

Experiences of adolescents living with a diagnosed chronic, auto-immune illness

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SUMMARY

The purpose of this study was to explore and describe the experiences of adolescents living with a diagnosed chronic auto-immune illness (CAI) due to the fact that there is a wider increase in the prevalence and incidence of auto-immune illnesses among adolescents. The researcher applied one primary scientific paradigm and two theories in this study, namely the *Gestalt paradigm*, *Field theory* and *Erikson's Theory of Adolescent Development*, pertaining to adolescents living with a CAI. A qualitative, explorative and descriptive case study approach was followed. Purposive sampling was used to select six adolescents with a diagnosed CAI. Data was collected through individual semi-structured interviews and observations. Qualitative data analysis using Creswell's "data analysis spiral" was used to analyse data and identify themes. It was clear that the adolescents' environments, as well as their intra- and interpersonal resources and outlook on life have an influence on the way they experience their illness. They experienced a continuum of feelings which ranged from support and encouragement from family and community members, to a lack of understanding from community members, and ridicule and isolation by peers. Sharing success stories and exploring a multidisciplinary, more holistic treatment plan that focuses on mind, body and soul, may benefit adolescents living with a CAI.

KEY CONCEPTS

Adolescent experiences

Chronic auto-immune illnesses

Field

Gestalt paradigm

Qualitative research

OPSOMMING

Die doel van hierdie studie was om die ervarings van adolessente wat met gediagnoseerde chroniese outo-immuunsiektes (COS) leef te verken en te beskryf aangesien daar 'n toename in die voorkoms van COS onder adolessente is. Die navorser het van een wetenskaplike paradigma en twee teorieë in hierdie studie gebruik gemaak wat van toepassing is op adolessente met 'n COS, naamlik die Gestalt paradigma, die Veldteorie en Erikson se Teorie van Adolessente Ontwikkeling. 'n Kwalitatiewe, eksploratiewe en beskrywende gevallestudie-benadering is gevolg. Doelbewuste streekproefneming is gebruik om ses adolessente met gediagnoseerde COS te selekteer. Data is deur middel van individuele semi-gestruktureerde onderhoude en waarnemings ingesamel. Kwalitatiewe data-analise met behulp van Creswell se 'data-analise spiraal' is gebruik om data te analiseer en om temas te identifiseer. Dit was duidelik dat die adolessente se omgewings, sowel as hul intra- en interpersoonlike hulpbronne en lewensuitkyk, 'n invloed het op die manier waarop hulle hul siekte ervaar. Hulle ervaar 'n kontinuum van gevoelens wat wissel van ondersteuning en aanmoediging vanaf familie en lede van die gemeenskap, tot 'n gebrek aan begrip van lede van die gemeenskap en bespotting en isolasie deur die portuurgroep. Die deel van suksesverhale en die verkenning van 'n multi-dissiplinêre, meer holistiese behandelingsplan wat fokus op die liggaam, psige en gees kan tot voordeel strek vir adolessente wat met 'n COS lewe.

SLEUTELWOORDE

Ervarings van adolessente

Chroniese outo-immuunsiekte

Gestalt paradigma

Veld

Kwalitatiewe navorsing

PREFACE

This dissertation is presented in article format in accordance with the guidelines as set out in the Manual for Postgraduate Studies – 2012 of the North-West University, and in conjunction with the guidelines of the Health SA Gesondheid Journal. Guidelines for the submission to this journal are attached (see Annexure E).

With regard to the study, consent was obtained from all research participants, as well as from the institution in which the research was primarily conducted namely; a provincial hospital in the Cape Peninsula (see Annexures B and C).

The researcher would like to note that relevant literature uses the terms *disease*, *illness* and *conditions* interchangeably when they refer to chronic auto-immune illnesses. For the purpose of this research, the researcher used *illness* as her chosen term. The researcher would further like to highlight that Crohn's disease is referred to as such, although it falls under the category of a chronic auto-immune illness.

The researcher used the Harvard referencing method throughout the study.

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SECTION A:
ORIENTATION TO THE RESEARCH

1. TITLE

Experiences of adolescents living with a diagnosed chronic, auto-immune illness.

2. ORIENTATION AND PROBLEM STATEMENT

2.1 Research background: Defining chronic auto-immune illnesses

Hatherill (2007:212) asserts that chronic illness necessitates perpetual therapeutic attention for a minimum of half a year, enduring daily life modifications and constant social accommodations and lifestyle changes due to the erratic nature of the illness. Kunneke and Orr (2005:428) discuss the characteristics of a chronic illness as: “requiring lengthy supervision by a health team; being permanent, for a long duration and irreversible; possibly resulting in residual impairment; having multiple causes, and displaying a variety of symptoms and manifestations which can vary in intensity”. According to the World Health Organisation (2012), chronic illnesses are by far the leading cause of mortality in the world, representing 60% of all deaths and are generally identified as interfering with the day by day functioning of an individual for more than three months in a year (Larsen, 2013:5-6; Mash & Wolfe, 2010:394-395).

This study specifically focuses on chronic auto-immune illnesses (CAI). The Arthritis Foundation of South Africa (2012a) describes the term “auto-immune” as the failure of an organism to recognise its own fundamental parts as ‘self’, which results in an immune response against its own cells and tissues. A common trait that auto-immune illnesses share is that the body’s immune response mistakenly detects a part of the body as a pathogen and therefore attacks itself (Nakken, Alex, Munthe, Szekanecz & Szodoray, 2012:1; National Institutes of Allergy and Infectious Diseases, 2007:28-30). Any illness that results from such an aberrant immune response is termed an auto-immune illness (Arthritis Foundation of South Africa, 2012a). Therefore, a CAI manifests the definitional characteristics and symptoms of both a chronic and auto-immune illness.

2.2 Research setting: Chronic auto-immune illness during adolescence

According to Hatherill (2007:213), chronic illnesses during adolescence tend to adversely affect psychosocial outcomes and it is further mentioned that the adolescent’s environment plays a crucial role in the adjustment of living with a chronic illness. The researcher was diagnosed with a CAI, namely Crohn’s disease as an adolescent and due to the fact that this was fairly rare within this field of illness and also in the medical field at the time, very little literature was available and, to a certain extent, little knowledge existed regarding adolescents’ experiences of living with a CAI.

Taking cognisance of Louw's (1998:505) notion that all adolescents go through social, cognitive and physical changes, the researcher is of the opinion that CAIs could directly affect the adolescent's self-esteem and cognitive processes. Supporting this notion, and with reference to adolescence and chronic illness, O'Donohue and Tolle (2009:3-6) consider adolescence to be a challenging stage that usually involves anguish, tense relations and trouble in finding and fitting in to novel societal positions and functions.

Kunneke and Orr (2005:430) discuss how the adolescent developmental task of gaining independence is often hampered when diagnosed with a chronic illness, and feelings of being isolated from peers by not physically being able to partake in "normal activities" may cause anguish. They are of the opinion that having opportunities to engage with their peers is crucial to adolescents' development - which a chronic illness often hampers them from doing. This was confirmed in the personal experience of the researcher with feelings of isolation when she could no longer play for her sports' teams, attend a full day of school, nor socialise with her peers due to her symptomatic exhaustion and weakness as a result of her Crohn's disease.

However, Videon (2005:55-56) is of the belief that although peer relations are paramount during adolescence, they do not override the adolescent's attachment to parents. Within the context of the study and from the researcher's experience of living with a diagnosed CAI, the relationship with her parents had a significantly positive impact on her welfare. This was due to the fact that she was reliant on them for: emotional support when ostracised from peers, funds for the exorbitant medical expenses, transport to and from doctors' appointments, good nutrition, and special dietary requirements on a daily basis.

2.3 Research motivation: Justifying the study

The prevalence of auto-immune illness is summarily rising and since cures are not yet available for most auto-immune illnesses, patients face a lifetime of illness and treatment, often enduring debilitating symptoms, loss of organ function, reduced productivity at work, and high medical expenses (United States Department of Health and Human Services, 2005:1-2). With regards to research on this topic, it is however evident that most literature and resources, such as the Arthritis Foundation of South Africa (2012a; 2012b), Arthritis Research UK (2012) and American Auto-immune Related Diseases Association (2012) and current and completed theses and dissertations from the Universities of South Africa, Western Cape, Stellenbosch and Pretoria that the researcher has encountered to date, is aimed at the experiences of adults living with a diagnosed CAI rather than adolescents.

2.3.1 Lack of adolescent-specific research

Based on the researcher's experience and the evident limited availability of information and data for adolescents diagnosed with a CAI, there is a shortfall in recent and relevant adolescent-based research. This could be attributed to the rarity of such diagnoses. For example, consider the available information on two prevalent CAIs: rheumatoid arthritis (RA) and pyoderma gangrenosum. Research has found that the general age of onset for RA is between 40 and 50 years of age (Arthritis Research UK, 2012; Helmick, Felson, Lawrence, Gabriel, Hirsch, Kwoh, Liang, Kremers, Mayes, Merkel, Pillemer, Reveille & Stone, 2008:17-18; National Health Service, 2012; Symmons, Turner, Webb, Astin, Barrett, Lunt, Scott & Silman, 2002:795-797). Similarly, Jackson and Callen (2012) state that although a range of ages may be affected by pyoderma gangrenosum, it generally occurs between the ages of 40 and 50 years and children account for only 3-4% of the total number of cases.

However, such statistics not only acknowledge the existence of CAIs within the adolescent context, but further emphasise the rarity of such incidents, and draw attention to the need for further adolescent-specific qualitative research, particularly considering the unique and significant stage of life that adolescence represents.

2.3.2 Significance of adolescent-specific research

Adolescence is discussed by Ben-Zur (2003:67) as being divided into three phases namely; early (ages 11-14), middle (ages 15-18) and late adolescence (ages 19-21). The ages of the research participants when interviewed fell into the early and middle adolescent phases.

Adolescence is described in terms of physical, cognitive, social and emotional, moral and religious development (Ben-Zur, 2003; Campbell, 2006; Gouws, Kruger & Burger, 2008; Lerner & Galambos, 1998; Thomas, 2005). Adolescence is further regarded as a period of identity versus role confusion, where the adolescent is required to balance a sense of "who I am" with a sense of "how do others see me" and "how do I connect with the larger picture" of values and cultural norms (Donald, Lazarus & Lolwana, 2002:78). Kaplan (2000:513-514) highlights Erikson's theory of adolescence, stating it is a period where either the development of a concrete personal identity occurs; or there is a loss of direction and purpose, resulting in role confusion.

Although there are basic, global developmental transitions through which adolescents go, one must be aware of personal developments and changes through which adolescents also go, according to their environmental influences and fields (Gouws et al., 2008:8; McGue, Elkins, Walden & Iacono, 2005:971). An adolescent being diagnosed and living with a CAI would therefore have an individual experience of the adolescent phase. This is affirmed by Senge's

(1994:175) mental models which are “deeply held internal pictures of how the world works that determine not only how we make sense of the world, but how we take action”. Ikehara (1999:66-67) explains that these models are applied individually, whereby each person has their own assumptions, meanings and values about the world and existence.

2.4 Problem statement and Research question

Stemming from the introduced research motivation and concern, the problem that has been identified for this study is that despite the fact that diagnosis of CAIs amongst adolescents is becoming more prevalent (Neinstein, 2001:293; Rattue, 2012), there is little to no information available on the adolescents’ emotional, psychological and physical experiences of living with a diagnosed CAI (Phillips, 2012; United States Department of Health and Human Services, 2005:i-iii). The researcher believes the implication of this lack of information brings about a lack of understanding and a lack of support for adolescents living with a CAI - leaving these adolescents misunderstood and unable to fully express themselves regarding their illness. Therefore the research question driving and motivating this study has been formulated as: What are the experiences of adolescents living with a diagnosed chronic auto-immune illness?

3. RESEARCH AIM

Fouché and De Vos (2011:94-95) refer to the study aim as being the end result the researcher wishes to attain – in other words, what the research plans to do in order to answer the research question. Considering the identified research problem and the research question that was formulated, the central research aim of this study was to explore the experiences of adolescents living with a diagnosed CAI.

4. PURPOSE AND SIGNIFICANCE OF THE RESEARCH

Through this study the researcher intended to aid parents of adolescents living with a diagnosed CAI and to assist professional people working with such families with a better understanding of the adolescents’ experiences of living with CAI. It was also hoped that through this study the caveat in research with regards to this phenomenon will be addressed and that further studies will follow this one.

5. SCIENTIFIC RESEARCH PARADIGM AND THEORIES

The following primary scientific paradigm and theories are relevant to this study, namely the Gestalt paradigm and Field theory and Erikson's Theory of Adolescent Development. These are defined, explained and contextualised within the parameters of this study in the sub-sections below.

5.1 Gestalt paradigm and Field theory

As the influence of a CAI on an individual appears to be systemic and subjective, it was decided to use a Gestalt paradigm in which to ground this study. The term Gestalt describes wholeness as a concept - although something may be encountered as an entity that comprises of different units (Latner, 2000:19). The researcher therefore believes that in terms of the Gestalt paradigm and in the context of this research, how adolescents are able to integrate themselves as a whole, will affect how adolescents might experience being diagnosed and living with a CAI.

Latner (2000:13) describes Gestalt therapy as having two central components, namely:

- considering things in the context of what is happening currently, and
- as individuals, we cannot be considered in isolation, but only through our associations with our environments, which is described as being our "field".

The concepts of "awareness" and "field" are inextricably linked, in that "the field is part of our awareness; our awareness is part of our field" (Latner, 2000:22). Field theory can thus be understood as a framework in which one takes note of the interrelated relationships that occur between humans and their environments. This was particularly suitable for this study as in trying to understand something; one must observe the whole situation (Parlett, 2005:47). Awareness is caused by the interaction between the person and their field, and is also regarded in terms of "wholeness", emphasizing that "the whole is greater than the sum of its parts" (Latner, 2000:19). The field is described as the sum of mutually impelling forces that collectively form a cohesive collaborative whole (Yontef & Fuhr, 2005:47). The fields of this research study are the participants' families, friends, school, community and medical fraternity.

Gestalt therapy is concerned with the "personal experiences and everyday life" (Latner, 2000:14). The Gestalt paradigm was therefore deemed suitable with regard to this study, as the researcher explored the everyday experiences of adolescents living with CAIs. Furthermore, Latner (2000:15) states that Gestalt therapy is "a present-centred approach", highlighting that "awareness", and the "field", only have meaning in terms of the present moment. The field therefore lays the foundation of Gestalt therapy, of which all is a part of, and all is

interconnected (Parlett, 1991:68). Thus in order to appreciate and be aware of an individual, one must look at individuals within their field - as was done in this study.

5.2 Erikson's Theory of Adolescent Development

Adolescence has already been introduced in section 2.3.2 and is also concisely defined in section 6.1. However, in this section, the research paradigm and theory of adolescence in regard to this study is elaborated upon. As has been mentioned, Erikson described adolescence as being a period where either the development of a concrete personal identity occurs; or there is a loss of direction and purpose, resulting in role confusion (Kaplan, 2000:513-514).

The three central concepts suggested by Erikson in his theory are described by Thomas (2005:86) as: focusing on the progression of a well-adjusted character, the integration of the young person into society according to "psychosocial stages", and finally, the person's challenge of successfully accomplishing the "specified identity crises at each psychosocial stage" and attaining "ego identity". In relation to the research, and specifically adolescents, the researcher would like to highlight the relevance of "ego identity".

Erikson's "ego identity" is described as being two-fold: one feature being "inner focused" – "knowing and accepting oneself", and the other being "outer-focused" - distinguishing and associating with a cultural value system and engaging in a shared belief or character system (Thomas, 2005:87). Therefore, through attaining Erikson's "ego identity", one is able to have a firm sense of oneself, as well as belonging and fitting in with a community (United States Department of Health and Human Services, 2010). It is with this aspect of Erikson's development theory in mind that the research is orientated to explore the experience of adolescents living with a CAI.

In acquiring a personal identity, the adolescent must possess a core belief system and relationships with family and community (Schmied & Tully, 2009:5). However, auto-immune illnesses can hamper individuals from establishing good social relationships due to the isolating nature of these illnesses; as well as causing increased strain and burden on patients, the adolescent's family and society (United States Department of Health and Human Services, 2005:1-2). As such the research explores the experience of adolescents living with a CAI within their immediate and larger fields - particularly if they are cut off from society, misunderstood or ostracised due to their medical conditions.

5.3 Connecting the paradigm and theories

The connection between field theory and the Gestalt paradigm is stated by Yontef and Fuhr (2005:83-84) who view an individual and their environment through a Gestalt lens; asserting that

an individual can only be appreciated and survive, in relation to their environment. Holism and the “ability of human beings to self-regulate”, striving to attain favourable life changes, and personal development all underpin the essence of a Gestalt approach (Yontef & Fuhr, 2005:83). It is this interplay between the individual and their environment where Yontef and Fuhr (2005:84) contend that both the human and their field “co-create each other.”

With regards to this research, the “field” and “adolescent development” are described as being interactional – specifically that “development is a function of the whole field” (Parlett, 2005:56). Wheeler as cited in Parlett (2005:56) asserts that an individual’s development cannot be viewed as a single entity in seclusion, but must be regarded in their totality and environments. McConville as cited in Parlett (2005:57) also describes the development of adolescents as encompassing “the biological, psychological, and social dimensions of an integrated field”. Frydenberg (2008:15) highlights adolescent changes such as “intrapersonal changes...cognitive development, maturation and emotional development...” as well as “interpersonal changes negotiating relationships” within their fields.

