Quality of life in Addison's disease in South Africa

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ABSTRACT

A number of European studies have shown that Quality of life (QoL) can be impaired by Addison's disease (AD). Replication of these findings in the stressful context of South Africa (RSA) was necessary. This study aimed to discover whether QoL was affected by AD in RSA, which different specific components of QoL were affected, and whether additional variables of age and gender played a role. This study involved a between-groups comparison of AD patients (n=18) with healthy controls (n=18) matched for age and living environment. In addition, between-groups comparisons were made from a larger group of patients from the South African Addison's disease database (n=75). All participants were tested using the Rotterdam Symptom Checklist (RSCL), the Beck Depression Inventory 1A (BDI-1A), and the Spielberger State-Trait Anxiety Inventory (STAI). No significant differences were found between AD patients and controls on any of the subscales of the RSCL, but significant differences were found for the BDI-1A (η^2=0.31) and the STAI (η^2=0.43). AD patients between the ages of 40-60 and all females with AD were significantly more impaired on the physical distress scale of the RSCL (p-values<0.01). This study concluded that those living with AD patients may suffer lowered QoL, that QoL may be generally lower in RSA regardless of disease presence, that AD patients may experience clinical levels of psychological distress, and that age and gender play a limited role in QoL in AD. Further research into these factors to develop more effective treatment packages for AD sufferers is necessary.

INTRODUCTION

In today's health-conscious society, we are predominantly concerned with our ability to lead fulfilled lives. Alexis Carrel (1952), winner of the 1912 Nobel-prize for Physiology and Medicine, said, "The quality of life is more important than life itself". Most people would agree that this quote fits our most pressing desire, namely a high quality of life (QoL). Obviously, those who suffer from chronic illness are unable to achieve the same degree of QoL as healthy individuals. Addison's disease (AD) is one chronic illness that severely impacts on the QoL of those who suffer from it. A number of studies conducted in Europe have evaluated the effect of AD and its treatments on the QoL of AD patients. However, given the difficulties facing both the South African public health-care system and the majority of people who need to make use of it, the application of foreign findings to local patients is questionable.

In this study, an overview of AD is followed by an account of the concept of QoL. Thereafter, a number of studies which seek to establish the relationship between AD and QoL are reviewed. While there is a substantial body of knowledge concerning this relationship, to date no attempt has been made to replicate these findings within a South African context. To this end, this study investigates whether QoL is negatively impacted by AD and which specific aspects of QoL are affected. It is hypothesized that South African AD patients will have a lower QoL when compared with healthy individuals.

What is Addison's disease?

Addison's disease is a rare, chronic disease with a prevalence of approximately 93 – 140 people per million (Arlt & Allolio, 2003). The disease was first described by Thomas Addison, in 1855, who noted that its symptoms occurred in connection with a diseased condition of the adrenal glands (Arlt, 2002). After the function of the adrenal glands had been discovered, the disease was found to be caused by a chronic insufficiency of the hormones that these glands secrete; thus, the disease is also referred to as chronic adrenal insufficiency (Clark & Grossman, 2006; McCutcheon & Oldfied, 1992; Smith, 2008).

In 70% of AD cases, primary adrenal insufficiency is caused by an autoimmune disorder, in which the immune system forms antibodies that attack the tissues and organs of the body, which results in the destruction of the outer adrenal cortex. The destruction of the

cortex leads to insufficient concentrations of a glucocorticoid (cortisol) and a mineralocorticoid (aldosterone), two important regulatory hormones. Long-term infections such as HIV and tuberculosis are known causes of AD, due to their destructive action on the adrenal glands. Thirty percent of AD cases are caused by inadequate secretion of adrenocorticotrophic hormone (ACTH) by the pituitary gland in the brain, which activates hormonal production in the adrenal glands; these cases are referred to as secondary adrenal insufficiency (Clark & Grossman, 2006; McCutcheon & Oldfied, 1992; Smith, 2008).

Approximately 50% of patients with AD will also have co-existent autoimmune disorders (Smith, 2008). Autoimmune polyendocrine syndromes refer to a group of concomitant disorders (e.g., pernicious anemia, diabetes, and hypothyroidism) that can occur in conjunction with AD (Eisenbarth & Gottlieb, 2004). These associated disorders can be grouped into two syndromes: autoimmune polyendocrine syndrome type 1 consisting of AD primarily alongside hypothyroidism and mucocutaneous candidiasis, and autoimmune polyendocrine syndrome type 2 consisting of AD, diabetes mellitus, and Hashimoto's thyroiditis (McCutcheon & Oldfied, 1992).

What is Quality of Life?

Quality of life is a multidimensional concept that can report on patients' subjective experiences of their disease and treatment. Advances in biomedical science and technology have resulted in a significant decrease in morbidity rates among the acutely ill, resulting in a larger proportion of chronically ill patients with health-related QoL concerns. Since 1984, the World Health Organization has regarded health as not only having physical dimensions, but psychological and social dimensions as well (de Haes *et al*., 1996). Chronic diseases and their treatments can adversely impact on one or more of these dimensions, leading to a diminished QoL.

Thus, research has begun to asses and measure QoL in the chronically ill. QoL measurement seeks to support decision making by developing insights into the consequences of diseases and their treatments, identifying groups of patients at risk for developing distress, and enabling the comparison of the efficacy of different treatment modalities or care programmes (de Haes *et al*., 1996).

However, much debate exists surrounding the practical issues involved in the evaluation of QoL. Kimmel (2000) highlights the controversies in selecting the appropriate measures with which to assess QoL by showing the multitude of QoL assessment tools that exist. In a study of QoL in chronically ill children, Janse, Sinnema, Uitewaal, Kimpen, and

Gemke (2008) used the Health Utilities Index mark 3 to test different perceptions of QoL in children by the patients, their parents, and their paediatricians concluding that multi-respondent assessment of QoL should be undertaken. Furthermore, multiple questionnaires were used in a study of QoL in cancer patients including the Sickness Impact Profile and the Functional Living Index-Cancer (Stephens, 2004). Other measures that have been used include the Karnofsky Performance Scale (Kimmel, 2000), and the Short Form 36 Health Survey Questionnaire (Lövas, Loge, & Husebye, 2002).

While debate exists on the appropriate measures to use, relatively little research has been conducted on QoL in chronically ill patients. Commenting on this, Stephens (2004) reported that only 20 of the 128 articles he examined referred to QoL. He argued that although QoL is crucial in decision making and clinical practice, the relevant research can be criticized on many levels, including poor design, inadequate sample sizes, and poor standardization of instrumentation. Thus, further research is required to fully assess the effects of chronic illness on QoL.

Quality of life in Addison's disease

AD typically presents with non-specific physical symptoms such as nausea, weight loss, abdominal pain, fatigue, confusion, and even coma, which makes diagnosis difficult without further biochemical testing (Anglin, Rosebush, & Mazurek, 2006; Stewart, 2004; Heijmans, 1999). Hyperpigmentation of the skin, and in some cases vitiligo, which are more obvious signs of adrenal insufficiency, can occur if hormone replacement therapy is not initiated immediately (Nieman & Chanco Turner, 2006). Anglin *et al*. (2006) call attention to the psychiatric sequelae of AD: patients may present with depression, confusion, inability to concentrate, forgetfulness, irritability, sleep disturbances, and mild psychoses.

