

CHAPTER 1

INTRODUCTION

1.1 BACKGROUND

Rheumatoid Arthritis (RA) is a chronic systemic inflammatory illness that has a predilection for peripheral synovial joints ¹. It affects women two to three times more often than men. It typically affects small and large joints in a symmetrical and additive pattern. Extra-articular manifestations of varying severity may occur, such as constitutional symptoms, rheumatoid nodules, viscosities, neuropathy, scleritis, lung involvement, lymph-adenopathy and pericarditis ². Rheumatoid Arthritis is the most common (potentially reversible) cause of physical dysfunction ¹. It is however a well-documented fact that functional disability worsens gradually with time ³ and that patients become unable to work ⁴.

The disease is known to occur in all populations, although much of the work on the impact of the disease on functional disability and mortality has been done in the industrialised world. According to the South African (SA) national census in 2001, 5% of the total population enumerated suffer from some form of disability. An estimated 30% of these disabilities are physical. The census did however not specify the types of physical disabilities accounted for ⁵. Epidemiological surveys reviewed by Kalla et al in SA have shown that the prevalence of RA in an urban black population was 0.9% which is similar to the prevalence of approximately 1% reported in Caucasians in other parts of the world ¹. However, a significantly lower prevalence of 0.12% was reported in the rural Tswana population. A lower prevalence of RA was also reported among the rural Xhosa and rural coloured population ¹. The urban-rural gradient differences in prevalence strongly suggest the role of an environmental agent in the pathogenesis of RA, but no causes have been conclusively identified to explain this variation in prevalence ¹. A survey of 256 patients with RA in SA among Caucasians, coloureds and blacks showed that the male/female ratio was 1:2.8 and that there was no significant difference among the races ¹.

Little is known about the natural history and long-term functional outcome of RA in black Africans. The disease seems to be milder with less extra-articular manifestations in Nigerians and Zimbabweans compared with British whites³. In a cross-sectional survey in the Western Cape, only 6% of black patients had American College of Rheumatology⁶ functional class 4⁷ (ACR) disability³. Tikly et al found in a longitudinal study at Chris Hani Baragwanth Hospital (CHBH) RA clinic that functional disability worsened gradually with time but that the proportion of patients with severe functional disability, on disease modifying anti rheumatic drugs (DMARDs) and low-dose corticosteroids, declined significantly in the medium term³.

South Africa is a large country with great diversity. The landscape and people change from province to province. Rich with culture, this country harbours within its borders people from very different backgrounds and social upbringing and unfortunately, as in most developing countries, also the rich and the very poor. It is for this reason that the results from other studies in other countries cannot just be applied directly to our population. There is a need to establish information about the effectiveness of Occupational Therapy (OT) with regard to people with RA in the South African population and for the purposes of this study, more specifically in the lower income groups and resource poor-settings.

The majority of people in the lower income groups rely on the subsidised treatment provided in the public health sector. This is also true of the patients who attend CHBH for their arthritis treatment. In SA there is a 2-tiered health system with a great imbalance in personnel distribution between the private and the public health sectors. Private health services consume 58% of the health total expenditure and capture a higher proportion of all types of personnel (except nurses) than the public sector⁸. In 1999, 73% of general practitioners were estimated to be working in the private sector in SA, despite the fact that this sector caters for less than 20% of the population⁸. Of the approximately 44.8 million people living in SA⁹, only 7 million are on medical aid (approximately 2.8 million are principle members and the rest are dependants)¹⁰.

Nationally the ratio of medical practitioners per 100 000 public sector dependant population was 19.7% in 2003 and the medical specialist ratio 8, 9% ⁸. Solomon et al found conclusively that there is a poorer disease outcome in the public health care versus private patients, who suffer from RA in SA ¹¹.

The management of RA is based on a multidisciplinary team approach in which OT plays a major role ¹². Other team members include the physician, rheumatologist, nursing staff, orthopaedic surgeon, podiatrist and physiotherapist.