Although the applicability and suitability of the various research concepts and theories is evident in the existent literature, Parlett (2005:49) highlights a particularly relevant feature of the concept of a field which can pertain to the onset and diagnosis of a CAI in adolescence. This can be observed in the fact that, within an instant, the field “can change dramatically” (Parlett, 2005:49). The diagnosed adolescent may have been living a relatively healthy and “normal” lifestyle, when suddenly they fell ill and were exposed to new fields such as hospitals, medical procedures and staff, and medication. Compounding this field change, adolescents may furthermore find themselves being isolated from the fields to which they are used to being exposed, such as sport and extra mural activities, attending a full day of school, writing all tests and examinations, and socializing. This aggravates the existent challenge of living with an active and debilitating illness.

6. DESCRIPTION OF CONCEPTS

This section defines and describes the relevant concepts pertinent to this study. The applicable concepts are adolescence and CAI.

6.1 Adolescence

The term adolescence is commonly understood to define the period of life between childhood and adulthood (Kaplan, 2004:1). Adolescence is also often interchangeably linked to the terms “teenage years” and “puberty”, however adolescence is not exclusive to either of these terms. Puberty refers to the hormonal changes that occur in early youth; and the period of adolescence

can extend well beyond the teenage years, however, there is no standard definition of “adolescence” (United States Department of Health and Human Services, 2010).

Abbott (2001:105) describes adolescence as deriving from a Latin word which means “to grow into maturity”. Abbott (2001:105) further discusses how the period of adolescence involves much physical and cognitive growth– involving “... interpersonal relationships, emotions and self-identity”. Atwater (1996:7) takes this notion of adolescence further in the following relevant phases of his “boundaries of adolescence”:

- Biological: which asserts that adolescence commences at puberty and terminates when physical and sexual maturity is reached;
- Emotional: which states that autonomy from parents commences adolescence and comes to an end when the adolescent acquires a “self-revised personal identity and emotional autonomy”;
- Cognitive: which views adolescence to start when “logical reasoning, problem solving and decision making skills” are utilized and comes to conclusion once “adult logical reasoning and autonomous decision making” is established;
- Interpersonal: where adolescence describes the move from parents to peer orientation;
- Social: where adolescence begins with “...entry into personal, family and work roles and ends with the attainment of adult privileges and responsibilities”.

6.2 Chronic auto-immune illnesses

CAIs have already been introduced in section 2.1, but further to the definition, the United States Department of Health and Human Services (2005:i) states that, “more than 80 human diseases are due at least in part to an inappropriate immune system response that results in damage to an individual’s organs, tissues, or cells. Auto-immune diseases can affect any part of the body, and have myriad clinical manifestations that can be difficult to diagnose”.

For the purpose of this study, the researcher will focus on the following CAIs as these were the illnesses with which the research participants were diagnosed: rheumatoid arthritis (RA) (inflammation of the joints), Crohn’s disease (inflammation of the digestive tract), scleroderma and pyoderma gangrenosum (both of which involve the skin and subcutaneous tissues). At this point it is important to highlight that although many of the patients spoke of their RA or arthritis during this study, technically and medically, many of them have what is known as juvenile rheumatoid arthritis. According to Scott (2012), juvenile rheumatoid arthritis, juvenile idiopathic arthritis and RA are terms often used synonymously by patients and in popular media.

There are over two hundred rheumatic illnesses, which are commonly referred to as arthritis (Arthritis Foundation of South Africa, 2012b; Nuffield Foundation, 2012). It is believed that chronic arthritis is the result of an abnormal response of a person’s immune system, which, due

to unknown causes, loses part of its ability to identify and distinguish between dangerous and normal cells and attacks the body's own joint components (Paediatric Rheumatology International Trials Organisation, 2003a:1). Consequently, illnesses such as RA, juvenile idiopathic arthritis and juvenile rheumatic arthritis are called auto-immune, in that the immune system reacts to and against the organs of its own body. However, the precise mechanisms that cause these CAIs, as with as most human chronic inflammatory illnesses, are currently unknown (Paediatric Rheumatology International Trials Organisation, 2003a:1).

One of the many forms of arthritis, RA, is described as being a "...systemic form of inflammatory arthritis affecting one's general health as well as a variety of one's joints" (Arthritis Foundation of South Africa, 2012b). Scott (2012) asserts that juvenile arthritis occurs in approximately 1 out of 1000 children and is defined as chronic arthritis presenting in a child under the age of 16, after other causes for arthritis have been excluded. Scott (2012) further states that often children with juvenile idiopathic arthritis have a similar illness to the adult RA.

In RA, the immune system mistakenly targets particular body parts creating stiffness, painful swelling and inflammation, particularly in joints and tendons. Pain, weakness and obstructed mobility are common side effects of the condition, as well as fatigue (Arthritis Foundation, 2008:1; National Health Service, 2012). Juvenile idiopathic arthritis is a chronic illness characterised by persistent joint inflammation; the typical signs of joint inflammation are pain, swelling and limitation of movement. "Idiopathic" indicates that the cause of the disease is unknown and "juvenile", in this case, means that symptoms appear before 16 years of age (Paediatric Rheumatology International Trials Organisation, 2003a:1).

Crohn's disease falls under the term inflammatory bowel disease due to the fact that this illness results in ulcerated, swollen and inflamed intestines. Common symptoms include: weight loss, diarrhoea (which may include blood or mucus) and fatigue. Swollen joints, ulceration in the mouth, rashes and inflamed eyes may also be experienced by some (National Association for Colitis and Crohn's Disease, 2011:3).

Scleroderma is a rare collagen-vascular illness resulting in tight skin as well as possible organ damage in some cases (Arthritis Foundation South Africa, 2012b). According to the Paediatric Rheumatology International Trials Organisation (2003b:1) the term "scleroderma" means "hard skin" and is typified by shiny, hard skin, which can either be localised (limited to skin tissue) or systemic (involving skin and organs). Symptoms of scleroderma vary and can include; heartburn, difficulty in breathing, and high blood pressure (University of Maryland Medical Center, 2011). According to the International Arthritis Foundation (2012), scleroderma results when the body produces too much collagen, with the surplus deposited in the skin and other

body organs, which results in tightening and hardening of the skin and organs to a degree of dysfunction.

Pyoderma gangrenosum is a rare but serious ulcerating skin illness that can occur on any skin surface, but is most commonly seen on the legs (Jackson & Callen, 2012). Clinically, it starts with sterile pustules that rapidly progress and turn into painful ulcers of variable depth and size with undermined bluish borders (Wollina, 2007:1). The prognosis of pyoderma gangrenosum is generally good; however, the illness may recur, and residual scarring is common. Patients usually suffer from severe pain as a result of the ulcers and patients may have systemic features such as fever (Brooklyn, Dunnill & Probert, 2006:181).

7. RESEARCH METHODOLOGY

7.1 Literature Review

This review section concisely details the relevant literature, existent research and the prevalent theories and concepts that are pertinent to this study and were explored and utilised in researching the experiences of adolescents living with a diagnosed CAI.

Literature was gathered using multiple methods and sources. Academic literature was sought in library-based research such as books, magazines and academic journals, and in internet-based journal publications and search engines such as EBSCOhost, Emerald Insight and Science Direct. These online journal publication searches proved expansive with initial searches returning hundreds of results, including many irrelevant or unrelated topics and theories.

Owing to the evident lack of existent research specific to this study area, and motivated by the exploratory nature of this research, the literature review for this research was a continuous research exercise where sources and resources continued to manifest as the research continued. The resources took the form of books, journal publications, online educational websites, medical publications, discussions and information packs. Furthermore, experts and medical practitioners working in the field of paediatric rheumatology and gastroenterology, as well as research academics were also consulted in order to attain a better understanding of CAIs.

Summarily then, in the absence of documented research and available data on the experiences of adolescents with chronic auto-immune illnesses and the effect thereof, the review of existent literature focussed on:

- Collating and understanding the core concepts of the study: Adolescence and chronic auto-immune illnesses (American Auto-immune Related Diseases Association, 2012;

Arthritis Foundation of South Africa, 2012a; 2012b; Gouws et al., 2008; Hatherill, 2007; International Arthritis Foundation, 2012; Kaplan, 2004; Thomas, 2005).

- The selection, motivation and application of central scientific theories and paradigms to the study area: Adolescence, Gestalt paradigm, and Field theory (Kaplan, 2000, 2004; Latner, 2000; Parlett, 1991, 2005; Thomas, 2005; Yontef & Fuhr, 2005).
- Applying an appropriate and trustworthy research methodology for the under-researched context and study field: explorative and qualitative research design, case study techniques, and data analysis and organisation (Greeff, 2011; Nieuwenhuis, 2007; Schurink, Fouché & De Vos, 2011; Siegle, 2002, Strydom, 2011a).

7.2 Research design

Due to fact that the researcher was interested in exploring and describing the experiences of adolescents diagnosed with a CAI, it was decided to use a qualitative case study approach. What made this approach applicable is the “descriptive style” of research (Welman, Kruger & Mitchell, 2005:188), which seeks greater awareness and strives to attain a thorough investigation about the chosen research topic (Henning, van Rensburg & Smit, 2004:41). More specifically, a case study design requires the observation of a phenomenon explored through one or more cases within a specific system (Creswell, 2007:73-74).

Case study research was particularly suitable for this research as according to Henning *et al.* (2004:41), it is used in attaining a detailed comprehension of the circumstances and meaning for those involved, thereby offering a qualitative tool to answer the research question of what are the experiences of adolescents’ living with a diagnosed CAI.

The researcher used applied research, which is described as being research that offers a basis for further understanding and insight (Fouché & de Vos, 2011:94). For this study, the research aimed to provide information about the experiences of adolescents living with a diagnosed CAI.

The research is also explorative and descriptive in nature. This is substantiated by the stated interest and study aim of realising and documenting an improved understanding of adolescents’ experiences of having to live with a CAI within their respective fields which concurs with the exploratory and descriptive research literature. Exploratory research is designed to enhance understanding and is often applied in study fields characterised by information shortfalls and with such a unique problem setting (Babbie & Mouton, 2006:80; Marshall & Rossman, 2011:69). Babbie (2009:89) explains that in descriptive research, “...the researcher observes and then describes what was observed.” For the purpose of this research, the researcher will describe not only her observations but also give an in-depth description of adolescents’ experiences of having to live with diagnosed CAIs.

The benefits and suitability of qualitative research for this study are therefore most specifically identified in the method's identified potential to enhance the understanding of a phenomenon and its deeper meanings (Fouché & De Vos, 2011:96), "particularly when sensitive topics are being explored" (Mack, Woodsong, MacQueen, Guest & Namey, 2005:2) such as living with a CAI. By offering multipart written explanations of the participants' personal experiences with regard to the research question, this research aims to realise such enhanced understanding.

7.3 Study participants: Population and Sampling

The population in this study is adolescents living with RA, Crohn's disease, scleroderma and pyoderma gangrenosum in the Cape Peninsula and Helderberg regions in the Western Cape. The locations were decided upon according to regular accessibility and contact for the researcher. The ages of the research participants, when interviewed for this study, fell into the early (ages 11-14) and middle age adolescent phases (ages 15-18) as categorized by Ben-Zur (2003:67) when he discusses Holmbeck et al.'s phases of adolescence.

For the purpose of this study, purposive sampling was also employed, which is a non-probability sampling method useful for describing something which is relatively unknown (Babbie, 2009:183; Kumar, 2005:179). Purposive samples are chosen according to the researcher's understanding of the population in relation to the goal of the study (Babbie, 2009:183). This method categorizes research participants into predetermined criteria that represent characteristics of the population, in relation to the data that the researcher seeks to investigate (Leedy & Ormrod, 2005:206; Strydom 2011b:202). In the case of this study the participants consisted of six adolescents between 11 and 18 years of age with the following inclusion criteria:

- males and females diagnosed with a CAI such as RA, Crohn's disease, scleroderma and pyoderma gangrenosum,
- the participants live in the Cape Peninsula and Helderberg regions of the Western Cape.
- they could speak English (albeit not their home language), and
- they voluntarily participated in the study.

In order to identify participants, the researcher asked specialists in the field of paediatric arthritis, such as a paediatric rheumatologist and nursing sisters, to identify appropriate potential research participants; namely adolescents living with a diagnosed CAI. The specialist subsequently approached potential participants and their guardian (if present or applicable) and introduced the concept of the research study to them. Where suitable and consented, the specialist then introduced the researcher to the participants and their guardian (where applicable) and the researcher offered a detailed outline and framework of the study and research process. The process was followed for all participants except one, where during the

process of identifying research participants, the researcher became aware of another potential participant who matched the criteria of inclusion. He and his parents were approached and consent was given to participate in the research study.

7.4 Methods of data collection

Interviews, specifically semi-structured interviews, and observations were the two qualitative data sources that the researcher used for the research study.

7.4.1 Interviews

Semi-structured interviews allow for an in-depth account about a participant's perceptions and experiences and using this method allows for more flexibility and participant input in the research data (Greeff, 2011:351). According to Hancock, Windridge and Ockleford (2009:17), "the semi-structured interview is possibly the most common qualitative research data gathering method in health and social care research as it is relatively straightforward to organise". Qualitative interviews are attempts to understand the world from the participant's point of view, unfolding the meaning of individual's experiences (Greeff, 2011:351). With regard to this study, the researcher strove to unfold the meaning of adolescents' experiences of being diagnosed and living with a CAI.

Preparing for such interviews requires the setting up of an interview schedule (see Annexure D), which serves as an outline for the interviewing process, where questions usually remain open-ended, allowing for greater versatility in collecting the data (Welman et al., 2005:167). Essentially, semi-structured interviews require participants to answer a set of predetermined questions, which are merely formulated to serve as a guide relating to the themes the researcher wishes to explore. Although all the research participants are asked the same questions, the researcher may adjust the formulation thereof, to best suit the specific participant (Nieuwenhuis, 2007:87; Welman et al., 2005:167). Nieuwenhuis (2007:87) further states that these questions are formulated from the research aims and purpose and are designed to give way for exploration and clarification of answers.

Bearing this in mind, Freeman, Felgoise and Davis (2008:221) warn the researcher of the fact that open-ended questions used in semi-structured interviews could result in the research losing focus, by participants speaking of events not related to the research question. To prevent this from happening, explanatory questions and phrases such as: "How have you experienced...", "Describe your..." and "In what way..." were used.

Interviews were also recorded to help ensure the accuracy and integrity of data capture. Participants were informed of the proposed use of digital voice recorders or video-cameras and such recordings were only undertaken with their consent.

7.4.2 Observations

Field notes are detailed observations, interpretations and written accounts of what the researcher heard, saw, experienced and thought about in the course of the interviewing process (Greeff 2011:359; Welman et al., 2005:199). During the interviews, the researcher took field notes of both verbal and non-verbal cues expressed by the participant and corroborated those findings with observations made while watching and/or listening to the videos of the semi-structured interviews. Merriam (2002:13) states that it is through observation that the researcher has data that reflects first-hand experience with the research participant.

7.5 Data analysis Procedures

Mouton (2001:108) describes data analysis as “breaking up the data into manageable themes, patterns, trends and relationships.” Nieuwenhuis (2007:99) refers to qualitative data analysis as trying “...to establish how participants make meaning of a specific phenomenon by analysing their perceptions, attitudes, understanding, knowledge, values, feelings and experiences in an attempt to approximate their construction of the phenomenon.”

The researcher made use of Creswell’s (2007) spiral of data analysis, which required that the researcher review the research data a number of times. The data review process incorporated organisation, perusal, classification and synthesis of the data, until the researcher had the final report (Greeff, 2011:350-351; Schurink, Fouché & De Vos, 2011:403).

The researcher organised the data by filing each participant’s recorded interviews, transcripts and field notes in separate folders, secured in a safe container. The researcher summarised information from each transcript, so as to have more manageable data with which to work and from which to find potential data themes. To identify and create themes for data analysis, the researcher followed the process recommended by Braun and Clarke (2006:93-100), namely: familiarising oneself with the data, generating initial codes, searching for themes and reviewing themes, defining and naming themes and producing the report. As this process was applied, data themes began to emerge, which according to Braun and Clarke (2006:98), capture that which is significant about the research data in relation to the research question, exhibiting a patterned response within the data.

Refining the themes resulted in acquiring sub-themes, and in turn allowed for greater descriptions of the adolescents’ experiences of living with a diagnosed CAI and these themes were then confirmed or modified from the research data as described by Malterud (2001:486).

Deciding on which themes were to be used, required researcher judgement, which necessitated flexibility. The researcher engaged in discussions with her supervisor to ensure that the themes matched the research data adequately and suitably.

7.6 Trustworthiness

Due to the fact that this is a qualitative study, the researcher paid attention to the trustworthiness of the study with regard to the four constructs of credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985:219; Maree, 2007:38; Schurink et al., 2011:419-421). Lincoln and Guba (1985:219) describe these four constructs of trustworthiness as determining “the ‘truth value’ of the study, its applicability, consistency and neutrality”. Siegle (2002) describes trustworthiness as that which allows for the researcher to persuade its readers that the research data is worth noting.