Although adrenal insufficiency can be fatal if left untreated, a normal life-span is expected by those patients who regularly take glucocorticoid and mineralocorticoid replacement medication. Still, virtually every study evaluating the effects of these life-long treatments reports that they fail to restore QoL in patients with this illness (Arlt *et al.*, 1999; Arlt, 2002; Gurnell *et al.*, 2008; Hahner *et al.*, 2007; Heijmans, 1999; Hunt *et al.*, 2000; Lövas *et al.*, 2002; Reisch & Arlt, 2009; Thomsen, Kvist, Anderson, & Kessing, 2006).

The majority of research has focused on the effects of traditional replacement therapies, i.e., fludrocortisone or hydrocortisone, on QoL in AD. For instance, in Norway, 79 patients with AD were asked to rate subjective health status (SHS; Lövas *et al.* 2002). They compared these data with normative data collected from the general Norwegian population

and found that patients with AD, had reduced general-health perception and vitality, and increased fatigue. This is unsurprising; more interesting is the fact that female patients reported poorer physical function than men, which might be due to adrenal androgen depletion, which is characteristic in females with adrenal failure (Lövas *et al.* 2002).

These authors also found lower mental health scores in females with autoimmune polyendocrine syndromes than those with solitary AD. These findings do not, however, indicate whether impaired mental health is due to having more than one illness, whether the neuroendocrinological nature of these concomitant disorders play some direct role in psychopathology, or whether it is simply living with a chronic illness that adversely affects QoL in these patients. Further research is thus necessary in these regards.

In a further examination of QoL in AD patients, a Danish study compared the SHS of 989 patients with AD to patients with osteoarthritis (Thomsen *et al.*, 2006). These researchers found that patients with primary and secondary adrenal insufficiency were approximately twice as likely to develop affective and depressive disorders when compared with the control group. Bergthorsdottir, Leonsson-Zachrisson, Ode´, and Johannsson (2006), found a higher prevalence of cardiovascular, respiratory, and infectious disease in a study of 1675 Swedish patients with AD when compared with the general population. A German study found significantly lower perceptions of SHS, regardless of origin of disease or concomitant disease, in 256 patients with adrenal insufficiency, matched for age and sex with individuals from the general population (Hahner *et al.*, 2007).

The studies reviewed above show the need for significant refinements in current replacement therapy because these treatments lack the ability to improve QoL in patients with adrenal failure. To this end, additional research is required to improve the efficacy of current treatments for AD.

Other studies have altered the frequency and dosage of traditional replacement therapies to establish their effects on QoL. For instance, Riedel *et al.* (1993) evaluated the effects of three different cortisol replacement regimes (regime I: 20mg twice daily; regime II: 30mg twice daily; regime III: placebo in the morning and 30mg cortisol in the evening) on SHS of 14 AD patients over a period of three weeks. They found that a 20mg dosage, twice-daily, was superior to a 30mg once-daily dosage on both SHS scales, but no replacement regime normalized the mean scores (as cited by Reisch & Arlt, 2009). While Lövas *et al.* (2002) noted that numerical differences found between the instruments used by Riedel *et al.* indicate that reduced psychological health may be a common feature of AD, Arlt (2002) argued that changes in the timing and dosage of the treatment did not result in relevant

improvements on these scales. Li Voon Chong, Sen, Johnson, Kyle, and MacFarlane (2001) found that daily replacement of 30mg of hydrocortisone was excessive in that it caused an increase in intraocular pressure throughout the day, which could lead to intraocular hypertension and glaucoma. These studies suggest that further research is needed to refine current treatment strategies.

Other studies have attempted to supplement traditional treatments with additional hormones that are naturally secreted by the adrenal glands in an attempt to improve QoL in patients with AD. For instance, Arlt *et al.* (1999) administered dehydroepiandrosterone (DHEA) to 24 women with AD, in a double-blind study, and measured their well-being and sexuality after 1 and 4 months of treatment, and again after 1 and 4 months of a placebo, with a 1-month washout period between them. They found that DHEA replacement improved well-being and sexuality in these patients and thus argued that DHEA should become part of hormone replacement therapy. Hunt *et al.* (2000) found similar benefits of DHEA in 39 patients with AD who were first given a 12-week course of DHEA, followed by a 12-week course of a placebo, with a 4-week washout period in between. They found improvements in self-esteem, mood, and fatigue, but, contrary to Arlt *et al.* (1999), found no effects on cognitive or sexual function and no effects on body composition, and bone-mineral density.

In an almost identical study, Gurnell *et al.* (2007) followed up Hunt *et al.*'s (2000) study with a randomized, double-blind design, in which half of their 106 patients with AD were given DHEA replacement therapy and half were given a placebo for a duration of one year. Gurnell *et al.* reported different long-term effects of DHEA replacement to Hunt *et al.*, including improvements in bone-mineral density at the femoral neck, increased total lean body mass, but again no improvements in cognitive or sexual function. Long-terms effects of DHEA could explain the differences between these studies.

The conflicting results concerning the effects of DHEA on sexuality in patients with AD may be explained by gender differences in the effects of insufficient DHEA in the body (Arlt, 2002; Lövas *et al.*, 2002). Further studies should be undertaken to evaluate these potential differences, as well as to contribute to the body of knowledge concerning DHEA replacement effects on QoL in AD (Reisch & Arlt, 2009).

To our knowledge, none of the studies reviewed thus far distinguish between different aspects of QoL. It is important that medical practitioners be made aware of the specific aspects of QoL that are negatively impacted on by AD. Current research suggests that health-care professionals can only warn AD patients of a generally reduced QoL, but cannot provide details on which particular aspects will be affected. The knowledge that, for instance,

depression is more prevalent in AD patients will allow health-care professionals to refer such patients to the appropriate clinicians at an early stage.

Relevance to South Africa

The literature on QoL in AD reviewed above stems from research conducted primarily in Europe. There are, however, clear differences between Europe and South Africa (RSA) in terms of health-care practices, health-care expenditure, unemployment rates, and availability of transportation, that make the application of the above findings to RSA and other developing countries tenuous. As AD is a chronic condition requiring regular medical attention, these problems facing the health profession could have a negative effect on patients' QoL.

In evaluating the public health-care system in Cape Town, Gibson (2001) argues that Apartheid has left its mark on South African health services. In particular, financial issues, racial disparities, and long waiting hours are highlighted as problems facing the treatment of chronically ill patients. Additional stressors include staff shortages, low staff morale, and overload of patients (McIntyre & Klugman, 2003). Draper and Louw (2007) studied medical students' perspectives on the South African public health system. They found that lack of resources, infrastructure, and government cooperation were prominent factors hampering health-care in RSA.

In contrast, a comparison of quality of health-care in Australia, Canada, New Zealand, England, and the United States indicated that although these countries do have certain issues in medical care that could be improved upon, these do not include availability of services and access to treatment (Hussey *et al*., 2004). As this differs from RSA, it is reasonable to assume that the QoL of chronically ill South Africans may be affected differently. Even though the standard of medical care is high in RSA, having to deal with the socio-economic constraints placed upon access to medical care may impact on a patient's overall QoL. Thus, in order to understand the relevance of the European findings of QoL in AD to patients in developing countries, these findings need to be replicated in RSA.