Of all the studies on the role of OT in the management of RA, most are based on work done in affluent industrialised communities ^{12 - 23}. Studies mostly focus on specific functions of the OT such as splinting and joint protection education ¹³. Only two studies could be found on comprehensive OT treatment programmes where OT's educate patients on how to preserve their joints, teach adjusted techniques, splint and issue assistive devices with the inclusion of home-based intervention ^{14, 24}. They both support the notion that OT's should be extending their role to the patients' physical home environment.

Between 80 and 120 patients attend the RA out-patient Clinic at CHBH in Soweto every Thursday. These patients currently receive OT intervention as out-patients at the clinic or in-patient rehabilitation when they are admitted to hospital. There have been no outreach programmes to the patients' homes or research on the effectiveness of the current programme offered.

1.2 STATEMENT OF THE PROBLEM

An important consideration with respect to the impact of RA is that while the disease may generally be less severe in developing countries, those patients who do have severe disease are more handicapped than their counterparts in industrialised countries because of the virtual absence of social resources and support from the state. In South Africa there are approximately 44 rheumatologists ¹ serving a population of 44.8 million ⁹ people, with only 3 currently at CHBH. This public sector, academic hospital is situated in the south of Johannesburg, South Africa. It provides health care services to approximately 3 million people living in

Soweto and the surrounding areas. There are primary public health care clinics in Soweto. CHBH relies on these clinics to refer patients who require special attention and diagnosis to the hospital. Unfortunately, early diagnosis is very often missed and patients only present late to CHBH with advanced disease and disability. According to Tikly et al ³, a delay in referral for specialist care has a significant direct relationship on functional class. The pattern of late presentation and referral is a reflection of the difficult socioeconomic conditions under which many indigent blacks in SA still live.

As Soweto is largely a poverty-stricken township, the people living here have very little in terms of resources. With many people unemployed or earning minimum wage, big families living together in small spaces and difficulty accessing whatever facilities are available, life for someone with RA can become very difficult. In a qualitative survey done at CHBH, women with RA noted hot water, an accessible dwelling and other buildings in the neighbourhood, and roads that are not too bumpy or at an incline as all important environmental factors because of the pain and mobility issues associated with RA ²⁵. The disease clearly disrupts the balance in people's lives across all the components of occupation, including work, leisure, self-care and rest, believed to support healthy occupational performance ²².

The OT department at CHBH runs an out-patient clinic simultaneously with the medical RA clinic days. The aim is to help as many patients as is possible with their functional problems. The out-patient treatment is often short due to the high numbers of patients that need to be seen. The main aim is to relieve pain by splinting and compensating for reduced effectiveness due to loss of function by prescribing assistive devices. Joint protection and energy saving principles get taught in groups of up to 50 patients at the clinic while they wait to see the doctor. In-patient treatment aims to provide a more comprehensive treatment approach to the condition. It is however often affected by patients going for medical tests or their poor potential for rehabilitation during their admission, as they are too sick. The treatment offered is thus not specifically client-centred in terms of personal solutions for the problems the patients experience in their daily functioning and in allowing them to manage their own disease in the functional aspects of their lives.

1.3 JUSTIFICATION

Research in industrialised countries has shown that empowering RA patients to self-manage the disease using a self-efficacy approach, can lead to changes in behaviour, pain or physical health and psychosocial health status^{20, 26, 27}. If we can then teach our patients coming from a resource deprived environment how to self manage the disease, wouldn't this then make up for the time constraints during in/out patient treatment and make our patient treatment more effective?

Teaching self-management of the disease is a relatively inexpensive tool to use in therapy and has even been shown to reduce the cost of other medical health care²⁶.

Patient self-assigned "global" arthritis scores strongly relate to disability, but less strongly to pain. This supports the notion that disability is a very large, and hence important, part of a patient's arthritis concerns that we as Occupational Therapists can help patients overcome or adapt to²⁸.

1.4 OBJECTIVES OF THE STUDY

The following questions then arise: "How can we empower our patients?" and "How can we ensure that what we teach them at the hospital gets applied at home?"

