachment (Arthritis in Children, [sa]). Joints of the lower extremities, especially the hips, are commonly affected. Approximately 50% of patients diagnosed with enthesitis-related arthritis have four or less joints that are affected during the disease process (Ravelli & Martini, 2007:771). Symptoms may include: joint pain without visible swelling, back pain and stiffness (Arthritis in Children, [sa]).

A diagnosis of enthesitis is made when the ligaments attach to the spine. Other joints that may be affected are the hip joints. The patient may also experience pain in the back together with a degree of stiffness. Complaints may thus include pain in the joints but, during assessment, no visible swelling can be observed.

It does not matter, what type of juvenile idiopathic arthritis is involved, as many children diagnosed with the condition experience some level of pain and many children's ability to participate in physical activities is often affected (Boros & Whitehead, 2010:630). Boros and Whitehead (2010:630) continue to indicate that when children experience long periods of active arthritis; their general growth is affected, their limbs grow to uneven lengths, they suffer joint erosion and they have less physical endurance.

In the next number of paragraphs, the focus will turn to types of inflammatory conditions that are found in adults and treated with biologic medication. The first is disease is psoriasis.

2.3.2 Psoriasis

Mosby's Dictionary of Medicine, Nursing and Health Professions (2006:1551) describes psoriasis as a chronic skin disorder with symptomatic characteristic that include: red patches, covered by thick, dry, silver adherent scales, due to an over

production of epithelial cells. Psoriasis generally appears on the outside of the elbows, knees or scalp, but it can, however, appear on any location. The psoriasis skin is thick, inflamed and well-defined. Some patients experience the affected areas to be itchy, burning and stinging (Psoriasis symptoms...[sa]).

Psoriasis is classified as a chronic condition that is identified by its red patches, with coverings of silver type scales, when there are too many epithelial cells produced by the body. Psoriasis can affect any parts of the body but common areas include elbows, knees and scalp.

Crow (2012:50-51) goes further to say that psoriasis is a chronic, non-contagious disorder of the skin but also differentiates between five sub-categories of psoriasis.

The first sub-type of psoriasis is chronic plaque psoriasis.

2.3.2.1 Chronic plaque psoriasis

Plaque psoriasis is the most common form of psoriasis (Plaque psoriasis, [sa]). The red scaly plaques are found in separate patches and this differs from patient to patient (Crow, 2012:51). These areas can often itch and be very painful. Sometimes the patches may even crack and bleed (Plaque psoriasis, [sa]).

Plaque psoriasis is a type of psoriasis that is identified by its separate patches which often itch and is accompanied with severe pain. These patches can crack and bleed but it has been reported that not one patient with a diagnosis of plaque psoriasis is identical to another.

A second sub-type of psoriasis is that of guttate psoriasis.

2.3.2.2 Guttate psoriasis

A patient with a diagnosis of guttate psoriasis presents with small, red, separate spots on the skin (Guttate Psoriasis, [sa]). Affected areas are often found on the patient's trunk and limbs. (Crow, 2012:51). Incidents of lesions on the scalp, face

and ears have, however, also been reported. In guttate psoriasis, the lesions are less thick than those found in plaque psoriasis but a patient can have both guttate psoriasis and another sub-type at the same time (Guttate Psoriasis, [sa]).

Inverse psoriasis is a third sub-type of psoriasis.

2.3.2.3 Inverse psoriasis

Inverse psoriasis is also known as intertriginous psoriasis and can present at the same time as another type of psoriasis somewhere else on the body (Inverse Psoriasis, [sa]). This type of psoriasis is found in the folds of the skin and can be identified by its red and scale free lesions (Crow, 2012:51). The areas are often subjected to irritation and rubbing, due to its location, and lacks the scale associated with plaque psoriasis due to the moistness of the environment (Inverse Psoriasis, [sa]).

Inverse psoriasis is often covered by folds of skin and symptoms are exacerbated by the moist environment and continuous rubbing of skin. Due to the moistness in these areas of the body the dry scales normally found in plaque psoriasis are not present.

Pustular psoriasis is another sub-type of psoriasis that exists.

2.3.2.4 Pustular psoriasis

Pustular psoriasis is characterised by white blisters surrounded by red skin (Crow, 2012:51). The white blisters are called pustules which are blisters of non-infectious pus (Pustular Psoriasis, [sa]). This can only be found in a specific area or it may cover the whole body (Crow, 2012:51).

Patients with pustular psoriasis are identified by the white blisters covered by red skin. These blisters can be limited to one area of the body or the whole body may be covered with it.

A fifth sub-type of psoriasis that can be found is that of erythrodermic psoriasis.

2.3.2.5 Erythrodermic psoriasis

This is not a common sub-type of psoriasis but it can be very dangerous. Symptoms include severe red inflammation and skin shedding over almost the whole body. Patients have the risk of losing a huge amount of heat through the skin (Crow, 2012:51). This type generally presents in patients whose plaque psoriasis is unstable thus meaning that the psoriatic lesions are not clearly defined (Erythrodermic Psoriasis, [sa]).

The next type of inflammatory condition under discussion is that of psoriatic arthritis.

2.3.3 Psoriatic arthritis

Psoriatic arthritis is an inflammatory rheumatic disease and is associated with the rheumatic disorder psoriasis. No exact explanation exists regarding the cause of psoriatic arthritis (Cantini, Noccoli, Nannini, Kaloudi, Bertoni & Cassara, 2010:300). According to *Mosby's Dictionary of Medicine, Nursing and Health Professions* (2006:1551), psoriatic arthritis is an arthritic condition associated with psoriatic abrasions of the skin and nails particularly between the distal inter-bony joints of the fingers and toes. As per Waldron (2012:35), patients diagnosed with psoriatic arthritis often experience joint destruction and loss of function. Day, Nam, Goodman, Su and Figgie (2012:28) report that not all people diagnosed with psoriasis will eventually be diagnosed with psoriatic arthritis. Only a portion of psoriasis patients will also be diagnosed with psoriatic arthritis.

Psoriatic arthritis is a rheumatic condition that goes along with another disorder called psoriasis. Not all psoriasis patients will also be diagnosed with psoriatic arthritis. Psoriatic arthritis involves joint deterioration as well as abrasion of the skin and nails.

The next type of arthritis to be discussed is a musculoskeletal condition called ankylosing spondylitis.

2.3.4 Ankylosing spondylitis

Ovayolu et al. (2011:655) define ankylosing spondylitis as a systemic chronic inflammatory disease that primarily affects the axial skeleton. Peh [sa] describes that the term ankylosing originates from the Greek word “Ankylos” which means stiffening of a joint and spondylitis from the Greek word “Spondylos” which means vertebra. Patients diagnosed with ankylosing spondylitis often experience a high level of pain which could lead to disability (Kang, Chen & Lin, 2010:1165). Tam, Gu and Yu (2010:399) report that the main source of pain is situated in the spine.

Mosby’s Dictionary of Medicine, Nursing and Health Professions (2006:107) defines ankylosing spondylitis as a chronic inflammatory disease. Where the disease originates remains unclear but it is evident that the disease first affects the spine and surrounding structures and those joints will eventually fuse. In very extreme cases the spine will “bend” forward and this is called a “bamboo spine”. The disease is more common amongst men, especially those younger than 30, and generally runs a course of 20 years. Other joints include: the hip, shoulder, neck, ribs and jaw joints but, as it is a systemic disease, patient’s eyes and heart may also be affected.

Ankylosing spondylitis mainly affects the area where the spine connects to the pelvis, which is called the sacroiliac joints, the hip joints as well as the spine (Ankylosing Spondylitis, [sa]). The area where ligaments, tendons and capsules are attached to bone (enthesis) plays a vital role during the disease when it becomes inflamed (Tam et al., 2010:339). The process is called enthistis and is the main cause of pain and stiffness (Ankylosing spondylitis, [sa]). The inflammation can further lead to transformation of the fibrous ligaments into bone and the joint grows together (Ankylosing Spondylitis, [sa]).

Research has found that HLA-B27 can be a causative factor in ankylosing spondylitis (Tam et al., 2010:399). Tam et al. (2010:403,404) however report that even though almost all ankylosing spondylitis patients have the HLA-B27 gene the exact reason for its involvement in the disease remains speculative.

Ankylosing spondylitis is an arthritic condition that mainly affects the axial skeleton. Genetic involvement has been detected but it is not clear to what extent. Areas often involved are the sacroiliac joints (area where the spine connects to the pelvis), hips and the spine. The disease process involves the stiffening and eventual fusing of the joints involved.

In the section that follows, the focus will be on rheumatoid arthritis.

2.3.5 Rheumatoid arthritis

Schneider, Manabile and Tikly (2008) describe rheumatoid arthritis as a chronic illness that impacts severely on the functional, social and employment aspects of a patient. Rheumatoid arthritis is a chronic progressive inflammatory disease that often effects physical and psychological well-being and is accompanied by pain (Grønning et al., 2010:1317; Nas et al., 2011:95). Rheumatoid arthritis is further a chronic inflammatory disease that can affect different tissues and organs but it generally affects the synovial joint (Williams, 2012:1).

Kangesan (2012:23) defines rheumatoid arthritis as:

... an autoimmune inflammatory arthritis with marked inflammation of the synovial membrane. Lymphocytes, macrophages and CD4+ cells infiltrate the synovium and play a central role in the disease process. Stimulated B cells produce immunoglobulins, including rheumatoid factor (RF), and macrophages produce inflammatory cytokines. These cytokines and immunoglobulins lead to the destruction of the joint. Of particular importance in this inflammatory cascade is tumour necrosis factor alpha (TNF- α), a pro-inflammatory cytokine which is targeted by some of the newer disease-modifying agents.

Rheumatoid arthritis has several characteristics that include: inflammation of the synovial joint, production of several anti-bodies, damage to joint cartilage, deforming of bone and systemic disorders that include: cardiovascular, pulmonary, psychological and skeletal disorders (McInnes & Schett, 2011:2205).

During a study to clarify the classification criteria for rheumatoid arthritis, Aletaha, Neogi, Silman, Funovits, Felson, Bingham, Birnbaum, Burmester, Bykerk, Cohen, Combe, Costenbader, Dougados, Emery, Ferraccioli, Hazes, Hobbs, Huizinga,

Kavanaugh, Kay, Kvien, Laing, Mease, Ménard, Moreland, Naden, Pincus, Smolen, Stanislawska-Biernat, Symmons, Tak, Upchurch, Vencovský, Wolfe and Hawker (2010:2570) found the following criteria appropriate to classify a patient with “definite RA”:

...is based on the confirmed presence of synovitis in at least 1 joint, absence of an alternative diagnosis that better explains the synovitis and achievement of a total score of 6 or greater (of a possible 10) from the individual scores in 4 domains: number and site of involved joints (score range 0-5), serologic abnormality (score range 0-3), elevated acute-phase response (score range 0-1), and symptom duration (2 levels; range 0-1).

The cause of rheumatoid arthritis currently remains unknown (McInnes & Schett, 2011:2205). Rheumatoid arthritis has been reported shortly after an acute viral infection or incidents following immunisation, but despite continuous research, no single organism has been identified as being the main cause of rheumatoid arthritis (Kangesan, 2012:23). It has thus been proposed that rheumatoid arthritis may be an abnormal immune reaction to an infection in a patient that may already be genetically susceptible (Kangesan, 2012:23).

Rheumatoid arthritis is a chronic inflammatory condition which mainly affects the joints' synovial membrane. The disease is characterised by cytokines that cause joint destruction. Currently, the exact cause of rheumatoid arthritis remains unknown.

In the above paragraphs the focus was on several types of inflammatory conditions. In the section that follows, the focus will move to an inflammatory bowel disease called Crohn's disease.

2.3.6 Crohn's disease

There are several types of disease that can be found in a patient's gastrointestinal tract. Two of these diseases are that of ulcerative colitis and Crohn's disease. Crohn's disease, like ulcerative colitis, is a type of inflammatory bowel disease which leads to dysfunction in a patient's gastrointestinal functioning (Ranson & Eri, 2013:64). Peyrin—Biroulet, Loftus (jr), Colombel and Sandborn (2010:141) report

that bowel damage is progressive in nature and patients often suffer impaired function.

Crohn's disease and ulcerative colitis is, however, not the same condition as they affect different parts of the gastrointestinal tract. Ulcerative colitis is only found in the large intestine or colon, whereas Crohn's disease has been identified in all parts of the gastrointestinal tract from the mouth to the anus. Crohn's disease can involve the complete thickness of the bowel wall where ulcerative colitis only involves the inner most lining of the colon. In Crohn's disease, the inflammation of the intestine is not necessarily continuous. Areas of infected intestine may be broken by a healthy area which is called a "skip" phenomenon. In ulcerative colitis this is never found (What is Crohn's..., [sa]).

The Crohn's and Colitis Foundation of America stipulates that the symptoms found in Crohn's disease may include: continuing diarrhoea, rectal bleeding, urgent need to move bowels, abdominal cramps and pain, sensation of incomplete evacuation, constipation, fever, loss of appetite, weight loss, fatigue, night sweats and disruption in the menstrual cycle. In severe cases, patients with Crohn's disease can experience tears (fissures) in the lining of the anus which may lead to pain and bleeding, especially, during bowel movements (What is Crohn's...[sa]).

The Crohn's and Colitis Foundation of America reports that up to 25% of patients suffering from a form of arthritis also may have Crohn's disease or ulcerative colitis (Arthritis, [sa]).

During the disease discussion, a golden thread could be found and that is a negative change to a patient's condition. In the next section the focus will move away from the specific disease to the effect the disease has on patients' quality of life.

2.4 QUALITY OF LIFE

Garip et al. (2011:769) define quality of life as the satisfaction that is experienced from life, the happiness and the way people view their situation within their own cultural and value system. Quality of life refers to physical, social, emotional,

cognitive and spiritual components which thus make it a positive, multi-dimensional and integrative construct. The patient's meaning of quality of life is influenced by individual and social influences as well as the context in which they may find themselves (Gill et al., 2013:32). Pain, disease activity and functional status are some of the factors that can affect a patient's quality of life negatively (Garip et al. 2010).

Patients diagnosed with rheumatoid arthritis describe their lives as being filled with several challenges. The continuous awareness of pain, the inability to complete normal functions and depression influenced by a person's own health belief and underlying psychological problems are but to name just a few (Pollard et al., 2005:43). According to Schneider et al. (2008) patients suffering from rheumatoid arthritis find it difficult to mobilise and complete daily activities, for example washing and dressing. Using public transport is a battle as it seldom accommodates patients' physical shortcomings. Finding and keeping employment is also a challenge. This can lead to social isolation as patients find it difficult to participate in social activities. This is supported by Schoffman, Wilcox and Baruth (2013) who report that arthritis and other rheumatic conditions negatively affect a patient's functioning, both physically and mentally.

As arthritis influences the daily functioning of persons, the burden of this disease is referred to as: Disability Adjusted Life Years (DALY) (Health statistics..., [sa]), which is defined as:

DALYs for a disease or health condition are calculated as the sum of the years of life lost (YLL) due to premature mortality in the population and the years lost due to disability (YLD) for incident cases of the health condition.

Disability adjusted life years are thus calculated as the years lost due to premature death and those years lost because of disability caused by a health condition.

Lundkvist et al. (2008:50) see DALY as one year of healthy life lost. During a study, Lundkvist et al. (2008:51) calculated the DALY lost per 100 000 due to Rheumatoid arthritis (a type of arthritis) in the Russian federation as 144. In South Africa the DALY lost per 100 000 was found to be 48. An explanation for the huge discrepancy

in South African statistics versus other countries is partly due to difficulties in finding accurate data (Lundkvist et al., 2008:51). The reality however remains that arthritis is a burden on patients and their families and influences both parties' quality of life.

Quality of life is seen through the eyes of every patient and it is influenced by their own personal experience, affected by their cultural, and value system. It is thus important to look at quality of life from a patient's social predisposition.

2.4.1 Quality of life and social predisposition

Recent studies have shown that the general population is more active than patients living with arthritis (Hutton, Gamble, Mclean, Butcher, Gow & Dalbeth, 2009:107). During a study to evaluate the obstacles that prevent an arthritis patient to be active Hutton et al. (2009:110) found that there were several psychosocial barriers that prevented an arthritis patient to be active, for example: fatigue, accessibility and cost but the major obstacle was arthritis or other health problems. Studies have shown that physical health problems, discomfort, fatigue and time constraints have greater impact in preventing an arthritis patient from participating in physical activity than environmental barriers, for example, cost and access to facilities (Hutton, Gamble, Mclean, Butcher, Gow & Dalbeth, 2010:518).

Poor health related quality of life is associated with several aspects, including: inability to work, obesity and the inability to participate in physical activity (Furner, Hootman, Helmick, Bolen and Zack, 2011:788). Schoffman et al. (2013) report that obesity impacts negatively on those living with arthritis. Studies have shown that there's a clear link between arthritis and markers that indicate poor general health, for example: co-morbidities, obesity and low levels of formal education (Hutton et al., 2009:113). Gill, Hill, Adams, Broderick, Black & Taylor (2010:174,175) go further to say that just poor health education has a negative effect on a patient managing their own disease. If a patient is not fully informed about his/her disease they cannot manage it appropriately or even report their symptoms correctly.

Shih, Hootman, Strine, Chapman and Brady (2006:1164) reported a link between younger age, lower socioeconomic status, being divorced or separated, having

recurrent pain, being physically inactive and having more limitations or medical co-morbidities in adults with arthritis.

When comparing active versus inactive arthritis patients, Hutton et al. (2010:512) have found that co-morbidities, obesity and psychological barriers in active arthritis patients are less compared to arthritis patients that are less active. In the less active arthritis patient self-confidence was also found to be low. Arthritis patients who are physically active have a better health related quality of life than those patients who don't (Furner et al., 2011:797). It is evident that a patient who perceives their quality of life to be better because they are physically active is associated with the fact that he/she is of the opinion that they have better control over the disease (Knittle, De Gucht, Hurkmans, Vlieland, Peeters, Roday & Maes, 2011:1618).

Every patient's definition of quality of life will differ from one another and according to Gill et al. (2013:30) it differs in such a way that cannot always be picked ascertained by survey measures. A qualitative study can thus hopefully explore and describe these sensitive issues of daily living.

In the paragraphs that follow the different treatment approaches for arthritis will be discussed.

2.5 TREATMENT APPROACHES FOR ARTHRITIS

Currently there is no cure for any form of arthritis (Marks & Allegrante, 2007:9). In Matthee (2008:11) it is reported that by following a positive outlook on life, regular exercise and taking the necessary medication, a patient's quality of life can improve to such an extent that previous tasks which presented to be impossible can be accomplished.