Rationale for research, aims, and hypotheses

As argued above, the application of European findings to developing countries is problematic. In order to replicate these results, it is necessary to control for the issues present in the South African public health system. In order to address this, this study compares QoL

in AD patients from the South African Addison's disease database with that of healthy controls.

Furthermore, the studies reviewed above leave significant questions that need to be addressed by additional research. While numerous studies have demonstrated that QoL can be impaired in patients with AD, it is unclear which specific aspects are most affected. This study addresses these issues in order to better equip health professionals in the treatment of AD. In particular, knowledge of differences in the specific aspects of QoL that are affected can assist health professionals to better inform AD patients of the consequences of their disease and allow for more effective treatment packages to be developed.

More significantly, research into which aspects of QoL are most vulnerable to chronic disease processes can give insight into the nature of QoL in healthy individuals. Thus, not only will patients with AD be able to understand the nature of their disease, but those who support and care for them will gain insight into the experiences of the chronically ill. Hopefully, this awareness would create better understanding, both within the medical profession and the broader community, of the nature of chronic illnesses such as AD and how people living with these illnesses may be affected.

In this study, the following questions have been addressed:

1. Are the European findings that QoL in AD is significantly lower than the general population replicated in RSA?
2. Do the specific aspects activate uniformly in AD or are their differences among the specific aspects of QoL?
3. Are there any additional variables that also have an effect on QoL in AD?

DESIGN AND METHODS

Design

This study is a cross-sectional, between-groups comparison of a group of AD patients with a group of healthy controls. In addition, following suggestions from the literature, within-groups analyses were performed to evaluate for the effects of gender and age on QoL in AD patients.

Madadi (2008) compared data collected from AD patients with those of healthy controls. Our study uses the data that were collected for the AD patients and reanalyses the results using within-groups comparisons to assess the role of age and gender in QoL. We refer to this group of participants as the AD group.

Concern has been raised over matching procedures in the previous study. Therefore, this study collected new control data to compare with the previously collected AD data. To our knowledge, there is no precedent for comparing historical clinical data with new control data. Thus, we acknowledge that the time gap between data collection may have an effect on the reliability of the data but there is no obvious reason to suggest that this should confound the results of our study. In addition, due to various factors that will be discussed in a later section, we were only able to collect control data for a subset of the original AD group. Between-groups comparison has thus been performed between a subset of the previously collected AD patients (AD subset group) matched to newly collected controls (control group).

Setting

This study was conducted in Cape Town and data were collected telephonically.

Participants

AD group

The minimum eligibility criterion for this group was a diagnosis of AD. Participants were recruited from the South African Addison's disease database (SAAD), comprising a list of all known AD patients, including those with polyendocrine syndromes, living in RSA. Dr Ian Ross, consultant endocrinologist at Groote Schuur Hospital, Cape Town, generated this list with the assistance of other specialist physicians throughout RSA. As such, all participants in

the AD group had been diagnosed with AD and were undergoing hormone replacement therapy at the time the data were collected.

Of the 140 patients in the database, data for 100 participants were collected in the previous study (Madadi, 2008). Seventy-five of these were deemed eligible for the current study since complete demographic data were available only for these participants.

AD subset group

Eighteen participants were selected for this subset based on the fact that we were able to secure matched healthy controls for these participants.

Control group

In order to obtain control data, we attempted to contact all 75 AD participants telephonically. The eligibility requirement for the control participants was that they should have lived with the AD patient over the past few years. This method of obtaining controls naturalistically matched for socioeconomic status, geographic location, and culture. In addition, controls were matched for age (we accepted a five year difference). From the 75 AD households we could only gain data from 18 control participants for the following reasons: 25 AD patients lived alone or without someone of a similar age; three potential controls declined participation, seven were deceased or chronically ill, and 22 could not be contacted despite numerous attempts.

Exclusion criteria were the presence of chronic disease or conditions that require chronic medication. Moreover, individuals diagnosed with any psychological disorder, which would adversely impact on QoL, were also excluded.

Measures

The study makes use of three well-known questionnaires: the generic Rotterdam Symptom Checklist (RSCL), the Beck Depression Inventory 1A (BDI-1A), and the Spielberger State-Trait Anxiety Inventory (STAI).

Generic measures of QoL are best for studies that compare groups of patients with differing conditions and studies that draw comparisons between patient-groups and the general population. Another advantage of generic measures is that they have been standardized, making between-groups comparisons more effective (Loge & Kaasa, 1998). Moreover, the fundamental reason for using these measures was to maintain consistency with the previous study (Madadi, 2008).

The Rotterdam Symptom Checklist

The RSCL is a generic measure of QoL that has been used predominantly in studies with cancer patients, but has been used for comparisons of non-cancer patients and healthy controls (de Haes *et al*., 1996). The RSCL separates QoL into four categories: the psychological distress scale, the physical distress scale, the daily activities scale, and an overall valuation of life.

The physical distress scale consists of 23 items referring to different physical symptoms. Some of the symptoms, such as headaches, may be experienced by people in general as well as by patients with chronic illness.

The psychological distress scale consists of 7 items referring to symptoms, such as depressed mood, which may be experienced by chronically ill and healthy individuals alike. In order to improve the accuracy of this scale, we supplemented the RSCL with the BDI-1A and the STAI.

For both the physical and psychological distress scales, responses are given on a 4-point Likert scale. Respondents are required to indicate how bothered they are by the particular symptom. Responses range from “not at all” to “very much”.

The daily activity scale consists of 8 items that pertain to the ability of the respondent to perform a range of tasks, e.g. housework. Respondents are required to indicate how able they are to perform each task. Responses range from “unable” to “without help”.

The overall valuation of life is measured by a single item, requiring respondents to rate the overall quality of their lives. Responses range from “Excellent” to “extremely poor”.

Akl and Schunemann (2006) argued that no justifiable standard exists for choosing one generic measure of QoL over another. Reliability and validity figures for the various instruments that these authors reviewed were similar across a wide range of clinical conditions. They maintained that fluctuations in sensitivity to certain aspects of QoL across the instruments did not justify choosing one measure over another. The reliability figures recorded for the RSCL reveal a Cronbach’s alpha of internal consistency ranging from .80 to .95 (de Haes *et al.,* 1996). These studies also report good construct and clinical validity for all subscales in the RSCL.

We chose the RSCL because it accurately measures the different components of QoL. This not only made comparisons of QoL and its components between the groups easier, but allowed us to identify which aspects of QoL in AD are most affected. Cross-cultural validity

studies of the RSCL have revealed that the scale is valid for use in multinational trials (de Haes & Olschewski, 1998). In the current study, this is particularly significant for applications of the RSCL within the multi-cultural South African context.

Beck Depression Inventory 1A

The BDI is one of the most widely used measures of detecting depression in all populations. By 1988, the BDI had been published for over 25 years, and had been used in over 1000 research studies (Beck, Steer, & Garbin, 1988). The BDI-1A was selected in order to maintain consistency with the previous study (Madadi, 2008).

The BDI was derived from repeated observations of symptoms, such as pessimism and sleep disturbances, that clinically depressed patients frequently exhibit. These observations were combined into 21 items that appear on the questionnaire in multiple-choice format. Respondents are required to select one of four options that most accurately describes how they have felt in the preceding week. The questionnaire was originally developed for use in clinical interviews, but has since most often been self-administered. The authors report that, when self-administered, the questionnaire generally takes 5 to 10 minutes to complete (Beck *et al.*, 1988).