7.6.1 Credibility

To ensure credibility, the researcher engaged in the following techniques as prescribed by Babbie and Mouton (2006:277) and Schurink *et al.* (2011:420):

- Prolonged engagement refers to remaining in the participants’ environment until researchers have all the data they need (Siegle, 2002). With regard to this research, the researcher spent an extended research period gathering and analysing data and ensured that all participants were thoroughly interviewed and all data was noted and recorded. Interviews were extended or repeated and questions were revisited until the researcher had sufficient information regarding the adolescents’ experiences of living with a diagnosed CAI.
- Peer debriefing occurs when the research data is discussed with a colleague who has a general understanding about the specific research, so as to aid researcher’s objectivity and give fresh perspectives to continue the research process (Reid & Gough, 2000:68; Siegle, 2002). With regard to this research, the researcher reflected and discussed her findings with her supervisor as often as possible.
- Member checks involve asking the source, which in the case of the current research study would be the research participants, to confirm whether the data and interpretation of the researcher’s findings is correct (Carlson, 2010:1105; Fenton & Mazulewicz, 2008). The researcher accomplished member checking by providing feedback to the participants about the researcher’s understanding of the meaning of their responses to interview questions. This feedback took the form of paraphrasing, which is defined as “repeating information a child has disclosed in whole or in part” (Evans, Roberts, Price & Stefek, 2010:586). Paraphrasing is used to “increase the descriptiveness of children’s

reports of their experiences” (Evans et al., 2010:585) and through the use of paraphrasing, the researcher was able to elicit more detailed accounts of the participants’ experiences of living with a CAI for the purposes of this study and its credibility.

7.6.2 Transferability

Transferability is described as being able to apply research data in various situations or with other participants (Shenton, 2004:69). There are two strategies for achieving transferability in a qualitative study namely, purposive sampling and thick description. Purposive sampling has already been introduced in section 7.3, but specifically with regard to transferability, the selection of participants with a wide range of CAIs assists in the applicability of the research results to the wider field of adolescents with CAIs.

Thick description occurs when the researcher gathers comprehensive and thorough descriptions of the research data and documents them with adequate detail, to allow for accurate transferability to the reader (Siegle, 2002). In this study, the researcher engaged with the participants over an extended period and collected and documented thorough accounts on the adolescents’ experiences of living with a diagnosed CAI, resulting in suitably comprehensive and applicable descriptions. Three interview skills to ensure such “thick” descriptions were used:

- detail-oriented probes ensuring that the researcher understood the “who, where and what” of the participants’ answers,
- elaboration probes to gain a comprehensive picture of the adolescents’ experiences of living with a CAI, and
- clarification probes to ascertain whether the researcher’s understanding and interpretation of the data was correct (Nieuwenhuis, 2007:87).

7.6.3 Dependability

Dependability is described as being able to prove that if the qualitative study is reproduced engaging with participants and contexts of a similar nature, the research data would also be similar (Babbie, 2009:278). Lincoln and Guba (1985:316) explain dependability as being met through ensuring credibility and Ryan (2006:1-2) further asserts that there can be no credibility without dependability - therefore being able to show credibility is enough evidence to prove that the study is dependable. As such, the researcher has gone to great lengths to ensure this “overlapping” technique (Lincoln & Guba, 1985:316) through prolonged engagement, peer debriefing and member checks (see section 7.6.1).

More specifically though, several focussed techniques were applied to ensure dependability and the reliable repetition of such a study, including:

- the purpose and motivation of the study is clearly and logically stated,
- the research design (as found in sections A and B) and its implementation is thoroughly described in its planning and execution,
- the operational detail of data gathering and what was done in the field is specifically described,
- well-established and widely practiced and accepted research methods were adopted in the form of explorative quantitative research and a case study approach,
- the handling, analysis and reduction of data is sequentially explained, leading to an interpretation and discussion of the research findings and conclusions, and
- the final effectiveness of the process and results are reflected upon and evaluated with recommendations for the future (Shenton, 2004:71-72; Schurink et al., 2011:420).

7.6.4 Confirmability

Confirmability involves the objectivity or neutrality of the research findings (Shenton, 2004:72). Moreover, confirmability inherently implies that the findings can be confirmed by another (Schurink et al., 2011:421). This was accomplished through what Ryan (2006:3) calls a "confirmability audit", where the researcher has recorded and collected all possible evidence of partiality, including the raw data, field notes, personal notes, themes and sub-themes of the research data. This record of research data, such as video and audio recordings, interview transcripts and analysis process notes, assists in confirming that the research results reflect the experiences and ideas of the participants, rather than the characteristics and preferences of the researcher (Shenton, 2004:72).

As a result of her own experience of living with a CAI, the researcher does acknowledge that she had to identify and bracket her own point of view and sometimes her emotions during interviews to ensure impartiality and accuracy upon reviewing any notes or recordings. However, the researcher further believes that her own CAI experience empowered her to be able to clearly identify and describe many of the experiences that emerged in the data and she could also discern authentic participant responses and when to explore or probe responses further.

In summary, confirmability occurs with the establishment of credibility, transferability and dependability (Thomas & Magilvy, 2011:153), and a consistent and verifiable "audit trail" (Shenton, 2004:72) of the methodological details of the research has been provided. This, combined with the regular contact with the research participants and supervisor, allowed for confident confirmation of the data findings, interpretations and conclusions.

8. ETHICAL CONSIDERATIONS OF THE RESEARCH PROCESS

Ethical clearance was obtained from the University of South Africa and the University of Cape Town (see Annexure A). Permission to undertake the study was obtained from Dr Christian Scott, Head of the Rheumatology ward at a provincial hospital in the Cape Peninsula (see Annexure B) and written consent was obtained from all participants, and where applicable also from their legal guardians (see Annexure C).

According to Welman *et al.* (2005:181), the two central concepts of remaining ethical in such a study, require that the research firstly, does no harm, and secondly, that research participants participate in the research study by their free will and informed consent. However, the ethical considerations of this study extended further than these two over-arching principles into seven identifiable aspects.

8.1 Avoidance of harm

Avoidance of harm refers to both physical and emotional harm, of which the latter is often more difficult to identify. It is the researcher's responsibility to ensure the best interests of the participants at all times (Strydom, 2011a:115). Research participants need to be extensively informed about the research content and process beforehand, specifically being made aware of potential discomforts and effect the research may have on them (Welman *et al.*, 2005:181).

To ensure this, the researcher met with the participants living with a CAI, before the semi-structured interviews took place to inform them of what the study would entail. During the interviews themselves, the researcher remained mindful that she needed to maintain a safe place for the participants. As such, the researcher did not continue probing if the participant felt uncomfortable with a question and did not place the video camera on the participant if they did not want to reveal themselves.

8.2 Informed consent

Informed consent is described as disclosing the following information to the possible participants:

- the goal of the research and research process,
- the potential advantages, disadvantages and dangers of the research, and
- the credibility of the researcher (Altermatt, 2011:2; World Health Organisation, 2011:14).

It is important that the research participants are able both "legally and psychologically...to give consent" (Welman *et al.*, 2005:181) and knowledgeable that they are voluntary participants who

may withdraw from the research study if, or whenever they so choose (Strydom, 2011a:117). Participants in this study were advised that if they so wish, they may remove themselves from the research and were further encouraged to ask questions or express concerns at any time during the research process. The researcher described and discussed the motivation, goal and procedures of the research process, as well as explained the participants' rights to confidentiality, with non-disclosure of information should they feel uncomfortable. These are all aspects, which according to Wiles, Crow, Heath and Charles (2006:3), are important to discuss with participants before the empirical study commences. The researcher requested that either the adolescent (if 16 years or older) and where applicable (if younger than 16 years), their guardians, sign a research consent form before the semi-structured interview was conducted (see Annexure C).

8.3 Deception

Strydom (2011a:119) describes the deception of participants as the changing or withholding of facts about the research process, for fear that the participants may not wish to partake in the research process if the truth of the study be told. There are evidently three ways in which the participants may be deceived:

- the disguise of the real goal of the study,
- the hiding of the real function of the actions of the subjects, and
- misrepresenting the experiences that subjects will go through (Altermatt, 2011:3; Strydom, 2011a:119).

Deception is not always done on purpose, but is rather something which may evolve during the research process. If this is to occur though, the matter must be dealt with and discussed in a debriefing interview with the researcher (Strydom, 2011a:119). Such debriefing of participants is to be conducted in a beneficial and compassionate manner, within a therapeutic context (American Psychological Association, 2010:10-11). Moreover, debriefing post-research gives the research participants a safe space in which they can work and process through their experience (Strydom, 2011a:122). Debriefing therefore serves as a safety measure to assist in the avoidance of harm of participants, through affording the researcher an opportunity to correct and clarify any misperceptions that the research participants may have (Strydom, 2011a:122).

The researcher experienced that the debriefing resulted in decreasing some of the displayed anxieties of the research participants. The researcher engaged in debriefing after the semi-structured interviews were conducted by having a relaxed, reflective discussion about the participants' experience of the interview and the interview questions. Of interest was that many of the participants shared some pertinent insights about their illnesses and their fields - of which they became aware as a result of the discussion during the semi-structured interview.

8.4 Research termination

In qualitative studies, the participants may become involved in the research within a therapeutic context and terminating the research may be difficult for them. It was therefore imperative that termination was executed as considerably and sensitively as possible (Strydom, 2011a:122). Before the semi-structured interviews commenced, the researcher discussed possible discomforts the participants may experience during the interview when recounting the experience of living with a diagnosed CAI. Due to the sensitivity of the research, as well as the possible emotional components thereof, three debriefing sessions (post interview) were also offered to the participants, should they feel the need.

8.5 Confidentiality

Violation of confidentiality occurs when participants are refused the right in choosing when, where, to whom, and to what extent their information may be disclosed (Altermatt, 2011:1; Wiles, et al., 2006:3). The researcher requested permission from the participants whether either a video or voice recording may be taken during the semi-structured interview to assist the researcher in taking field notes, so that she could focus on the interview and participant, rather than writing down the participants' answers verbatim. The participants were therefore given the opportunity to give or not to give their consent prior to the use thereof.

For those research participants who felt uncomfortable being in view of the camera, the camera was used for an audio rather than visual recording. In instances like these, the researcher took observation notes of the participants' non-verbal cues, which according to Welman *et al.* (2005:196) enriches the empirical data. The research participants were informed that both the researcher and the researcher's supervisor will have access to the recordings, which would be kept safe in a locked container in a locked cabinet at the offices of the Centre for Child, Youth and Family Studies in Wellington (South Africa).

8.6 Actions and competence

Actions and competence of researchers are required to be ethically based during the entire research process (Strydom, 2011a:115). The researcher clearly stated and explained the goal of the study, as well as ways in which to uphold an ethical standard during the research process, and did not engage in any research that required aptitudes for which she had not been sufficiently trained. According to Welman *et al.* (2005:182) and the United Nations Educational, Scientific and Cultural Organisation (2003), these are important aspects to take note of and to resolve before the research commences.

Furthermore, Strydom (2011a:124) is of the opinion that researchers should remain objective during the process and respect the belief systems and values that may differ from their own. In

the case of this study, the researcher worked with a study leader and in the later stages of the study, with a co-study leader that assisted in objectivity.

Due to the fact that the researcher was diagnosed with a CAI as an adolescent, she is of the further opinion that her personal experiences resulted in her competence to deal with the medical terminology and to an extent, a greater understanding of the participants' experiences.

8.7 Publication of research

To avoid misinterpretations or to be misleading, the release of research findings through publication must be conducted in a correct and unbiased manner (American Psychological Association, 2010:11; Strydom, 2011a:126; Welman et al., 2005:182). As such, the researcher therefore stated the findings clearly and comprehensively. Moreover, the researcher also stated weaknesses or shortfalls within the study, credited those that contributed to the research, and ensured research participants that they have the right to information about the research findings in an unbiased manner. These represent acknowledged methods that further uphold the ethical considerations of research (Strydom, 2011a:126; National Health and Medical Research Council, 2007: 19-20).

9. REPORT LAYOUT

In this section (A) the researcher gave a discussion of the rationale and motivation for the study, formulated the research question, aims and objectives of the study, presented an introductory literature review of the main concepts that were identified for the study, and discussed the research methodology and ethical aspects applicable to the study.

Section B consists of a scientific article that was written in accordance with the guidelines of the Health SA Gesondheid Journal. The researcher also intends to submit the article to this journal for possible publication after the examination process is completed. In the article the researcher gives a discussion of the whole research process together with a discussion of the research findings.

In section C the researcher evaluates the aim of the study, indicates whether the research question was answered, draws and explains conclusions and makes recommendations with regards to future research on adolescents diagnosed with a CAI in terms of patient-doctor communication, medical collaboration, family-based research and finally, school and teacher CAI awareness and education.

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SECTION B:
ARTICLE

EXPERIENCES OF ADOLESCENTS LIVING WITH A DIAGNOSED CHRONIC, AUTO-IMMUNE ILLNESS

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KEYWORDS

Adolescent experience

Chronic auto-immune illness

ABSTRACT

The purpose of this study was to explore and describe the experiences of adolescents living with a diagnosed chronic, auto-immune Illness (CAI) due to the fact that there is a wider increase in the prevalence and incidence of auto-immune illnesses among adolescents. The researcher applied one primary scientific paradigm and two theories in this study, namely the Gestalt paradigm, Field theory and Erikson's Theory of Adolescent Development, pertaining to adolescents living with a CAI. A qualitative, explorative and descriptive case study approach was followed. Purposive sampling was used to select six adolescents with a diagnosed CAI. Data was collected through individual semi-structured interviews and observations. Qualitative data analysis using Creswell's "data analysis spiral" was used to analyse data and identify themes. It was clear that the adolescents' environments, as well as their intra and interpersonal resources and outlook on life have an influence on the way they experience their illness. They experienced a continuum of feelings which ranged from support and encouragement from family and community members, to a lack of understanding from community members, ridicule and isolation by peers. Sharing success stories and exploring a multidisciplinary, more holistic treatment plan that focuses on mind, body and soul, may benefit adolescents living with a chronic, auto-immune illness.

SLEUTELWOORDE

Ervarings van adolessente

Chroniese outo-immuunsiekte

OPSOMMING

Die doel van hierdie studie was om die ervarings van adolessente wat met gediagnoseerde chroniese outo-immuunsiekte (COS) leef te verken en te beskryf aangesien daar 'n toename in die voorkoms van chroniese outo-immuunsiektes onder adolessente is. Die navorser het van een wetenskaplike paradigma en twee teorieë in hierdie studie gebruik gemaak wat van

toepassing is op adolessente met 'n COS, naamlik die Gestalt paradigma, die Veldteorie en Erikson se Teorie van Adolessente Ontwikkeling. 'n Kwalitatiewe, eksploratiewe en beskrywende gevallestudie-benadering is gevolg. Doelbewuste streekproefneming is gebruik om ses adolessente met gediagnoseerde COS te selekteer. Data is deur middel van individuele semi-gestruktureerde onderhoude en waarnemings ingesamel. Kwalitatiewe data-analise met behulp van Creswell se 'data-analise spiraal' is gebruik om data te analiseer en om temas te identifiseer. Dit was duidelik dat die adolessente se omgewings, sowel as hul intra- en interpersoonlike hulpbronne en lewensuitkyk, 'n invloed het op die manier waarop hulle hul siekte ervaar. Hulle ervaar 'n kontinuum van gevoelens wat wissel van ondersteuning en aanmoediging vanaf familie en lede van die gemeenskap, tot 'n gebrek aan begrip van lede van die gemeenskap en bespotting en isolasie deur die portuurgroep. Die deel van suksesverhale en die verkenning van 'n multi-dissiplinêre, meer holistiese behandelingsplan wat fokus op die liggaam, siel en gees kan tot voordeel strek vir adolessente wat met 'n COS lewe.

ACRONYMS

CAI	Chronic Auto-immune Illness
COS	Chroniese Outo-immuunsiekte
RA	Rheumatoid Arthritis

1. INTRODUCTION

The Arthritis Foundation of South Africa (2012a) describes the term “*auto-immune*” as the failure of an organism to recognise its own fundamental parts as ‘self’, which results in an immune response against its own cells and tissues. A common trait that auto-immune illnesses share is that the body’s immune response mistakenly detects a part of the body as a pathogen and therefore attacks itself (Nakken, Alex, Munthe, Szekanecz & Szodoray, 2012:1; National Institutes of Allergy and Infectious Diseases, 2007:28-30). Any illness that results from such an aberrant immune response is termed an auto-immune illness (Arthritis Foundation of South Africa, 2012a).

Auto-immune illnesses are chronic illnesses, as they interfere with the day to day functioning of an individual for more than three months in a year (Mash & Wolfe, 2010:394-395). According to the Paediatric Rheumatology International Trials Organisation (2003a:1), “A disease is said to be chronic when the appropriate treatment does not lead to an immediate recovery, but only to an improvement of symptoms and laboratory test results. This also means that when the diagnosis is made, it is impossible to say for how long the child is going to be sick”.

Hatherill (2007:212) asserts that chronic illness necessitates perpetual therapeutic attention for a minimum of half a year, enduring daily life modifications and constant social accommodations and changes due to the erratic nature of the illness. However, defining chronic illnesses is complex as they continue indefinitely, yet they are all characterised by one of the following features first laid out by the Commission on Chronic Illness in 1957: requiring lengthy supervision by a health team; being permanent, for a long duration and irreversible; possibly resulting in residual impairment; having multiple causes, and displaying a variety of symptoms and manifestations which can vary in intensity (Johnson & Chang, 2008:3; Smeltzer, Bare, Hinkle & Cheever, 2010:145-147).