The aims and objectives of this study were to

- Primarily, establish if home-based OT intervention, in addition to the existing in/out-patient treatment for patients with RA shows an immediate and/or sustained improvement in patients' functional ability, by teaching patients self-management.
- Evaluate the patients' functional status and severity of their arthritis.
- Empower patients to apply self management-learnt in hospital, at home.
- Evaluate the importance of the role of OT and the range of intervention in the management of patients with RA who live in the Soweto Township.

Patients were evaluated using the Stanford Health Assessment Questionnaire (HAQ) ^{28, 29, 30}, the SF-36 (Short Form Physical and Mental Health summary scales) ^{31, 32} and the Disease activity score using a 28 tender and swollen joint count, excluding the general health component (DAS28-3V) ^{33, 34}. The study also includes a qualitative approach using focus groups to evaluate the patients' change in knowledge and skill with regards to self-management of the disease.

1.5 NULL HYPOTHESIS

A comprehensive OT treatment approach, including home-based intervention is no better than a one week intensive in-patient treatment programme at CHBH, with respect to reducing functional disability and improving health related quality of life.

1.6 OPERATIONAL DEFINITIONS

Rheumatoid Arthritis: An autoimmune disease which causes chronic inflammation of the joints, the tissue around the joints, as well as other organs in the body ^{1,2}.

Home based intervention: Occupational Therapy services provided in the home of the individual being treated ^{14, 24}

Occupational Performance: occupational performance is the individual's experience of being engaged in self-care, productivity and leisure, contributing to quality of life.

Comprehensive Occupational Therapy intervention: training of motor function, instruction on joint protection and energy conservation, implementing the use of assistive devices, splinting, training of skills, whether received as in or out-patient, and home based intervention, ^{13, 14, 16, 17, 18, 24}.

1.7 ABBREVIATIONS

AA: African Americans

AD: Assistive device

ADL: Activities of Daily Living

AHAQ: Alternate Health Assessment Questionnaire

AIMS: Arthritis Impact Measure Score

ANCOVA: Analysis of Co-variance

AROM: Active Range of Motion
ASMP: Arthritis Self-management Programme RA: Rheumatoid Arthritis
BP: Bodily pain
CASI: Chronic Arthritis Systemic Index
CBT: Cognitive Behavioural Therapy
CCT: Controlled Clinical Trial
CHBH: Chris Hani Baragwanath Hospital
COPM: Canadian Occupational Performance Measures
DAS28: Disease Activity Score using 28 tender and swollen joint count
DAS28-3V: Disease Activity Score using 28 tender and swollen joint count with three variables
DI: Disability Index
DMARDs: Disease Modifying Anti-Rheumatic Drugs
EC: Energy Conservation
EMS: Early Morning Stiffness
ESR: Erythrocyte Sedimentation Rate
GH: General Health
HAQ: Health Assessment Questionnaire
HAQ-DI: Health Assessment Questionnaire Disability Index
HRFS: Health Related Functional Status
HR-QOL: Health Related Quality of Life
IAS: Intra-Articular Steroid
JP: Joint Protection
MACTAR: McMaster-Toronto Arthritis Questionnaire
MCS: Mental Competent Scale
MDT: Multi Disciplinary Team
MH: mental Health
MOHO: Model of Human Occupation
NHW: Non-Hispanic Whites
OD: Other Design
OT: Occupational Therapy / Occupational Therapist
OTA: Occupational Therapy Assistant
OP: Occupational Performance
PCS: Physical Competent Scale

PF: Physical Functioning

PI-HAQ: Personal Impact Health Assessment Questionnaire

RADAI: Rheumatoid Arthritis Disease Activity Index

RCT: Randomized Control Trial

RE: Role Emotional

RP: Role Physical

SA: South Africa

SE: Shared Epitope

SES: Socio-economic Status

SF: Social Functioning

SF 36: Short Form 36

TEFR: Therapeutic Education and Functional Re-adaptation

VT: Vitality

WHOQOL: World Health Organisation Quality of Life

WOMAC: Western Ontario and McMaster Universities of Osteo-arthritis Index