Kangesan (2012:25) describes two main categories of treatment that include control of symptoms and disease modifying anti-rheumatic drugs (DMARDs). When DMARDs are started for the first time, they can be used in conjunction with oral or intramuscular steroids in order to resolve the symptoms quicker. Even intra-articular

steroid injections directly into the affected joint can be performed in order to deal with an acute flare (Kangesan, 2012:25).

Chronic medication plays an integral part of an arthritis patient's day to day programme. There are two main categories of disease modifying anti-rheumatic drugs. They are traditional disease modifying anti-rheumatic drugs and then there are newer biologic agents (Kangesan, 2012:25). Pucino et al. (2006:16) report that biologic medication has modernised the treatment of rheumatoid arthritis as it reduces the signs and symptoms of rheumatoid arthritis, and reduces the radiographic deterioration of the joints. All is not just good about the biologic agents. Kangesan (2012:25) reports that the biological agents have, however, also been associated with diseases including cancer, infection and activation of dormant tuberculosis, congestive heart failure and multiple sclerosis.

Several types of biologic medication agents exist (Kangesan, 2012:25). For the purpose of this study the researcher will discuss six types; namely Rituximab (MabThera), Abatacept (Orencia), Tocilizumab (Actemra), Etanercept (Enbrel), Infliximab (Remicade/Revellex), and Humira (adalimumab).

The first biologic to be discussed is Rituximab (MabThera). Rituximab is a chimeric mouse/human monoclonal antibody which binds to a transmembrane antigen called CD20 (Snyman, 2013:1003). In the South African Rheumatism and Arthritis Association (SARAA) Biologic Guidelines (2011) Rituximab is described as a monoclonal antibody which reduces the CD20 positive B-cells thus reducing joint damage. Rituximab is administered via two intravenous infusions of 500mg or 1000mg 14 days apart together with 125mg methylprednisolone. Paracetamol and antihistamine may also be given (SARAA biologic guidelines, 2011). Rituximab is prescribed in rheumatoid arthritis patients who have shown poor results or intolerance to one or more tumour necrosis factor-alpha inhibitors (Snyman, 2013:1003). The SARAA Biologic Guidelines (2011) advise that re-treatment should be given to patients that have responded to treatment at six months or when the disease flares.

The second biologic to be discussed is Abatacept (Orencia). Moreland, Bate and Kirkpatrick (2006:185) describe Abatacept as a fusion protein that selectively controls the signal that is required for T-Cell activation in the body. Abatacept, as per Ruderman and Pope (2005:21), is a novel fusion protein that is designed to selectively control the T-Cell co-stimulatory signal transmitting through the CD28-CD80/86 pathway. Abatacept is prescribed in patients with active rheumatoid arthritis who have had inadequate response to other disease modifying anti-rheumatic medication. The pharmacological action of abatacept is to minimise the signs and symptoms and inhibit the structural damage caused by the disease and thus improve the patients physical functioning (Snyman, 2013:345). Abatacept is administered intravenously. The prescribed dose is 750mg-1000mg every four weeks with a loading dose of three doses given at weeks naught, two and four (SARAA Biologic Guidelines, 2011).

A third biologic to be discussed is Tocilizumab (Actemra). Tocilizumab is used in the treatment of moderate to severe active rheumatoid arthritis, polyarticular and systemic juvenile idiopathic arthritis (SARAA Biologic Guidelines, 2011). Tocilizumab is a humanised anti-IL receptor monoclonal anti-body (SARAA Biologic Guidelines, 2011). Interleukin 6, or IL-6, a cytokine is believed to be one of the factors responsible for causing inflammation in rheumatoid arthritis. The pharmacological function of Tocilizumab is to block the spot where interleukin 6 cytokines attach to the cell surfaces thus preventing the cells being activated or turned on. The overall result is that the cells cannot facilitate the process of inflammation in rheumatoid arthritis which leads to the reduction of rheumatoid arthritis symptoms for example, swelling and pain (Tocilizumab, [sa]). Tocilizumab is administered intravenously for an hour every four weeks (SARAA Biologic Guidelines, 2011).

A fourth biologic to be discussed is Etanercept (Enbrel). Etanercept is a tumour necrosis factor receptor (Paller, Siegfried, Langley, Gottlieb, Pariser, Landells, Hebert, Eichenfield, Patel, Creamer & Jahreis, 2008:241).

Etanercept (Biologic Drugs, [sa]) is defined as:

...consists of 2, P-75 TNF receptor proteins and human immunoglobulin, joined at the Fc portion. The process of joining two receptor molecules effectively increases the half-life of the molecule. Natural circulating TNF receptor has an extremely short half-life and cannot be used therapeutically.

The drug is prescribed for patients suffering from rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and juvenile idiopathic arthritis and is administered via a sub-cutaneous injection once or twice a week (Etanercept, [sa]). In patients suffering from the above conditions, the body overproduces a protein called tumour necrosis factor (TNF) which causes inflammation and damage to bones, cartilage and tissue. The pharmacological action of Etanercept is thus to block the action of the TNF proteins in order to reduce the inflammation and overall damage.

A fifth biologic to be discussed is Infliximab (Remicade/Revellex). Infliximab is a chimeric monoclonal antibody which binds tumour necrosis factor-alpha (Hsia, Ruley & Rahman, 2006:107). TNF-alpha is produced by the body's immune system but in some individuals the body produces more than that which is required and this initiates the body's immune system to attack and damage healthy parts of the body. Infliximab is then administered to block the damage caused by too much TNF-alpha (Remicade, [sa]). Infliximab is a modern biologic that specifically blocks the TNF-Alpha molecules that damage healthy parts of a patient's body. Infliximab is administered via an infusion over a two hour period and is prescribed for the treatment of patients diagnosed with rheumatoid arthritis, Crohn's disease, ankylosing spondylitis, ulcerative colitis and psoriatic arthritis (Hsia et al., 2006:107). Possible negative consequences of infliximab administration may include: increased risk for infection, reaction to the infusion, increased risk of developing lymphoma or other cancers and liver problems (Remicade, [sa]).

The sixth biologic to be discussed is Adalimumab (Humira). Adalimumab is a Tumour Necrosis Factor (TNF) Antagonist (Pucino et al., 2006:21). Adalimumab is a fully human monoclonal anti-body and is administered via a 40mg subcutaneous injection (Simpson & Scott, 2006:1487). Burmester, Panaccione, Gordon, McIlraith and Lacerda (2013:517) report that Adalimumab is a fully human monoclonal

antibody, TNF antagonist, that is prescribed for the treatment of six inflammatory conditions; rheumatoid arthritis, juvenile idiopathic arthritis, ankylosing spondylitis, psoriatic arthritis, psoriasis and Crohn's disease. It is said that Adalimumab improves a patient's quality of life as it improves the function of affected patients (Pucino et al., 2006:21).

Gill et al. (2013:28) are however of the opinion that quality of life measures are often problematic and rarely consider the participant's perspective. Ahlmén, Nordenskiöld, Archenholtz, Thyberg, Rönnqvist, Lindén, Andersson and Mannerkorpi (2005:105) are further of the opinion that patients and their medical specialists view the benefits of treatment in different ways. It is suggested that further research be conducted on how the patients experience their role within the treatment programme.

It is evident from the above literature that the patient's perspective is rarely considered and that more needs to be done to investigate the influence of arthritis on their quality of life once they have started taking biologic medication.

Arthritis is a condition that has been around for centuries and affects the patient's life in different ways. In the following section, the focus will be on what social workers can do to improve the lives of patients living with arthritis.

2.6 SOCIAL WORK SERVICES TO PEOPLE LIVING WITH ARTHRITIS

Arthritis has a major psychosocial impact on society and there is, therefore, a growing interest in psychosocial interventions to manage pain and disability amongst arthritis patients (Dixon, Keefe, Scipio, Perri & Abernethy, 2007:241). In order to assist the arthritis patient in dealing better with the psychosocial challenges they experience, social workers utilise three primary methods, namely: individual, group and community work.

The first methodology that will be discussed is that of individual/case work.

2.6.1 Individual counselling/Case work

The *New Dictionary of Social Work* (1995:32) defines the individual interview as a therapeutic conversation between a social worker and a client. Providing an opportunity for patients to be in contact with a therapist will allow the patient to be empowered to take control over their situation.

When patients are diagnosed for the first time they are often left to deal with the diagnosis alone (Matthee, 2008:11). Eustice (2014) is of the opinion that, newly diagnosed patients experience a level of uncertainty which can lead them to look for answers in the form of how the future will look and living with the disease, as well as finding some form of reassurance. Through experience, Eustice (2014) has seen that newly diagnosed patients experience a level of fear, accompanied by questions which may include:

- Will I become disabled?
- How will arthritis change my life?
- Will I be able to continue working?
- How will I cope?

At the time of diagnosis, patients often experience disempowerment and they should be assisted to regain control (Eustice, 2014). The researcher is of the opinion that the social worker can utilise the modality of case work to assist the patient taking back control. This can be done using eight points, identified by Eustice (2014), as a guideline:

- Educate

It is critical that patients have knowledge and understanding of their health condition (Eustice, 2014). Social workers with experience in arthritic conditions can assist patients by educating them regarding the disease and thus empower them to take control over their situation.

- Motivate

Chronic pain is a major stressor in a patient's life which can lead to emotional dysfunction (Eustice, 2014). Involving the patient in individual sessions with the social worker, the professional can assist the patient to devise methods in order to maintain a positive outlook (Eustice, 2014).

- Participate

Even though chronic arthritis limits the patient from participating in certain activities the patient can still participate in others (Eustice, 2014). During individual sessions with the social worker the patient can be guided in identify those activities he or she is still able to do. This will teach the patient to rather focus on those activities that he or she can participate in rather than those he or she cannot.

- Medicate

Several medications are available to manage the arthritis and medical doctors must find the most appropriate combination to manage the patient's specific arthritis. This is often accompanied with a trial and error period during which the treating specialist attempts to find the right combination (Eustice, 2014). During individual therapy the social worker should encourage the patient to provide the specialist with adequate feedback in order to assist finding the drugs that provide the most relief.

- Communicate

Arthritis does not only have an effect on the patient's life, it also affects the patient's family and those around them. It is therefore important to communicate one's needs to others (Eustice, 2014). The social worker can assist by empowering the patient with communication techniques but if needed the patient's family can also be involved in family counselling.

- Meditate/Relaxation

Pain and fatigue are two co-morbidities associated with arthritis. Relaxation techniques will enable the patient to ease muscle tension that will assist in fighting fatigue (Eustice, 2014). Social workers can teach patients relaxation techniques during individual sessions.

- Eliminate stress/Stress management

Managing stress is very important in the life of an arthritis patient as an increased stress level will increase a patient's level of fatigue (Eustice, 2014). Together with the relaxation technique, the social worker can empower the patient with methods to keep his or her stress levels under control.

- Quality of life

Maintaining an optimum quality of life is very important. This can be done by setting realistic goals, maintaining an active lifestyle and concentrating on positive thinking (Eustice, 2014). Social workers are trained how to problem solve and plan appropriately. These techniques can be used to assist patients to set achievable goals and maintain a positive attitude despite their arthritis. The social worker can further bring the patient in contact with exercise activities that are appropriate for patients living with arthritis.

The second methodology in social work that will be discussed is group work.

2.6.2 Group work

As per the *New Dictionary of Social Work* (1995:29) group work is a method utilised in social work where individual and group objectives are achieved within the context of a group by following a group work process. The group work process, as per the *New Dictionary of Social Work* (1995:29), is a systematic set of actions aimed at achieving specific objectives and also includes involving the group work process.

Groups are then a method in social work that has a specific system within which individual and group objectives are reached. Three different types of groups will be discussed. The first is support groups.

2.6.2.1 Support groups

During group work, participants are provided with an opportunity to provide one another with support and therefore help influencing each other in a mutual manner.

The end result is that each participant has the potential to experience a sense of greater personal, interpersonal and environmental control over his or her life and thus has greater capacity to deal with high risk situations (Gitterman & Shulman, 2005:xii).

Group participants are likely to share their concerns and experiences once they experience a level of support from and within the group. As members reach out to one another they invest of themselves into each other thus participating in interpersonal processes. By sharing common experiences and concerns, group members are open to hear others' views and suggestions and even be challenged by them. This takes the sole responsibility of problem solving and providing help away from the social worker (Gitterman, 2006:92).

This methodical process can be applied to patients living with and suffering from arthritis. By involving patients in a support programme they can learn from others' experiences and be challenged to change their way of looking at the situation. From the above literature it is evident that members are more likely to listen to those in a similar situation and with whom they can identify, than just listening to a so called expert. In the context of arthritis, medical professionals can support and guide, but patients are the support system that can identify what the others are going through.

Therapeutic groups are the next type of group that will be discussed.

2.6.2.2 Therapeutic groups

Group therapy is a form of psychosocial treatment that is facilitated by a group leader or therapist and made up of members that attend to interact and discuss certain issues (Group therapy, [sa]). Therapeutic groups are most often closed, meaning that these type of groups run for a pre-determined length of time and no new members may join during this time (Davis-Mintun, 2007). The purpose of these groups is to create a safe environment where participants can experiment and explore new behaviours but receive feedback within a social context at the same time (Davis-Mintun, 2007).

The next group to be discussed is that of educational groups.

2.6.2.3 Educational groups

Educational groups are specifically utilised when patients are taught about a certain condition or situation, within a group context, for example arthritis (Hammond, [sa]). Patients have the opportunity to learn about a certain topic, ask questions and learn from others, within the group context. The purpose of the therapist is to stimulate inter-participant support and provide a non-judgemental environment that is conducive and beneficial to all participants (Hammond, [sa]).

The third methodology in social work that will be discussed is community work.

2.6.3 Community work

Social workers responsible for community work aim to promote social justice as a major goal in their daily work. This is done by utilising intervention strategies that involve community development (Makaros & Weiss-Gal, 2014:103). Ford and Lynch (2013) stress that community work should involve a process of active consultation with communities in order to address inequality and injustice and aim to bring a change to both community and society levels.

The *New Dictionary of Social Work* (1995:13) agrees with the above by defining community work as a combined effort by community members and a social worker to improve the social functioning of the larger community. This will be done by: 1) Increasing the communities' knowledge about a certain topic, thus providing them with the necessary skills to manage social problems and needs, 2) Ensuring that the community has access to adequate resources to fulfil in the needs of the community and 3) Ensuring participation of the community when formulating specific welfare policy (*New Dictionary of Social Work*, 1995:13).

The literature distinguishes, amongst others, two practice models when undertaking community work.

The first practice model is community education.

2.6.3.1 Community education

In Community ... [sa], community education is defined as an educational activity that is directed at the education and learning of adults outside the traditional educational setting. Community education, as per Community Education [sa] can further be defined as:

Community education is education and learning which is rooted in a process of empowerment, social justice, change challenge, respect and collective consciousness. It is within the community and of the community, reflecting the developing needs of individuals and their locale. It builds the capacity of local communities to engage in developing responses to educational and structural disadvantage and to take part in decision making and policy formation in the community.

The overall focus of community education is thus to enhance learning, empower people and contribute to society. Participants in community education are participating as equal partners when identifying the needs, designing and implementing programmes and changing them on an ongoing basis (Community Education, [sa]).

The researcher is of the opinion that community education can thus be utilised within society, educating them on the signs and symptoms of arthritis, what to do when you have been diagnosed with arthritis and how you can live optimally with your diagnosis.

The second practice model when working in communities that will be discussed is social marketing.

2.6.3.2 Social marketing

Social marketing refers to the use of commercial marketing techniques in order to attempt the improvement of social problems. The advantage of social marketing is that it can reach a target group and can assist in changing people's behaviour (Conducting a social marketing..., [sa]). As per Weinreich (2006), in social

marketing, normal marketing techniques are used to sell ideas, behaviours and attitudes. Peattie and Peattie (2009:262) report that social marketing campaigns mainly focus on bringing forth a change in behaviour in order to improve the well-being of individuals and society as a whole. An example of a social marketing campaign may include stimulating the decrease in certain behaviour, such as littering, or the focus can rather be to improve certain behaviour such as recycling (Peattie & Peattie, 2009:262). In the United States of America, social marketing has been utilised in campaigns related to drug abuse, heart disease and organ donation (Weinreich, 2006).

Within the milieu of arthritis, the social worker can consult with arthritis sufferers in order to create social upliftment and change. This can create awareness within the arthritis community and society as a whole, create bigger access to resources and involve patients when drawing up social policies related to arthritis.

In the next section, the theoretical frameworks on which the study is built will be discussed.

2.7 THEORETICAL FRAMEWORKS

The researcher will use a practice perspective as well as a meta-theory for the study. The meta-theory that will be used is the general systems theory from which the practice perspective, the bio-psychosocial framework, was developed. It is thus important to first look at the general systems theory.

2.7.1 General systems theory

Systems theory sees the world as being structured and that systems can be best understood by studying them holistically and not as individual units. The general systems theory further defines a system as an entity that consists of different parts that interact with and influence one another and these components are all part of a complete whole. Each system has a unique structure and the ability to exist over time and space (Green, 2008:172). Flamand [sa] goes further and describes the systems theory as the interdisciplinary study of complicated systems with a special

interest on how parts relate to one another and to the system as a whole. The focus is thus on the interactions between the different parts with a special emphasis on its solidarity and the importance within the system (Goldenberg & Goldenberg, 2004:508).

Within the context of the general systems theory, Green (2008:172) defines a social system as: "... a defined structure of interacting and interdependent persons that has the capacity for organized activity". Social systems evolve over time which allows each system to develop its own unique characteristics and take on a specific role (Green, 2008:172). The systems theory also provides a framework in which the structural qualities of a social system of any size and the unique interaction between its members can be understood (Green, 2008:167).

Rothery (2005:112) credits Gordon Hearn for focussing on the systems theory within the context of social work for the first time. The following concepts are outlined:

- Groups can be seen as systems and have a level of predictability and pattern in terms of how members interact with one another;
- Occurrences within the system can often be explained circularly rather than by linear cause and effect;
- Systems are however not completely predictable as there are other factors for example that can influence them.

The aim of social work is often to restore and enhance the ability to function socially of those they work with. In the general systems theory systems are seen to be ever involving and purposeful, constantly interchanging with their environments, which needs to be taken in consideration when problem solving and determining possibilities for intervention and change. The systems theory thus assists the social worker by focusing on the interaction between the system and its environment (Green, 2008:168). Social workers find this beneficial as it provides guidance in identifying, defining and addressing problems within social systems. This is done by identifying how a system functions, what aspects of the system impact negatively on people and what can lead to positive change within the system.