According to the United States Department of Health and Human Services (2005: i), “More than 80 human diseases are due at least in part to an inappropriate immune system response that results in damage to an individual’s organs, tissues, or cells. Auto-immune diseases can affect any part of the body, and have myriad clinical manifestations that can be difficult to diagnose”.

For the purpose of this study, the researcher will focus on the following chronic, auto-immune illnesses (CAIs): *rheumatoid arthritis* (RA) (inflammation of the joints), *Crohn’s disease* (inflammation of the digestive tract), *scleroderma* and *pyoderma gangrenosum* (both of which involve the skin and subcutaneous tissues). At this point it is important to highlight that although many of the participants spoke of their RA during this study, technically and medically, they

have Juvenile Rheumatoid Arthritis. According to Scott (2012), juvenile rheumatoid arthritis, juvenile idiopathic arthritis and RA are often used synonymously by patients and in popular media. Moreover, it is also important to note that relevant literature uses the terms *disease*, *illness* and *conditions* interchangeably when they refer to CAIs. For the purpose of this article the researcher refers to illness as the chosen term.

2. RESEARCH BACKGROUND

There are over two hundred rheumatic illnesses, which are commonly referred to as arthritis (Arthritis Foundation of South Africa, 2012b; Nuffield Foundation, 2012). It is believed that chronic arthritis is the result of an abnormal response of a person's immune system, which, due to unknown causes, loses part of its ability to identify and distinguish between dangerous and normal cells and attacks the body's own joint components (Paediatric Rheumatology International Trials Organisation, 2003a:1). Consequently, illnesses such as RA, juvenile idiopathic arthritis and juvenile rheumatoid arthritis are called auto-immune, in that the immune system reacts to and against the organs of its own body. However, the precise mechanisms that cause these CAIs, as is with most human chronic inflammatory illnesses, are currently unknown (Paediatric Rheumatology International Trials Organisation, 2003a:1).

Rheumatoid arthritis, which forms part of CAIs, is one of the many forms of arthritis described as being a "...systemic form of inflammatory arthritis affecting one's general health as well as a variety of one's joints" (Arthritis Foundation of South Africa, 2012b). Scott (2012) asserts that juvenile arthritis occurs in approximately 1 out of 1000 children and is defined as chronic arthritis presenting in a child under the age of 16, after other causes for arthritis have been excluded. Scott (2012) further states that often children with juvenile idiopathic arthritis have a similar illness to the adult RA, but with the onset in childhood. As a result, the terms "juvenile rheumatoid arthritis" and "RA" are sometimes used as synonyms by patients.

In RA, the immune system mistakenly targets particular body parts creating stiffness, painful swelling and inflammation, particularly in joints and tendons. Pain, weakness and obstructed mobility are common side effects of the illness, as well as fatigue (National Health Service, 2012). Juvenile idiopathic arthritis is a chronic illness characterised by persistent joint inflammation; the typical signs of joint inflammation are pain, swelling and limitation of movement. "Idiopathic" indicates that the cause of the disease is unknown and "juvenile", in this case, means that symptoms appear before 16 years of age (Paediatric Rheumatology International Trials Organisation, 2003a:1).

Crohn's Disease, as a CAI falls under the term inflammatory bowel disease due to the fact that this illness results in ulcerated, swollen and inflamed intestines. Common symptoms include: weight loss, diarrhoea (which may include blood or mucus) and fatigue. Swollen joints, ulceration in the mouth, rashes and inflamed eyes may also be experienced by some (National Association for Colitis and Crohn's Disease, 2011:3).

Scleroderma as a CAI is a rare collagen-vascular illness resulting in tight skin as well as possible organ damage in some cases (Arthritis Foundation South Africa, 2012b). According to the Paediatric Rheumatology International Trials Organisation (2003b:1), the term scleroderma means "hard skin" and is typified by shiny, hard skin, which can either be localised to skin tissue or be systemic, involving skin and organs. Symptoms of scleroderma vary and can include; heartburn, difficulty in breathing, and high blood pressure (University of Maryland Medical Center, 2011). According to the International Arthritis Foundation (2012), scleroderma results when the body produces too much collagen, with the surplus deposited in the skin and other body organs, which results in tightening and hardening of the skin and organs to a degree of dysfunction.

Pyoderma gangrenosum as a CAI is a rare but serious ulcerating skin illness that can occur on any skin surface, but is most commonly seen on the legs (Jackson & Callen, 2012). Clinically, it starts with sterile pustules that rapidly progress and turn into painful ulcers of variable depth and size with undermined bluish borders (Wollina, 2007:1). The prognosis of pyoderma gangrenosum is generally good; however, the illness may recur, and residual scarring is common. Patients usually suffer from severe pain as a result of the ulcers and patients may have systemic features such as fever (Brooklyn, Dunnill & Probert, 2006:181).

3. PROBLEM STATEMENT

Michaud, Suris and Viner (2007:vi) state: "The incidence and prevalence of chronic conditions is rising in most developed and developing countries and will constitute the main cause of death by 2020". The general age of onset for RA is believed to be between 40 and 50 years of age (Arthritis Research UK, 2012; Helmick, Felson, Lawrence, Gabriel, Hirsch, Kwoh, Liang, Kremers, Mayes, Merkel, Pillemer, Reveille & Stone, 2008:17-18; National Health Service, 2012; Symmons, Turner, Webb, Asten, Barrett, Lunt, Scott & Silman, 2002:795-797). Similarly, Jackson and Callen (2012) state that although a range of ages may be affected by pyoderma gangrenosum, it generally occurs between the ages of 40 and 50 years and children account for only 3-4% of the total number of cases. With regard to scleroderma, the average age of onset is generally between 25 and 55 years (Jacob, 2011; Raynaud's & Scleroderma Association,

2011:2) and Crohn's disease is in the age range of 20-30 years (Gomez, 2000:48-49; Rangasamy, 2011).

Although the average age of diagnosis RA has been documented to occur during middle adulthood, today there is an increase in the prevalence of RA in adolescents (Arthritis Research UK, 2012). Significantly though, this identified increase is not limited to RA. Indeed, there is a wider increase in the prevalence and incidence of most of the auto-immune illnesses among adolescence (Michaud *et al.*, 2007:vi; Nakazawa, 2008:25-27; Rattue, 2012; Sawyer, Drew, Yeo & Britto, 2007:1481). In this regard the American Auto-immune Related Diseases Association (2012:1) reports that "auto-immune disease is one of the top ten causes of death in children aged 1-14, and it is one of the top eight causes of death in children and young adults aged 15-24. In fact, auto-immune disease has a high prevalence in the paediatric and adolescent population, and the prevalence is rising."

Phillips (2012) further indicates, *"Most books and articles written about chronic illness are targeted for adults with diseases. Much information, all of which is very valuable, is given about the particular disease, such as its symptoms, treatment, and lifestyle changes necessitated. But there is a unique population that is not addressed often enough in this written material: the adolescent with chronic illness"*.

According to Hatherill (2007:212), chronic illnesses during adolescence tend to adversely affect psychosocial outcomes. Supporting this notion O'Donohue and Tolle (2009:3-4) consider adolescence to be a trying stage that usually involves anguish, tense relations and trouble in finding and fitting in to novel societal positions and functions. Donald, Lazarus and Lolwana (2002:78) reaffirm this complexity where they describe adolescence as a period of identity versus role confusion; where the adolescent is required to balance a sense of "who I am" with a sense of "how do others see me" and "how do I connect with the larger picture" of values and cultural norms. Kaplan (2000:513-514) expounds on this in highlighting Erikson's theory of adolescence as being a period where either the development of a concrete personal identity occurs; or there is a loss of direction and purpose, resulting in role confusion.

The National Research Council and Institute of Medicine (Eccles & Gootman, 2002:58) identify that adolescence is a phase where there is an "increase in peer focus and involvement in peer-related social, sports, and other extracurricular activities". Moreover, having opportunities to engage with their peers is crucial to adolescents' development - something which a chronic illness often hampers them from doing (Kunneke & Orr, 2005:430). The researcher confirms this in her own experience of feelings of isolation when she could no longer play for her sports'

teams, attend a full day of school, nor socialise with her peers, due to her exhaustion and weakness as a result of being diagnosed with Crohn's disease.

Eccles (1999:38) states: "As adolescents become physically mature they often seek more independence and autonomy, and may begin to question family rules and roles, leading to conflicts...". However, Videon (2005:55) is of the belief that although peer relations are paramount during adolescence, peer relations do not override the adolescent's attachment to parents. Both of these view-points offer valuable insights when exploring the adolescents' fields, as a CAI affects an entire family system. It is therefore apparent that the relationship between the parent and the adolescent has a significant impact on the adolescent's welfare (Koepke & Denissen, 2012:82-85).

From the researcher's experience of living with a diagnosed CAI, the relationship with her parents had a significantly positive impact on her welfare, as she was reliant on them for; emotional support when ostracised from peers, funds for the exorbitant medical expenses, transport to and from doctors' appointments, good nutrition and special dietary requirements on a daily basis.

Hatherill (2007:213-214) indicates that the adolescent's environment in general plays a crucial role in the adjustment of living with a chronic illness. This implies that the reactions towards, and information about an CAI within the adolescent's family, community, school and the medical fraternity with whom they engage, can affect the adolescent's experience of living with an CAI (American Autoimmune Related Diseases Association, 2012).

The important role that the environment plays is highlighted by the Gestalt therapy approach. In this regard, Latner (2000:13) describes Gestalt therapy as having two central components namely: considering things in the context of what is happening currently and; as individuals, one cannot be considered in isolation but only through the associations with one's environments, which is described as being one's "field". Latner (2000:15) further states that Gestalt therapy is a present-centred methodology; highlighting that "awareness" and the "field" only have meaning in terms of the present moment.

Levin and Levine (2012:2-3) are of the opinion that the field lays the foundation of Gestalt therapy, of which all is a part and interconnected. It is with this notion, that Bowman (2012:32-33) reiterates Perls' assertion that in order to appreciate and be aware of an individual, one must look at the individual within their field. With regard to this study the researcher looked at the experience of adolescents living with a CAI in their respective fields.

Although there are basic, global developmental transitions through which adolescents go, one must take cognisance of personal developments and changes through which adolescents also go, according to their environmental influences and fields (Gouws, Kruger & Burger, 2008:8; McGue, Elkins, Walden & Iacono, 2005:971). An adolescent being diagnosed and living with a CAI would therefore have an individual experience of the adolescent phase. This is affirmed by Senge's (1994:175) mental models which are "deeply held internal pictures of how the world works that determine not only how we make sense of the world, but how we take action". Ikehara (1999:66-67) explains that these models are applied individually, whereby each person has their own assumptions, meanings and values about the world and existence. In the context of the study it could therefore be understood that although there may be some shared symptoms and procedures through which the participants have gone due to their CAI, each participant would have an unique experience of living with a CAI in their particular fields.

In light of the fact that it is evident that the diagnosis of auto-immune illnesses amongst adolescents is becoming more prevalent (Hatherill, 2007:212; O'Donohue & Tolle, 2009:3; Phillips, 2012), very little information and research however seems to be available on the adolescents' experiences of living with a CAI. An extended search on current and completed theses and dissertations from the Universities of South Africa, Western Cape, Stellenbosch and Pretoria indicated a focus aimed at the experiences of adults living with a diagnosed CAI rather than adolescents.

As a result of this lack of research and understanding, Neinstein (2001: 294) states that most adolescents with chronic disease therefore make their way into the adult health system in an unplanned and uncoordinated manner. The importance of exploring the experiences of adolescents living with a diagnosed CAI was highlighted by the National Institute of Environmental Health Sciences who in their examination of autoimmunity research stated: "There are still numerous gaps in knowledge in this field" (Ball, 2010:40).

With the evident scarcity of understanding of adolescents' experiences of living with a diagnosed CAI, there is little informed support on an emotional level available for these adolescents. Support from the medical fraternity, local community, family and friends (the adolescents' field) may therefore also be limited due to a lack of understanding about the experiences of living with a diagnosed CAI and the impact it has on their developmental phase – both emotionally and socially. The prevalent lack of knowledge may undesirably compound their experiences, exacerbating feelings of isolation and concepts of the "self", especially considering that adolescents become "very sensitive about others' opinions of them" (Louw, 1998:512).

Stemming from this established significance of adolescent development and CAIs, and the identified lack of relevant and recent research regarding the emotional, psychological and physical experiences of adolescents with CAIs, the primary *research question* arising from this problem statement is: *what are the experiences of adolescents living with a diagnosed CAI?*

3.1 Research aim

Fouché and De Vos (2011:94-95) refer to the study aim as being the end result the researcher wishes to attain – in other words, what the researcher plans to do in order to answer the research question. Considering the identified research problem and the research question that was formulated the central research aim of this study was to explore the experiences of adolescents living with a diagnosed CAI.

3.2 Purpose and significance of the research

Through this study the researcher intended to aid parents of adolescents living with a diagnosed CAI and to assist professional people working with such families with a better understanding of the adolescents' experiences of living with CAI. It was also hoped that through this study the caveat in research with regards to this phenomenon will be addressed and that further studies will follow this one.

4. RESEARCH DESIGN AND METHOD

Due to the fact that the researcher was interested to explore and describe the experiences of adolescents diagnosed with a CAI it was decided to use a qualitative case study approach. What made this approach applicable is the descriptive style of research (Welman, Kruger & Mitchell, 2005:188), which according to Henning, van Rensburg and Smit (2004:41) seeks greater awareness and strives to attain a thorough investigation about the chosen research topic. According to Creswell (2007:40) and Leedy and Ormrod (2001:147), the use of qualitative research allows researchers to gain insights and comprehensive descriptions about the social reality of the participants. For this research, the researcher was not only interested in observing a phenomenon but also in attaining a detailed comprehension thereof; more specifically the experiences of adolescents living with a diagnosed CAI.

The benefits and suitability of qualitative research for this study are therefore most specifically identified in its potential to enhance the understanding of a phenomenon and its deeper meanings (Fouché & De Vos, 2011:96), "particularly when sensitive topics are being explored" (Mack, Woodsong, MacQueen, Guest & Namey, 2005:2) such as living with a CAI. By offering multipart written explanations of the participants' personal experiences with regard to the research question, this research aims to realise such enhanced understanding.

According to Creswell (2007:73-74), a case study design requires the observation of a phenomenon explored through one or more cases within a specific system. Supporting the selection of the case study approach for this research, Henning *et al.* (2004:41) describe using a case study design in attaining a detailed comprehension of the circumstances and meaning for those involved. Merriam (2002:8) further asserts that the entity which is to be analysed, defines a case study, which in the case of this research is adolescents living with a diagnosed CAI.

With the aim of realising and documenting an improved understanding of adolescents' experiences of living with a CAI within their respective fields, the explorative nature of the research approach is evidently very suitable. Exploratory research is designed to enhance understanding and is often applied in study fields characterised by information shortfalls and with such a unique problem setting (Babbie & Mouton, 2006:80; Marshall & Rossman, 2011:69). Babbie (2009: 89) explains that in descriptive research, "...the researcher observes and then describes what was observed." For the purpose of this research, the researcher will describe not only her observations but also give an in-depth description of adolescents' experiences of having to live with diagnosed CAIs.

4.1 Population and Sampling

The population in this study was all adolescents living with RA, Crohn's disease, scleroderma and payoderma gangrenosum as CAIs, in the Cape Peninsula and Helderberg regions of the Western Cape.

For the purpose of this study, purposive sampling was also employed, which is a non-probability sampling method useful for describing something which is relatively unknown (Babbie; 2009:183; Kumar, 2005:179). Purposive samples are chosen according to the researcher's understanding of the population in relation to the goal of the study (Babbie, 2009:183). This method categorizes research participants into predetermined criteria that represent characteristics of the population, in relation to the data that the researcher seeks to investigate (Leedy & Ormrod, 2005:206; Strydom 2011b:202).

In the case of this study the participants consisted of six adolescents between 11 and 18 years of age with the following inclusion criteria:

- males and females diagnosed with a CAI such as RA, Crohn's disease, scleroderma and payoderma gangrenosum,
- the participants live in the Cape Peninsula and Helderberg regions of the Western Cape.
- they could speak English (albeit not their home language), and
- they voluntarily participated in the study.

In order to identify participants, the researcher asked specialists in the field of paediatric arthritis, such as a paediatric rheumatologist and nursing sisters, to identify appropriate potential research participants; namely adolescents living with a diagnosed CAI. The specialist subsequently approached potential participants and their guardian (if present or applicable) and introduced the concept of the research study to them. Where suitable and consented, the specialist then introduced the researcher to the participants and their guardian (where applicable) and the researcher offered a detailed outline and framework of the study and research process. The process was followed for all participants except one, where during the process of identifying research participants, the researcher became aware of another potential participant who matched the criteria of inclusion. He and his parents were approached and consent was given to participate in the research study.

In order to contextualise the participants' specific illness and main symptoms thereof, Table 1 below provides a brief summary of each research participant, their CAI and the main symptoms they experience as a result of their condition.

Table 1: Research participants and their auto-immune illnesses and symptoms.

