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Occupational therapy services and condition related factors affecting occupational performance in South African children with juvenile idiopathic arthritis

Moodley, Darrel Dhaneshin

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Student number	0704188V		
Name of Degree	Master's in occupational therapy – Dissertation	Date submitted	23/03/2018

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APPLICATION FOR CHANGE OF TITLE OF APPROVED RESEARCH REPORT, DISSERTATION OR THESIS

Student Surname and Initials: Moodley D.D. Student Number: 0704188V

Degree: MSc – Occupational Therapy (Dissertation) Department: Health Science – Occupational Therapy

Telephone: 0846261477 E-mail: darrelmoodley@hotmail.co.uk

Current Title:

A review of the current Occupational Therapy management for clients with Juvenile Idiopathic Arthritis in five hospitals in South Africa.

New Title:

Occupational therapy services and condition related factors affecting occupational performance in South African children with Juvenile Idiopathic Arthritis.

Motivation / Reason for title change:

The revision of the research title is to provide clarity to the reader on the scope of the research study.

Approvals / signatures:

Student Signature: _____ Date: 16/03/2018

==========

Supervisor 1 – Name & Surname: Lizelle Jacobs

Department: Occupational Therapy

Supervisor Telephone: (011) 717 3701 Supervisor E-mail: Lizelle.Jacobs@wits.ac.za

Supervisor Signature: _____ Date: 16/03/2018

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NAME: (Principal Investigator)	Mr Darrel Dhaneshin Moodley
DEPARTMENT:	Occupational Therapy CMJAH, CHBAH,RMH and Klerksdorp Hospital
PROJECT TITLE:	A Review of Occupational Therapy Services in South Africa for Children with Juvenile Idiopathic Arthritis
DATE CONSIDERED:	29/08/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Lizelle Jacobs
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	23/03/2015

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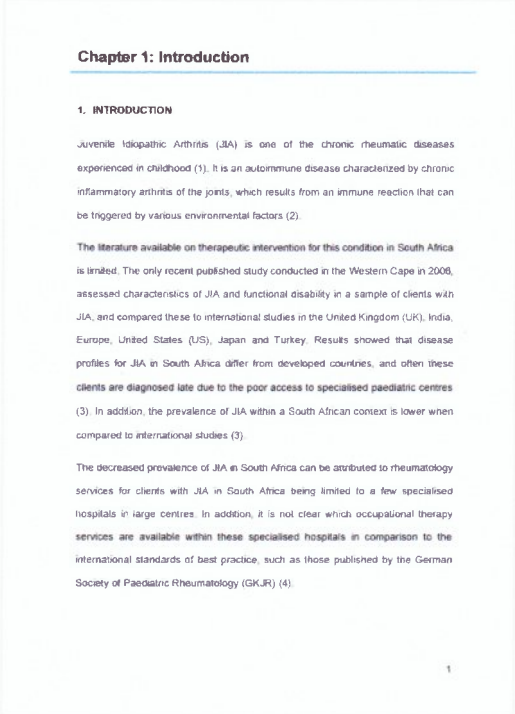
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Chapter 1: Introduction

1. INTRODUCTION

Juvenile Idiopathic Arthritis (JIA) is one of the chronic rheumatic diseases experienced in childhood (1). It is an autoimmune disease characterized by chronic inflammatory arthritis of the joints, which results from an immune reaction that can be triggered by various environmental factors (2).

The literature available on therapeutic intervention for this condition in South Africa is limited. The only recent published study conducted in the Western Cape in 2006, assessed characteristics of JIA and functional disability in a sample of clients with JIA, and compared these to international studies in the United Kingdom (UK), India, Europe, United States (US), Japan and Turkey. Results showed that disease profiles for JIA in South Africa differ from developed countries, and often these clients are diagnosed late due to the poor access to specialised paediatric centres (3). In addition, the prevalence of JIA within a South African context is lower when compared to international studies (3).