Within the context of the research study, the researcher explores the patient's interaction between the medication and the disease which thus leads to a quality of life. On evaluation of the gathered data, the researcher will base his findings on the grounds provided by the general systems theory. A patient system is made up of different parts and in light of the study: medical history, daily functioning, relationships, work, leisure time and finances and each patient's quality of life, will differ, because of the systemic influence of the above mentioned parts' sub-systems. As Hearn (1958) explains that systems are not entirely predictable, the researcher is not ensured that every participant in the study will have a quality of life due to the use of the medication and therefore it is critical that all aspects that influence a patient's quality of life be explored. The theory thus guides the researcher with the predictability of the system but also with the fact that each systems interaction with its environment will have a different outcome.

In the next section the focus will now turn to the bio-psycho-social framework.

2.7.2 Bio-psycho-social framework

Engel (1980:535-543) agreed that the general systems theory was the new theory for medicine. The medical practitioner was now able to not only focus on studying and treating a patient's organs but was able to acknowledge that there are systemic interactions between the different systems, for example: the interactions between a cell, molecule, the patient's family, and society (Short, 2006:128).

Engel (1980:535-543) challenged the traditional linear cause and effect of medical conditions by introducing the bio-psycho-social framework which was a whole new way of looking at health-illness issues, at the time. Friedman and Downey (2012:372) report that Engel practiced from the viewpoint that diseases cannot be adequately treated when the professional believes that the disease manifestation is purely, due to biophysical causes, isolated from social behaviour. The focus therefore was on the patient as a whole (Friedman & Downey, 2012:372). Lane (2014) reports that biological, psychological and social factors are different parts incorporated into a whole. Within the bio-psycho-social framework, a patient's disease process is influenced by biological, psychological and social factors (Somers

et al., 2012:502) which are interlinked, the same as the systems and sub-systems, in the systems theory. Waddell (2006:55) is of the opinion that the inability to work requires a bio-psycho-social framework that focusses on and addresses the biological, psychological and social factors that are involved in the illness and disability.

The bio-psycho-social framework is thus a way of thinking about clinical care but also a practical and clinical guide (Borrell-Carrio et al., 2004:576). As per Waddell (2006:58), the bio-psycho-social framework is evaluating the patient, within the context of the person, health problem and their social situation. Waddell (2006:58) describes the different aspects of the bio-psycho-social framework as:

- 1) Biological aspect of the model is aimed at the specific mentality of a physical condition
- 2) The psychological aspect of the model is aimed at acknowledging that personal or psychological factors are influential in defining a patient's functioning
- 3) The social aspect also acknowledges that the social context together with its pressures and constraints plays an important role in a patient's functioning.

The philosophy surrounding the bio-psycho-social framework is to understand how suffering, disease and illness are affected by so many different aspects, from society down to the smallest molecule. Practically, it is a way of understanding that, in order to make an accurate diagnosis, achieve an appropriate outcome and provide adequate humane care, the patient's personal experiences should be taken into consideration (Borrell-Carrio et al., 2004:576). Faleiros and Machado (2006:432-424) are of the opinion that by using the bio-psycho-social framework all aspects that play a role in a patient's quality of life are being considered. These include patients' personal attitude and belief system, social factors like education, community influences as well as family systems, for example family upbringing.

Margalit, Glick, Benbassat, Cohen and Margolis (2007:219) are of the opinion that the bio-psycho-social framework to care is aimed at improving a patient's satisfaction and their overall health outcome.

The bio-psychosocial framework will guide this process as such an orientation allows the professional to have a patient-centred interview and tries to provide adequate support and treatment for both biomedical and psychosocial components of the patient's problem (Margalit et al., 2007:219). With the assistance of the theoretical framework, the researcher will be able to focus on each patient's story during the individual interviews. He will then be of the mind-set that the patient's physical condition will be influenced by their psychological functioning as well as their social background and situation. The researcher will further be of the understanding that physical, psychological and social aspects may influence the patient's personal experience surrounding the chronic biologic arthritis treatment and the role that it plays in their quality of life. This will thus enable the researcher, when interpreting the data, to not just focus on the physiological outcome but to also take into consideration the impact of patient's biological, psychological and social systems on their overall quality of life.

2.8 SUMMARY

This chapter focused on the conceptualisation of arthritis including quality of life within an arthritis context, treatment and the theoretical frameworks that will guide the research project.

It is evident that there is plethora of information available regarding the different types of arthritis as well as medical explanation on the possible disease process. There are however still areas that can further be investigated, especially the impact of the arthritis on the patient's quality of life, from a qualitative point of view.

In Chapter 3 the focus will be on the research methodology employed in the study, the research findings and an interpretation thereof.

Chapter 3:

Research methodology, research findings and interpretation

3.1 INTRODUCTION

The goal of the study was to explore and describe how arthritis patients experience the influence of arthritis on their quality of life after commencing with biologic arthritis medication. The focus of this chapter is specifically on the following research objectives of this study, namely; to explore and describe the quality of life as experienced by arthritis patients while taking the biologic arthritis medication, and to make conclusions and recommendations in order to enhance the field of social work intervention with arthritis patients.

Subsequently, this chapter presents an overview of the research methods (thus, Section A), which were utilised to undertake the empirical research of this study, by focusing on the research question, research approach, the type of research, research design, method of data collection, data analysis and trustworthiness of the qualitative data collected, as well as the ethical considerations. This will be followed by an analysis and interpretation of the research findings (thus, Section B).

SECTION A: RESEARCH METHODOLOGY

3.2. RESEARCH METHODOLOGY

In section 3.2 an overview of the research methodology will be provided and the research question that guided the study will be stated. The researcher will further provide detail regarding the research paradigm, research approach and design that were utilised during the study. The study population and sampling techniques will be described in detail. Attention will also be given to the data collection and data analysis process. The reader will come to understand that a pilot study was performed as well as the reasons behind pilot testing. The section will be ended by discussing the ethical considerations that were addressed during the study.

3.2.1 Research Question

The research question for the research was: “What is the influence of biologic arthritis medication on the quality of life of arthritis patients?”

3.2.2 Research approach

The approach that was utilised within the study was that of qualitative research. The reason for choosing the qualitative research approach was that the researcher wanted to strive to understand what the arthritis patient experienced their quality of life to be while taking biologic arthritis medication. Ong and Richardson (2006:369) describe qualitative research as an approach that is used to have a gateway into the subjective world of the participant; by focusing on the way meaning is given to personal experiences with reference to their cultural and social contexts; which thus links to what the researcher was aiming to achieve. According to Bansal and Corley (2011:235) qualitative research is not just about filling the shortcoming within the research community, but it is also about changing the way society thinks and talks about a phenomenon. Qualitative research can further be explained by the five characteristics of qualitative research, as described by Chesebro and Borisoff (2007:9):

- a) Natural setting: the research is conducted in a setting chosen by those participating in the research. The setting that was used for the research was decided by the research participants.
- b) Researcher as participant: the research participants see the researcher as an integral part of the research. As the researcher participated in the conversation, he was thus seen as part of the research process.
- c) Participants’ centred communication: the research participants determined the flow of communication. The researcher only facilitated and never determined the flow of communication.
- d) Participants’ intentionality: the research aims to capture the meaning of conversation from the participants’ point of view. The researcher aimed to capture how the participants perceived their situation, and not the meaning he could add to the situation.
- e) Pragmatic: the information collected from the qualitative research allows existing social problems to be resolved. The information gathered from the research

can be used to recommend social work intervention that could make a difference in arthritis patients' lives.

The researcher is of the opinion that society rarely observes and understands what arthritis patients go through on a daily basis and, by following a qualitative research approach, the researcher could obtain first-hand knowledge of how arthritis has influenced the social functioning of patients, and their experience of quality of life, since taking biologic arthritis medication.

3.2.3 Type of research

Applied research was used in this study, striving to provide more insight in the experience of arthritis patients on their quality of life while taking biologic medication. In gaining insight into the patients' experience regarding the quality of life while taking biologic arthritis medication social work interventions can be recommended which can thus help to address all spheres of the patients' functioning, for example: the medical, social and psychological spheres and not just the medical aspect thereof.

According to Jupp (2006:8), in applied research, the main focus is the use of knowledge rather than finding more knowledge for its own purpose. Ghosh, Bagchi, Sen and Bandyopadhyay (2011:15) state that the purpose of applied research is to get answers to specific questions.

The purpose of the study was thus to explore the influence of biologic arthritis medication on the quality of life of arthritis patients. Schutt (2012:13) explains that exploratory research seeks to find out how people get along in the context of interest and what meaning they give to their actions as well as that which concerns them. Exploratory research as per Babbie (2012:19) can help eliminate any misconceptions that exist in the field of interest and can assist in focusing any future research. In the context of the research study, the researcher explored how the patients are coping with their arthritis condition and how the biologic medication has influenced their quality of life. Descriptive research, according to Fouché and De Vos (2011:96), begins with a well-defined subject and the purpose of the research is to provide an accurate description of the subject. During the research, the

researcher described the phenomenon of living with arthritis and the effect that it has on a patient's quality of life. The researcher further described how the patients experience the effect of biologic medication on their quality of life (Schutt, 2012:13). This was done in order to make recommendations for social work interventions with patients living with arthritis.

The researcher thus conducted this study with an exploratory and descriptive research purpose.

3.2.4 Research design

The research design that was utilised in the proposed study was that of case studies, and to be more specific, the collective case study. The purpose of the collective case study is to compare cases and concepts in order to develop a broader understanding of a particular issue (Crowe et al., 2011). The advantage of case studies, according to Fouché and Schurink (2011:320), is that it allows the researcher to engage with a single person or a small number of people while they are busy with their activities. The researcher thus becomes familiar with the participants' social world, and is then able to identify patterns in the participants' lives, words and actions in relation to a certain topic. Crowe et al. (2011) also report that others see case studies to have a disadvantage as they are very time consuming.

The researcher aimed to create an opportunity where he could learn about the experiences that arthritis patients, who use modern biologic medication, have regarding their quality of life. The researcher will further aim to make his findings accessible to those social workers and other professionals that operate in the medical field, specifically those who work with arthritis patients; so that they can contribute to understanding these patients better and, potentially, improve social work service delivery.

3.2.5 Study population and sampling

The population in the proposed study consisted of all the arthritis patients from a rheumatology practice in Muckleneuk, Pretoria which uses a chronic biologic medication to treat arthritis. These patients all reside in the Gauteng Province and

were specifically chosen to tighten the boundaries from which a sample was drawn and were easily accessible.

This study followed two different sampling techniques in two stages.

The first stage consisted of purposive sampling. Babbie (2007:204) describes purposive sampling as a method wherein the researcher identifies participants on the basis of who will be the most suitable or representative for the study. First the practice drew up a list of potential participants from their data base. The practice then contacted each patient and invited them to participate in the study.

In order to be contacted by the practice (and thus considered for the study), the patients had to meet the following criteria:

- Patients had to be diagnosed with arthritis
- They had to be patients of the specific Rheumatology practice in Muckleneuk, Pretoria
- They had to use a biologic medication for the treatment of arthritis, and
- Reside in the Gauteng Province

A sampling size of 60 was reached. The study then proceeded to the second sampling technique.

The second stage consisted of volunteer sampling. In volunteer sampling, participants volunteer to take part in the proposed study (Blankenship, 2010:87). As the practice contacted the list of patients, the telephone numbers of those who agreed to voluntarily participate in the study were forwarded to the researcher. He then made contact with the participants and individual interviews were scheduled. Data saturation was achieved after 10 interviews and the researcher discontinued the interviewing of participants after the 11th participant in the study.

3.2.6 Data collection

Individual interviews and specifically, semi-structured one-to-one interviews with an interview schedule (see Appendix C) were used as method of data collection. Eleven individual interviews of approximately an hour each were conducted.

King and Horrocks (2010:1) report that interviewing is the most commonly used method of data collection in qualitative research. Seidman (2013:13) is of the opinion that interviews are an important tool to gain insight into educational and other important social issues by understanding the experience of the individuals whose lives reflect those issues. Interviews were specifically selected as a data collection method, as it allowed the researcher to develop an in-depth understanding of the participants' experiences surrounding their arthritis (Seidman, 2013:9).

King and Horrocks (2010:3) provide certain characteristics of the qualitative research interview:

- During the interview the researcher places emphasis on open ended, non-leading questions and thus focuses on the participant's personal experiences. By doing this, the researcher aimed to build rapport with the participants (King & Horrocks, 2013:3)
- As the researcher asked the questions he might be seen as being in a more powerful position. King and Horrocks (2010:3) also report that the balance is often complicated by factors such as age, gender and status of the two parties. King and Horrocks (2013:3) however emphasise that the participant can withdraw at any moment without any consequences
- Qualitative interviewers usually try to minimise any power imbalance between researcher and the participant (King & Horrocks, 2010:3)
- Aspects of confidentiality and anonymity play an integral part in many of the qualitative interviews (King & Horrocks, 2010:3).

The motivation in utilising semi-structured interviews is that it allowed the researcher to gain a comprehensive picture about the participants' beliefs, perceptions or accounts about living with arthritis and the influence biologic medication has on their quality of life (Hesse-Biber & Leavy, 2011:351). Hesse-Biber and Leavy (2011:352)

report that semi-structured one-to-one interviews are suitable when the interviewer is interested in complexity or process, or when an issue is controversial or personal. These types of interviews are quite flexible as they are guided and not directed by, a set of pre-determined questions on an interview schedule. During the semi-structured interviews, the interviewer attempted to guide the conversation to remain more loosely around those questions. Participants were allowed the freedom to talk about what is of interest or importance to them. Hesse-Biber and Leavy (2011:102) elaborate further by explaining that even though the researcher attempts to ask each participant a set of questions, the conversation is guided to flow naturally and often in unexpected directions. During these moments, the researcher allowed the conversation to develop and explore the topics relevant to the participant.

Before the interview started, the researcher explained the confidentiality aspects and procedures. Field notes were taken during the interviews but the researcher has learnt through experience that the field notes are not always adequate and therefore the researcher, in the letter of informed consent (see Appendix D), requested the permission of participants to make a digital recording of the interviews.

3.2.7 Data analysis

The researcher made use of a data analysis spiral when he analysed and interpreted the gathered information.

Creswell (in Schurink, Fouché & De Vos, 2011:403) believes that using analytical circles when analysing and interpreting data within the qualitative research project can be described best by using the analogy of a spiral image. In this particular study, the researcher utilised open coding and followed the process of thematic analyses as described below (Schurink et al., 2011:404):

- **Data collection and preliminary analyses**

The researcher applied a principle of having a twofold data collection and preliminary data analysis process. Data were collected at the site and while it occurred, the researcher initiated the analysis process by identifying possible underlying themes. Secondly, the researcher analysed data away from the research site. This was done from field notes and the transcribed interviews (Schurink et al., 2011:405).

- **Organisation and management of the data**

This was the first time the researcher analysed the data away from the research site (Schurink et al., 2011:408). The researcher transcribed the digitally recorded interviews and typed the field notes personally as this provided him with the opportunity of familiarising himself with the data. This further enabled the researcher to identify whether there were any gaps that required further investigation. The researcher further organised data by creating data file folders, index cards and computer files that advanced easy access to information. The researcher further altered data in text units that assisted in the analysis process, for example: a word, a paragraph or a sentence (Schurink et al., 2011:408).

- **Writing and reading of memos**

As Schurink et al. (2011:405) advise, the researcher read through the gathered data several times in order to familiarise himself with the information before he broke it down into smaller pieces. He further made notes that assisted him in identifying the relevant themes contained in the data.

- **Generating categories and coding the data**

During this section, the researcher aimed to identify themes that “lead the way”, attempted to identify ideas or language that were regularly repeated, as well as identifying the participants’ belief patterns. Schurink et al. (2011:410) state that the researcher can make sense of the gathered data, by identifying the leading themes, language or ideas that are regularly repeated as well as identifying the patterns of belief.

When reading through the data, the researcher identified certain categories and themes. Different colours were used to code these categories and themes (Grinnell & Unrau, 2005 in Schurink et al., 2011:411).

- **Testing emergent understandings and searching for alternative explanations**

At this point, the researcher studied the gathered information and, while doing this, he tested his understanding of the data (Kreuger & Neuman, 2006 in Schurink et al., 2011:415).

Flick (in Schurink et al., 2011:416) is of the opinion that the researcher should critically challenge all identified categories and patterns during which he looks for alternative explanations. In the study, the researcher used literature to control whether the chosen patterns and themes were the most credible.

- **Interpreting and developing typologies**

Schurink et al. (2011:416) report that, when the researcher interprets the data, the focus is to make sense of the information and look for lessons that can be learned from the gathered information. The researcher further developed systems that could be used to categorise the different concepts.

- **Presenting the data**

The researcher presented the findings of the study in an analytical and logical manner (Schurink et al., 2011:418).

In the above paragraphs the researcher described the analysis process that was utilised during the research study. It is, however, important to focus on the aspect of trustworthiness in qualitative research.

- ❖ **Trustworthiness**

Lincoln and Guba (in Schurink et al., 2011:419-421) are of the opinion that it is important to ensure trustworthiness during the study and address four constructs:

- **Credibility/authenticity**

This is similar to internal validity and here the researcher compares the research participants' views with the researcher's reconstruction and representation of those views. It is important for the researcher to stipulate boundaries in order to ensure validity within the parameters of the setting, population and theoretical framework (Schurink et al., 2011:419, 420). In order to ensure validity, the researcher utilised the general systems theory (and the bio-psychosocial framework) as his theoretical framework, had a specific setting where the research was conducted and stipulated the population from which the research was drawn.

- **Transferability**

This is similar to external validity and thus focuses on duplication of the said research (Lincoln & Guba, 1999 in Schurink et al., 2011:420). The researcher aimed to increase transferability by utilising different literature sources in order to validate the research. The researcher further continuously weighed the research against the theoretical framework in order to ensure its validity (Schurink et al., 2011:420).

- **Dependability**

This is similar to reliability where the researcher will enquire whether the research process is logical, adequately documented and double checked (Lincoln & Guba, 1999 in Schurink et al., 2011:420). In this study, dependability was a challenge as the social world from which the study was conducted forever changed and developed (Schurink et al., 2011:420, 421).

- **Conformability**

This is similar to objectivity where the research data is confirmed by another. The researcher ensured conformability by comparing the research data to current literature. This ensured that objectivity was always adhered to (Lincoln & Guba, 1999 in Schurink et al., 2011:420).

3.2.8 Pilot study

Pilot testing is the testing of the bigger research project on a small scale in order to test the feasibility of the study (Fouché & Delpont, 2011:73). In the qualitative research project, the researcher had a practice run by utilising the interview schedule with two participants with similar traits to those who participated in the actual research study (Fouché & Delpont, 2011:75). These two participants did not form part of the main study.

3.2.9 Ethical considerations

During a research study, ethical issues can always occur. In the paragraphs that follow, the researcher will discuss these aspects as reported in Strydom (2011a:115-126) and how they were addressed in this study.