PARTICIPANTS & AGES	SPECIFIC DISEASE	MAIN SYMPTOMS OF THE DISEASE AS EXPERIENCED BY THE PARTICIPANTS
Participant A – Boy 18 Years Old	Rheumatoid Arthritis	Leg pains and had difficulty walking
Participant B – Girl 15 Years Old	Juvenile Arthritis	Joints affected and in a wheel chair
Participant C – Boy 14 Years Old	Pyoderma Gangrenosum	Pimples, dry skin and ulceration
Participant D – Boy 17 Years Old	Rheumatoid Arthritis	Pain, swelling and discomfort
Participant E – Girl 16 Years Old	Scleroderma	Dry skin and skin calcification
Participant F – Boy 18 Years Old	Crohn's Disease	Ulceration, weight loss and fatigue

4.2 Data generation

The researcher used a semi-structured interview schedule (see Annexure D) and with the permission of the participants and their guardian (where applicable), videotaped or voice recorded the interviews and took field notes.

According to Greeff (2011:351), a semi-structured interview is used when the researcher seeks an in-depth account about a participant's perceptions and experiences. Nieuwenhuis (2007:87) and Welman *et al.* (2005:167) further state that semi-structured interviews require participants to answer a set of predetermined questions that merely serves as a guide relating to the themes identified by the researcher. In the case of this research, the themes identified were about the experiences of participants living with a CAI. The semi-structured interviews serve as an outline for the interviewing process, with the questions usually remaining open-ended, allowing for greater versatility in collecting the data. Semi-structured interviews were applicable to this research study, as they gave an in-depth and first-hand account of the experiences of adolescents living with a diagnosed CAI.

Field notes are used to detail observations, interpretations and written accounts of what the researcher heard, saw, experienced and thought about in the course of the interviewing process (Greeff, 2011:359; Welman *et al.*, 2005:199). During the interviews, the researcher noted both verbal and non-verbal cues expressed by the participant, which offered further insights into the adolescents' experiences when they were unable to express themselves. This served to support the accuracy and reliability of the research data when the researcher conducted the data analysis.

Audio or visual recordings are utilised during the qualitative interviews to ensure accuracy of data recording and the ability to revisit and re-analyse the raw data (Willig, 2008:26). During the interview process, the researcher positioned the video camera to either film body language and audio if the research participant gave permission to do so; or alternatively, the researcher pointed the camera away from the participant and merely recorded the audio conversation, with their permission to do so.

4.3 Data analysis

Data was analysed using Creswell's (2007) spiral of data analysis, which required the researcher to review and continue to revisit the research data. Creswell's spiral of data analysis provided logical steps to follow with the data review process incorporating organisation, perusal, classification and synthesis of the data, until the researcher had the final report (Greeff, 2011:350-351; Schurink, Fouché & De Vos, 2011:403).

The researcher organised the data by filing each participant's recorded interviews, transcripts and field notes in separate folders, secured in a safe container. The researcher summarised information from each transcript, so as to have more manageable data with which to work and from which to find potential data themes. To identify and create themes for data analysis, the researcher followed the process recommended by Braun and Clarke (2006:93-100), namely: familiarising oneself with the data, generating initial codes, searching for themes and reviewing themes, defining and naming themes and producing the report. More specifically, the researcher highlighted transcriptions, re-watched and listened to the video and audio recordings, as well as made written notes in the margins of the transcripts.

With regard to the data-coding strategies, the researcher used a notebook and computer, to write and/or type ideas which were then integrated with observational field notes. As per the process outlined by Booth, Colomb and Williams (2003:85-88) initial coding was done per question in the semi-structured interview schedule, which then became more detailed when the researcher analysed each sentence of the various responses to the questions. Data themes then began to emerge, which capture that which is significant about the research data in relation to the research question, exhibiting a patterned response within the data.

Braun and Clarke (2006:98) discuss refining the data themes, which results in acquiring sub-themes, and for the purpose of this study, allowed for greater descriptions of the adolescents' experiences of living with a diagnosed CAI. These themes from the research data were then confirmed or modified from the research data as described by Malterud (2001:486). Deciding on which themes were to be used, required researcher judgement, which necessitated flexibility. In this regard the researcher engaged in discussions with her supervisor, to ensure that the themes matched the research data adequately and suitably.

5. TRUSTWORTHINESS OF RESEARCH

Due to the fact that this is a qualitative study, the researcher paid attention to the trustworthiness of the study with regard to the four constructs of credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985:219; Maree, 2007:38; Schurink *et al.*, 2011:419-421). Lincoln and Guba (1985:219) describe these four constructs of trustworthiness as determining "the 'truth value' of the study, its applicability, consistency and neutrality". Siegle (2002) describes trustworthiness as that which allows for the researcher to persuade its readers that the research data is worth noting.

5.1 Credibility

To ensure credibility, the researcher engaged in the following techniques as prescribed by Babbie and Mouton (2006:277) and Schurink *et al.* (2011:420):

- **Prolonged engagement** refers to remaining in the participants' environment until researchers have all the data they need (Siegle, 2002). With regard to this research, the researcher spent an extended research period gathering and analysing data and ensured that all participants were thoroughly interviewed and all data was noted and recorded. Interviews were extended or repeated and questions were revisited until the researcher had sufficient information regarding the adolescents' experiences of living with a diagnosed CAI.
- **Peer debriefing** occurs when the research data is discussed with a colleague who has a general understanding about the specific research, so as to aid researcher's objectivity and give fresh perspectives to continue the research process (Reid & Gough, 2000:68; Siegle, 2002). With regard to this research, the researcher reflected and discussed her findings with her supervisor as often as possible.
- **Member checks** involve asking the source, which in the case of the current research study would be the research participants, to confirm whether the data and interpretation of the researcher's findings is correct (Carlson, 2010:1105; Fenton & Mazulewicz, 2008). The researcher accomplished member checking by providing feedback to the participants about the researcher's understanding of the meaning of their responses to interview questions. This feedback took the form of paraphrasing, which is defined as "repeating information a child has disclosed in whole or in part" (Evans, Roberts, Price & Stefek, 2010:586). Paraphrasing is used to "increase the descriptiveness of children's reports of their experiences" (Evans *et al.*, 2010:585) and through the use of paraphrasing, the researcher was able to elicit more detailed accounts of the participants' experiences of living with a CAI for the purposes of this study and its credibility.

5.2 Transferability

Transferability is described as being able to apply research data in various situations or with other participants (Shenton, 2004:69). There are two strategies for achieving transferability in a qualitative study namely, "purposive sampling" and "thick description".

Purposive sampling, or deliberate sampling, Punch (2005:293) defines as the use of samples which are "drawn from a population in a deliberate or targeted way, according to the logic of the

research.” With specific regard to transferability, the selection of sample participants with a wide range of CAIs assists in the relevance and applicability of the research results to the wider field of adolescents suffering with CAIs.

Thick description occurs when the researcher gathers comprehensive and thorough descriptions of the research data and documents them with adequate detail, to allow for accurate transferability to the reader (Siegle, 2002). In this study, the researcher engaged with the participants over an extended period and collected and documented thorough accounts on the adolescents’ experiences of living with a diagnosed CAI, resulting in suitably comprehensive and applicable descriptions. Three interview skills to ensure such “thick” descriptions were used:

- detail-oriented probes ensuring that the researcher understood the “who, where and what” of the participants’ answers,
- elaboration probes to gain a comprehensive picture of the adolescents’ experiences of living with a CAI, and
- clarification probes to ascertain whether the researcher’s understanding and interpretation of the data was correct (Nieuwenhuis, 2007:87).

5.3 Dependability

Dependability is described as being able to prove that if the qualitative study is reproduced engaging with participants and contexts of a similar nature, the research data would also be similar (Babbie, 2009:278). Lincoln and Guba (1985:316) explain dependability as being met through ensuring credibility and Ryan (2006:1-2) further asserts that there can be no credibility without dependability - therefore being able to show credibility is enough evidence to prove that the study is dependable. As such, the researcher has gone to great lengths to ensure this “overlapping” technique (Lincoln & Guba, 1985:316) through prolonged engagement, peer debriefing and member checks.

More specifically though, several focussed techniques were applied to ensure dependability and the reliable repetition of such a study, including:

- the purpose and motivation of the study is clearly and logically stated,
- the research design (as found in sections A and B), and its implementation is thoroughly described in its planning and execution,
- the operational detail of data gathering and what was done in the field is specifically described,
- well-established and widely practiced and accepted research methods were adopted in the form of explorative quantitative research and a case study approach,
- the handling, analysis and reduction of data is sequentially explained, leading to an interpretation and discussion of the research findings and conclusions, and

- the final effectiveness of the process and results are reflected upon and evaluated with recommendations for the future (Shenton, 2004:71-72; Schurink *et al.*, 2011:420).

5.4 Confirmability

Confirmability involves the objectivity or neutrality of the research findings (Shenton, 2004:72). Moreover, confirmability inherently implies that the findings can be confirmed by another (Schurink *et al.*, 2011:421). This was accomplished through what Ryan (2006:3) calls a "confirmability audit", where the researcher has recorded and collected all possible evidence of partiality, including the raw data, field notes, personal notes, themes and sub-themes of the research data. This record of research data such as video and audio recordings, interview transcripts and analysis process notes assists in confirming that the research results reflect the experiences and ideas of the participants, rather than the characteristics and preferences of the researcher (Shenton, 2004:72).

As a result of her own experience of living with a CAI, the researcher does acknowledge that she had to identify and bracket her own point of view and sometimes her emotions during interviews to ensure impartiality and accuracy upon reviewing any notes or recordings. However, the researcher further believes that her own CAI experience empowered her to be able to clearly identify and describe many of the experiences that emerged in the data and she could also discern authentic participant responses and when to explore or probe the responses further.

In summary, confirmability occurs with the establishment of credibility, transferability and dependability (Thomas & Magilvy, 2011:153), and a consistent and verifiable "audit trail" (Shenton, 2004:72) of the methodological details of the research has been provided. This, combined with the regular contact with the research participants and supervisor, allowed for confident confirmation of the data findings, interpretations and conclusions.

6. ETHICAL ASPECTS OF THE RESEARCH PROCESS

Ethics in research serve as a principled guideline for actions taken during the research process (American Psychological Association, 2010; World Health Organisation, 2011: xi-xii). Ethical clearance was obtained from the University of South Africa and the University of Cape Town (see Annexure A). Permission to undertake the study was obtained from the Head of the Rheumatology ward at a provincial hospital in the Cape Peninsula (see Annexure B), and written consent was obtained from all participants, and where applicable also from their legal guardians (see Annexure C).

According to Welman *et al.* (2005:181), the two central concepts of remaining ethical in such a study, require that the research firstly, does no harm, and secondly, that research participants participate in the research study by their free will and informed consent. However, the ethical considerations of this study extended further than these two over-arching principles into seven identifiable aspects that the researcher applied during the research:

- Avoidance of harm (Strydom, 2011a:115; Welman *et al.*, 2005:181)
- Informed consent (Altermatt, 2011:2; World Health Organisation, 2011:14)
- Avoidance of deception (American Psychological Association, 2010:10-11; Strydom, 2011:119)
- Sensitive research termination (Strydom, 2011:122)
- Ensured confidentiality (Altermatt, 2011:1; Wiles, Crow, Heath & Charles, 2006:3)
- Appropriate actions and competence (Strydom, 2011:115; United Nations Educational, Scientific and Cultural Organisation, 2003)
- Ethical publication of research (National Health and Medical Research Council, 2007:19-20; Strydom, 2011:126)

The researcher employed multiple methods and techniques to ensure the ethical nature of this research. Prior to conducting the interviews, the researcher thoroughly informed the participants and guardians of the purpose, nature and extent of the study. Research was only conducted with the informed consent of the participants, as confirmed by themselves or, where applicable, their legal guardians (see Annexure C). Interviews were conducted according to the consent and comfort of the participants, which determined the use of recording devices and the pace and depth of questioning. Debriefing was used after the interviews to relieve participant concern and anxiety (where necessary) as the research was completed and terminated. Debriefing also acted as a further data clarification mechanism allowing the researcher to verify the accuracy and detail of responses.

Confidentiality was ensured through the consent process regarding participation and interview recording equipment (video and audio), and furthermore through the private and secure storage of the recordings and the full disclosure that the researcher and the researcher's supervisor will have access to the recordings. Finally, the research process, the data findings and recommendations, the study limitations, and all those that contributed to the research were clearly and comprehensively stated and credited. As such, considering the experience of the researcher living with a diagnosed CAI and moreover, that no aspect of the research required aptitudes for which the researcher had not been sufficiently trained or prepared, the actions taken and competence demonstrated were deemed to be ethically sound.

7. RESULTS

The researcher identified the following two main themes from the data, which are discussed in the following sections with their related sub-themes and categories:

- Participants' experiences of living with a diagnosed chronic, auto-immune illness, and
- Participants' experiences with regard to the support received within their fields

7.1 Main theme 1: Participants' experiences of living with a diagnosed, chronic, auto-immune illness

By way of an introduction to Main theme 1, a brief tabulated synopsis is depicted in Table 2 below.

Table 2: Sub-themes and categories of Main theme 1

MAIN THEME 1: Participants' Experiences of living with a diagnosed, chronic, auto-immune illness		
SUB-THEME 1 Lifestyle Adjustments	SUB-THEME 2 Emotional Experience	SUB-THEME 3 Resilience <i>Making the best of the situation</i>
<ul style="list-style-type: none">• Physical changes• Loss of autonomy		

According to Olsson (2012) chronic illness during adolescence can lead to major psychological and social effects. Sawyer, Drew, Yeo and Britto (2007:1481) explain that "many health professionals report that managing the complexity and range of health concerns in adolescents is more challenging than for other age groups" and as a result, adolescents living with a CAI have a "dual crisis" (Woodgate, 1998:210). This is because in addition to the normal developmental changes of adolescence (as previously discussed), they also have to deal with the on-going demands and challenges of illness management (Olsson, 2012; Woodgate, 1998:210).

7.1.1 Lifestyle Adjustments

The American Psychological Association (2012) asserts that chronic illnesses can cause challenges in daily living and create and necessitate lifestyle adjustments which may be stressful such as, “giving up favorite [sic] activities, limiting social engagements, adapting to new physical limitations and special needs, and paying for what can be expensive medications and treatment services”.

The researcher would like to state that although there are varied adjustments for those living with a chronic illness, with regard to this study, physical changes and loss of autonomy were identified as the primary aspects of the participants’ experience in terms of living with a diagnosed CAI.

7.1.1.1 *Physical Changes*

One must take cognizance of the fact that adolescents are aware of their body image, as their bodies go through many pubescent changes. Therefore much of an adolescent’s teenage years are preoccupied with thoughts about how they perceive their physiques (Kaplan, 2000:474). Some general distresses experienced by adolescents include, “body image, [and] weight” (Frydenberg, 2008:13-16) and many adolescents wish to be different from how they look (Kaplan, 2000:474).

The concept of body image is directly related to CAIs through the direct impacts and symptoms of the illnesses themselves, as well as many adverse side effects of medications that are taken to try and alleviate the illness’ symptoms. Possible adverse side effects of many of the medications include:

- renal impairment,
- elevated blood pressure,
- harm to the liver and the lining of the stomach,
- bleeding,
- swelling of the gums,
- hair loss or bodily hair growth,
- queasiness and vomiting,
- increased appetite which can result in weight gain and stretch marks,
- acne,
- inhibited growth,
- headaches, and
- resistance against contaminations may also be changed, causing recurrent, or severe, infections depending on the extent of immune-suppression (Arthritis Foundation of South Africa, 2012b; International Arthritis Foundation, 2012; National Association for Colitis

and Crohn's Disease, 2011; National Health Service, 2012; National Institutes of Allergy and Infectious Diseases, 2007; Paediatric Rheumatology International Trials Organisation, 2003a, 2003b; United States Department of Health and Human Services, 2005).

From the empirical findings it seems as if the physical changes that accompany the different diagnoses pose specific challenges on the research participants. Participant F expressed how when he left the hospital after diagnosis, he didn't know if his life would be normal again or if he would be able to play sport again. He further discussed physical changes such as weight loss and severe tiredness, which he experienced as frustrating and impacted the emotional challenges he experiences. Participant A clearly shared this sentiment when he said, "I just felt, just lui man [sic], I don't feel like doing anything." An emergent theme was the negative impact that living with a CAI had on the participants' emotions about their illness and the effects on their self-confidence. Participant F further captured the effects of his CAI on his confidence when he expressed: "I lost quite a lot of confidence...I couldn't look at myself in the mirror eventually."

Participant B described how when her knees and hip became infected with arthritis, she couldn't walk and had to be carried and assisted with bathing by her mother, which she experienced as gestures of support and care. When asked what was now different in Participant B's life as a result of her arthritis she said, "I can't go bath when I want to because my mother must like help me." The researcher found it interesting that Participant B did not refer to her wheel chair as an adjustment that she needed to make due to the physical changes brought on by her juvenile arthritis. When the researcher enquired about this, her response was an assertion that she could walk before her diagnosis. The researcher also noticed that this was not a topic that Participant B wanted to discuss any further and therefore the researcher did not pursue this aspect further.

Participant A, who at times also experienced difficulties walking, expressed how his friends would assist him if he was unable to walk. He further spoke of how his ability to play soccer was affected by not being able to partake in games as he used to. His restriction in walking, as previously mentioned, also affected his socialisation, as he said he could not do what his peers could do.