Tests of reliability for the BDI-1A have shown Spearmen-Brown reliability at .93 and internal consistency of test items at .86 (Strauss, Sherman, & Spreen, 2006). Additionally, validity has been established against other scales such as the MMPI-D scale (r = .75). Moreover, as the test is simple to administer, it is suitable in a multi-cultural society such as RSA where English is often a second language. Studies have revealed that translating the BDI into languages such as Xhosa would be unnecessary if respondents can understand English (Steele & Edwards, 2008). Thus, the use of the BDI-1A for respondents whose second language is English does not seem to be problematic.

Spielberger State-Trait Anxiety Inventory (Form Y)

The STAI is a widely used measure of anxiety. By 2003, the STAI had been used in over 3000 studies (Caci, Baylé, Dossios, Robert, & Boyer, 2003). It is divided into two separate questionnaires:

1. State anxiety - measures temporary emotional responses involving unpleasant feelings of tension and worried thoughts.
2. Trait anxiety – measures the likelihood that individuals will experience state anxiety if exposed to stressful events.

Each questionnaire consists of 20 items in 4-point Likert scale format. The state anxiety questionnaire asks respondents to indicate to what extent they are currently experiencing feelings, such as nervousness. Responses range from “Not at all” to “Very much”. The trait anxiety questionnaire requires respondents to indicate how often they experience feelings, such as restlessness. Responses range from “Almost always” to “Almost never”.

The STAI was selected to maintain consistency with the previous study (Madadi, 2008) and because it can be administered telephonically. Excellent psychometric properties have been reported for the revised version of the STAI (Form Y) that we have used (Hersen, Hilsenroth, & Segal, 2004). The STAI has also been translated into more than 60 languages and has shown applicability to diverse populations. Thus, its use in the multi-cultural context of RSA is appropriate.

Procedure

Madadi (2008) telephoned[1] AD patients using contact numbers given to Dr. Ross when he compiled the SAAD. Following standard ethical guidelines, informed consent was obtained from each participant (Madadi, 2008). We telephoned these same numbers and asked to speak to the patients who participated in the previous study. We then asked these previous participants if they were living with someone of similar age to them, e.g., husband, or wife, and, if so, whether or not we could speak with this individual. These individuals then became our control participants.

All participants were asked if they were willing to participate in our study. If they agreed, each participant was informed of the basic purpose of the study, that they were welcome to terminate their involvement at any time, and that complete confidentiality would be maintained for any data collected from them. They were then given a basic overview of the questionnaires and informed consent was verbally obtained.

Respondents were first asked to state their age, sex, and race. Before administering the RSCL, participants were urged not to spend too much time thinking about their responses[2]. Thereafter, the RSCL was administered and participants were required to complete all items before moving to the next questionnaire. The RSCL requires approximately 8 minutes to complete (de Haes *et al*., 1996).

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[1] All questionnaires are suitable for use in telephonic interviews (Beck *et al.*, 1988; de Haes *et al*., 1996; Madadi, 2008).

[2] The RSCL manual suggests that answers should reflect a participant’s immediate response to each item.

Next, the participants were asked to complete the BDI-1A, which requires 5-10 minutes to complete (Beck *et al.*, 1988). Once all items on the BDI-1A had been answered, the participants were asked to complete the STAI, which requires approximately 10 minutes to complete. The entire battery of questionnaires required 15-25 minutes to complete depending on telephone reception and the hearing ability of the participant.

After each questionnaire had been completed, participants were asked if they wished to continue. If they became fatigued and wished to take a break, the participant was allowed as much time as desired.

Once the questionnaires were completed, participants were thanked and asked if they had any questions regarding the study. No concerns were raised by any participant and the researchers' contact details were given in case they had any queries at a later stage.

Ethical Considerations

This study adhered to the ethical guidelines for research with human subjects as specified by the Health Profession Council of South Africa (HPCSA) as well as the University of Cape Town (UCT) Codes for Research. Ethical approval was obtained from the Faculty of Health Sciences Research Ethics Committee at UCT for the use of clinical participants (Madadi, 2008). Additionally, ethical approval was obtained from the Psychology Department's Research Ethics Committee at UCT for the use of control participants.

Informed consent was verbally obtained from each participant before data were collected. Participants were informed of the basic purpose of the study, that they were welcome to terminate their involvement at any time without negative consequences for themselves, that complete confidentiality would be maintained for any data collected from them, and that their information would be used for research purposes only.

There are no risks associated with the tests that were administered. However, if participants were uncomfortable with any of the questions that were asked it was reiterated to them that they could withdraw from the study at any time. Participants were allowed to rest at any time during the administration of the tests.

Participants were aware that there were no direct benefits for their participation in this study. However, they were also aware that they were assisting in adding to a knowledge base of how QoL can be impaired in AD. As each participant had either been diagnosed with AD or was living with someone who had a diagnosis of AD, this could have been a motivating factor for their participation in this study.

Data Analysis

We sought to evaluate for differences between a subset of the AD group (n=18) and a healthy control group (n=18). These groups were matched for age and living environment. A MANOVA was performed with these two groups as the two levels of the independent variable, and the 6 subscales of QoL (Physical Distress Scale, Psychological Distress Scale, Daily Activities Scale, Overall valuation of life, General QoL, BDI-1A, and STAI) were used as the dependent variables. As only one analysis was performed, significance was set at $p<0.05$.

The appropriate analyses for the within-groups analyses (n=75) were factorial ANOVAs. This required six separate factorial ANOVAs for each separate subscale of QoL as the dependent variable. We used age and gender as the independent variables.

The number of tests that were run for the within-groups analyses are an obvious concern. The probability of erroneously finding a significant result for any particular analysis is greatly increased when multiple analyses are performed. Thus, it was necessary to apply a more stringent significance level and only accept significance at $p<0.01$.

We initially sought to evaluate for the effects of race as well, since it seemed particularly relevant in a multi-racial community such as RSA. However, there were extreme differences in the sample sizes of our four race groups (White, n=57; Coloured, n=15; Indian, n=2; Black, n=1), and due to the underrepresentation of certain groups, we concluded that no meaningful results could be derived from such an analysis.

RESULTS

Between-groups comparisons of AD subset and control group

In order to investigate the effect of AD on QoL, we compared scores on the six subscales of QoL between the AD subset group (n=18) and controls (n=18). A MANOVA was performed with the AD subset group and the control group as the two levels of the independent variable (Group), and scores on the six subscales (Psychological Distress Scale, Physical Distress Scale, Daily activities Scale, Overall valuation of life, BDI, STAI) as the dependent variables. As one composite test was performed, significance was set at α=0.05. We hypothesized that participants in the AD subset would have higher scores on the different subscales.

Descriptive statistics for all the variables are reported in Table 1 (Appendix A). Results of the MANOVA indicated a significant effect for Group, $F(6, 29)=4.86$, $p<0.05$, $\eta^2=0.50$. Thus, 50% of the variance in scores on the different subscales of QoL can be explained by whether or not participants had AD. Univariate MANOVA results were explored to test which specific subscales of QoL were affected by whether participants had AD or not.