3.2.9.1 Avoidance of harm

The researcher attempted to protect the participants against any form of harm they might experience during the investigation by informing all participants of the impact of the study (Strydom, 2011a:115). This was done by providing each participant with a letter of informed consent (see Appendix D), where the purpose of the study was explained. This provided participants an opportunity to decide beforehand, based on the information, whether they still wanted to participate in the study or not (Strydom, 2011a:115), (also see Appendix B).

3.2.9.2 Voluntary participation

As per Rubin and Babbie (in Strydom, 2011a:116) participation should always be voluntary and no one should be forced to participate in the study. In the research, the researcher included a voluntary clause in the informed consent letter where it was stipulated that no one was forced to participate and they could have withdrawn at any point without any consequence.

3.2.9.3 Informed consent

The researcher attempted to address the aspect of informed consent by providing each potential participant with a detailed letter describing the purpose of the study; highlighting the fact that they may withdraw at any point if they were not comfortable continuing with the study. This was in compliance with Ruane (2005:19) who reported that every person has a right to decide whether they would like to be part of a research study or not. No one must be forced or “tricked” into participating in a research project. Each potential participant has the right to be aware of all aspects that might influence their decision to be part of the study or not. Other factors that were also included in the letter were: competence, volunteerism, full information on research procedures (including the fact that the interview was digitally recorded), privacy, research setting, reporting and that the data will be kept and stored at the University of Pretoria for 15 years. Informed consent, therefore, included providing the potential participants with a written statement that included an introduction about the planned research project as well as an explanation about the project (Hargreaves, 2006:264; Ruane, 2005:19).

3.2.9.4 Deception of subjects and/or respondents

In the referred study, the researcher refrained from deceiving the participants at any time as all information was given beforehand in the letter of informed consent (see Appendix D). When participants are deceived, their right to be a free human being, capable of making their own decisions, is taken away due to the fact that the researcher abuses the participant into getting what they want (Rodriquez, Valdebenito & Mandragon, [sa]).

3.2.9.5 Violation of privacy/anonymity/confidentiality

Privacy refers to keeping something to oneself, so that others cannot evaluate or observe it (Strydom, 2011a:119). In the proposed research, the researcher conducted the interviews in a venue, chosen by the participant, where no one could hear the conversation and no one could see who participated in the research.

According to the *New Dictionary of Social Work* (1995:13) confidentiality is: “A principle in social work according to which particulars which have been obtained from clients within the professional relationship will not be disclosed without their permission”.

In this study, keeping information confidential was difficult as participants can share confidential information with others who did not participate in the interviews. This was combatted by verbally emphasising the aspect of confidentiality beforehand and requesting the participants to honour the principle of confidentiality. The researcher ensured anonymity by using pseudonyms, such as referring to participants using the letters of the alphabet, for example, participant A in the transcribed interviews. The researcher was the only one that had access to the digital recordings and the field notes. This further ensured that no one had access to the true identity of the participants when the research findings were reported on.

3.2.9.6 Compensation

According to Strydom (2011a:121) the question should be asked whether it is ethical or not to compensate a participant for participating in the study. In this research study, this was not an issue as no compensation was provided and all participation was voluntarily.

3.2.9.7 Debriefing of respondents

When debriefing respondents, the researcher's focus was to work through any feelings that were experienced during the interviews, as well as any harm that the participants could have suffered. The researcher further clarified after every interview, any misperceptions that the participants might have had (Strydom, 2011a:122).

If it seemed necessary to refer the participant for further counselling, a referral would have been made to a social worker in private practice who had agreed to this, but this was not necessary as no participant requested, or needed, further counselling.

3.2.9.8 Actions and competence of researchers

The researcher himself was continuously supervised by his appointed supervisor at the university in order to monitor his competence throughout the research process. The researcher has also successfully completed a postgraduate research methodology module MWT 864 and a mini-dissertation in his 4th year of his BSW degree.

3.2.9.9 Release or publication of the findings

The researcher presented the findings of the research in the form of a research mini-dissertation, which will be available in the library. The information is accurate, objective and includes all the necessary information. All resources utilised, have been acknowledged and recognised. The researcher also reported any shortcomings or errors that were experienced during the study. Confidentiality was further ensured throughout the whole document.

Strydom (2011a:126) states that the study must be presented to the public in the form of a written document, otherwise the research will have no future value, even if it is a highly scientific investigation. The researcher intends to write a manuscript for possible publication in an accredited journal.

During section A, the researcher focused on the research methodology. In the paragraphs that follow, the research will focus on section B, the research findings.

SECTION B: RESEARCH FINDINGS & INTERPRETATION

3.3 EMPIRICAL FINDINGS AND INTERPRETATION

This section will discuss the research findings and provide an interpretation thereof. The researcher will first present the biographic data obtained from the participants and provide an interpretation thereof (thus Section 1). The following sub-section (thus, Section 2) will focus on themes and sub-themes originating from the individual interviews.

Section 1: Biographic profile of participants

This section will analyse the research participant's biographic information. The purpose of the section is to orientate the reader broadly on the participants in the study.

3.3.1 Participants' biographical information

The biographic information of the participants is presented as follows:

(i) Gender of the participants

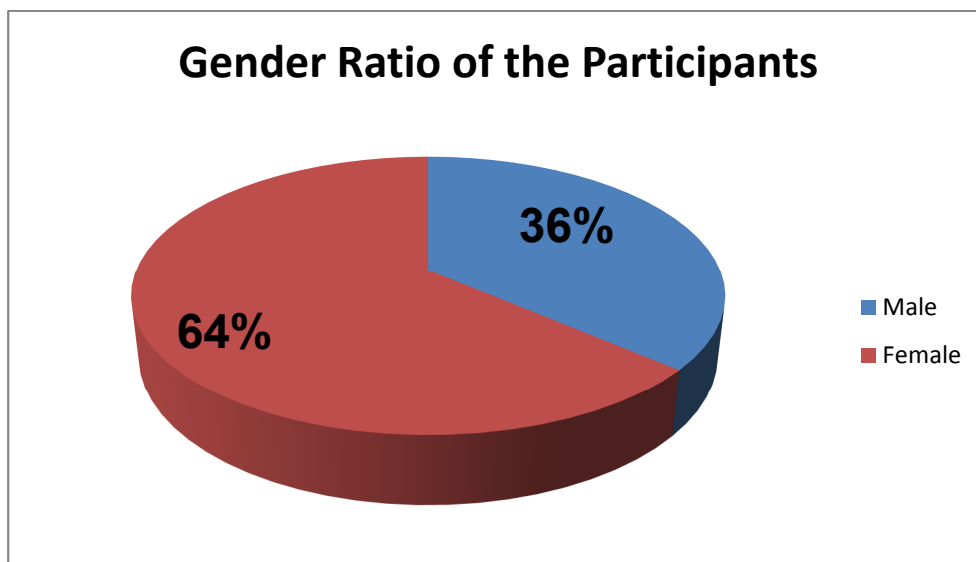


Figure 1: Gender of the participants

Figure 1 reflects that from the participants participating in the study (n=11), seven (n=7) were female and four (n=4) male.

(ii) Diagnosis of the participants

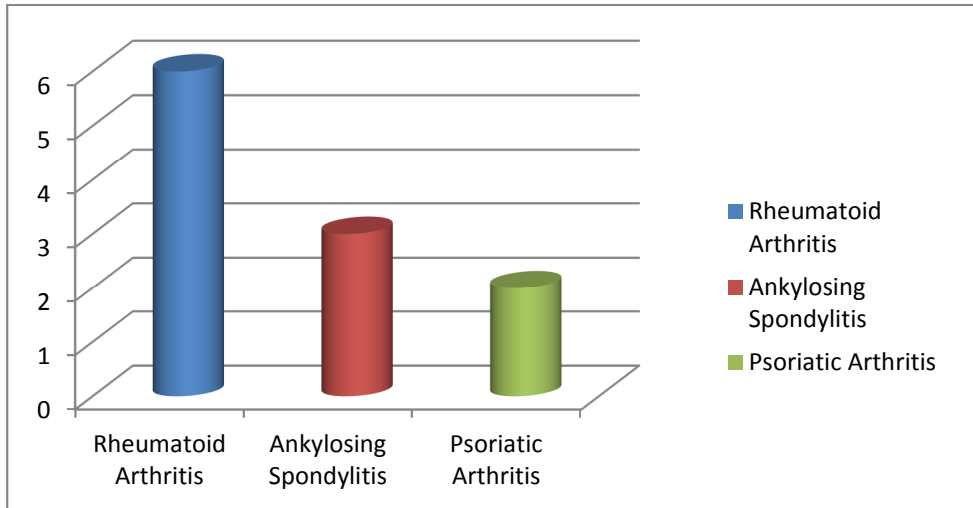


Figure 2: Diagnosis ratio

From the sample in the study, and as reflected in Figure 2, six participants (n=6) suffered from Rheumatoid Arthritis, three (n=3) from Ankylosing Spondylitis and two (n=2) from Psoriatic Arthritis.

(iii) Biologic medication

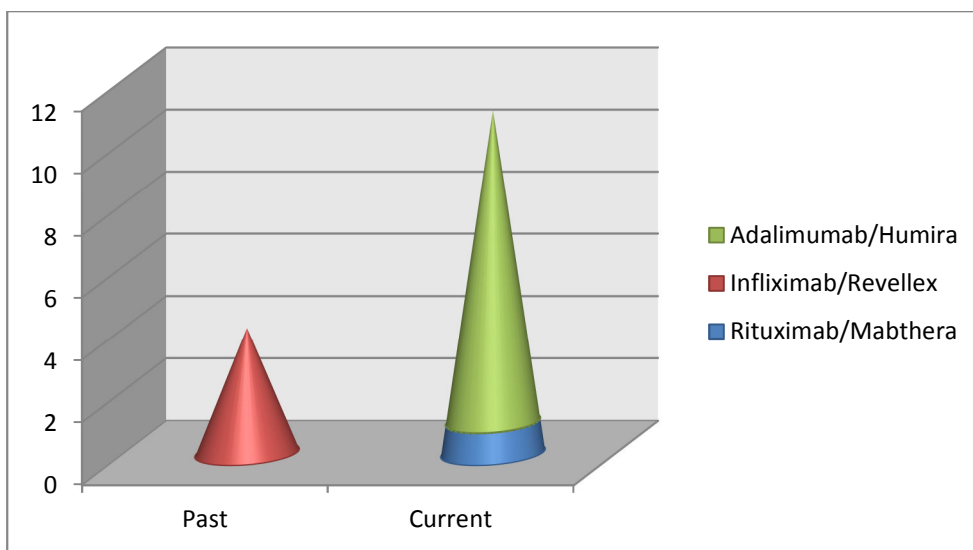


Figure 3: Biologic medication used by the participants

From the participants in the study, four patients (n=4) had received Infliximab (Revellex) before, but had to change due to several reasons. At the time of the study, 10 participants (n=10) were receiving Adalimumab (Humira) and one (n=1) participant Rituximab (Mabthera).

During section 1, the researcher discussed the biographic data. In section 2, the researcher will focus on themes and sub-themes.

Section 2: Themes and sub-themes

3.3.2 Themes and sub-themes

During the data analysis process, the researcher extrapolated a set of themes and sub-themes. In order to share the participants' views, perceptions and experiences, verbatim quotations will be provided together with a discussion of each theme and sub-theme.

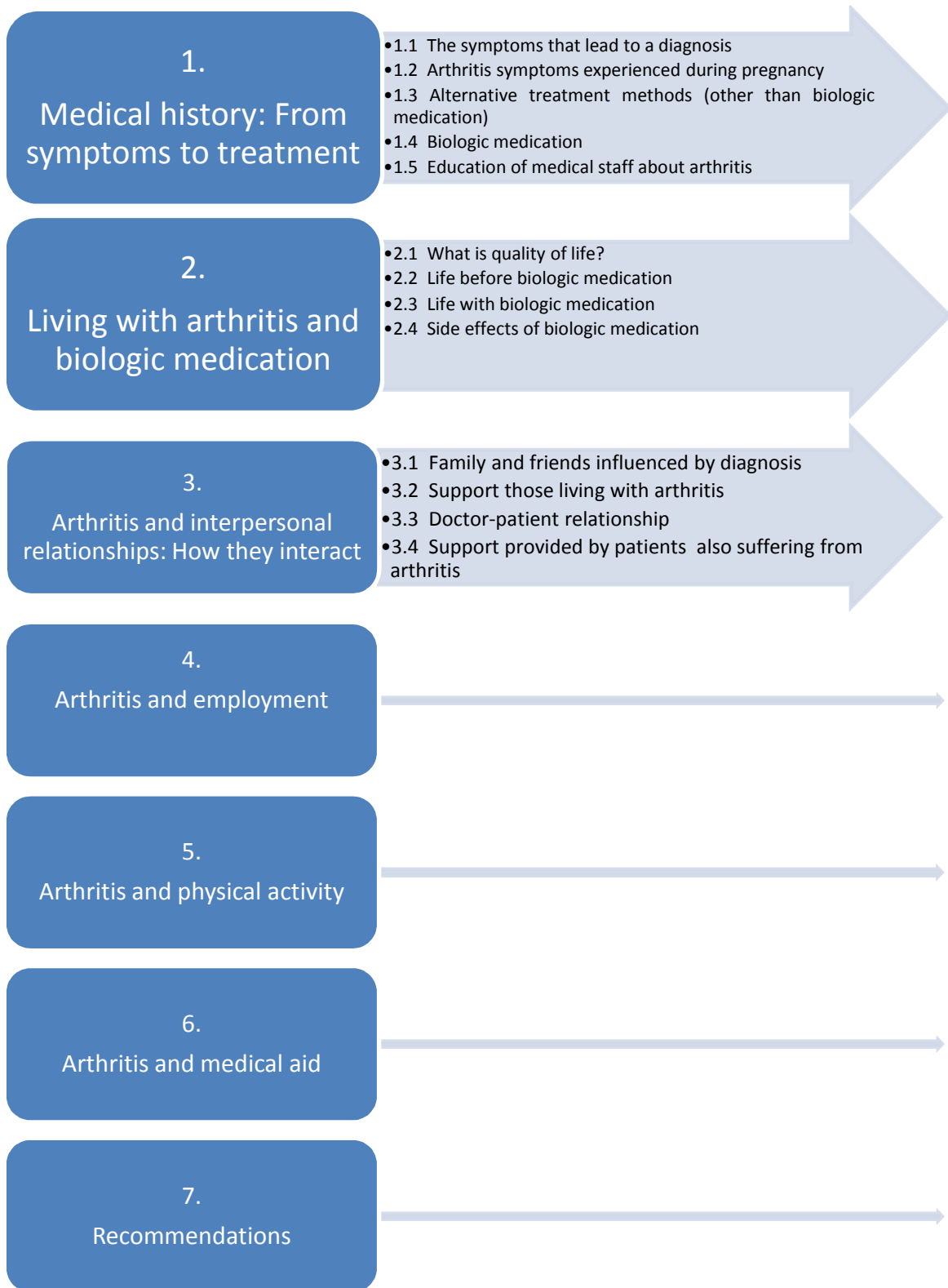


Figure 4: Themes and sub-themes

THEME 1: MEDICAL HISTORY: FROM SYMPTOMS TO TREATMENT

Under this theme ‘medical history: from symptoms to treatment’ the data crystallised into five sub-themes. The first sub-theme refers to the symptoms that lead to a diagnosis; the second theme focuses on arthritis symptoms experienced during pregnancy. The researcher identified alternative treatment, other than biologic medication, as the third sub-theme. Biologic medication and disease education are the last sub-themes.

Sub-theme 1.1: The symptoms that lead to a diagnosis

In the life of an arthritis patient, it may be a journey from the day when symptoms are first experienced until an official diagnosis is made. The participants shared that receiving an accurate diagnosis is often not an immediate experience.

“I was only diagnosed when I was 48, ok, but when I was younger, even at high school, my knees used to swell up and then mmm, we would go to the doctor and they would say no, we would have to go to an orthopaedic surgeon and by the time you get the booking to get to the orthopaedic surgeon, the swelling had gone down, so then you have to explain to the doctor no this is what happens. Then he looks at you like, with that look that says, you making this up, so one of them, he said it could have been the cartilage and we had this cartilage exploration procedure, but luckily they never took anything out ... One said I was too fat, one mmm said I shouldn’t run, I shouldn’t do anything, but the only thing I could actually do is, they could find what it was, they were always saying it is cartilage problems or something.”

“...and I think that because they only discovered this thing later on in life, this disease later on, mmm, they took X-Rays and he [the medical practitioner] could see, mmm there were growths on the vertebra. Ya [sic], spurs, but when I look at it, I can’t see it but when he looked at it, he could see it...”

The research data guided the reader to realise that arthritis are seldom diagnosed during the first doctor’s visit. It often involves visits to several medical practitioners before an official diagnosis is made.

Diagnosis is a tool of classification within the context of medicine and is unfortunately not an instant process. It involves a process of acknowledging a medical problem, taking the history of medicine, as well as the theory of disease into consideration. It organises illness by identifying a problem, considering treatment options, predicts outcomes and provides an explanatory framework. A diagnosis is made at a point

where illness, disease, patient, doctor, complaint and explanation come together (Jutel, 2009:278).

Several reasons, however, exist for a delay in diagnosis. Sheppard, Kumar, Buckley, Shaw and Raza (2007:1577) stipulate that a delay in diagnosis can be due to a delay in the patient reporting it to a family practitioner. Arthritis is an example of a chronic condition where self-reporting might be influenced due to a lack of knowledge and understanding of the condition (Gill et al., 2010:174). Once at the family practitioner, a further delay may be experienced when the referral is made to the specialist, and then when the patient waits to be evaluated, eventually, by the rheumatologist (Sheppard et al., 2007:1577).

In the context of both the systems theory and the bio-psychosocial framework, it is evident that making a diagnosis is not just a linear process of cause and effect. Several factors influence the process, for example, getting to a medical professional, reporting the symptoms and getting to a specialist to evaluate and confirm a diagnosis. This thus supports Green's (2008:168) viewpoint that a patient system interacts with the environment; which in this case can be the general practitioner and the rheumatologist and during this interaction, there may be a change in symptoms. The change in symptoms can further be related to systemic influences, for example physiological changes, environmental factors and or any other systemic variable. Within the bio-psychosocial framework, a patient's disease process is influenced by biological, psychological and social factors (Somers et al., 2012:502).

Matthee (2008:11) reports that repetitive doctor visits, as shared by the above participants, without receiving an official diagnosis, create feelings of self-doubt and confusion. The emotions experienced by the participant can thus be explained at the hand of the bio-psychosocial framework (Engel, 1980:535-543). The symptoms experienced by the participants (biological processes) which are not diagnosed properly cause feelings of self-doubt and confusion (psychological process) which can eventually lead to rejection by members of the community (social processes).