Participant D, who is an avid dancer, spoke of how arthritis has physically affected his life by stating that, "I don't participate as much as I would have liked to...my career would depend on my body." He further elaborated that he remembered how in primary school, he wanted to do hurdles, but his teacher said he could not because of his condition. Participant D further expressed feelings of disappointment and of being isolated due to the physical changes caused

by his RA by saying, “It’s fine, just know that I have it, don’t exclude me...I don’t want special treatment because I have arthritis, I don’t want to be singled out, just make me one of the group.” He indicated that he would like to be a professional dancer, which will be hampered if his arthritis is active. Participant F, who is an enthusiastic tennis player, concurred with Participant D saying, “I also couldn’t play sport, I was way too weak and tired.”

Although some participants commented on how their CAI impacted on their physical changes and the challenges that it brought about, in some instances however, participants seem to be unaware that their physical conditions and changes were a result of their illnesses and medication taken to alleviate the illness’ symptoms. It was from the researcher’s own knowledge and research about the illnesses discussed, that she was able to observe this discrepancy. There were several identified examples hereof. Participant A spoke of his tiredness, but did not attribute fatigue to his illness. Participant C had severe pimples, stunted growth, weight gain and a disproportioned body, however he did not mention these side effects as impacting him socially and the only physical change he attributed to his condition were his pimples. Participant E could not list ways in which her condition has affected her life besides dry skin. After consultation with the participants’ specialists, it was confirmed that these responses are due to a lack of informed knowledge and understanding about their conditions.

7.1.1.2 Loss of autonomy

Frydenberg (2008:137) asserts that “achieving autonomy and independence” are pivotal objectives during adolescence and that not being able to attain these may result in much anxiety. Eccles (2012) emphasises how vital social acceptance is deemed during adolescence, as well as a need for adolescents to develop a sense of identity. Eccles (2012) further highlights that belonging to a peer group is crucial in achieving this sense of identity.

As is evident from research Table 1, participants also experienced a loss of autonomy through living with a diagnosed CAI, particularly in being unable to do what their peers can do, or what they used to be able to do before being diagnosed with a CAI. This is exemplified in the research data where participants A and D are struggling to walk, and participant B is bound to a wheel chair and unable to dress or feed herself independently.

From the research there are several identifiable ways in which the adolescents’ autonomy is lost:

- the conduction of innumerable medical procedures,
- the administration of drug trials and medications,
- experiencing chronic fatigue, which result in being unable to engage and partake in sport, social activities and a full day at school,

- being unable to make any decisions without considering possible health implications and risks, and
- continuously having to consult with medical specialists and related medical personnel.

The researcher herself experienced a loss of autonomy and independence upon diagnosis of her CAI and during the initial stages of living with the illness, and therefore can confirm the documented experiences of the participants.

7.1.2. Emotional Experience

Hobfoll (2001:337) believes that loss underlies all stress. This notion supports the researcher's expectancy that the conducted interviews and personal experience of adolescents diagnosed and living with CAIs will reveal much stress; especially considering the loss they experience. Such identified examples of loss include health, autonomy, clear skin, thick hair, good complexion, friendships, finances, routine, security, confidence, hope of remission and a cure, and the relief from pain (Arthritis Foundation of South Africa. 2012b; Holtzman, 2012; Paediatric Rheumatology International Trials Organisation, 2003a; 2003b).

Such is the impact of chronic pain that it may result in a secondary psychological condition such as depression, fear, frustration, anger and or anxiety - attributable to the fact that a person's physical and emotional experiences are interlinked (Bruns & Disorbio, 2005:2; National Institute of Mental Health, 2011:4). Moreover, poor or limited support from the medical fraternity, as well as a lack of understanding from family and friends, evidently compound the disruption that chronic pain and fatigue have on an adolescent's lifestyle, with their emotional well-being being directly affected by the inability to do the things they used to do (Dick & Riddell, 2010:238-239; Malleson, Connel, Bennett & Eccleston, 2001:189).

Faced with symptoms of CAIs such as chronic pain, the emotional impact hereof is evident in the study participants' responses. They expressed emotions that involved being scared, feeling hopeless, saddened, alone and depressed. Participant F commented, "At the time I thought I was going to die or something...I felt like there was sort of no hope and scared." Participant A noted, "Sometimes I feel sad" and participant D reflected, "There's still the fear you know, that it might get worse...I don't want it to get worse at all...I'm not going to lie, I do feel saddened by it, because it's, you know, it's my body."

It became evident from the research that many of the identified emotions stemmed from unanswered questions and feelings of "why me?" Some of these questioning feelings may be attributable to the fact that there is no known cause for these CAIs (American Auto-immune Related Diseases Association, 2012; Arthritis Foundation of South Africa, 2012b; Paediatric

Rheumatology International Trials Organisation, 2003a). Participant F emphatically expressed this: “It feels a little bit unfair at times, like, I guess you get frustrated with yourself that you’re ill, and you wish this never happened and why, why, why me?”. This concept was further and concretely expressed by participant C when he expressed the following: “Sometimes I think, why must I also get hurt?...and drink tablets?...my family doesn’t drink it...I feel I’m the only one that’s sick and all the other people that I ask are sick, but they are not sick and can walk around”. This evidently made participant C feel sad and lonely.

7.1.3 Resilience: Making the best of the situation

Olson (2012) highlights that adolescents living with a chronic illness are at risk of emotional turbulence and that it is partly the responsibility of the field to prevent poor adjustment outcomes in adolescents and to attempt to promote positive well-being and enjoyment of their lives. Olson (2012) goes on to define resilience, specifically with the context of adolescents diagnosed with a CAI, as their capacity to negotiate and adapt to the day-to-day demands of their illness.

Frankl (2006:66), the founder of logotherapy, said the following in his book *Man’s Search for Meaning*, “Everything can be taken from a man but one thing: the last of the human freedoms - to choose one’s attitude in any given circumstances, to choose one’s own way.” Of significance for those diagnosed with CAI, it is herein implied that although one cannot always control what happens in life, one can control how one responds to it (Allegrante, 2012; Hobson, 2011).

With regard to this study, making the best of the situation was a strong sub-theme that emerged from the research data. Participant F asserted this statement by declaring, “I kinda accepted the situation and I realised there’s nothing I can do about it...eventually you get used to not having energy and you just accept that you got the disease and must just make the best out of the situation...everyone has their struggle.” It was through making the best of the situation and choosing “one’s own way” (Frankl, 2006:66) that the researcher believes the participants’ have heightened their ability to connect, empathise and support others living with a CAI or who have gone through hardships. This supports Frankl’s (2006:66) view that people have the ability to create meaning and move forward, even within adverse contexts like being diagnosed with CAI.

Participant D also confirmed this notion: “I’m open more now to other things, you know, more accepting of diseases and stuff like that...you appreciate your life more.” He further shared that seeing other children with arthritis in hospital gave him perspective about his own condition, which assisted him in understanding community ignorance about arthritis. Significantly, he found a positive perspective in the situation when he stated, “I saw there are actually children with arthritis that have it worse than what I have it, children that can’t actually walk and that makes

me feel bad, you know...so then I'm actually happy that mine's not so severe as other childrens".

Participant B, who is currently in a wheelchair, disclosed great insight and empathy when she said, "It's actually like an eye-opening...sometimes for my cousins also, cause they used to, like sometimes, laugh at people that are in a wheelchair, but now they are like, more understanding and that [sic]." Participant F summed up the perceived ability to connect, empathise and support one another: "It's actually quite strange, there is an automatic connection between the two people that have it...it's like something you have in common."

From the participant responses, the researcher believes that the desire to be treated normally is evidently linked with feelings of resilience and making the best of the situation. Participants F and D succinctly expressed this when the former said, "I want to be treated normally" and the latter said, "I don't want special treatment because I have arthritis, I don't want to be singled out, just make me one of the group." This was further confirmed by the participants who indicated that they want to feel accepted as normal adolescents and not be defined by their illnesses. Participant D commented, "People with arthritis are normal people," and Participant F said, "I want to be treated normally." Participant B captured the issue of "normality" when she expressed that although those diagnosed with a CAI may look different from others, people are all human, which ultimately means they are the same: "They might, like, be different, but they aren't...we are all humans like that [sic]."

Woodgate (1999:221-222) summarises that an understanding of what contributes to resilience in the experience of adolescents diagnosed with a CAI is important in developing caring and effective treatment plans. The researcher believes this to be true for all adolescents living with a CAI and further enforces the motivation for and value of this study.

7.2 Main theme 2: Participants' experiences with regard to the support received within their fields

According to Yontef and Fuhr (2005:86) individuals can only be appreciated and survive in relation to their environment, which from a Gestalt perspective can be referred to as their field (Parlett 2009:71). Parlett (2005:46) asserts that the field has a way of naturally positioning itself so that those situations and occurrences which are most "relevant or pressing... [are] ...readily discoverable in the present." In terms of this study, diagnosis of a CAI may be regarded as a relevant or pressing situation, which in time may become less relevant, as the adolescent and members of their fields experience new situations and life changes, as well as coping methods of living with and adjusting to the specific condition.

Parlett (2005:47-48) discusses how an individual's field is always altering. This is amplified in the case of an adolescent being diagnosed and living with a CAI, who experiences a multitude of changes within their fields, such as their school, community and the medical fraternity. That said, one must remain mindful of the fact that there are also other changes which occur in the adolescent's fields, which are unrelated to their diagnosis of and living with a CAI.

Sub-themes and categories that have been identified under main theme 2 are reflected in Table 3 below and will be discussed in the subsequent sub-sections.

Table 3: Sub-themes and categories of Main theme 2

MAIN THEME 2: Participants' experiences with regard to the support received within their fields	
SUB-THEME 1 Support of the immediate field	SUB-THEME 2 Support of the larger field
<ul style="list-style-type: none"> • Family • Friends • School 	<ul style="list-style-type: none"> • Medical Fraternity • Community

7.2.1 Support of the Immediate Field

There is evidence to suggest that the way adolescents perceive themselves is greatly shaped by the manner in which they are treated by the significant people in their lives (Geldard & Geldard, 2008:247; Yontef & Fuhr, 2005:84). With regards to the study; family, friends and the school were identified as categories that form part of the participants' immediate field.

7.2.1.1 *Family*

Frydenberg (2008:137) brings attention to the fact that chronic illnesses put pressure on both family systems and the adolescent's personal resources, where maintaining normality in their lives becomes strained. This is observed when a family's primary focus becomes the chronically ill adolescent, where the adolescent then tries to integrate and engage within social systems. This in turn results in the parents' or siblings' social systems being adversely affected and somewhat deserted. In this regard, the Arthritis Foundation (2012) highlights the fact that "siblings of children with arthritis will feel a full spectrum of emotion from guilt that they're healthy, to resentment, anger, loneliness and a need for attention."

It was significant that the participants of this study did not experience the effects of their conditions being a burden on their families. Rather, their experiences of their families' reactions to them living with a CAI were deemed loving and supportive.

In this regard, participant A introduced the family field aspect: "When I was smaller I couldn't walk...my mommy had to carry me to hospital." Participant F spoke of how his family, although worried about him, treated him normally and supported him. He said, "They've got me whatever I've needed or helped me whenever I've needed help with something." Participant D also expressed feeling supported and understood by his family: "Since I was very young, you know, I'm like the only child who always has to go to hospital and stuff like that...I realised my parents are doing so much for me...so it's hard for them as well...my family has been impacted."

7.2.1.2 *Friends*

Eccles and Gootman (2002:59) identify the significance of social acceptance during adolescence, but more specifically, they further assert the importance of "friendship networks" and how, during adolescence, these social systems are arranged into "...relatively rigid cliques that differ in social status within school and community settings." In this regard, adolescence is the developmental phase where the peer group can have a great effect on determining an individual's behaviour, and belonging to a peer group is deemed an important development milestone in an adolescent's life (Bester, 2007:177-178; Donald *et al.*, 2002:244). Adolescent behaviour towards peers is largely influenced by their morals and what they deem important criteria for identity and acceptance within their peer group. In the context of this study there were varied experiences with regard to support from friends.

From the data, acceptance into specific peer groups occasionally appeared to be difficult for the adolescents living with a CAI. Negative learner attitudes towards the participants, or about their conditions, were experienced by participants B, D and E. Participant B disclosed, "Some of my friends, because they were popular...just didn't wanted to be my friends anymore because of it [the CAI], but I was fine with it...cause some of them still stayed my friend." Participant E admitted, "Sometimes I do not talk to them...people who are making fun of me...I feel awful." Finally, participant D posed a poignant question to the researcher: "I'm fine with it, so why are you not fine with it?"

With regard to friends' responses, participant C came to the conclusion that "they [the friends] don't understand what I'm going through." On the other end of the response spectrum however, support from friends evidently assisted greatly in the adolescents' experiences of living with a CAI. In this regard, participant A described how his friends always used to help him in his daily activities, which made a big difference in minimising his feelings of being ostracized. Participant

F also recalled his friends visiting him in hospital and being really concerned about him, as well as the numerous messages he received, which made him very happy. Participant F expressed the following in this regard: "...well they came to visit me in the hospital...and I got a lot of messages on Facebook and stuff...I was very happy about it."

7.2.1.3 School

Schools are institutes where adolescents spend a majority of their time, when they are well enough to attend. As such, it was evident that as part of the study participants' field, the school environment would play a role in the experience of being diagnosed with a CAI. Marin and Brown (2008:1) acknowledge that although a major focus of school is to achieve academically, it has far greater effects on adolescents which also require more social environments within school, co-created by learners and teachers. Olsson (2012) also brings attention to the fact that absence from school due to chronic illnesses could interfere with the adolescents' participation in their school environment and increase social isolation.

Landsberg (2005:431) highlights that on many occasions, teachers do not know how to handle a chronically ill child, which may lead to them being "...overly sympathetic or, conversely, not take into account the effect that the disease has on the learner's school experience". In relation to this study, Faller (2010:22-23) highlights the importance of teachers' awareness that symptoms of the particular CAI arthritis can vary vastly. Adolescents living with a CAI may encounter difficulties sitting, walking up flights of stairs and carrying books and bag, which would require assistance and understanding. In this regard, participant E expressed the following about her teachers: "They treat me as the same person who doesn't have the disease," which she appreciated and experienced as positive. Participant B said, "They're [the teachers] very friendly and helpful."

Participant F asserted that, "It was really a struggle to get all the work I needed to catch up...I would say it was like they had to do it...some of my teachers are very aware that I have the disease but some act like it never happened." From this comment it was clear that Participant F's experience with regards to support from teachers was not entirely positive, and although he stated that he wanted to be treated normally - according to him the teachers only helped him because they "had to", not because they cared. Participant F further expressed feelings of frustration about the lack of understanding about his Crohn's disease when he said, "The general sort of school people, they don't really understand what it is or what it's about."

7.2.2 Larger field

A feature of the concept of a field which can pertain to the onset and diagnosis of a CAI in adolescence is that within an instant, the field “can change dramatically” (Parlett, 2005:49). The diagnosed adolescent may have been living a relatively healthy and ‘normal’ lifestyle, when suddenly they fell ill and were exposed to new fields such as hospitals, medical procedures, staff, and medication.

From the empirical data it was evident that the community and the medical fraternity form part of the larger field of the participants and play specific roles in the participants’ experience of being diagnosed with a chronic illness.

7.2.2.1 *Community*

Hill (2012) is of the notion that in time of illness, support from the community can reduce stress and potentially also reduce some of the physical symptoms of illness. Hill (2012) discusses Jacobsen’s three basic forms of social support which assist in enhancing survival as:

- emotional support - fostering and encouraging feelings of comfort,
- cognitive support - providing information, knowledge, and advice, and
- material support - the offer and provision of goods and materials.

Due to the fact that the community is a field in which all adolescents find themselves, there is a large call for community awareness about CAIs. Compounded by the lack of research, the greater community of adolescents remain insufficiently informed about CAIs with an absence of knowledge of the conditions and a misunderstanding of the impact and effects thereof (Alliance for the Canadian Arthritis Program, 2005; American Auto-immune Related Diseases Association, 2011; Arthritis Queensland, 2012).

This lack of community understanding of CAIs was expressed by participant F: “Um it’s quite frustrating because often people [the community] like, like might judge you or something because you got a disease or something, like it’s weird or strange or whatever. But they, they don’t understand.” Participant D also reflected on the lack of community awareness when he stated that community members would say, “Isn’t that old people?” He then noted that, “They’re [community members] so ill-informed about Arthritis you know.”

However, examples of the care and difference a community can make in assisting an adolescent living with a CAI, is demonstrated where participant B shared that she was sponsored a wheelchair and is driven to and from school daily, thanks to a community initiative and project to assist children with disabilities. This resulted in participant B experiencing and

acknowledging community support, care and represents an indication of community awareness about how debilitating her condition is.

7.2.2.2 *Medical fraternity*

For the successful treatment of illness in adolescence, Christie and Viner (2005:301) assert that it is essential that doctors have an understanding about adolescent development, for example; physical examinations necessitate sensitivity towards the adolescent's privacy and integrity. Christie and Viner (2005:301) also highlight the importance of doctors' proficiency in adolescence as a developmental phase, so to "manage issues of adherence... identity, consent and confidentiality, and relationships between young people and their families...".

From the research data, it was evident that participants, who felt valued and well treated by the medical fraternity, experienced the support they received as pivotal in their coping with their diagnosed conditions. Participant B identified the doctors and sisters with whom she has been in contact as "nice and kind", while participant C mentioned that the hospitals, doctors and staff "look after me when I'm ill...[and] ask me a lot of questions" - which he found to help him in dealing with his condition.