Psychological Distress Scale

Levene's test for homogeneity of variance was not significant, $F(1,34)=1.58$, $p>0.05$. An inspection of the normal probability plot revealed the data to be normally distributed and independence of observations was upheld. The univariate MANOVA results for psychological distress revealed no significant effect for Group, $F(1,34)=1.93$, $p>0.05$, $\eta^2=0.05$. Thus, whether or not participants had AD did not have a significant effect on their psychological distress levels.

Physical Distress Scale

Levene's test for homogeneity of variance was not significant, $F(1,34)=0.32$, $p>0.05$. An inspection of the normal probability plot revealed the data to be normally distributed and independence of observations was upheld. The univariate MANOVA results for physical distress revealed no significant effect for Group, $F(1,34)=4.11$, $p>0.05$, $\eta^2=0.11$. Thus, whether or not participants had AD did not have a significant effect on their physical distress levels.

Daily Activities Scale

Levene's test for homogeneity of variance was not significant, $F(1,34)=1.86$, $p>0.05$. An inspection of the normal probability plot revealed the data to be normally distributed and independence of observations was upheld. The univariate MANOVA results for daily activities revealed no significant effect for Group, $F(1,34)=0.57$, $p>0.05$, $\eta^2=0.02$. Thus, whether or not participants had AD did not have a significant effect on their ability to perform daily tasks.

Overall valuation of life

Levene's test for homogeneity of variance was not significant, $F(1,34)=0.82$, $p>0.05$. An inspection of the normal probability plot revealed the data to be normally distributed and independence of observations was upheld. The univariate MANOVA results for overall valuation of life revealed no significant effect for Group, $F(1,34)=0.75$, $p>0.05$, $\eta^2=0.02$. Thus, whether or not participants had AD did not have a significant effect on their valuations of their lives on the whole.

Beck Depression Inventory 1A

Levene's test for homogeneity of variance was significant, $F(1,34)=20.94$, $p<0.001$. However, MANOVA is robust in cases where this assumption is violated, especially in cases such as ours where there are equal cell sizes. An inspection of the normal probability plot revealed the data to be normally distributed and independence of observations was upheld. Univariate MANOVA results for this subscale are reported in Table 2 as follows:

Table 2.

MANOVA Univariate results for the BDI

Source	*df*	*SS*	*MS*	*F*	*p*	η^2
Group	1	774.69	774.69	14.93	<0.01	0.31
Error	34	1764.28	51.89			
Total	35	2538.97				

As indicated in Table 2, a significant effect for Group was found for depression. Tukey's HSD post hoc test revealed a significant difference between the AD subset group (M=12.11, SD=9.52) and the control group (M=2.83, SD=3.63), $p<0.05$. Thus, the results indicated that patients with AD had significantly greater levels of depression than controls. Analysis of the

effect size revealed that 31% of the variance in scores on the BDI was explained by whether or not participants had AD.

In addition, conversion of these scores according to the interpretative guidelines of the BDI-1A indicated that the mean score for the AD subset group falls within a clinically significant range (mild to moderate depression) while the mean score for the control group falls within the normal range (Strauss *et al*., 2006).

Spielberger State-Trait Anxiety Inventory

Levene's test for homogeneity of variance was not significant, $F(1,34)=0.09$, $p>0.05$. An inspection of the normal probability plot revealed the data to be normally distributed and independence of observations was upheld. Univariate MANOVA results for this subscale are reported in Table 3 as follows:

Table 3.
MANOVA Univariate results for the STAI

Source	*df*	*SS*	*MS*	*F*	*p*	η^2
Group	1	1260.25	1260.25	26.12	<0.01	0.43
Error	34	1640.50	48.25			
Total	35	2900.75				

As indicated in Table 3, a significant effect for Group was found for anxiety. Tukey's HSD post hoc test revealed a significant difference between the AD subset group (M=33.17, SD=7.56) and the control group (M=21.33, SD=6.27), $p<0.05$. Thus, the results indicated that patients with AD had significantly greater levels of anxiety than controls. Analysis of the effect size revealed that 43% of the variance in scores on the STAI was explained by whether or not participants had AD.

In addition, conversion of these scores indicated that the mean anxiety score for the AD subset group falls within a clinically significant range (moderate) while the mean anxiety score for the controls falls within the mild range.

Conclusion of Between-Groups Comparisons of AD Subset and Control Group

While we had hypothesized that AD patients would have higher scores of impairment on all subscales of QoL, significant differences between AD patients and controls were only indicated for depression and anxiety with AD patients falling within the clinically significant range on both of these measures.

Within-groups comparisons of the AD group

We had initially wanted to test for differences between scores on the different subscales of QoL to see if certain aspects were more affected and whether or not age and gender had an effect on these. However, assumptions for factorial ANOVA were violated for the Daily Activities Scale and the BDI-1A. Additionally, scores on the BDI-1A and STAI were not in the same scale as scores on the subscales of the RSCL. Consequently, a composite factorial ANOVA to test differences in performance on the different subscales could not be performed. However, as this comparison was one of the main aims of this study, mean scores for the different subscales are reported below in Table 4. As all subscales of the RSCL were converted into a percentage scale, rudimentary conversion of the anxiety and depression scores into percentages was also performed to allow for comparisons across scales. As this conversion did not account for the weightings of the anxiety and depression scales, statistical significance could not be ascertained from these comparisons.

Table 4.

Mean scores for AD Group on the Different Subscales of QoL

	Subscale					
	Psych D*	Phys D*	Activity*	Overall QoL	Depression	Anxiety
M	31.58	22.99	8.62	19.32	28.73	33.42

** Psych D = Psychological Distress*
Phys D = Physical Distress
Acivities = Daily Activities

Within-groups comparisons were possible, however, to test for age and gender effects on QoL. In order to establish the effect of age and gender on the different components of QoL, six separate factorial ANOVA's were performed with scores on the different subscales of QoL as each dependent variable:

Test a. Psychological Distress Scale

Test b. Physical Distress Scale

Test c. Daily Activities Scale

Test d. Overall valuation of life

Test e. Beck Depression Inventory 1A

Test f. Spielberger State-Trait Anxiety Inventory

Descriptive statistics for all of these variables are reported in Table 5 (Appendix B) and marginal means for these variables are reported in Table 6 (Appendix B). Because of the large number of analyses performed, we only accepted significance at $p<0.01$ in order to control for type 1 errors. We hypothesized that both age and gender would have an effect on the outcome of the scores on the different subscales of QoL.

Test a. Psychological Distress Scale

Levene's test for homogeneity of variance was not significant, $F(7, 65)=1,32$, $p>0.05$. An inspection of the normal probability plot revealed the data to be normally distributed and independence of observations was upheld. No significant main effect was found for age, $F(3, 65)=0.79$, $p>0.01$, $\eta^2=0.04$, no significant main effect was found for gender, $F(1, 65)=2.32$, $p>0.01$, $\eta^2=0.03$, and no significant interaction were found, $F(3, 65)=0.22$, $p>0.01$, $\eta^2=0.01$. Thus, it was concluded that age and gender do not have an effect on psychological distress.

Test b. Physical Distress Scale

Levene's test for homogeneity of variance was not significant, $F(7, 65)=1,00$, $p>0.05$. An inspection of the normal probability plot revealed the data to be normally distributed and independence of observations was upheld. Factorial ANOVA results for the effect of age and gender on physical distress are reported below in Table 7.