A conclusion can thus be made that even though patients' experience physiological symptoms, several factors can influence an ultimate diagnostic process, but the lack of a proper diagnosis, can also lead to psychological and social dysfunction which

may once again have an impact on the biologic responses, for example, high blood pressure.

In the above paragraphs, the reader was guided through a discussion on the symptoms that lead to an arthritis diagnosis. In sub-theme 1.2, the reader will develop an understanding that arthritis patients may experience a decrease in symptoms during pregnancy.

Sub-theme 1.2: Arthritis symptoms experienced during pregnancy

From the data, it became evident that patients may experience a decrease in disease activity during pregnancy. The participants explained the connection between arthritis symptoms and pregnancy as follows:

“Wel, kyk toe ek swanger geraak het, het ek mmm...’cortisone goeters’ aangehou, maar dit is asof die siekte heeltemaal in remissie gaan as jy swanger is. Dis die wonderlikste nege maande...” / [“When I fell pregnant, I carried on with cortisone stuff, but it is as if the disease goes into remission when you are pregnant. It is the best nine months...”].

“...ek dink ... was nog half in ‘denial’ toe ek swanger is en pyn gaan weg, en toe dink ek dalk miskien is hulle verkeerd gewees en toe ‘eventually’, ek dink die tweeling was ‘n paar maande, twee of drie maande oud, toe ek nou agterkom, nee, ek sal maar moet terugkom [sic] na die dokter toe en die medikasie weer gebruik en alles en so...” / [“I think ... was in complete denial when I was pregnant, even to such an extent that I thought the diagnosis was incorrect. It was about two or three months after the twins’ birth that I realised that I will have to go back to the doctor and use the medication and so on...”].

The above data bring to light that patients can experience a decrease in arthritis symptoms during pregnancy. Literature confirms that patients experience a reduction in disease activity during pregnancy (Østensen and Villiger, 2007). In a prospective nationwide longitudinal study conducted in the Netherlands amongst 84 RA females who had not yet conceived or were in the early stage of pregnancy, De Man, Dolhain, Van de Geijn; Willemsen and Hazes (2008:1241-1248) evaluated the patients’ disease activity before, during and after pregnancy. The results indicated that disease activity indeed shows a decrease during pregnancy but increases again after the delivery (De Man et al., 2008:1241). Patients experience changes in their immune system during pregnancy in order to assist the foetus to develop and grow.

Some of these changes may contribute to the decrease in arthritis symptoms during pregnancy (Patient information..., [sa]).

The data gathered during the research indicate that a reduction in the symptoms associated with arthritis may even be so intense that patients may speculate whether the disease is actually present.

Considering the above information within the context of the bio-psychosocial framework, it can be understood that the patient system can experience a reduction in symptoms as it is influenced by several physiological processes during pregnancy which can affect a patient's physical and psychological experiences (Engel, 1980:534-543).

From the data it became evident that the participants were treated with both alternative methods and biologic medication. Sub-theme 1.3 provides an overview of the alternative treatment methods available to arthritis patients.

Sub-theme 1.3: Alternative treatment methods (other than biologic medication)

Several types of treatment options exist that might provide some relief to the symptoms experienced by an arthritis patient. Participants shared alternative methods for the treatment of arthritis that ranged from oral medication to UV lights.

“So then they tried all sorts of drugs. Methotrexate was awful, the worst thing imaginable, like having oral chemo therapy. Nausea, incredible nausea and according to my wife, I went yellow... So then there were other things he had me on, pain pills. I can't remember all the medication...cortisone was bad, it was horrible. It affected my eyesight ...”

“...UV en ek weet nie wat alles nie. Soos 'n bestraling, jy klim binne in die ding, dan brand hulle vir jou vir, sê hulle begin vir sê vir vyf minute en dan maak hulle die kursus al hoe langer. Naderhand staan jy 'n half uur onder daai ligte. Ek meen, dis in die middel van die winter, dan is jy bruin gebrand, né. Al wat werk vir daai goed is die son. Jy moet in die son kom, lat [sic] die son dit kan brand.” / [“UV and I don't know what else. It is like radiation. You get inside the thing and they burn you. You start for five minutes and they increase the time every session. Eventually you stand underneath the light for half an hour. I mean it's in the middle of the winter and you're tanned. The only thing that works for it is the sun, so that the sun can burn it”].

As per the above quotations, different treatment methods are available for the management of arthritic conditions. During the research, participants shared their most personal experiences pertaining to being on the receiving end of these treatment methods. For some, these experiences were rather unpleasant, however, they did acknowledge that they served a purpose.

As per the *Centers for Disease Control and Prevention* in the United States of America (Frequently asked..., [sa]) the main focus for the treatment of arthritis is to control the pain, limit joint damage and improve or maintain a patient's quality of life.

Several types of medication are available to manage the symptoms that are associated with arthritis. Treatment categories include pain relievers, anti-inflammatories, disease-modifying anti-rheumatic drugs (DMARD), biologics and corticosteroids. (Types of drugs, [sa]). Methotrexate is one example of a DMARD. The Arthritis Foundation of America advises that DMARD's are often slow but effective in slowing or modifying the disease process and are regularly associated with side effects, including nausea and vomiting (Drug guide: DMARDs, [sa]). Chronic medication thus plays an important part in the arthritis patient's day to day life (Kangesan, 2012:25).

Not only oral medications are used to treat the symptoms associated with arthritic conditions. In some conditions the use of alternative methods, like UV therapy is appropriate.

Matz (2010:73) defines phototherapy as follows:

...the use of nonionizing electromagnetic radiation for therapeutic purposes. The beneficial, as well as side effects associated with this approach, very much depend on the nature and distribution of endogenous absorbing molecules (known as chromophores) in the target tissues. Phototherapy of skin disease is mainly restricted to the use of ultraviolet (UV) radiation.

The use of UV lights, according to the literature, is called phototherapy or light therapy. The therapy involves the exposure of skin to ultraviolet light on a regular basis in order to slow the growth of affected skin cells (Phototherapy, [sa]).

The participants also shared that medical doctors often use different treatment options based on the effectiveness in terms of patients' response. Within the context

of the bio-psychosocial framework it can be explained that every patient is different and it can therefore not be expected that every patient will respond in the same manner to specific treatment. It can therefore be interpreted that a patient's response to treatment will be influenced by biological, psychological and social factors relevant to his/her context, which are all interlinked and can, therefore, not be viewed in isolation (Somers et al., 2012:502).

In the above paragraphs, the researcher focused on traditional methods of arthritis treatment, ranging from managing the symptoms to relieving pain. The discussion under sub-theme 1.4 will shift the focus to a more modern treatment of arthritis, which is biologic medication.

Sub-theme 1.4: Biologic medication

Several types of biologic medication are used to manage the different types of arthritic conditions. In the excerpts that follow, the reader will be exposed to some of the biologic medications prescribed for the treatment of arthritic conditions that the participants suffer from.

"...Sjoe, ek moet nou eers mooi dink. Ek het eers Revellex probeer. Dit voel so lank terug...die eerste keer het dit goed gewerk. Die tweede keer 'n bietjie minder en die derde keer absoluut niks... en toe was ek op Mabthera, en dit werk goed". / ["Sjoe, I should think first. I first tried Revellex. It feels so long ago. The first time it worked well. The second time a little less and the third time absolutely nothing...and then I went on Mabthera and it works well"].

"...then they came up with Humira and mmm, that has helped. It has taken a long time for it to make a difference ... I've taken one injection a week..."

The medications mentioned above are examples of biologic medication that are used in the treatment of different types of inflammatory arthritis (Pucino et al., 2006:19). Biologics, as per the participants' description, are seen as a drug that makes a difference in their overall ability to function as normally as possible. Biologics, as described by the American Arthritis Foundation (Drug guide...[sa]) are:

...medications genetically engineered from a living organism, such as a virus, gene or protein, to stimulate the body's natural response to infection and disease. Biologics target proteins, cells and pathways responsible for the symptoms and damage of rheumatoid arthritis and other types of inflammatory arthritis.

Modern biologic medication is reserved for patients that are unresponsive to traditional medication (Kangesan, 2012:22). The purpose of biologic medication include: reducing the signs and symptoms, limiting joint deterioration and improving the physical function and quality of life of the patient (Pucino et al., 2006:19).

Together with the research data and current literature, the researcher developed the understanding that biologics are a modern method of combatting the effect of arthritis. During the interviews, some patients shared that they had used more than one biologic medication up to the time of the study. In the South African Rheumatism Arthritis Association' Biologic Guidelines (SARAA) (2011), patients may experience adverse effects that can lead to a change in biologic medication; or the limited response to a biologic medication may warrant the use of another.

The researcher has thus developed the understanding that there are several treatment options for the management of arthritis. Relevant to sub-theme 1.3 and 1.4, is the bio-psychosocial framework that can assist the researcher to interpret the physical responses of patients to treatment as the biological component of the model. The emotional experiences can be seen as the psychological component of the model, and lastly the social component also acknowledges that the patient's social context and pressures could play a role in how they will respond to treatment (Waddel, 2006:58).

To put the above into perspective, the reader should acknowledge that the arthritis condition causes physiological processes within the patient's body that manifest in the form of symptoms which can be seen by others and experienced by the patient him/herself. Living with the condition leads to psychological responses which can be worsened by social pressures, for example, trying to complete normal activities. (Matthee, 2008:10-11). By receiving arthritis treatment, the aim is thus to reduce pain and limit joint damage (Frequently asked, [sa]) and this is done by addressing the physiological processes caused by arthritis. A reduction in arthritis may increase the patient's belief in the medication and may lead to the patient experiencing less social pressures as they are able to complete certain activities, for example, being employed. This may lead to the applicable treatment being more effective.

During the above two sub-themes, arthritis treatments (other than biological medication) as well as biologic medication were considered. During data analysis, it

became evident that disease education amongst medical staff is of paramount importance in order to improve the treatment of arthritis patients.

Sub-theme 1.5: Education of medical staff about arthritis

Not all medical professionals have the same knowledge of arthritic conditions. The participants shared some of their less positive experiences related to doctors and the arthritis diagnosis.

"...the doctors look at you like they don't believe what you're saying to them, or they think that you have alternative, other hidden agendas to why you're saying all these things and they don't believe you...actually I just gave up trying to go to the doctor...you unfortunately build up a mistrust towards doctors."

"...I think a lot of the doctors, mmm, especially the GP's, don't know much about AS [arthritis] at all, mmm, especially if you go in and say your knees are sore. They're not going to say it's a back problem. You know, that's a, you know, anyway, especially when you're going to the doctor and it's not sore anymore."

To be vulnerable by sharing private facts about their body, to a medical stranger and not being believed, reflects the voice of the above participants.

In a study where the *General Practice Research Database* in the United Kingdom was used to evaluate the use of disease modifying anti-rheumatic drugs (DMARD's) in RA patients, the result was that a large number of patients suffering from arthritis, and in this case, specifically, rheumatoid arthritis, are not being treated with DMARD's. This may have a long-term negative effect on the patient's joint status and the overall general health (Edwards, Arden, Fisher, Saperia, Reading, Van Staa & Cooper, 2005:1394).

The level of care in patients living with arthritis increases once they receive intervention from a rheumatologist. This is the view of Feldman, Bernatsky, Haggerty, Leffondré, Tousignant, Roy, Xiao, Zummer and Abrahamowicz (2007:1419). Feldman et al. (2008:1419) conducted a study in Québec to determine whether patients, suspected of having new-onset rheumatoid arthritis, consulted with a rheumatologist. Any delays in these consultations were documented and factors associated with prompt consultation were determined. Research data suggested that most of the patients suspected of having new-onset rheumatoid arthritis do not

receive rheumatology care (Feldman et al., 2007:1419). The researcher is thus of the understanding that these patients are not referred to the appropriate level of care.

Rosemann, Wensing, Joest, Backenstrass, Mahler and Szecsenyi (2006) are of the opinion that General Practitioners should focus more on disability and pain and on giving information about treatment, as these topics are not appropriately addressed.

The findings of the present study share an important message: constant failure leads to a person eventually giving up. The social pressures of a doctor not acknowledging the patient's awareness of what is going on with their body, causes a psychological response of rejection. A circular motion of constant sharing and rejection appears to eventually lead to a total mistrust in the medical profession.

A conclusion, based on the literature, can thus be made that arthritis patients receiving assistance from the first line of medical practitioners do not always get the most appropriate treatment and are not referred to the most appropriate level of care. The psychological effect on the patient may be that they will refrain from approaching medical doctors for any medical concern which may lead to critical life saving diagnosis to be missed. It can thus be concluded that there is a need to increase General Practitioners' knowledge of arthritic conditions which will lead to better treatment of the arthritis patient.

In the following paragraphs, the focus will be placed on the experience of patients living with arthritis and biologic medication.

THEME 2: LIVING WITH ARTHRITIS AND BIOLOGIC MEDICATION

Important information gathered from the data under this theme was the patients' perception of quality of life. The participants also experienced quality of life before and after biologic medication to play an important part when living with arthritis. Another important sub-theme identified was that of side effects due to biologic medication.

Sub-theme 2.1: What is quality of life?

How people define quality of life can differ one from another. The participants expressed how they perceive quality of life:

“Quality of life to me would be that you could do things for yourself. Obviously you’ve got to be healthy, have a little bit of money...I don’t say you’ve got to be rich. I don’t think that it is necessarily good quality of life. You’ve got to have enough money to be able to look after yourself efficient [sic], and you’ve got to be healthy enough to look after yourself and not rely on other people. Be self-sufficient I think is quality of life.”

“...jy weet, ek dink om net om baie gelukkig te wees met alles wat jy kan doen. Jy weet, ek dink nou sommer aan, kyk die advertensies op TV, van sê nou maar botter of iets, en daar draf die meisie en sy lyk so gesond en sy spring in die lug op die strand en weet gesond doen wat jy wil, maar dit is glad nie wat ek is nie. Weet ek is geswel, seer, sit op die bank. So kwaliteit van lewe vir my ek dink is beweeglikheid, mmm, leef tot jou volle potensiaal.” / [“...you know, I think just to be very happy with everything that you can do. You know, I now think about the advertisement on TV, say about butter or something, and the girl runs and she appears to be so healthy and she jumps in the air on the beach and you know, healthy, do what you want to. That is completely not what I am. You know, I sit on the couch. I am swollen and sore. Quality of life for me I think is to live to one’s fullest potential”].

From the personal framework of two participants comes a true reflection of what opinion about quality of life entails. On the one hand quality of life is to be healthy enough in order to be self-sufficient and on the other hand, even though you are not completely healthy, quality of life is still to be able to live to your fullest potential.

Garip et al. (2011:769) explain this phenomenon by defining quality of life as the gratification taken from life, the happiness as well as perceiving their specific unique situation from the context of their culture and values. Quality of life encompasses physical, social, emotional, cognitive and spiritual components, which thus makes it a positive, multi-dimensional and integrative construct. The patient’s meaning of quality of life is influenced by individual and social influences, as well as the context they may find themselves in (Gill et al., 2013:32).

From the above it is evident that culture and values differ from person to person and the way they influence a person will thus vary. According to Engel (1980:535-543), this phenomenon can be understood by acknowledging that a person’s personal experience within a social context creates a certain amount of pressure and

experience which may lead to a point where the patient develops a personal understanding of what they see the own quality of life to be.

During sub-theme 2.1, it became clear that every person has a different conceptualisation of 'quality of life', and that several factors influence how a person interprets their own quality of life to be. Sub-theme 2.2 will describe how living without biologic medication influences an arthritis patient's quality of life.

Sub-theme 2.2: Life before biologic medication

Life is often full of challenges and, for those living with arthritis, the reality is even worse. In the following quotations, participants share how life was for them without biologic medication.

"Ek't baie gehuil, want mmm die pyn was baie erg, maar ek het baie gehuil vir die feit dat jy voel so hulpeloos jy weet, want jy't baie seer, want as jy loop dis 'n stadige loop. Op 'n stadium hier by die werk, ek het so gelag. As ek nou daaraan dink, lag ek, maar hulle het my op so stoel gesit, dan stoot hulle my toilet toe, oralste [sic], want ek kon net nie loop nie. Regtig waar, ek kon nie. Dit was net vir my verskriklik erg." / ["I cried a lot, because of the severe pain, but I cried for the fact of feeling so helpless you know, because when you walk it's so slow. At a stage here at work, I laughed so much. If I think about it now, I laugh, but they put me on an office chair and pushed me to the toilet, everywhere, because I could not walk]."

"...I used to suffer a lot more with regards to mmm getting out of bed and your day to day activities you know. Your day to day activities just turning a faucet or washing your hair or something like that but it, you get, it's not pleasant. It takes you a little bit longer to get out of bed because you got to wait for your joints to warm up you know, all of that..."

As shared by the participants, living with arthritis is much more than that what meets the eye. Crying due to the pain is indicative of the emotional responses experienced by patients living with arthritic conditions (Managing..., [sa]). From the biopsychosocial framework it can be understood that the physical pain leads to an emotional response. This can cause further emotional turmoil as some cultures do not see crying as being socially acceptable which, within the context of the said framework, can be seen as a social stressor (Engel, 1980:535-543).

The data further stress that pain in itself is a problem. Pain, disease activity and functional status are some of the factors that can affect a patients' quality of life

negatively (Garip et al., 2010). In a study with twenty three patients suffering from rheumatoid arthritis, focus group interviews were conducted in order to determine the impact of arthritis on the daily life of the patient. The patients were randomly selected from 47 eligible patients (based on selection criteria) who were involved in a longitudinal study that focused on the treatment and follow-up of patients recently diagnosed with RA at the Department of Rheumatology, Sahlgrenska University Hospital in Mölndal, Sweden (Lütze and Archenholtz, 2007:68). Lütze and Archenholtz (2007:68) established that arthritis had a negative impact on a patient's whole life situation and affected the way they completed many of their activities of daily living. This is confirmed by the above quotations where the patients could not walk to the toilet due to the severe arthritis pain. The patient had to depend on others to push her to the toilet in order to complete a basic physiological activity.

Marks and Allegrante (2007:6) specify that functional limitations caused by arthritis may include, but are not necessarily limited to, daily activities such as bending, kneeling, dressing, toileting and bathing. The research data confirm the above by reporting that the basic activities of going to the toilet, getting out of bed and even washing one's hair is affected by the disease.

When considering the effect of arthritis on a patient's overall functioning, Engel's (1980:535-543) bio-psychosocial framework can be practically understood. When a patient is being diagnosed with arthritis, he/she does not only carry the label of an illness. The disease subsequently affects the patient's ability to complete daily activities of living as described above which can cause both psychological as well as social problems. If a person cannot perform socially acceptable behaviour, for example cleaning the house or preparing meals, further psychological stress can be experienced which may also lead to physiological disturbances of diseases.

During the discussion under sub-theme 2.2, it became evident that arthritis affects many facets of a patient's life. Sub-theme 2.3 will describe whether biologic medication brings about change in a patient's quality of life.