Participants who felt like "numbers" or "objects", developed resistance towards their medical practitioners and expressed their desire to be treated like a person and not an object. Re-affirming this notion was participant E's description of her hospital visits: "I go in there, then there's one doctor. I can handle one doctor...then they call other doctors and I get all woozy...They all want to touch me and feel my skin and all that...I get bored and angry."

Participant F felt the need for collaboration amongst specialists and professionals in designing a rehabilitation programme including diet, exercise, medication and lifestyle changes, when he expressed the following: "I wasn't really that well informed when I left the hospital, so I was quite afraid...I think that doctors should really put more emphasis on trying to [sic], especially if you're a sportsman or something like that, they should really try make you get back to what you are, or get even stronger...I didn't receive any help in that respect...I think it's very disjointed, I feel that different sectors don't believe in each other almost...everyone needs to come together...and discuss the best plan for you forward."

There appears to be the need for follow-through in terms of medical treatment, as well as continued medical care. Participants expressed a sense of feeling at a loss and alone when in rehabilitation. They further expressed a desire to return to being physically active again, with which they were not assisted unless they sought external, private facilitation. Examples of such facilitators would be nutritionists, physiotherapists, sport scientists and the likes.

The researcher agrees with participant F's suggestion that a multi-disciplinary approach may serve participants and their families in assisting the adolescent in their healing, particularly when considering the emergent revelation of the study that many of the participants were unable to describe their condition, what causes it or what is used to treat it. The last discussion seems to be in accordance with Landsberg's (2005:431) view that for families in general to survive chronic illnesses, there is a need for support by, "...family members, peers, the health team, support groups and other social structures like schools...".

The Principle of Singularity acknowledges that every individual and experience is distinct, as well as acknowledging the significance that each individual attributes to them (Parlett, 1991:71). With regard to adolescents living with a diagnosed CAI, one must therefore be mindful of the fact that each adolescent and their surrounding fields may react differently to the adolescent's diagnosis. Ways in which reactions and coping methods may differ could be the ways in which members of the field choose to treat the adolescent in dealing with their emotions, reactions and the complexity of the new life changes and experiences that occur when such a diagnosis is made.

8. RECOMMENDATIONS

From the research findings, it became clear that although the research participants displayed much resilience and acceptance of their conditions, there are several distinct aspects which require further attention and understanding.

8.1 Patient-doctor communication

With regard to the medical fraternity, it is recommended that further research explores the patient-doctor relationship, as well as the relationships between professionals and specialists working in the medical field, albeit different disciplines.

Based on the results, the patient-doctor relationship is important in supporting the participant and their families in increasing their awareness and knowledge about their diagnosed CAI, as well as possible short and long term side effects of their conditions and medications taken to alleviate their symptoms. In medical training, doctors should therefore be made aware of the terminology and jargon they use and the importance of speaking in "non-medical" terms, when explaining a CAI to an adolescent and their family. The medical fraternity should realise that certain patients may not be able to access information about their CAI, which does not mean that they have less of a right to understand their CAI and ask the necessary questions.

Finally, there is the emergent importance of taking cognisance of the participants' environments and the fact that they may not be able to access information resources, or possess the ability to read such resources that describe their conditions. As such, as part of their ethical responsibility and within the code of conduct of the doctor-patient relationship, medical practitioners should equip their patients with information about their condition. This will assist them in making informed decisions and healthy lifestyle choices.

8.2 Medical collaboration

There was substantial evidence in the research and interviews of this study that greater collaboration between medical experts is required in rehabilitating adolescents living with a CAI. This would necessitate a multi-disciplinary approach in treating adolescents living with a CAI, through the range of involved professions, specialising and working in the fields of both CAIs and adolescence, such as specialist doctors, psychologists, social workers, sport scientists, bio-kineticists, physiotherapists, dieticians and nutritionists.

8.3 Awareness and education – School and Community

The role of schools as a vital and integral part of an adolescent's field, and the inherent presence and responsibility of teachers, suggests that they should be better informed and supported in terms of knowledge and awareness regarding CAIs. Teachers are not medical experts, and are not expected to have specialist knowledge of CAIs, but increased access to information and improved understanding would empower their significant role in the development and maturation of adolescents with CAIs and could mitigate against unintentional ostracism and prejudice.

8.4 General recommendation

With regards to the participants interviewed, it was of interest that they expressed themselves as living in the present, without expressing feelings of loss from past activities unless specifically asked through probing and reflection. Further exploration could be done on reasons contributing to the fact that participants do not readily recount or focus on "what was", but instead focus on the "now" and how to live an adapted lifestyle. Questions remain as to whether this serves as a coping mechanism, is part of resilience, or is shaped by the participants' fields.

9. LIMITATIONS OF THE STUDY

The research findings were primarily contextualised within one public hospital setting, where the semi-structured interviews were conducted. The results of the qualitative research are therefore localised and limited by this context.

There was a singularity in the socio-economic groups represented by the participants, whose limited financial means evidently impeded their ability to access relevant information about their CAIs. The researcher believes this to have attributed to their lack of understanding of general medical terminology applicable to their CAI. This in turn affected their ability to give detailed accounts about their experiences of living with CAI.

The research participants were not all verbally expressive and descriptive in sharing their experiences and therefore some research data lacks depth and insight, and therefore had to be interpreted by paraphrasing during the interviews.

10. CONCLUSION

The research emphasises the theoretical assumption that each individual's experience is unique, to which they attribute their own meanings. Specifically, although adolescents living with a CAI share the physical experience of being diagnosed, undergoing various tests, procedures, treatments and living with the condition, the data confirms that an individual's identified coping mechanisms and experiences of the condition, differ from adolescent to adolescent and from field to field. Even though each individual's experience is unique, certain themes (and thus patterns) were identified. The researcher was able to highlight the themes of adolescents' experiences and their shared, general feelings of living with a CIA.

In identifying these themes and sub-themes from the research data, the researcher aimed to enlighten medical specialists, families, and the general public on how they too, as part of an individual's field, may assist in coping with a CAI. This exploratory research and qualitative information will therefore serve a dual purpose. Firstly, the identified experiences, strategies and shared feelings could assist adolescents living with a diagnosed CAI in attaining and strengthening their internal resources for living with such a illness; and secondly, the research may assist in diagnosed adolescents feeling less isolated and having their needs better understood and met if the fields in which they live are more knowledgeable about the experiences of living with a CAI and how to accommodate them.

The wider medical fraternity and all those affected by CAIs should be encouraged by this research to speak more openly, honestly and frequently about CAIs, their impact, and the hope for the future. The researcher believes that this will in turn; inform medical practice, assist in community and family support behaviour, guide further research and ultimately improve the quality of life of adolescents living with a CAI.

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SECTION C:
EVALUATION OF THE RESEARCH, LIMITATIONS, CONCLUSIONS AND
RECOMMENDATIONS

1. INTRODUCTION

The purpose of this section is to indicate whether the aim that was set for this study was adequately met and whether the research question that was formulated was answered. The researcher further presents a summary of the conclusions and recommendations which is based on the research results, and also provides a discussion of the studies limitations and possible research opportunities.

2. OVERVIEW OF THE RESEARCH TOPIC AND PROBLEM STATEMENT

The problem that has been identified is that the diagnosis of chronic, autoimmune illnesses (CAIs) amongst adolescents is becoming more prevalent in the medical field. However, little information is available on adolescents' experiences of living with a diagnosed CAI, therefore little support on an emotional, psychological and physical level is available for these adolescents. Support from the medical fraternity, local community, family and friends are therefore also limited, which may undesirably affect the adolescents' experiences. The researcher believes that this may lead to feelings of isolation and not belonging to a group which could lead to adverse effects on adolescent development.

3. EVALUATING THE ANSWERING OF THE RESEARCH QUESTION

The primary research question of this study was formulated as: what are the experiences of adolescents living with a diagnosed CAI? The research aim was therefore to explore the experiences of adolescents living with a diagnosed CAI.

The semi-structured interviews conducted sought to realise the following research objectives:

- *Identify trends and common experiences within adolescents living with a diagnosed CAI.*
This objective was met by the researcher taking field notes and recording the semi-structured interviews to help ensure the accuracy and integrity of data capture. Participants were informed of the proposed use of digital voice recorders or video-cameras and such recordings were only undertaken with their, and where applicable their guardian's consent.
- *Make informed recommendations to parents and professionals working with adolescents that have been diagnosed and are living with a CAI.*
This objective was met under the recommendations section of section B that detailed four recommendations regarding: improved patient-doctor communication, enhanced

medical collaboration, greater awareness and education, and a general recommendation for further research into the unique perspectives of the participants.

- *Offer valuable and insightful contributions to further understanding and expand the knowledge bases of CAIs and also the adolescence developmental phase.*

This objective was met under the results discussion in section B. The researcher identified two main themes. Firstly, participants' experiences of living with a diagnosed, CAI, and secondly, participants' experiences with regard to the reaction of their immediate field.

The first main theme of living experiences was divided into 3 sub-themes with their respective categories:

- Lifestyle Adjustments - Physical changes, Loss of autonomy
- Emotional challenges
- Resilience - making the best of the situation.

The second main theme of field experiences was divided into 2 sub-themes with their respective categories:

- Immediate field - Family, Friends, School
- Larger field - Medical fraternity, Community

The researcher conducted a literature review by gathering literature using multiple methods and sources. Literature was sought using library-based research including books, magazines and academic journals and internet-based journal publication search engines such as EBSCOhost, Emerald Insight and Science Direct. The limited number of identified scientific publications confirmed the lack of research specific to adolescents' experiences of living with a diagnosed CAI.

The researcher identified the population of the study by asking specialists in the field of paediatric arthritis to identify potential research participants, specifically adolescents living with a CAI. The researcher used purposive sampling to select the population namely, adolescents living with rheumatoid arthritis, Crohn's disease, scleroderma and pyoderma gangrenosum (which are termed CAIs), in the Cape Peninsula and Helderberg regions in the Western Cape.

The researcher obtained ethical clearance from the University of South Africa and the University of Cape Town (see Annexure A). Permission to undertake the study with research participants was obtained from the Head of Paediatric Rheumatology at a provincial hospital in the Cape

Peninsula (see Annexure B) and written consent was obtained from all participants and where applicable, their legal guardians (see Annexure C).

4. LIMITATIONS REGARDING THIS STUDY

The identified limitations of the research are explained in the following sub-sections according to the main themes of the study.

4.1 Living experience

- Due to the fact that meeting the participants and interviews were conducted on the same day, the researcher and participant did not know each other well, which could have hampered a more in-depth and honest account of the participant's experiences of living with a diagnosed CAI.

4.2 Field experience

- Interviews were conducted at a provincial hospital in the Cape Peninsula. Although interviews were held in a private room, the environment and fact that the participants were at the hospital for a check-up may have influenced their emotive responses.
- Pre-interviews and interviews had to be conducted on the same day, due to travel and time constraints - participants therefore did not have much time to prepare themselves for the semi-structured interviews.
- Owing to disparate levels of language ability among participants, basic communicative English was used for most interviews, resulting in less detailed descriptions of adolescents' experiences of living with a diagnosed CAI.

5. SUMMARY OF THE RESEARCH FINDINGS

Although some participants mentioned their illnesses' effects on their self-confidence, they did not comment on the physical changes that have taken place, although many of which were observable and evident to the researcher. Further studies could investigate whether this may be due to the adolescents' resilience, coping strategies or desire to be seen and treated as normal adolescents.

Of further interest, is that the participants interviewed expressed themselves as living in the present, without expressing feelings of loss from past activities; unless specifically asked through probing and reflection. Further exploration could be done on why participants do not readily recount or focus on "what was", but instead focus on the "now" and how to live an

adapted lifestyle. Questions remain as to whether this serves as a coping mechanism, is part of resilience, or is shaped by the participants' fields.

Finally, there is the emergent importance of being aware of the participants' environments and the fact that they may not be able to access information resources, or possess the ability to read such resources that describe their conditions. Therefore, as part of their ethical responsibility and within the code of conduct of the doctor-patient relationship, medical practitioners should equip their patients with information about their condition. This will assist them in making informed decisions and healthy lifestyle choices. This emphatically highlights the need for doctors to speak in non-medical terms, avoiding technical jargon and to assist the patient and family in understanding the illness and related terminology.

6. CONCLUSIONS OF THE STUDY

The research emphasises the theoretical assumption that each individual's experience is unique, to which they attribute their own meanings. Specifically, although adolescent's living with a CAI share the physical experience of being diagnosed, undergoing various tests, procedures, treatments and living with the condition, the data confirms that an individual's identified coping mechanisms and experiences of the condition, differ from adolescent to adolescent and from field to field. Even though each individual's experience is unique, certain themes were identified. The researcher was able to highlight these themes of adolescents' experiences and their shared, general feelings of living with a CAI.

7. RECOMMENDATIONS

From the research findings, it became clear that although the research participants displayed much resilience and acceptance of their illnesses, there are several distinct aspects which require further attention and understanding.

7.1 Patient-doctor communication

The researcher is of the opinion that the patient-doctor relationship is important in supporting the participant and their families in increasing their awareness and knowledge about their diagnosed CAIs, as well as possible short and long term side effects of their illnesses and medications taken to alleviate their symptoms.

With regard to the medical fraternity, it is recommended that further research explores the patient-doctor relationship, as well as the relationships between professionals and specialists working in the medical field, albeit different disciplines.

In medical training doctors should be made aware of the terminology and jargon they use and the importance of speaking in “non-medical” terms when explaining a CAI to an adolescent and their family. The medical fraternity should realise that certain patients may not be able to access information about their CAI, which does not mean that they have less of a right to understand their CAI and ask the necessary questions.

7.2 Medical collaboration

There was a distinct need raised by the research participants for greater collaboration between medical experts in rehabilitating adolescents living with a CAI. It is recommended that there be a multi-disciplinary approach in rehabilitating adolescents living with a CAI, through the range of involved professions specialising and working in the fields of both CAIs and adolescence, such as specialist doctors, psychologists, social workers, sport scientists, bio-kineticists, physiotherapists, dieticians and nutritionists.

7.3 Family-based research

It is recommended that further research be conducted with the families of those living with a diagnosed chronic, auto-immune illness, to assist in understanding the adolescents’ fields. The researcher believes that by families sharing their experiences, it may serve as a form of support; not only for the families, but for the adolescents living with a CAI as well. It is recommended that the psychological and emotional implications of the experiences of being diagnosed, as well as living with a CAI, be explained to the families, to those working in the medical fraternity and to the community through awareness programmes offering hope and support.

7.4 School and teacher CAI awareness and education

The role of schools as a vital and integral part of an adolescent’s field, and the inherent presence and responsibility of teachers, suggests that they should be better informed and supported in terms of knowledge and awareness regarding CAIs. Teachers are not medical experts, and are not expected to have specialist knowledge of CAIs. However, it is recommended that there be increased access to information, as an improved understanding about adolescence and CAIs would empower the teacher’s significant role in the development and maturation of adolescents with CAIs and could mitigate against unintentional isolation and prejudice.

8. FINAL COMMENT

It is therefore a final conclusion that in order to voice the experiences of adolescents living with a CAI, inform medical practice, assist in community and family support behaviour, guide further research and ultimately improve the quality of life of adolescents living with a CAI; the wider

medical fraternity and all those affected by CAIs must be encouraged by this research to speak more openly, honestly and more frequently about these illnesses, their impact, and the hope for the future.

ANNEXURE A: ETHICAL CLEARANCE UNIVERSITY DOCUMENT



UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6626 • Facsimile [021] 406 6411
e-mail: lamees.emjedi@uct.ac.za

30 September 2011

HREC REF: 394/2011

Ms D Badenhorst
C/o Dr C Scott
Paediatric Rheumatology
Red Cross

Dear Ms Badenhorst

PROJECT TITLE: EXPERIENCES OF ADOLESCENTS LIVING WITH A DIAGNOSED CHRONIC, AUTO-IMMUNE CONDITION

Thank you for submitting your response to the queries raised by the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the FHS HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until 15 October 2012.

Please send us an annual progress report (website form FHS 016) if your research continues beyond the approval period. Alternatively, please send us a brief summary of your findings so that we can close the research file.

Please note a minor typing error under Section 7 of the consent form: "participas"

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.

lemjedi

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

ANNEXURE B: ETHICAL CLEARANCE SPECIALIST LETTER



**RED CROSS WAR MEMORIAL
CHILDREN'S HOSPITAL**
RONDEBOSCH, CAPE TOWN 7700, SOUTH AFRICA



Dr C Scott
School of Adolescent and Child Health
University of Cape Town
Red Cross Childrens Hospital
Klipfontein Rd, Rondebosch
Cape Town
7700
Chris.Scott@uct.ac.za
Tel: 0216585319

06/11/12

To whom it may concern

I hereby confirm that I gave Daniella Badenhorst permission to interview patients in my Rheumatology clinic during the course of her research into the experiences of adolescents living with a diagnosed chronic auto-immune illness in 2011 and 2012. Her study was also approved by the University of Cape Town ethics committee.

Yours faithfully

A handwritten signature in black ink, appearing to be 'Chris Scott'.

Dr Chris Scott
Senior Specialist Paediatric Rheumatology
Red Cross War Memorial Children's Hospital.

ANNEXURE C: CONSENT TO PARTICIPATE FORM

UNIVERSITY OF SOUTH AFRICA CONSENT TO PARTICIPATE IN RESEARCH

Experiences of adolescents living with a diagnosed chronic, auto-immune condition.