Table 7.

Factorial ANOVA Summary Table for the Physical Distress Scale in AD Group

Source	*SS*	*df*	*MS*	*F*	*p*	η^2
Age	1844.26	3	614.75	3.15	0.03	0.13
Gender	893.58	1	893.58	4.58	0.03	0.07
Age*Gender	252.25	3	84.08	0.43	0.73	0.19
Error	12691.68	65	195.26			

As is indicated in Table 7, the main effects for age and gender are close to the $p<0.01$ level. Because an n of 75 is not a very large sample, post hoc tests were performed on these effects in order to avoid incorrectly retaining null hypotheses (type 2 errors).

Tukey's HSD post hoc test indicated a significant difference between the 40-60 age group (M=30.63, SD=16.17) and the 20-40 age group (M=18.11, SD=11.11), $p<0.05$. Additionally, a significant difference was indicated between the 40-60 age group (M=30.63, SD=16.17) and the 60 and older group (M=19.58, SD=14.52), $p<0.05$. Thus, these results

indicated that age does have an effect on physical distress which is most apparent in the 40-60 age group.

Tukey's HSD post hoc test also indicated a significant difference between males (M=16.88, SD=13.06) and females (M=26.17, SD=15.42). Thus, this result indicated that females have greater physical impairment than males.

Therefore, the factorial ANOVA of the effect of age on physical distress indicated that physical distress was greater in the 40-60 age group and also that it was greater in females of all ages. These results, however, need to be analysed with caution as the p-values did not meet the more stringent $p<0.01$ level, and the effect sizes show that very little of the variance was explained by these effects (Table 7).

Test c. Daily Activities Scale

Levene's test for homogeneity of variance was significant, $F(7, 65)=4.13$, $p<0.05$. An inspection of the normal probability plot revealed the data might not be normally distributed. Independence of observations was upheld, but as two assumptions for factorial ANOVA were violated and there were unequal cell sizes, a factorial ANOVA could not be run. The decision to use a non-parametric equivalent of factorial ANOVA was not made at this point as preliminary results in factorial ANOVA indicated that there would probably be no significant effects (all p-values>0.05). Thus, it was concluded that age and gender do not have an effect on the ability to perform daily activities.

Test d. Overall valuation of life

Levene's test for homogeneity of variance was not significant, $F(7, 65)=0.76$, $p>0.05$. An inspection of the normal probability plot revealed the data to be normally distributed and independence of observations was upheld. No significance main effect was found for age, $F(3, 65)=2.53$, $p>0.01$, $\eta^2=0.10$, no significant main effect was found for gender, $F(1, 65)=0.14$, $p>0.01$, $\eta^2<0.01$, and no significant interaction was found, $F(3, 65)=0.22$, $p>0.01$, $\eta^2=0.01$. Thus, it was concluded that age and gender do not have an effect on overall valuation of life.

Test e. Beck Depression Inventory 1A

Levene's test for homogeneity of variance was significant, $F(7, 65)=3.91$, $p<0.05$. An inspection of the normal probability plot revealed the data to be normally distributed and independence of observations was upheld. However, as an assumption for factorial ANOVA

was violated and there were unequal cell sizes, a factorial ANOVA could not be run. The decision to use a non-parametric equivalent of factorial ANOVA was not made at this point as preliminary results in factorial ANOVA indicated that there would probably be no significant effects (all *p*-values>0.05). Thus, it was concluded that age and gender do not have an effect on depression.

Test f. Spielberger State-Trait Anxiety Inventory

Levene's test for homogeneity of variance was not significant, $F(7, 65)=0.92$, $p>0.05$. An inspection of the normal probability plot revealed the data to be normally distributed and independence of observations was upheld. Results for factorial ANOVA on the effect of age and gender on anxiety are reported below in Table 8.

Table 8.

Factorial ANOVA Summary Table for the STAI in AD Group

Source	*SS*	*df*	*MS*	*F*	*p*	η^2
Age	272.96	3	90.99	2.89	0.04	0.12
Gender	18.72	1	18.72	0.59	0.44	0.01
Age*Gender	26.21	3	8.74	0.28	0.84	0.01
Error	2046.05	65	31.48			

As is indicated in Table 8, the main effect for age approaches the $p<0.01$ level. Thus, post hoc testing was performed on this effect.

Tukey's HSD post hoc test indicated no significant differences between any of the age groups. As the effect size for age also indicated that very little of the variance is explained by this effect (Table 8), it can be concluded that no meaningful effect for age can be obtained from these results.

Conclusion of Within-Groups Analyses

Therefore, while we hypothesized that age and gender would have an effect on the different components of QoL, the results of all six factorial ANOVAs indicated that there were only significant effects for both of these variables on the physical distress scale.

DISCUSSION

A number of European studies have evaluated the effects of AD on QoL (Arlt *et al.*, 1999; Arlt, 2002; Gurnell *et al.*, 2008; Hahner *et al.*, 2007; Heijmans, 1999; Hunt *et al.*, 2000; Lövas *et al.*, 2002; Reisch & Arlt, 2009; Thomsen *et al.*, 2006). Our study was designed in order to investigate whether these European findings could be replicated in RSA. In terms of this, this study produced mixed results.

Our study showed *no effect of AD on any of the subscales on the RSCL*. While this particular measure is not commonly used for QoL assessment in AD, other QoL instruments in European studies have shown that QoL is negatively affected in AD. For instance, Lövas *et al.* (2002) tested QoL in 79 Norwegian AD patients using the Short Form 36 (SF-36) and the Fatigue questionnaire and discovered that AD patients had reduced general health perception and vitality, and increased fatigue. Similarly, using the SF-36, and the Giessen Complaint list, a German study found significantly lower perceptions of subjective health status (SHS) in 256 patients with AD than individuals from the general population (Hahner *et al.*, 2007).

Our study had hypothesized that due to the problems facing South African public health services, QoL in local AD patients would be even more affected than in European AD patients. However, in comparison to the European studies reviewed above, our study actually showed no significant difference between South African AD patients and controls on the RSCL.

One of the reasons for this could be that the RSCL does not measure the same aspects of QoL as other measures that have been used previously to assess QoL in AD. In addition, certain limitations of this study, such as sample size (n = 18) and the time gap between data collection, could have confounded the results of the study. Further research on QoL in South African AD patients using different measures and a larger sample may be necessary.

Also possibly relevant is the fact that the control group recruited in this study were not normal healthy controls per se. We recruited as controls people that were living in the same household as the AD patients. This was done to match for socioeconomic status, geographic location, and culture. As such, these controls were either the direct caregivers of the AD patients, or were otherwise involved in their support structure. An abundance of research on the QoL of family caregivers of the chronically ill exists. A range of social, physical, and psychological factors can be affected, and caregivers may experience impairments in physical health, social and family life, stress, anxiety, and depression (Lim &

Zebrack, 2004). Baanders and Heijmans (2007) investigated the impacts of chronic disease in patients and their partners and found significant reports of personal life strain, impaired social relations, and financial burdens in the latter group. In a longitudinal study, Nijboer, Triemstra, Tempelaar, Sanderman, and van den Bos (1999) evaluated the determinants of mental health in caregivers of cancer patients. The authors found that negative caregiver experiences were associated with lower incomes, higher patient dependencies, and a high involvement in care-giving tasks. Therefore, it could be concluded that while AD patients in our study reported QoL impairments on the RSCL, the controls experienced similar levels of impairment due to the strain placed on them by caring for their partners.