Sub-theme 2.3: Life with biologic medication

In the following quotations the reader is introduced to three participants who have experienced a change in their quality of life since they have been receiving biologic medication.

"I've been on it for about six years now...ya, it's really made a huge difference. So I take it, once or twice a month and two or three days before I'm supposed to take it, I can really feel I need to have an injection, so I mean, even though it has eliminated the pain completely, obviously not because there has been mmm, erosion in the joints from before I've starting taking it, that was for about 24 years that I've had arthritis before I started, so there is actually damage there, which, that is not going to go away, but mmm yah, generally you know, I can go to gym, I can walk on the treadmill, mmm I can use a theroband, for as before I couldn't even use a theroband... I can cycle now, you know I can do lot of things that I wasn't able to do beforehand without having my knees swell up and hurting or anything like that, so that's made a really huge difference."

"...dit verander jou manier van dink. Mmm, jy voel skielik weer of jy kans sien vir die lewe, want dit vat die, vir my was dit die moegheid, die lamheid, mmm...die lelik vat hy weg. So dit is nie meer so duidelik nie. Jy voel nie meer of die, hierdie meulsteun om die die nek is die heelyd saam met jouself saamdra nie. Mmm, dis minder sigbaar vir ander mense so jy voel jy kan beter cope daarmee. Mmm, dit maak net die lewe aansienlik makliker. Mmm, die manier hoe jy dink, die manier hoe jy voel." / ["...it changes the way you think. Mmm, you feel you can face life's challenges again. It eliminates the feelings of fatigue which isn't that obvious anymore. You don't feel as if you're carrying this millstone around your neck all the time. Mmm, it's less visible to other people so you feel you can cope better with it. Mmm, it makes life extremely easier. Mmm, the way you think and feel"].

"I don't have 'flair ups' anymore. Obviously, I experience the odd pain here and there, mmm, I can do a lot more than what I was able to do before, mmm. So it definitely has changed my quality of life. Sometimes even changing the gear of my car was a mission and holding a telephone to my ear was a mission, you know mmm and ever since the Humira, it's just been amazing, it really has made a huge difference."

Through the voices of the participants, the reader realises that the biologic medication has brought about change in the levels of pain, fatigue and disability experienced by the arthritis sufferer.

Activities that previously seemed impossible are often possible due to the use of biological medication. A possible conclusion that can be made, based on the above quotations, is that the patients have much more social freedom due to their ability to be more visible in the community, for example visiting the gym. Psychologically, the patients feel empowered as they can experience the ability to face life's challenges. Biologically, the patients experience an improvement in their physical health as they

suffer less from “flair ups” associated with the arthritis condition. The biological, psychological and social aspects, as per Engel (1980:535-543), conclude who we are as human beings.

Theoretically, Pucino et al., (2006:19) agree with the above by reporting that experimental and clinical studies have established that biologic agents reduce signs and symptoms of arthritis, slow radiographic progression of the disease and ultimately improve the physical functioning and quality of life of those treated with the medication. The outcomes for patients treated with biologic agents, therefore do appear to show improvement (Pollard et al., 2005:43).

Sub-theme 2.4 will, however, provide evidence that not everything is positive about biologic medication and that adverse effects do appear.

Sub-theme 2.4: Side effects of biologic medication

The following quote introduces a testimony from a patient who underwent surgical procedures and developed meningitis which could not be cleared at first.

“... toe kry ek nou in 2007 weer ‘n rugoperasie en toe vermoed ek in teater het ek breinvliesontsteking gekry, want hoekom ek dink dit was in die teater, is twee dae nadat ek uit die teater uit gekom het, toe kom ek agter iets is nie reg met my nie. Maar ek is toe uit die hospitaal uit ontslaan en ek is toe nou huis toe, maar toe begin ek siek word. Mmm...die simptome is maar soos griep en in en uit na die huisdokter toe en so na ‘n week of wat, toe mmm...toe is ek baie siek. Toe moes hulle my met ‘n ambulans van [naam van die dorp] af deurvat na [naam van hospitaal] toe. Toe is ek nou siek, en toe het hulle baie gesukkel om hierdie breinvliesontsteking onder beheer te kry, want jou normale behandeling vir breinvliesontsteking, is mmm...ek het die nie-aansteeklike een gehad, so weet, maar ‘anyway’, dis nog steeds erg... Die standaard behandeling is maar twee weke antibiotika in die hospitaal en dan stuur hulle jou huis toe, wat hulle toe nou ook gedoen het, maar binne vyf dae was ek weer terug in die hospitaal. Toe kry hulle dit nie opgeklaar nie, en toe is ek op die ou einde, twee maande in die hospitaal met dit wat hulle dit nie, uh...kon, die rede vind hoekom dit nie wil opklaar nie, met die medikasie nie, jy weet. Toe mmm...in die hospitaal was ek onder die behandeling van ‘n... internis...en hy het toe begin om te wonder of dit nie die Revellex is wat dit veroorsaak het nie. Want ek het die Revellex voor dit gebruik, jy weet en omdat hulle geen ander rede kry nie, het hulle tot sover gegaan om my sinuskanale ‘te check’ tussen my brein en my sinuskanale en ‘als [sic] om te sien of daar nie ‘n lekkasie is jy weet, dat daar, dat die bakterieë deur die sinusholtes in die brein ingaan en aanhou ingaan of so...so hulle het als [sic] probeer. Weet, ek het ‘lumber punctures’ gehad, elke week en ek het toe mmm...en uiteindelik toe het hy so half tot die slotsom gekom dit moet maar die Revellex wees.” / *[“...in 2007 I underwent a back operation aain and I suspected that I contracted meningitis in theatre. I suspect it was in theatre because two days after I came out of theatre I realised that something was not right. I was however discharged from hospital and went home but that is when I became ill.*

Mmm ...the symptoms are very flu like. I went in and out of the house doctor but after a week or so I became very ill. They transported me to hospital in an ambulance. At hospital they struggled to get the meningitis under control, because the normal treatment for meningitis, mmm, I did not have the contagious one but it was still bad. The standard treatment is two weeks of antibiotics in hospital after which they discharge you home. This happened to me but I was re-admitted into hospital after five days. They could not get it cleared and I ended up being in hospital for two months. They just could not determine the reason for the meningitis not clearing, you know. In hospital I was under the management of a physician and he started wondering if it isn't the Revellex that is causing it. I was using Revellex before you know, and because they couldn't find the exact reason, they even went as far as checking whether the sinus channels between my brain and the sinuses aren't leaking in order to check whether the bacteria aren't going to the brain via the sinuses. You know, I had weekly lumbar punctures and eventually I got to the conclusion that it must be the Revellex"].

During sub-theme 2.3, the data indicated the positive results participants associated with the different biologic arthritis medication. In sub-theme 2.4, the opposite was highlighted. From the above excerpt it can be understood the medical staff were of the opinion that the biologic medication was possibly preventing the patient being cured from the infection which caused the meningitis.

Among patients suffering from arthritis, biologic agents are associated with opportunistic infections, such as tuberculosis and herpes virus-related infections. Research does not provide adequate results that biologics are associated with an increased risk of fungal infections or *Pneumocystis Jirovecii* pneumonia (Kourbeti, Ziakas & Mylonakis, 2014). A limited number of incidents of heart failure and demyelinating disease have also been reported (Nurmohamed & Dijkmans, 2005:662).

According to compiled information from the *Food & Drug Administration* in the United States, social media and MedsFacts user submissions between January 2004 and October 2012 only one incident of a patient on Infliximab was associated with meningitis (MedsFacts..., [sa]).

Going further than the above example and considering future safety of biologic medication it can be understood that, currently, limited information is available to evaluate the long-term safety of biologic agents in the treatment of arthritis conditions (Nurmohamed & Dijkmans, 2005:662).

Within the bio-psychosocial framework, a patient's disease process is influenced by biological, psychological and social factors (Somers et al., 2012:502). This is similar to systems and sub-systems that are interlinked within the context of the general systems theory (Goldenberg & Goldenberg, 2004:508). According to Lane (2014) biological, psychological and social factors are different parts incorporated into a whole. The above phenomenon can thus be explained by not considering the disease manifestation purely because of biophysical reasons isolated from social behaviour. The patient should be evaluated as a whole (Friedman & Downey, 2012:372). It can therefore be understood that the patient's disease process can be influenced by considering the psychological and social influences.

In Theme 3 the focus will turn to arthritis and interpersonal relationships and how they interact.

THEME 3: ARTHRITIS AND INTERPERSONAL RELATIONSHIPS: HOW THEY INTERACT

During the data analysis process it was identified that family and friends are influenced by an arthritis diagnosis. It is further affected by a patient accepting and dealing with the diagnosis. Very important relationships in the life of arthritis patients include their relationship with the medical doctor as well as support from their significant others.

Sub-theme 3.1: Family and friends influenced by diagnosis

From the research data below, the reader can develop the understanding that family and friends play a very important role in the survival of an arthritis patient. The reader will be introduced to patients that could not survive without the help of friends and family.

“So, dit was vir my baie sleg dat ek nie, weet, die kinders. Ek het verskriklik gesukkel om die kinders te kry waar hulle moes wees, skool toe en huis toe en sport toe en dit. Weet ek moes staatmaak op ander mense of vriende of my suster of wat ookal so dit het hulle nogal sleg beïnvloed. Ek het nogal die tendens om hulle te beskerm daarteen, hulle besef nie en sukkel om als [sic] gereël te kry, weet en hulle besef nie eintlik hoe siek ek is nie en ek verkies dit

so.” / [“I struggled extremely to get the children where they needed to be. I had to rely on family and friends. I tried to protect them, so that they didn’t really know how sick I was”].

”Want skielik, ja jou wederhelfte, jou man sorg vir jou by die huis, maar dit, jy’s daar en skielik word ’n ou se hele lewe nou weer verander, want jy’s nou weer in die hospitaal... Ek kon sien dis ook nie vir hom lekker nie, weet want dis ook nie lekker om ’n vrou te hê wat in die hospitaal is, uit die hospitaal uit, ‘moan en groan’ by die huis sy het seer. Sy kan nie dit, sy kan nie dat. So dis ’n groot effek op hom ook gewees. Hy sal dit nie sommer vir my sê nie, maar ek kan mos sien.” / [“Because suddenly, you husband cares for you, but it, you are there and suddenly one’s life changes again as you are back in hospital. I could see that I wasn’t pleasant for him having a wife that was in and out of hospital, moan and groan at home that she is in pain. She can’t do this, she can’t do that. So it had a major impact on him. He wouldn’t share it with me, but I could see it”].

”Dan sit jy met skilfers...jy krap heeldag. Dit lyk of jy flippen rabies [sic] het of iets want jy krap heel dag. Dan sê my vrou vir my, moenie krap nie, hou op krap, maar sommer so, terwyl ’n mens praat, sit en krap jy heeltyd. Jy dink nie eers daaraan nie, jy sit net en krap. Ons het naderhand die ‘vacume cleaner’ in the kamer gehad. As jy opstaan in die oggend, dan suig jy dit vinnig op met die ‘vacuum cleaner’.” / [“You sit with dandruff, and scratch the whole day. My wife would tell me to stop, but even amongst people, without thinking about it, you scratch. We had the vacuum cleaner in the room, so that you can clean the room when you wake up in the morning.”].

“...my man moes die vrou en die man in die huis wees. Ek kon nie self bad nie, ek kon nie aantrek nie...” / [“...my husband had to be the wife and husband in the household. I couldn’t bath, nor dress myself”].

The message shared by the participants is that a patient seldom suffers in isolation. As explained by Goldenberg and Goldenberg (2004:508), a system consists of different parts and the whole is greater than the sum of its parts. It can be understood, in the context of the above data, that each participant has a life, family and household which are all interlinked. The parts cannot be separated, meaning that the patient cannot be married and not have a household.

Lütze and Archenholtz (2007:68) agree that arthritic conditions do not affect only the patient, but also their family and friends and those around them. The above quotes show that family and friends need to accommodate the arthritis patient in their schedule, either by driving children around or by physically taking over the running of the household. In a focus group study conducted with 23 arthritis patients selected from a longitudinal study at the Department of Rheumatology, Sahlgrenska University Hospital in Mölndal, Sweden, Lütze and Archenholtz, (2007:68) established that patients often experience a change of role positions in the family due to their inability to complete certain important functions within the household.

Human beings experience different roles and responsibilities, for example being a parent, spouse, and employee (Lütze & Archenholtz, 2007:68). As an arthritis patient completing those roles and responsibilities is often influenced by how you feel, how fatigued you are in terms of your condition and how much support you have around you (Backman, Del Fabro Smith, Smith, Montie & Suto, 2007:382).

The above sub-theme can be concluded by considering that the patient's biophysical condition (arthritis) affects their psychological and social functioning as described by the bio-psychosocial framework. When a patient is sick, the way he feels and interacts with others around him/her is affected (Engel, 1980:535-543).

From the above information, it is evident that arthritis affects the patient systems but also other systems influenced by the patient. It is therefore critical that those living with arthritis be supported.

Sub-theme 3.2: Support those living with arthritis

Living with a chronic illness, such as arthritis, is easier with the support of others than living with it alone. In the following quotations, the participants share the importance of support.

"...they were kind of very supportive. No one made me feel left out or anything. I had a great group of friends. I still do have a great group of friends..."

"...my verloofde het vir my 'n rolstoel gekoop wat soos 'n kampstoel werk. Jy vou hom op en sit hom in 'n sak. So as ons na 'stars in the park' gaan en daai tipe goed gaan, waar ons baie gaan stap, dan vat ons die rolstoel saam en dan ry ek in die rolstoel. Dan bly ek nog steeds saam met hulle, ek doen nog steeds alles saam met hulle, maar wanneer ek nou voel dit raak te veel, ek kan nou nie meer loop nie, dan is daar 'n alternatief. So almal het maar aangepas. Mmm, hulle weet hoe ver ek kan ... as ek sê ek kan nou nie meer nie, dan weet hulle dis nou tyd." / ["...my fiancé bought me a wheelchair that works similar to a camping char. You fold it up and it fits in a bag. So if we go to stars in the park and that type of thing where we walk, then we taking the wheelchair along en then I would ride along in the chair. I still remain with them, I still do things with them, but when I feel it becomes too much, I can't anymore, and then there is an alternative. Every one adjusted. They know how far I can ... when I say I can't anymore, then they know that it is time"].

The data above share the message that life cannot be normal when you live with a chronic condition, such as arthritis. Walking long distances should not normally be a

problem, but for an arthritis sufferer, it can be a problem. In order to feel like a “normal” person and to fit into society, certain adjustments need to be made from time to time. Within the context of the above example, the social systems responded to the physical problem of the participant by adjusting and providing a support function. The participants were never allowed to feel as though they were managing the condition on their own. In the first quotation it is apparent that the participant’s friends were very supportive and never allowed the person to feel left out. In the second quotation it becomes clear that the participant’s family accepted that the person could not walk long distances and needed a fold up wheelchair. The important message that may be taken from the examples is that, despite their condition, the patient is still being acknowledged and they are still seen as being important.

From a theoretical context it is evident that a patient system cannot function in isolation and is dependent on interaction with the environment (Green, 2008:168). The patient system can, however, be unpredictable as patients can walk at one moment and at another they cannot. Simpson, Franks, Morrison and Lempp (2005:887) therefore reiterate the importance of family, friends and professional support.

In the above paragraphs the focus was placed on the impact the arthritis condition has on family and friends and that an arthritis patient depends on family and friends for support. Another relationship that is crucial in the life of an arthritis patient is the doctor-patient relationship.

Sub-theme 3.3: Doctor-patient relationship

Every person needs to know that they can trust their doctor. The following participants shared their feelings surrounding their perceptions related to the doctor-patient relationship.

“Ja, dit moet iemand wees wat jy rerig voel, dra jou belange op die hart... Mmm, so partykeer is dit vir my half ‘n riem onder die hart om te kan sien dis vir haar so belangrik dat, dit frustreer my, maar dis nou maar iets waarmee ek moet saamleef, want dit frustreer haar ook, want sy wil help en dinge wil net nie in plek val nie.” / [“It is often very comforting to know that the fact that you’re not getting

better, also frustrates her. She wants to help you but things do not want to fall in place”].

“...ek onthou van, sy wou my op ‘n mmm, toetsmiddel gesit het, toe die...Revellex nie gewerk het nie en toe het sy al die toetse gedoen en al die vraelyste ingevul, pakke en pakke papierwerk wat ons moes doen en toe sê hulle my vlakke van inflammasie is nie hoog genoeg nie en ek onthou daai dag, sy was verskriklik ongelukkig. Sy sê sy kan sien hoe erg is die inflammasie, sy kan die bloedtoetse sien, maar nou sê die mense ek is nie erg genoeg nie...” / [“I remember, when the Revellex didn’t work, she wanted to put me on a test drug. After she completed all the relevant documentation, she was told that I was not sick enough. I can remember how angry she was”].

From the above data it is evident that the concept of doctor-patient relationship is of great importance in the participants’ patient process. A sense of belonging is experienced in the participant’s relationship with their doctor.

The concept of doctor-patient relationship has gone through a process of metamorphoses over the past couple of years (Kaba & Sooriakumaran, 2007:57). It used to be the perception that patients were too ignorant to make decisions on their own behalf; and therefore doctors felt comfortable in making decisions for their patients. There developed a great divide between patient and doctor (Kaba & Sooriakumaran, 2007:64).

The research data, however, describe a picture of a medical doctor that sees the patient as a unique human being that believes in co-operation rather than confrontation (Balint, 1969:269). Kaba and Sooriakumaran (2007:65) report that with a patient-centred care approach, both parties share a sense of responsibility. The patient and not the illness should be the primary focus of medicine, this meaning that the doctor should listen to the patient in order to identify the actual problem instead of just prompting a list of signs and symptoms. When decision making is shared between patient and doctor the most appropriate treatment approach, applicable to the patient’s unique situation, will be identified. In the quotations provided above, the doctor is the bridge between medicine and the unique experiences and needs of the patient (Balint, 1969:269-276). Both patient and doctor are systems and interact with one another. They also have a reciprocal responsibility towards one another (Green, 2008:172).

The above data reiterate the importance of a good doctor-patient relationship. Patients also have a very important role to play in supporting one another and this will be discussed under sub-theme 3.4.

Sub-theme 3.4: Support provided by patients also suffering from arthritis

Everyone has a need to learn. In the following quotations, the participants share their opinion on the topic of support provided by patients also suffering from arthritis.