You are asked to participate in a research study conducted by Daniella Badenhorst (BEdPsych), from the Child, Youth and Family studies at the Huguenote College (UNISA). The results of the research will be used in the dissertation of limited scope to fulfil the requirements of the degree: Masters in Diaconology. You were selected as a possible participant in this study because you are an adolescent living with a chronic auto-immune condition such as Inflammatory Bowel Disease or Rheumatoid Arthritis.

1. PURPOSE OF THE STUDY

The study is designed to explore and describe the experiences of adolescents being diagnosed and living with a chronic, auto-immune condition such as Inflammatory Bowel Disease or Rheumatoid Arthritis.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

- **Consent**

Sign a consent form to participate in the research study, as well as for a video recording of the interview, which will remain confidential

- **Semi-Structured Interview**

Engage in one 60 minute interview with the researcher, either telephonically or in person in the Western Cape, in Somerset West or a location that suits both the participant and researcher. The researcher will ask broad, open-ended questions, which you can answer as you please.

3. POTENTIAL RISKS AND DISCOMFORTS

If at any time the participant feels uncomfortable talking about personal experiences or becomes too emotional to continue with the interview, the participant might terminate the interview. Participants will be given names of professionals with whom to consult, should there be a need for debriefing. These fees will be for the participant's/guardians account.

4. POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

The average age of diagnosis of IBD and Rheumatoid Arthritis is middle adulthood; most literature therefore focuses on the experiences of adults being diagnosed and living with these auto-immune chronic conditions and not on adolescents. The research in which you are participating may contribute to an increased body of knowledge with regard to auto-immune illness and the understanding of the adolescence developmental phase with regard to the illness. Furthermore there is the possibility that this information may form a basis for further research and possible therapeutic interventions. Subjects will not benefit from participation.

5. PAYMENT FOR PARTICIPATION

The subject will not receive payment for participation.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of using a pseudonym for subjects; interview recordings and process notes will be safely stored by the researcher and only the researcher and her supervisor will have access to them for the sake of data collection and analyses for the proposed study. The subjects have the right to review/edit video recordings, which will be erased after the completion of the dissertation.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact
Miss Daniella Badenhorst (Researcher): 082 434 9377
Mrs Issie Jacobs (Study leader): 021 873 1181
Dr R Bloem (Head: Institute for Child, Youth and Family Studies): 021 873 1181

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Prof Naas swart at the Unit for Research Development (021 873 1181).

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me by Daniella Badenhorst in Afrikaans/English and I am in command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

NAME OF SUBJECT/PARTICIPANT

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the subject/participant*] and/or [his/her] representative _____ [*name of the representative*]. [He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/*English*] and no translator was used.

Signature of Investigator

Date

ANNEXURE D: SEMI-STRUCTURED INTERVIEW SCHEDULE

1. Can you name your auto-immune illness and briefly explain what your condition entails?
2. At what age were you diagnosed with your condition?
3. Can you describe some of the feelings that you experienced after you were diagnosed?
4. Can you mention the physical and emotional side-effects you experience from your condition?
5. How has the condition affected your life?
6. How would you like people to deal with your condition?

ANNEXURE E: SA HEALTH JOURNAL GUIDELINES



Cover page

The format of the **compulsory cover letter** forms part of your submission and is located on the first page of your manuscript and should always be presented in English. You should provide all of the following elements:

- **Article title:** Provide a short title of 50 characters or less.
- **Significance of work:** Briefly state the significance of the work being reported on.
- **Full author details:** Title(s), Full name(s), Position(s), Affiliation(s) and contact details (postal address, email, telephone and cellular number) of each author.
- **Corresponding author:** Indicate to whom all correspondence should be addressed to.
- **Authors' contributions:** Briefly summarise the nature of the contribution made by each of the authors listed, along the lines of the following: *J.K. was the project leader, L.M.N. and A.B. were responsible for experimental and project design. L.M.N. performed most of the experiments. P.R. made conceptual contributions and S.T., U.V. and C.D. performed some of the experiments. S.M. and V.C. prepared the samples and calculations were performed by C.S., J.K. and U.V. wrote the manuscript.*
- **Possible reviewers:** Authors are encouraged to provide the names and full contact details (including email) of two or three potential referees to evaluate the work (referees should not be people with whom the researcher has recently collaborated or published).
- **Summary:** Lastly, a list containing the number of words, pages, tables, figures and/or other supplementary material should accompany the submission.

A letter from a statistical consultant needs to be presented upon submitting your article to this journal. Ensure that this letter is uploaded in Step 4 of the online submission process.

Submission language: English (UK)

Title: The article's full title should contain a maximum of 95 characters (including spaces).

Abstract (first-level heading)

- Do not cite references in the abstract.
- Do not use abbreviations excessively in the abstract.
- The abstract should be written in English.
- The abstract should be no longer than 250 words and must be written in the past tense. The abstract should give a succinct account of the objectives, methods, results and significance of the matter. The structured abstract for an Original Research article should consist of five paragraphs labelled Background, Objectives, Method, Results and Conclusion.
 - **Background:** *Why do we care about the problem?* The context and purpose of the study (what practical, scientific or theoretical gap is your research filling?).
 - **Objectives:** *What problem are you trying to solve?* What is the scope of your work (a generalised approach, or for specific situation). Be careful not to use too much jargon.
 - **Method:** *How did you go about solving or making progress on the problem?* How the study was performed and statistical tests used (what did you actually do to get the results). Clearly express the basic design of the study, name or briefly describe the basic methodology used without going into excessive detail. Be sure to indicate the key techniques used.
 - **Results:** *What is the answer?* The main findings (as a result of completing the above procedure/study what did you learn/invent/create?). Identify trends, relative change or differences on answers to questions.
 - **Conclusion:** *What are the implications of your answer?* Brief summary and potential implications (what are the larger implications of your findings, especially for the problem/gap identified in your motivation?).

Introduction (first-level heading)

The introduction contains two subsections, namely the background section and the literature review.

- **Problem statement (second-level heading):** The setting section should be written from the standpoint of readers, that is, without specialist knowledge in that area and must clearly state and illustrate the introduction to the research and its aims in the context of previous work

bearing directly on the subject. The setting section to the article normally contains the following five elements.

- **Aims of the study/Key focus (third-level heading):** A thought-provoking introductory statement on the broad theme or topic of the research.
 - **Background (third-level heading):** Providing the background or the context to the study (explaining the role of other relevant key variables in this study);
 - **Trends (third-level heading):** Cite the most important published studies previously conducted on this topic or that has any relevance to this study (provide a high-level synopsis of the research literature on this topic).
 - **Research objectives (third-level heading):** Indicate the most important controversies, gaps and inconsistencies in the literature that will be addressed by this study. In view of the above trends, state the core research problem and specific research objectives that will be addressed in this study and provide the reader with an outline of what to expect in the rest of the article.
 - **Definition of key concepts (third-level heading)**
 - **Contribution to field (third-level heading):** Explanation of the study's academic (theoretical and methodological) or practical merit and/or importance (provide the value-add and/or rationale for the study).
-
- **Literature review (second-level heading):** The literature review is the second subsection under the Introduction and provides a brief and concise overview of the literature under a separate second-level heading, e.g. literature review. A synthesis and critical evaluation of the literature (not a compilation of citations and references) should at least include or address the following elements, ensure these are in the literature review. Define conceptual (theoretical) definitions of all key concepts; A critical review and summary of previous research findings (theories, models, frameworks, etc.) on the topic; A clear indication of the gap in the literature and for the necessity to address this void; and A clearly established link exists between formulated research objectives and theoretical support from the relevant literature.

Research method and design (first-level heading)

This section should include:

- **Design (second-level heading):** Describe your experimental design clearly, including a power calculation if appropriate. Note: Additional details can be placed in the online supplementary location.
- **Materials (second-level heading):** Describe the type of organism(s) or material(s) involved in the study.

- **Data collection method/Procedure (second-level heading):** Describe the protocol for your study in sufficient detail (clear description of all interventions and comparisons) that other scientists could repeat your work to verify your findings.
- **Data analysis (second-level heading):** Describe how the data were summarised and analysed, additional details can be placed in the online supplementary information.
- **Context of the study (second-level heading):** Describe the site and setting where your field study was conducted.

Results (first-level heading)

This section provides a synthesis of the obtained literature grouped or categorised according to some organising or analysis principle.

Tables may be used and/or models may be drafted to indicate key components of the results of the study.

- Organise the results based on the sequence of Tables and Figures you will include in the manuscript.
- The body of the Results section is a text presentation of the key findings which includes references to each of the Tables and Figures.
- Statistical test summaries (test name, p-value) are usually reported parenthetically in conjunction with the biological results they support, use SI unit.
- Present the results of your experiment(s)/research data in a sequence that will logically support (or provide evidence against) the hypothesis, or answer the question, stated in the Introduction.

All units should conform to the **SI convention** and be abbreviated accordingly. Metric units and their international symbols are used throughout, as is the decimal point (not the decimal comma).

Ethical considerations (first-level heading)

Articles based on the involvement of animals or humans must have been conducted in accordance with relevant national and international guidelines. Approval must have been obtained for all protocols from the author's institutional or other relevant ethics committee and the institution name and permit numbers provided at submission.

- **Potential benefits and hazards (second-level heading):** What risks to the subject are entailed in involvement in the research? Are there any potential physical, psychological or

disclosure dangers that can be anticipated? What is the possible benefit or harm to the subject or society from their participation or from the project as a whole? What procedures have been established for the care and protection of subjects (e.g. insurance, medical cover) and the control of any information gained from them or about them?

- **Recruitment procedures (second-level heading):** Was there any sense in which subjects might be 'obliged' to participate – as in the case of students, prisoners, learners or patients – or were volunteers being recruited? If participation was compulsory, the potential consequences of non-compliance must be indicated to subjects; if voluntary, entitlement to withdraw consent must be indicated and when that entitlement lapses.
- **Informed consent (second-level heading):** Authors must include how informed consent was handled in the study.
- **Data protection (second-level heading):** Authors must include in detail the way in which data protection was handled.

Trustworthiness (first-level heading)

This refers to the findings of the study being based on the discovery of human experience as it was experienced and observed by the participants.

- **Reliability (second-level heading):** Reliability is the extent to which an experiment, test, or any measuring procedure yields the same result on repeated trials. Without the agreement of independent observers able to replicate research procedures, or the ability to use research tools and procedures that yield consistent measurements, researchers would be unable to satisfactorily draw conclusions, formulate theories, or make claims about the generalisability of their research.
- **Validity (second-level heading):** Validity refers to the degree to which a study accurately reflects or assesses the specific concept that the researcher is attempting to measure. While reliability is concerned with the accuracy of the actual measuring instrument or procedure, validity is concerned with the study's success at measuring what the researchers set out to measure. Researchers should be concerned with both external and internal validity. External validity refers to the extent to which the results of a study are generalisable or transferable. Internal validity refers to (1) the rigor with which the study was conducted (e.g. the study's design, the care taken to conduct measurements, and decisions concerning what was and wasn't measured) and (2) the extent to which the designers of a study have taken into account alternative explanations for any causal relationships they explore. In studies that do not explore causal relationships, only the first of these definitions should be considered when assessing internal validity.

Discussion (first-level heading)

This section normally contains the following four elements. It is suggested that sub-headings are used in this section:

- **Outline of the results (second-level heading):** Restate the main objective of the study and reaffirm the importance of the study by restating its main contributions; summarise the results in relation to each stated research objective or research hypothesis; link the findings back to the literature and to the results reported by other researchers; provide explanations for unexpected results.
- **Practical implications (second-level heading):** Reaffirm the importance of the study by restating its main contributions and provide the implications for the practical implementation your research.

Limitations of the study (first-level heading): Point out the possible limitations of the study and provide suggestions for future research.

Recommendations (first-level heading): Provide the recommendations emerging out of the current research.

Conclusion (first-level heading)

This should state clearly the main conclusions of the research and give a clear explanation of their importance and relevance, with a recommendation for future research (implications for practice). Provide a brief conclusion that restates the objectives; the research design; the results and their meaning.

Acknowledgements (first-level heading)

If, through your study, you received any significant help in conceiving, designing, or carrying out the work, or received materials from someone who did you a favour by supplying them, you must acknowledge their assistance and the service or material provided. **Authors should always acknowledge outside reviewers of their drafts and any sources of funding that supported the research.**

- **Competing interests (second-level heading):** A competing interest exists when your interpretation of data or presentation of information may be influenced by your personal or financial relationship with other people or organisations that can potentially prevent you from executing and publishing unbiased research. Authors should disclose any financial competing

interests but also any non-financial competing interests that may cause them embarrassment were they to become public after the publication of the manuscript. **Where an author gives no competing interests, the listing will read ‘The authors declare that they have no financial or personal relationship(s) which may have inappropriately influenced them in writing this paper.’**

- **Authors' contributions (second-level heading)*:** This section is necessary to give appropriate credit to each author, and to the authors' applicable institution. The individual contributions of authors should be specified with their affiliation at the time of the study and completion of the work. An ‘author’ is generally considered to be someone who has made substantive intellectual contributions to a published study. Contributions made by each of the authors listed, along the lines of the following (please note the use of author initials):

J.K. (University of Pretoria) was the project leader, L.M.N. (University of KwaZulu-Natal) and A.B. (University of Stellenbosch) were responsible for experimental and project design. L.M.N. performed most of the experiments. P.R. made conceptual contributions and S.T. (University of Cape Town), U.V. (University of Cape Town) and C.D. (University of Cape Town) performed some of the experiments. S.M. (Cape Peninsula University of Technology) and V.C. (Cape Peninsula University of Technology) prepared the samples and calculations were performed by C.S., J.K. (Cape Peninsula University of Technology) and U.V. wrote the manuscript.

References (first-level heading)

Begin the reference list on a separate page with no more than 60 references. *Health SA Gesondheid* uses the **Harvard referencing style**, details of which can be downloaded from the journal website. **Note: No other style will be permitted.**

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Child consent in South African law: Implications for researchers, service providers and policy-makers

Ann Strode, Catherine Slack, Zaynab Essack

Children under 18 are legal minors who, in South African law, are not fully capable of acting independently without assistance from parents/legal guardians. However, in recognition of the evolving capacity of children, there are exceptional circumstances where the law has granted minors the capacity to act independently. We describe legal norms for child consent to health-related interventions in South Africa, and argue that the South African Parliament has taken an inconsistent approach to: the capacity of children to consent;

the persons able to consent when children do not have capacity; and restrictions on the autonomy of children or their proxies to consent. In addition, the rationale for the differing age limitations, capacity requirements and public policy restrictions has not been specified. These inconsistencies make it difficult for stakeholders interacting with children to ensure that they act lawfully.

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Children under the age of 18 are legal minors and, accordingly, have limited legal capacity to act independently without the assistance of an adult.¹ However, South African legislators recognised that children have evolving capacity, and consequently passed laws that permit children to make certain decisions independently. Some of these laws are in operation, while other provisions will be implemented in the future.

Medical treatment

Currently, children can consent independently to medical treatment from the age of 14; those below 14 require consent from a parent, legal guardian or other designated person.² In the future, children will be able to consent to medical treatment from the age of 12, if they have 'sufficient maturity'.³

HIV testing

Currently, children can consent independently to an HIV test from the age of 12, when it is in their best interests, and below the age of 12 if they demonstrate 'sufficient maturity'; i.e. they must be able to understand the benefits, risks and social implications of an HIV test.^{4,5} This norm is not likely to change in the immediate future.

Access to contraceptives

Currently, children can consent to contraceptives and contraceptive advice from the age of 12.⁶ This norm is not likely to change in the immediate future.

Termination of pregnancy

Currently, girls can consent to a termination of pregnancy at any age.⁷ This norm is not likely to change in the immediate future.

Operations

Currently, children cannot consent independently to a medical operation until they are 18.² When s129(3) of the Children's Act

comes into operation, a child over the age of 12 may consent to surgical operations if he/she (i) has 'sufficient maturity and has the mental capacity to understand the benefits, risks, social and other implications of the surgical operation'; and (ii) is assisted by a parent or guardian.⁸

Male circumcision

Currently, boys are able to consent independently to circumcision only when they are 18 as the procedure is classified as an operation. In the future, when s12(8) of the Children's Act comes into operation, boys below age 16 can only be circumcised for 'religious' or 'medical reasons on the recommendation of a medical practitioner' whereas those above 16 may undergo circumcision for any reason.¹⁰ Boys over 16 must receive counselling prior to the circumcision, and they have the right to refuse circumcision.¹¹

Health research

Currently, there is no clear legal statute specifying when children can independently consent to research; however, there are ethical norms. For clinical trials, these norms require parental consent and child assent.¹² For other forms of health research, these norms generally require consent from a parent; however, they do allow independent consent from older adolescents for low-risk research.¹³ In the future, when s71 of the National Health Act is implemented, parental/legal guardian consent will be mandatory for all health research; in addition, children will be required to 'consent' alongside their parent if they have 'sufficient understanding'.⁵ There is no mention in this Act of the need to obtain assent from a child who does not have the required understanding to consent to the research. However, this would be considered good practice, considering that the Children's Act specifies that children have a right to participate in an appropriate way in matters that affect them.¹⁴

Sex

Currently, it is an offence to have sex below the age of 16, even when sex is consensual.¹⁵ This means that if one or both of the persons engaged in consensual sex are below the age of 16, they are committing a criminal offence. This norm is not likely to change in the immediate future.

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