An alternative explanation for these findings is that QoL in RSA in general is of a lower standard than that of Europe. Social and political factors that affect the population of RSA as a whole, such as crime, poverty, and political uncertainty, may have played some role in the QoL reports of our controls. This would suggest that such factors were more influential than health-status in our participants' considerations of their QoL, since factors affecting the population as a whole would lower baseline QoL scores. It could be argued that a noticeable difference should still exist between individuals suffering AD, and healthy individuals who live under the same social and political conditions. However, the effects of these socio-political conditions could mask the effects of a chronic illness, such as AD.

Research on QoL in AD from other developing countries could elucidate the validity of the above arguments. In our study, comparison of both the results from the AD subset group and the control group with normative data from European countries could indicate a generally lower QoL in all South Africans. Table 9 below compares means from healthy populations in Europe with means from our AD subset group and control group on psychological and physical distress to indicate how a generally lower QoL may be evident in RSA. Significance testing with a larger sample of South African participants is necessary to confirm whether QoL in RSA is generally poorer than in Europe.

Table 9.

Table comparing normative means with AD subset and control means

		Our groups		Normative groups	
		AD subset	Control	Dutch study*	SORK study*
Psychological distress scale	*M*	30.44	20.5	17	12.7
Physical distress scale	*M*	21.22	12.83	9.9	8.9

**Original Dutch validation study*

***Conducted in the Netherlands*

While no effect of AD was found in our study on any of the subscales of the RSCL, *significant differences were found between South African AD patients and healthy controls on measures of depression and anxiety*. Depression and anxiety are common features reported in AD and other chronic illnesses. For example, Hahner *et al*. (2007) found significantly higher levels of depression and anxiety in AD patients compared with healthy controls using the Hospital Anxiety and Depression Scale (HADS). Additionally, in a review of 25 patients with AD, Cleghorn (1951) found negativism and depressive disorders in 80% and 48% of patients respectively. A further study found a 2.14 times greater rate of affective disorders in patients with AD, and a 1.71 times greater rate of depressive disorders in the same sample, as opposed to patients suffering from osteoarthritis (Thomsen *et al*., 2006). These authors concluded that conventional replacement therapy may not guarantee the psychological well-being of patients with AD.

Our study has certainly supported these earlier findings, in that higher levels of depression and anxiety were indicated in our AD subset group. This suggests that while traditional replacement therapies allow patients to lead relatively normal lives, they may be troubled by psychological symptoms like depression and anxiety. It is widely reported that depression, anxiety, and other psychiatric disorders negatively impact on prognoses and outcomes of physical illnesses (Cassano & Fava, 2002; MacHale, 2002). Additional research should be geared toward establishing the underlying causes of psychiatric manifestations in AD and other chronic illnesses. Specifically, it would be useful to determine whether negative cognitions and thought patterns, harmful coping strategies, or biological factors play a definitive role in developing depression and anxiety in chronic illness. Research on the role that cortisol plays in AD, for instance, may provide a biological explanation for the levels of depression and anxiety that were evident in AD patients.

Cognitive-behavioural therapy has shown success in treating depression in physical illness, suggesting that negative cognitions may play a causal role in the psychological distress of the chronically ill (MacHale, 2002). For instance, Lustman, Griffith, Freedland, Kissel, and Clouse (1998) treated patients with type 2 diabetes mellitus over 10 weeks with cognitive-behavioural therapy and supportive diabetic education. The authors concluded this to be an effective treatment of major depression in endocrinological diseases, such as diabetes. Further research, with specific focus on AD, could ensure better psychological well-being in AD sufferers in the form of comprehensive treatment packages, which could

include standard hormonal replacement therapies as well as valuable psychotherapeutic interventions.

A further repercussion of our findings between the AD subset group and the control group is that the scope of practical interventions is narrowed. The concept of QoL is extremely broad and multivariate. Social, political, cultural, emotional, and health-related factors undoubtedly form a complex integrated system of influence in an individual's QoL. The diversity of possible interventions falls largely outside the scope of medical and mental health practice, and the efficacy and feasibility of such interventions are obscure. However, our findings have shown that AD patients are particularly burdened by psychological symptoms, which provides health professionals with a clearer direction for effective intervention.

An initial aim of this study was to determine whether specific aspects of QoL are more or less impaired than others by AD. This required within-groups analyses across all the measures in this study, which could not be performed for reasons already mentioned. It would have been particularly useful to determine whether scores on the psychological distress scale of the RSCL coincided with scores on the BDI-1A and STAI. However, scores on these measures are not presented on similar scales and thus only a tentative comparison can be made of the results in Table 4. What these results did suggest was that AD patients scored similarly on the psychological distress scale of the RSCL and on measures of depression and anxiety. In contrast, scores on the physical distress scale, the daily activities scale, and the overall valuation of life scale appear much lower. Thus, *psychological aspects of AD appear to be the dominant feature affecting QoL*.

However, the results obtained from the between-groups analysis indicate that AD patients reported greater levels of depression and anxiety than controls, yet no difference was found for psychological distress between these groups. Since validation studies have shown the psychological distress scale to be correlated with the STAI (r=.74) for anxiety and the HADS (r=.61) for depression, this irregularity requires explanation.

The RSCL items on the psychological distress scale deal with broad psychological concepts in very non-specific terms, while the BDI-1A and STAI deal with specific cognitions and thought patterns that are commonly found in clinical patients suffering from depression and anxiety respectively (Beck *et al.*, 1988; Caci *et al.*, 2003; de Haes *et al*., 1996). Thus, a plausible explanation for the disparity between scores on the psychological distress scale of the RSCL and scores of depression and anxiety is that the RSCL measures

general psychological stress while the BDI-1A and the STAI measure clinical depression and anxiety.

To explain this further: we argued earlier that QoL may be generally impaired in RSA, regardless of the presence of chronic illness, because of the stressful South African environment. We also argued that our controls have additional psychological stressors due to the fact that they care for someone who is chronically ill. Thus, we argue that controls in RSA would also suffer from psychological stress. In order to explain why controls and AD patients did not score differently on the psychological distress scale of the RSCL, we argue that the RSCL only detects these general stressors of living, not the clinical factors measured by the BDI-1A and STAI.

As AD patients showed significantly greater impairment on the BDI-1A and the STAI, it is reasonable to suggest that these measures not only detect general psychological stressors, but that they specifically detect clinical depression and clinical anxiety. This thus indicates, in support of the findings reviewed earlier, that patients with AD may suffer from clinical psychological disorders as well as general psychological stressors. Our results support this hypothesis, as AD patients fell into clinically significant ranges for both the BDI-1A and the STAI.

More significantly though, these findings highlight the importance of studying QoL in AD within developing countries such as RSA. By not supplementing the RSCL with the BDI-1A and the STAI, we would have wrongfully concluded that patients with AD do not suffer from psychological distress compared to controls. Instead, this study has suggested the possibility that all South Africans, regardless of the presence of a disease, suffer from psychological stressors while patients with chronic illness, such as AD, are at risk for clinical psychological disorders. Further research, with statistical comparisons between the different components of QoL could confirm this hypothesis.