“Mmm, en veral [naam van hospitaal] hospitaal, as jy soheentoe gaan, mmm. Die susters is verkliklik ondersteunend, mmm, baie oulike susters en jy ontmoet ander wat in dieselfde bootjie as jy is. Party het lupus, party het ook ‘rheumatoid’. Daar is soveel verskillende tipes arthritis dat jy ontmoet mense wat nog nooit gehoor het. Dan gesels jy met hulle. O, genade, hoe voel jy en weet, jy kry verkliklike netwerk. Al sien jy daai mense nooit weer nie, dit is iets wat jy geleer het. Partykeer sien jy die mense oor en oor, so jy vorm naderhand ‘n band met hierdie mense wat verstaan. Mmm, want as jy met iemand gaan gesels wat nie dieselfde siekte het nie, of wat nie deur pyn gaan elke dag nie, ag siestog, ‘shame’, maar hulle verstaan nie. As jy met iemand praat, deur dieselfde gaan, dan dink jy maar ek kan vir hierdie ou iets positiefs sê wat my gehelp het en daai tannie sê weer iets wat jou kan help. Jy leer die heelyd bymekaar...” / [“Mmm, and especially [name of hospital] Hospital, when you go there, mmm. The sisters are extremely supportive, mmm, very nice sisters and you meet others that are in a similar position that yourself. Some have lupus, others also have rheumatoid. That are such a lot of different types of arthritis that you meet people that you have never heard about. Then you chat to them. O my goodness, how do you feel, and you know, you develop an amazing network. Even if you don’t see the people again, it is something you have learnt. Sometimes you see the people over and over again and you form a bond with these people that understand. Mmm, because if you go and chat to someone that hasn’t got the disease or doesn’t live with pain every day, ag shame, but they don’t understand. If you go and speak to someone that goes through the same, then you think I can say something positive to this person that have helped me and that person says something that can again help you. You learn from one another all the time...”].

“...nie net vir wanneer ek dit nodig het nie, maar ook te voel dat, dit gaan nou snaaks klink, maar my pyn en lyding nie verniet is nie. Mmm, dat ek iets kan teruggee, want in hierdie 14 jaar moes ek êrens langs die pad iets geleer het, so om dit te kan gebruik en vir ander mense te kan teruggee, want dit is wat vir my die lewe die moeite werd maak, is om te kan teruggee...” / [“...so that I can share what I have learnt and experienced over the past 14 years. That is what makes life worthwhile”].

A common denominator amongst patients living with arthritis is the disease itself. A theme that runs through a lot of research is that arthritis has a major impact on a patient’s life (Lütze & Archenholtz, 2007:64) and by living with the disease the patient becomes an expert in the field. The above excerpts show that patients find it

rewarding to share their knowledge but also have the need to learn from one another. Living with a condition thus allows the patient to accumulate a level of experience and expertise that they would like to share with others. By meeting other patients with more knowledge and experience than themselves allows the patient to share, for example, coping techniques which allows patients to be better equipped on how to survive (Lütze & Archenholtz, 2007:67).

The need for patient support programmes thus exist among the research participants, based on the above excerpt. This will allow newly diagnosed arthritis patients to learn survival techniques, and also receive psychosocial support at the same time (Lütze & Archenholtz, 2007:64). Literature confirms that arthritis patients need to be encouraged and to be involved in educational programmes, which will allow them to be exposed to others living with the same disease, thus creating the opportunity for patients to learn from one another (Grønning, Skomsvoll, Rannestad & Steinsbekk, 2012:113).

The bio-psychosocial framework allows the reader to understand that arthritis patients are all individual systems that, when put together, will again interlink with one another. Patients will naturally connect due to their disease being the common denominator and a level of acceptance will be experienced on a social level. Psychological and physiological knowledge will thus be shared due to its ability to interlink on a systemic level (Engel, 1980:535-543).

In the above paragraphs, the theme: arthritis and relationship: how they interact, as well as the sub-themes that followed, were discussed. In the discussion to follow, the research data related to arthritis and employment will be presented.

THEME 4: ARTHRITIS AND EMPLOYMENT

The participants shared that they often attempt to “hide” their condition or make adjustments in order to keep employment. They have shared that not all employers understand a condition like arthritis.

“I tried not to let it affect my job. I didn’t change my job, or do anything less physical because of it, so maybe, by saying that, I sort of, what’s the word, I’ve increased my pain threshold, maybe, I’ve...I know I’ve got a problem with it. I know it’s going to hurt if I do certain things and I’m careful not to do them, if that

makes sense? That's how I work around it...I know I can't jump of the fourth rung of a ladder. I need to go all the way down the ladder to get off, you know..."

"...wanneer ek by die werk was, was dit baie hard gewees om daar te wees...maar ek het dit weggesteek. Ek het nie dat dit 'n 'issue' by die werk word en uh...laat ek uh toegelaat dat dit my werk beïnvloed nie, so ek het maar so 'n bietjie van 'n front voorgehou ... 'n 'pose' gehou as jy dit so kan stel" / ["...it was often tough to be at work, but I always managed to hide it. I never allowed it to influence my work performance"].

"...I had an instance...about a month ago...was actually on the site already walking around with the foreman and their safety officer came up to me on the site and says what's wrong with your back? And I said no, I've got AS, stiff spine, you know. Other than that everything is fine. He then said, no you're disabled and you're not allowed on this site. I said no, I'm not disabled. I said I'm not registered disabled. I've got no stickers on me car and he said, no, no, no...with that condition, you are regarded as a partially disabled. He knew the condition...I thought you're a partially disabled individual and he...well I talked my way out of it, but wanted, basically to throw me off site..."

"Maar by my vorige werk het ek lank daar gewerk, 13 jaar en dit was een van die redes hoekom [sic] ek daar bedank het, want dit was 'n, 'n mens waarvoor ek gewerk het wat nie rerig simpatie of iets met ander mense het nie, so hulle was mmmm, hulle het half my 'gejudge' as ek moet gaan of hulle vertel daarvan en hulle het dit afgemaak asof ek niks makeer nie en jy weet, jy voel half asof jy, jy, jy voel skuldig omdat jy hierdie siekte het en jy moet hulle vra om by die dokter, of spesialis toe te gaan of iets. So ja, dit was moeilik daar gewees en dit was een van die redes hoekom ek daar weg is..." / ["I worked at my previous company for 13 years. One of the reasons that I left there was that I felt judged because of my disease. They made me feel as if there was nothing wrong with me and they made me feel guilty because of the disease. I always had to ask permission to go to the doctor."]

From the above research data, it can be understood that the arthritis patient has the need to be employed, even if they need to hide their disease from those around them. Some patients are open about their condition and make adjustments in the way they perform certain activities in order to retain employment. As with many in society, the above excerpts show that the arthritis patients are not protected from abuse in the work place.

In a study to evaluate the problems faced at work because of their arthritis, Lacaille, White, Backman and Gignac (2007:1269) established that patients are often reluctant to disclose or draw attention to their arthritic condition as it may cause discrimination and others may see it as favouritism if there is a level of accommodation because of the condition. In their study, conducted with 36 employed adults with inflammatory arthritis from rheumatology practices and outpatient arthritis treatment programmes in Vancouver patients also confirmed that

colleagues and employers seldom understand what it is like to live with a chronic arthritic condition (Lacaille et al., 2007:1269). This is confirmed by the above quotations. Patients tend to change employment if circumstances at work don't improve for the better.

Literature, however, also displays the other side of the coin where not all patients are able to continue working at the same level as they had envisaged before they became ill because of the impact the disease has on their overall functioning (Scott, Smith & Kingsley, 2005:117).

The conclusion can thus be made that the arthritis patient has the need to be employed, but their ability to perform all activities normally is often compromised and thus they often experience a level of discrimination at the office due to their disability. An explanation can be provided at the hand of the bio-psychosocial framework as set out in Engel (1980:535-543) and Waddell (2006:58). Physiologically the patient's disease creates a situation where they are different from others which may affect their ability to function normally in the workplace. The psychological need for feeling normal often forces the patient to make adjustments in order to just retain their employment. Socially the pressures are often so high to conform to normality, as viewed by others, that a change in work is often necessary.

A theme that appeared right throughout the data analysis process was physical activity and arthritis and is the focus of theme 5.

THEME 5: ARTHRITIS AND PHYSICAL ACTIVITY

Being diagnosed with arthritis does not mean the person should be less active. Participants shared their opinion surrounding arthritis and physical activity.

"...tell them it's good to exercise, mmm, a lot of swimming is nice. I would encourage people to be active in that sense, because if you can be, the more mmm ... ability you have during the day, mobility should I say, you'd have during the day and mmm, because you can feel very sorry for yourself and just curl up in a bed..."

"...hulle het ook op 'n stadium gestuur, daar by die universiteit, daar in [woonbuurt], daar was 'n warm water swembad vir 'aerobics' en daai tipe goete" / [... they also at a stage send me, there by the university, in a [neighbourhood], there was a hot water swimming pool for aerobics and that type of stuff].

“...ek kan nie in ‘n gym rerig iets doen behalwe swem nie...jy kan nie loop nie, jy kan nie draf nie, jy kan nie goed optel nie, ook niks doen nie, behalwe swem. So dis iets waarmee ek sukkel...” / [“...I can’t do much in the gym other than swimming. I can’t walk, run nor pick up anything. Just swimming. You can’t walk, run or pick up anything heavy, just swimming...”].

From the above data it became clear that both health professionals and patients themselves are of the opinion that it is important to remain active, even though one is diagnosed with an arthritic condition. As echoed by the above data, swimming is the recommended form of exercise for patients suffering from arthritis. Swimming is a non-weight bearing exercise that encourages joint mobility (Matthee, 2008:11).

In the TUFTS University Health & Nutritional letter (2010) patients suffering from arthritis are encouraged to stay physically active. Physical exercise allows the joints to move, thus preventing them from stiffening. During the physical activity, muscles around the joint strengthen thus protecting joints from rubbing against one another which can eventually, if not prevented, lead to wearing down of the cartilage around the joint.

In a study, 65 rheumatoid arthritis patients, of which 43 were female, were recruited from Rheumatology Outpatient Clinics of the Dudley Group of Hospitals NHS Trust, United Kingdom. In the evaluation of patients’ physical activity, it was found that inactive RA patients have a much higher risk of developing cardiovascular diseases than their active counterparts (Metsios, Stavropoulos-Kalinoglou, Panoulas, Wilson, Nevill, Koutedakis & Kitas, 2009:188). De Jong and Vliet Vlieland (2005:177) further report that moderate or high-intensity exercise amongst arthritis patients was found to improve the aerobic capacity, muscle strength, functional ability as well as a patients psychological well-being.

By remaining physically active, the physiological risk of complications can be better controlled. This may have positive psychological effects in the sense that the person remains positive due to endorphins that contribute to a “happy feeling”, being naturally produced and the levels of pain being controlled due to the strengthening of the muscles, thus preventing joints rubbing against joint which can cause pain. On a social level the patient will feel more accepted due to his/her ability to participate in normal activities (Engel, 1980:535-543).

Both literature and research data thus reiterate the importance and the health benefits of exercise, even when one is diagnosed with an arthritic condition.

In the following theme, the aspect of arthritis and medical aid will be addressed.

THEME 6: ARTHRITIS AND MEDICAL AID

From the data it became evident that arthritis impacts on several spheres of a patient's overall functioning. In the quotations that follow, patients expressed their opinion related to the topic of arthritis and medical aid.

“Dit was nou nogals 'n groot stap, want mmm, dis 'n groot gap wat jy ekstra moet betaal...en dis juis 'n tyd wat my man se werk besluit het hulle betaal niks meer as wat opgaan op die medies nie...ons moes die verskil, om op daai [sic] plan te kom betaal...so dit was nogal 'n groot stap gewees, maar as jy eers gewoon is daaraan en jy doen dit, dit was die moeite werd, so ons kan nooit afgaan van daai plan af nie. So ja, dit was 'n groot stap van ons. Moes baie doeke ook koop in daai tyd.” / [“It was a major step, because mmm, it was a big gap that you had to fund extra ... and it was the same time that my husband's employer decided not to subsidise more should you go onto a higher plan ... we had to pay the extra, so it was a big step but once you get used to it and you did it, it was worth it, so we can't go off the plan. So yes, it was a big step for us. We also had to buy nappies during that time.”].

“Nee, vir Humira spesifiek betaal my medies gelukkig, heeltemaal...weet soos ek gesê het, vandat ek begin werk het, is ek siek, so ons het nou nie spesiaal aanpassings gemaak, soos geld gaan leen of so iets nie, maar mmm, die mediese uitgawes vat 'n groot, geweldige hap uit ons begroting, definitief.” / [“No, my medical aid covers Humira completely. As I was sick ever since I have been working, I never had to make financial changes in order to afford the medical aid, however, it takes a lot of money from our budget”].

Based on the above data, research participants shared their indirect views that the cost of biologic treatment is very expensive. The above assumption is made based on the fact that participants refer to the need for medical aid funding of the medicine and that medical schemes further require members to be on a specific plan in order to qualify for the benefit from which the medication is funded.

Literature confirms that the medication is indeed expensive. As per Normohamed and Dijkmans (2005:661), the cost of biologic medicine, in the United States of America, ranged between \$US16000 (R176580.80) and \$US20000 (R220726.00),

per annum, in 2005. No current international or South African statistics are available.

A research report on the economics of treatment in early rheumatoid arthritis was published in 2009 and stated that biologic medication typically exceeds the cost of traditional anti-rheumatic approaches. It has also been proven that biologic medication is associated with positive outcomes, which may lead to fewer hospitalisations, fewer physician visits and an improved ability to remain employed which will reduce the incidence of disability. The end result can thus lead to overall cost saving (Bansback, Marra, Finckh & Anis, 2009:83).

The research participants are, however, of the opinion that they experience benefits on biological, psychological and social spheres due to the biological medication and are thus prepared to make adjustments in order to make the necessary financial provision in order to afford the medicine.

In the paragraphs that follow, recommendations from participants in relation to living with arthritis will be discussed.

THEME 7: RECOMMENDATIONS

During the research interviews, participants made their own recommendations on how to survive with an arthritis diagnosis. These recommendations are considered important as it could be used to tailor social work intervention for people living with arthritis.

“...soos wat ek sê, ‘n ou het nie ‘n keuse nie, jy moet maar daarmee saamleef en ja. Gaan na die beste dokter toe onder andere en kry die nodige medikasie om dit te te keer...moenie by ‘n huisdokter bly nie. Gaan na ‘n spesialis toe.” / [“...as I say, you need to live with it. Go to the best doctor and get the necessary medication. Go to a specialist, don’t stay at the family practitioner”].

“...om nie oor te gee nie. Nie gedefinieer te word deur die siekte wat jy het nie en om positief te bly.” / [“...don’t give up. Don’t be defined by the disease, but remain positive”].

“Arthritis will not define who I am.” This is the message shared by the above research data. It is evident that the biological condition, arthritis, can lead to a

psychological response. It is, however, a conscious decision whether the arthritis patient is going to allow the psychological response to be either positive or negative. According to the data, it is socially recommended that the most appropriate level of care should be sought and that the patient should not just remain at the general practitioner level. Seek assistance from a specialist.

Literature reiterates the same sentiment as the research data. Patients are encouraged not to allow the disease to define them as a person (Barhum, [sa]). Patients should learn how to live with the disease, therefore it is recommended that the patient should find appropriate medical assistance. The patient should take responsibility for their own fate. Look for a solution until he/she feels the problem has been addressed (Matthee, 2008:11).

3.4 SUMMARY

In this chapter, the researcher was exploring how arthritis patients experience the influence of arthritis on their quality of life since they started taking biologic arthritis medication.

This chapter presented an overview of the research methods which were utilised to undertake the empirical research of the study.

Subsequently, this chapter focused on the analysis and interpretation of the research findings. Through this chapter, the researcher presented the empirical findings gathered from individual interviews with 11 participants. The empirical findings were presented through seven main themes, namely: medical history from symptoms to treatment, living with arthritis and biologic medication, arthritis and relationships, how they interact, arthritis and employment, arthritis and physical activity, arthritis and medical aid, as well as recommendations.

Generally, the unpredictability of the disease came across as well as the impact arthritis has on the patient. Patients shared their stories from before they started taking biologic medication as well as how their lives have been transformed since they have started to use biologic medication. The data highlighted that all is not just

good about biologic medication, but that there are also side effects associated with the treatment. Patients also shared the need for patient support and the willingness to help others.

In the next chapter, the study will be summarised through the key findings. It will be determined whether the goal and objectives of the study were reached, and provide recommendations for, amongst others, social work intervention with arthritis patients and for future research on the topic of arthritis.

Chapter 4

Conclusions and recommendations

4.1 INTRODUCTION

This chapter concludes the research report. In this final chapter, the researcher will outline the research findings with regards to the quality of life of arthritis patients taking biologic medication. In presenting the empirical findings of this study, the researcher will indicate whether the goal and objectives of the study were accomplished and will thereafter answer the research question. The researcher will then proceed to present the key findings, conclusions and recommendations emanating from this study. Lastly, the chapter offers some recommendations for future research.

4.2 RESEARCH GOAL AND OBJECTIVES OF THE RESEARCH STUDY

The **goal** of the study was to explore and describe how arthritis patients experience the influence of arthritis on their quality of life after commencing with biologic arthritis medication.

This goal was achieved through the objectives that are outlined below, and the description of their respective accomplishments.

The **objectives** of the study were as follows:

- **Objective 1:** To conceptualise and describe arthritis, the treatment options, including the biologic arthritis medication and the influence of this disease on the quality of life of patients

This objective was achieved in Chapter 2 (see paragraphs 2.2, 2.3, 2.4 and 2.5) where the causes of arthritis, different types of arthritis, quality of life and the treatment of arthritis were discussed.

- **Objective 2:** To explore and describe the quality of life as experienced by arthritis patients while taking biologic arthritis medication

This objective is comprehensively addressed in Chapter 3 (see, amongst others, sub-theme 2.3). Following the data analysis process, the presentation and interpretation of the research findings highlight that quality of life, as experienced by patients suffering from arthritis, has improved since they have been taking biologic medication compared to the time before using this revolutionary treatment. The participants described their quality of life as follows:

- To be able to do things for oneself
 - To be self-sufficient
 - To live to one's fullest potential.
- **Objective 3:** To make conclusions and recommendations in order to enhance the field of social work intervention with arthritis patients

This objective is addressed throughout Chapter 3 (see Section B) under Themes 1 to 7. Following the data analysis process, the presentation and interpretation of the research findings highlighted that patients experience the negative influence of arthritis on their quality of life, since taking biologic arthritis medication, to have decreased compared to before they started taking biologic arthritis medication. These findings were interpreted by using the general systems theory and bio-psychosocial framework as theoretical frameworks. Detailed conclusions and recommendations are set out in Chapter 4 (see paragraph 4.3.2).

The study aimed to answer the **research question**, namely:

- ❖ What is the influence of biologic arthritis medication on the quality of life of arthritis patients?