Additionally, knowledge of which components of QoL are most vulnerable to disease processes would have shed light on the nature of QoL in healthy individuals. What is apparent, however, is that depression and anxiety may be the aspects of QoL that are most easily affected by chronic diseases. Further research is needed to firmly establish this knowledge in other chronic illnesses as well. Those who care for sufferers of chronic disease, such as AD, could be made aware that the psychological components of QoL are most affected by disease. Hopefully, this would help to create better awareness in the medical profession and the broader community of how chronic illness can affect psychological well-being.

The findings thus far have focused on differences in specific aspects of QoL that can be affected in AD. However, we also sought to establish whether additional variables could affect patient QoL. Following suggestions from the literature, we were interested in establishing gender differences in QoL in AD patients. Lövas *et al*. (2002) found higher SHS impairment in women; whereas Arlt *et al*. (1999) suggested that these differences may be due to lower levels of androgen, which impacts on sexual interest and satisfaction, in female AD patients. While our study did not focus on sexual functioning specifically, our results did suggest that *physical functioning is more impaired in females suffering from AD*. Further research is necessary to establish the relationship between gender and QoL, and the role that physical functioning, and in particular sexual functioning, plays in QoL.

Additionally, our study evaluated for age differences in QoL in AD patients. An effect for age was only found for physical impairment. This is unsurprising as it would be expected that physical complaints would increase with age regardless of whether one has AD or not. However, our results indicated that *AD patients between the ages of 40 and 60 were more distressed by physical ailments than older AD patients*. A possible interpretation of this difference may be that patients in the 40-60 age group are more distressed by physical impairment as they are often still active members of the community. In 2001, the South African census reported a generally accepted retirement age of 65 (Statistics South Africa, 2005). Thus, the daily lives of older AD patients would presumably require less physical activity, and these individuals would be less distressed by physical ailments.

Lastly, we had also initially sought to establish whether QoL in AD would be reported uniformly across different races since it seemed particularly relevant in a multi-racial community such as RSA. However, due to large differences in sample sizes of various race categories, testing for meaningful effects for race could not be attempted. This implicates a further limitation of our study, in that our sample was highly unrepresentative of the racially diverse community of RSA. While it may be that AD is more prevalent in certain racial populations of RSA, it is more likely that the South African AD database is comprised from patients of a certain socio-economic status. AD sufferers in poorer, remote communities in RSA may not be receiving medical attention and appropriate diagnoses. Thus, as public health services become available to such communities, racially representative samples should be available to future researchers.

This study found limited effects for age and gender on QoL in AD. However, it is likely that in developing countries, such as RSA, race and socio-economic status would be

more significant factors associated with a lower QoL in AD patients. Future research should take these factors into account.

CONCLUSION

This study found that while QoL, as measured by the RSCL, was not significantly more impaired in a subset of AD patients than in controls, South African AD patients suffered from higher levels of depression and anxiety. These findings suggest that caregivers of AD patients also suffer impaired QoL, that QoL is generally lower in RSA than in Europe, and that AD patients suffer from clinical forms of psychological distress. Our study also found that age and gender played a limited role in determining physical impairment reports in South African AD patients. Future research should be directed towards differences in QoL valuations across different race and socio-economic groups, as well as which specific aspects of QoL are more impaired by AD, with the use of consistent, comparable measures. Research of this nature would be invaluable to health professionals in aiding the treatment of AD patients to ensure that individuals who suffer from chronic illnesses, such as AD, achieve a high QoL. Moreover, this knowledge would reveal the nature of QoL in healthy individuals, and which aspects of QoL are most vulnerable to disease processes. This information would help those who care for the chronically ill to understand fully the implications of chronic disease and how the lives of those living with these diseases may be affected.

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APPENDIX A.

Descriptive Statistic Table for Between-Groups Comparison

Table 1.

Descriptive Statistics Summary: AD subset and Control groups.

Measure		Group: AD Subset	Group: Control
Psych D*	*n*	18	18
	M	30.44	20.50
	SD	24.10	18.46
Phys D*	*n*	18	18
	M	21.22	12.83
	SD	13.41	11.32
Activities*	*n*	18	18
	M	3.67	1.17
	SD	13.62	4.06
Overall QoL	*n*	18	18
	M	19.61	14.94
	SD	11.66	19.64
Depression	*n*	18	18
	M	12.11	2.83
	SD	9.52	3.63
Anxiety	*n*	18	18
	M	33.17	21.33
	SD	7.56	6.27

**Psych D = Psychological Distress*
Phys D = Physical Distress
Activities = Daily Activities

APPENDIX B.

Descriptive Statistics Tables for Within-Groups Analyses

Table 5.
Descriptive Statistics for all variables in AD Group

			Subscale					
Age	Gender		Psych D*	Phys D*	Activities*	Overall QoL	Anxiety	Depression
under 18								
		n	2	2	2	2	2	2
	Male	*M*	7.50	6.50	0.00	8.50	3.00	25.00
		SD	3.54	3.54	0.00	12.02	4.24	1.41
		n	2	2	2	2	2	2
	Female	*M*	35.50	21.00	0.00	8.50	12.00	30.00
		SD	23.33	9.90	0.00	12.02	16.97	1.41
20-40								
		n	10	10	10	10	10	10
	Male	*M*	24.50	17.00	0.00	15.20	12.60	33.00
		SD	25.27	10.99	0.00	9.44	11.17	9.50
		n	8	8	8	8	8	8
	Female	*M*	28.38	19.50	0.50	14.63	10.88	33.38
		SD	24.32	11.84	1.41	13.80	8.79	4.10
40-60								
		n	8	8	8	8	8	8
	Male	*M*	30.63	22.63	8.25	27.13	18.00	34.25
		SD	32.00	16.49	15.28	17.56	6.59	4.77
		n	19	19	19	19	19	19
	Female	*M*	42.89	34.00	13.21	21.16	15.00	33.74
		SD	30.27	15.21	18.18	12.06	4.84	5.51
60 and older								
		n	5	5	5	5	5	5
	Male	*M*	20.00	11.60	13.40	20.20	11.80	29.40
		SD	17.20	10.88	29.96	18.21	7.05	3.65
		n	19	19	19	19	19	19
	Female	*M*	30.89	21.68	12.68	20.37	11.21	30.11
		SD	29.72	14.85	27.10	13.02	8.64	4.43

** Psych D = Psychological Distress*
Phys D = Physical Distress
Acivities = Daily Activities

Table 6.
Marginal Means for AD Group

			Subscale					
Variable		*n*	Psych D*	Phys D*	Activity*	Overall QoL	Depression	Anxiety
Age	under 18	4	21.50	13.75	0.00	8.50	7.50	27.50
	20-40	18	26.22	18.11	0.22	14.94	11.83	33.17
	40-60	27	39.26	30.63	11.74	22.93	15.89	33.89
	60 and older	24	28.63	19.58	12.83	20.33	11.33	29.96
Gender	Male	25	24.20	16.88	5.32	19.48	13.40	32.04
	Female	48	35.42	26.17	10.33	19.23	12.69	32.08
Subscale Marginal Means		73	31.58	22.99	8.62	19.32	12.93	32.07

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