Based on the patients' experiences, the influence of biologic arthritis medication on the quality of life of arthritis patients is:

- Since taking biologic medication, the arthritis patients experienced a reduction in their levels of pain, fatigue and disability
- Activities that previously seemed impossible are often possible due to the use of biologic medication
- Patients have much more social freedom due to their ability to be more visible in the community, for example visiting the gym
- Patients experience an improvement in their physical health as they suffer less from “flair ups” associated with the arthritis condition.

After answering the research question briefly, the attention of this chapter moves towards the key findings, conclusions and recommendations of this research study.

4.3 KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

The key findings, conclusions and recommendations that are listed below are the result of two sources of data, namely the literature review and the individual interviews with arthritis patients currently using biologic medication.

4.3.1 Literature review

(i) Key findings: literature review

The key findings as per the literature review are listed below:

- Arthritis is an inflammatory condition that affects both young and old
- There are over 100 different forms of arthritis
- Arthritis is a medical condition that affects the patient’s ability to complete certain activities, for example activities associated with daily living, such as bathing
- Arthritis affects the patients’ physical, psychological and social functioning mainly in a negative way
- Arthritis has an impact on both the patient and the community at large, for example it may limit the patient from being employed which increases the risk

for the patient to be dependent either on others for daily survival, or on government's social security (i.e., disability grant)

- Several risk factors have been identified that increase the risk for the development of arthritis, e.g. infection
- Currently no cure is available to eradicate any form of arthritis completely
- Different categories of arthritis treatments are available but the main aim of all treatment is to control the pain, limit joint damage and improve or maintain a patient's quality of life
- Types of treatment include: pain relievers, anti-inflammatories, disease-modifying anti-rheumatic drugs, corticosteroids and biologics
- Biologic medication is a modern form of arthritis treatment that is genetically engineered in laboratories
- Biologic medication reduces the signs and symptoms of the disease and reduces the radiographic deterioration of the joints
- Not all medical service providers share the same knowledge regarding arthritis
- Quality of life is a concept that differs from patient to patient and is influenced by their cultural and value system
- Biologic medication tends to improve a patient's quality of life
- Social workers play an integral role in the services provided to patients living with arthritis through different methods of service delivery which include individual counselling/case work, group work and community work.

(ii) Conclusions: literature review

The following conclusions are drawn from the literature review:

- All age groups are at risk for the development of the inflammatory condition called arthritis
- Arthritis affects all spheres of a patient's life, including the physical, social and psychological aspects
- In order to limit the impact arthritis has on society, arthritis management requires collaboration between the medical fraternity and civil society at large

- Biologic medication can be seen as a breakthrough in the treatment of arthritis as it reduces the signs and symptoms of the disease, as well as minimising the radiographic deterioration of the joints
- Quality of life is a construct defined by a patient's personal experience influenced by their own culture and values
- Social workers can utilise their knowledge and skills via the different social work methods in order to empower arthritis patients towards coping with their condition.

4.3.2 Arthritis patients: research participants

The next section will focus on the key findings, conclusions and recommendations from the individual interviews with arthritis patients (i.e. research participants).

(i) Key findings: arthritis patients

The key findings from the individual interviews with arthritis patients are listed below:

- Patients suffering from arthritis experience several signs and symptoms associated with the condition, such as pain and fatigue
- Arthritis patients often visit several medical practitioners, which may even be over a period of years, before an official diagnosis is made
- As per the patients' experience, arthritis signs and symptoms come and go as per disease activity
- Female participants reported the experience of a decrease in arthritis symptoms during pregnancy. These symptoms return again after delivery
- Several types of arthritis treatments are available for managing the arthritis condition ranging from traditional methods to biologic medication
- Patients often experience medical practitioners, especially general practitioners, to have a lack of knowledge pertaining to arthritis which causes a mistrust amongst patients towards medical practitioners in general
- The participants' view pertaining to quality of life is influenced by their frame of reference which differs from patient to patient, for example: for one participant it is important to be able to be healthy enough in order to be self-sufficient. For

another quality of life is, even though they are not healthy, to be able to live to his/her fullest potential

- The impact of arthritis is experienced in several spheres, ranging from the inability to complete daily activities like dressing and bathing and walking, to emotional turmoil due to pain
- Employment is important to make a person feel human. The research data indicated that participants will attempt to “hide” their condition or make adjustments at work to ensure retention of employment
- Patients often experience a lack of knowledge from the employer pertaining to arthritis which impacts negatively on the patients psychological functioning
- Biologic medication is seen as the miracle drug. The data of this study revealed that, with biologic medication, patients experience less fatigue, the pain symptoms are reduced and they are able to complete activities that were previously impossible, for example going to the gym or changing the gears of an automobile
- Side effects are also associated with biologic medication, such as the inability to be cured of meningitis which are assumed to be directly related to the use of biologic medication
- Family and friends are affected by the arthritis diagnosis, for example, some of the participants experienced immobility associated with their arthritis and therefore had to depend on family and friends to transport the children back and forth from school. This proves that family and friends often need to go out of their way to accommodate the patient
- Family and friends support is crucial in the life of an arthritis sufferer as it makes them feel included and not all alone. For example, one of the participants mentioned that it means the world to her if she can go out with her family, even though it sometimes means they need to push her around in a wheelchair
- Several relationships are important, especially that of the doctor-patient relationship, which specifically refers to the relationship they have with the medical practitioner. The participants felt strongly that they should know their medical practitioner takes their arthritis treatment seriously. One of the participants shared that the rheumatologist became so upset when approval

for a new test drug was declined because she could see how ill the patient was. Within this experience the patient felt that the rheumatologist showed a sense of compassion and care, which lead to a sense of belonging in the patient's relationship with the medical specialist

- A common denominator amongst patients living with arthritis is the disease itself. Patients find it beneficial to have a support system where they can network and learn from one another but also share how they manage to cope with the disease
- Arthritis patients are encouraged to participate in physical activity as it assists with mobility
- Biologic medication is very expensive and patients are reliant on medical aids for funding
- Based on the research data, it became evident that patients are encouraged not to let the disease define them but, in order to live with it, they need to seek help until the appropriate level of care are obtained.

(ii) Conclusions: arthritis patients

The following conclusions are drawn from the key findings pertaining to the arthritis patients:

- It appears that arthritis signs and symptoms are more prevalent during disease active periods and this negatively affects the medical practitioner's ability to make an arthritis diagnosis. Patients can therefore go years before an official diagnosis of arthritis has been made
- Patients may experience intermittent periods where there is a decrease in arthritis symptoms, for example, a female arthritis patient may experience less arthritis symptoms during pregnancy but may notice an increase in symptoms after delivery
- In order to ensure that arthritis patients have trust in medical professionals it seems imperative that health professionals, especially general practitioners, increase their knowledge related to arthritic conditions

- Quality of life is a variable construct which is affected by the patient's values and culture
- The effect of arthritis may be experienced in different facets of the patient's life. At home the patient may struggle to complete certain activities, but also at work they may need to adapt in order to retain employment
- Biologic medication may have positive and negative connotations, for example, the patient may suddenly be able to complete activities which they may never have been able to complete, but he/she may also experience side effects associated with the medication
- Support plays a vital role in the survival of an arthritis patient. Support may be experienced from different angles, for example: family and friends, doctor-patient relationship and support from other patients
- Patients can seldom afford biologic medication without the assistance of a medical aid
- Living with arthritis is often a conscious decision and may require the patient to participate in physical activities which increase joint mobility or the patient may need to persevere until they have received the necessary medical care.

(iii) Recommendations: arthritis patients

The following paragraphs indicate, based on the key findings and conclusions, the recommendations relevant to arthritis patients currently on biologic medication:

a. Recommendations for social work practice

- An awareness campaign, facilitated by social workers with experience in arthritic conditions, in collaboration with other health care workers is recommended in order to create awareness at different levels of society focusing on aspects such as:
 - Disease education, for example educating the community on signs and symptoms associated with arthritis
 - Where to go when a person suspects that he/she, or significant other, may suffer from arthritis

- To know what an arthritis diagnosis means, what it entails and what to do in order to cope better with an arthritis diagnosis
- What to do when significant others suffer from arthritis
- How to adapt the home, community and work place in order to enable the optimal functioning of the person with arthritis
- Social workers working in the field of arthritis should continuously strive toward improving the quality of life of arthritis patients they work with by setting up support networks and facilitating programmes that aim toward empowering those living with arthritis
- Social workers are encouraged to partner with rheumatology practices during which time social workers would be available to provide patients, even those who are newly diagnosed, with the necessary support. Social workers specialising in arthritic conditions could assist with disease education and individual counselling which may in turn lead to patients being empowered to manage/cope with their diagnosis better, which may lead to an improved quality of life
- Support groups are recommended for arthritis patients and their support system. These groups would mainly be targeted at arthritis patients and families with patients living with arthritis. These groups should ideally be facilitated by a social worker specialising in arthritic conditions. The aim of these groups should be to provide a safe environment where patients can experience a sense of belonging, but also where they can learn from one another and share their own experiences of living with arthritis. The social worker could facilitate a process of identifying the needs of the patients for further education, for example, legal aspects pertaining to arthritis and the work place and then source a professional to address the group. As the group grows, the social worker should empower patients within the group to take over the facilitation role; thus leading to a situation where patients take ownership of supporting their peers. The social worker could then assist with the establishment of more support groups, which could eventually lead to a network of arthritis support groups. The overall

vision is to equip arthritis patients with the necessary skills in order to improve their overall quality of life

- A “fit for life” programme is recommended. Due to their ability to facilitate and co-ordinate big community projects it is recommended that these “fit for life” programmes be co-ordinated and facilitated by social workers working with patients suffering from arthritic conditions. The goal of these programmes should be to provide a safe environment where patients can be encouraged to be physically active which will aim to improve their quality of life experience, but also to create a safe environment for patients to support each other. It is recommended that the social worker liaise with the local gym and their practicing physio-therapist, as part of the social support initiative, to get involved in this programme. Patients will be encouraged to attend a water-aerobics session once a week facilitated by a professional physio-therapist that is knowledgeable about arthritic conditions. At the end of each session the social worker will facilitate a support session where patients will be encouraged to interact with each other, thus creating an opportunity of sharing and networking with other patients
- It is recommended that social workers working in the field of arthritis set up a database of patients that have proved to be involved in support programmes and shared their desire to provide guidance to newly diagnosed arthritis patients. The aim is then to partner a newly diagnosed arthritis patient with a more “senior” patient with a similar diagnosis and characteristics in order to establish a buddy support system. A context can then be created where the “senior” patient can share surviving techniques to the newly diagnosed patient but also provide support, for example picking up the children from school. Social workers are encouraged to then work closely with these buddies in order to provide further therapeutic support should it be required
- Social workers working in the field of arthritis should always seek to advocate for arthritis patients when presenting at conferences and workshops.

b. Recommendations for policy

- Investigate current, refine or develop policy related to the management and treatment of arthritis. Such policy should address aspects including, but not limited to, the employment conditions of people living with arthritis and securing the employment of people once diagnosed with the disease, medical aid and the requirements patients need to comply with in order to receive the full benefit provided by medical aids, specifically towards the funding of biologic medication; and, thirdly, aspects related to the pricing (i.e. affordability) of disability insurance.

c. Recommendations for education and training (including Continuous Professional Development)

- The design and implementation of a continuous development programme is recommended in order to enable all health care workers to be continuously up to date with the latest developments related to arthritis research and management, in order to ensure that first line practitioners, for example physio-therapists and general practitioners, be equipped with the necessary skills to identify possible arthritis signs and symptoms. This will ensure that patients are referred to specialist intervention much sooner. Apart from the medical focus, training should also enable attendees with the knowledge and skills to promote the psychosocial quality of life of arthritis patients.

d. Recommendations for future research

- Initiate a research study that covers a more extensive geographical area, which would be more representative of the ethnic diversity in South Africa
- Embark on future studies which cover more of the biologic medication used in the treatment of arthritis. It was beyond the scope of this study to investigate all the possible combinations and factors associated with the use of biologic medication and the impact thereof on the quality of life of the person living with arthritis.

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APPENDIX A

Ethical Clearance



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

24 April 2014

Dear Prof Lombard

Project: The quality of life of arthritis patients taking biologic arthritis medication
Researcher: PA Matthee
Supervisor: Dr CL Carbonatto
Department: Social Work and Criminology
Reference number: 29304352

Thank you for the application that was submitted for ethical review.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 24 April 2014. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof. Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: karen.harris@up.ac.za

Research Ethics Committee Members: Dr L Blokland; Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris (Acting Chair); Ms H Klopper; Dr C Panebianco-Warrens; Dr C Puttergill; Prof GM Spies; Dr Y Spies; Prof E Taljard; Dr P Wood

APPENDIX B

Permission Letter: Dr Elsa van Duuren

Dr Elsa van Duuren

BMedSci, MBChB, MSc (Sports Medicine), MMed (MedPhys)
Rheumatologist / Rumatoloog

Suite 209A Jakaranda Hospital
213 Middelberg Street,
Muckleneuk, Pretoria

Tel: 012 343 0428 / 343 1223
Cell: 082 492 5993
Fax: 012 343 1223

P.O. Box 2429, Brooklyn Square, 0075

PR 031 000 0172790

14/02/2014

To Whom It May Concern:

I, Dr Elsa van Duuren, hereby give Pierre Mathee, student number 29304352 permission to involve patients in my practice in his research project.

Yours truly,



DR E.M. VAN DUUREN

APPENDIX C

Interview Schedule

1. Introduction

- i. Please tell me something about yourself

2. Medical history

- i. Give me a little history related to your health
- ii. Which type of arthritis have you been diagnosed with and when?
- iii. What treatment have you had thus far?
- iv. When did you start taking the biologic arthritis medication?

3. Quality of life

- i. What do you understand by the term “quality of life”?
- ii. Describe your life before taking the biologic arthritis medication?
- iii. Has your quality of life changed since taking the biologic arthritis medication? If yes, in which way?

4. Daily functioning

- i. Tell me how you managed your daily activities of living before taking biologic arthritis medication and what challenges did you have
- ii. Tell me how you managed your daily activities of living since taking biologic arthritis medication and what challenges do you have

5. Relationships

- i. Tell me about your relationships with your family, friends and loved ones and has your chronic arthritis influenced these relationships in any way
- ii. Tell me how your family, loved ones and friends understand your arthritis diagnosis and how it affects your functioning and quality of life
- iii. Tell me about the support you get from family, loved ones and friends

6. Work

- i. Tell me about your type of work and whether your chronic arthritis has affected your ability to function as normal at work, in any way

- ii. Has the fact that you suffer from a chronic disease lead to any form of stigmatization or discrimination in the work place

7. Leisure time

- i. Tell me about your hobbies and the way spend your free time and whether your chronic arthritis has affected this in any way
- ii. What do you do to relieve the stress you experience as a result of your disease – if any

8. Finances

- i. How has the fact that you are on the expensive chronic medication affected your financial situation

9. Recommendations

- i. If you had an opportunity to discuss your quality of life experiences with your health professional, since taking the biologic arthritis medication, what would you say
- ii. If you had an opportunity to discuss your quality of life experiences with other patients, since taking the biologic arthritis medication, what would you say?
- iii. Any other suggestions or advice you would like to give with regard to people suffering from the same disease

APPENDIX D

Letter of Informed Consent



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work & Criminology

LETTER OF INFORMED CONSENT

1. NAME OF RESEARCHER

Name: Mr PA Matthee

2. NAME OF UNIVERSITY

Department of Social Work and Criminology, University of Pretoria, Private Bax X20,
Hatfield, Pretoria 0028

3. RESEARCH TITLE

The quality of life of arthritis patients taking biologic arthritis medication

4. THE PURPOSE OF THE STUDY

The purpose of the study is to explore how arthritis has influenced the quality of life of patients since taking the biologic medication

5. DESCRIPTION OF THE PROJECT

The researcher will conduct research to explore how arthritis has influenced the quality of life of patients since taking the biologic medication. Focus group interviews will be conducted. The interviews will be recorded with a tape recorder in order to assist the researcher to transcribe the data and in order to formulate conclusions and make recommendations regarding social support programmes related to the aspect of quality of life.

6. NUMBER OF PARTICIPANTS

In the research project, the researcher will include 12 arthritis patients who take the biologic medication Humira, reside in the Pretoria area and attend the Rheumatology practice in Sunnyside Pretoria.

7. RISKS INVOLVED IN THE RESEARCH STUDY

The researcher will aim to minimize harm at all times. The research participants will be informed of the study before hand by means of informed consent and this will ensure that no one is deceived to participate in the study. Participation is thus completely voluntary

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and participants have the opportunity to withdraw at any stage. All participants will be debriefed by the researcher after the interview.

8. BENEFITS OF THE RESEARCH STUDY

The participants in the projects will get the opportunity to reflect how they see a change in their quality of life since taking the biologic arthritis medication. The information gathered during the study, will enable social workers to improve service delivery to arthritis patients by drawing up social support programmes. The information can further enable the multi-disciplinary team to understand the arthritis patient better.

9. VOLUNTARY PARTICIPATION

Although the researcher seeks my permission to be part of the research project, it does not obligate me to take part. My participation is voluntary. I will be free to stop participating at any point, and will experience no negative consequences for stopping.

10. RECORDS OF PARTICIPATION IN THIS RESEARCH

The information provided as part of this research and all my responses will be dealt with confidentially. After data has been collected, the data will be labeled with code numbers, not with any names, to protect confidentiality and anonymity. The data will be stored in a safe in the Department of Social Work and Criminology, University of Pretoria for 15 years as required. This data could be stored for archival purposes or for further research. The only individuals who will have access to this information will be the researcher and his supervisor, or future students and their supervisors, who have been trained in methods of protecting confidentiality.

AGREEMENT TO PARTICIPATE IN THE RESEARCH STUDY

My signature indicates that I have read, or listened to, the information provided above and that I received answers to my questions. I have freely decided to participate in this research and I know I have not given up any of my legal rights.

I hereby freely give my permission to participate in the research project.

This document is signed at _____ on the _____ day of _____ 2014.

PARTICIPANT SIGNATURE:

.....

I have explained the study to the participant, and provided him/her with a copy of the participant information sheet.

Name and Surname: **Mr PA Mathee**

RESEARCHER SIGNATURE.....Date.....

APPENDIX E

Confirmation of Editing

**CONFIRMATION OF EDITING
SERVICES**

9 November 2014

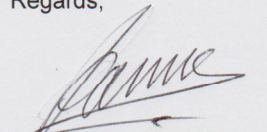
To whom it may concern:

This serves as a letter of confirmation that the Dissertation titled:

**THE QUALITY OF LIFE OF ARTHRITIS PATIENTS TAKING BIOLOGIC
ARTHRITIS MEDICATION**

Compiled by Mr Pierre Armand Mathee has been edited and checked for language
and grammatical errors.

Regards,



Mr Rick Garner

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