The decreased prevalence of JIA in South Africa can be attributed to rheumatology services for clients with JIA in South Africa being limited to a few specialised hospitals in large centres. In addition, it is not clear which occupational therapy services are available within these specialised hospitals in comparison to the international standards of best practice, such as those published by the German Society of Paediatric Rheumatology (GKJR) (4).

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Chapter 1: Introduction 1. INTRODUCTION Juvenile Idiopathic Arthritis (JIA) is one of the chronic rheumatic diseases experienced in childhood (1). It is an autoimmune disease characterized by chronic inflammatory arthritis of the joints, which results from an immune reaction that can be triggered by various environmental factors (2). The literature available on therapeutic intervention for this condition in South Africa is limited. The only recent published study conducted in the Western Cape in 2006, assessed characteristics of JIA and functional disability in a sample of clients with JIA, and compared these to international studies in the United Kingdom (UK), India, Europe, United States (US), Japan and Turkey. Results showed that disease profiles for JIA in South Africa differ from developed countries, and often these clients are diagnosed late

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Name of Supervisor 1: Lizelle Jacobs

Telephone: (011) 717 3701

Email: lizelle.jacobs@wits.ac.za

Signature: _____

Date: 13 March 2018

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Full name	Darrel Dhaneshin Moodley
Student number	0704188V
Title of submitted Research Project: Occupational therapy services and condition related factors affecting occupational performance in South African children with Juvenile Idiopathic Arthritis *Please note that if this title is different to your previously approved title, no further action can be taken by the Faculty Office until a change of title has been approved.*	

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Occupational therapy services and condition related factors affecting occupational performance in South African children with Juvenile Idiopathic Arthritis

Darrel Dhaneshin Moodley

Dissertation submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Master of Science in Occupational Therapy.

Johannesburg, 2018

DECLARATION

I, Darrel Dhaneshin Moodley declare that this dissertation is my own work. It is being submitted for the degree of Master of Science in Occupational Therapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

…….

March 2018

In memory of my mother

Rita Nagar Moodley

1964-2014

ABSTRACT

Juvenile Idiopathic Arthritis (JIA) is sixth most common childhood disease and is the main cause of acquired disability in children, in the developed world (1). The purpose of this study was to determine occupational therapy assessment and treatment services offered by government institutions for clients with JIA. Furthermore, to determine condition related factors which influence occupational performance in these children.

The research was completed in two phases. The first phase of the study used a self-administered questionnaire, completed by nine occupational therapists who provide services to clients with JIA at four government institutions. The second phase utilised the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) which was administered to 37 children with JIA who attended two specialised JIA clinics in Gauteng.

It was found that no formalised standardised assessments were used by occupational therapists and services provided to clients with JIA included: Splinting; assistive devices; pain management; education and physical exercise. Condition related factors identified from the JAMAR, as well as the occupational therapy services currently offered, were in keeping with international studies. These clients' identified needs were met, except for educational services.

A common concern shared by the occupational therapists, was the need for a specific standardised assessment tool and treatment protocol to optimise the services provided to clients with JIA at government institutions.

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OPERATIONAL DEFINITIONS

Assessment	“Specific method, instrument, tool, or strategy that is used as part of the evaluation process” (2: p 1026).
Assistive devices / technology	“Items, equipment, or systems used to maintain or improve functional capacities of individuals with disabilities” (2: p 1026).
Juvenile Idiopathic Arthritis (JIA)	“Children under the age of 16 years of age who have chronic arthritis (lasting >6 weeks) and in whom no other specific cause of arthritis can be identified” (3: p 1078).
Occupation	“Everyday life activity” (4: p 2).
Quality of life	“Comparative state of well-being and functioning that includes level of comfort, enjoyment, and ability to participate in meaningful activities or occupations” (2: p 1033).
Splint	“Temporary device used to facilitate recovery from an injury or to enhance function” (2: p 1034).

ABBREVIATIONS

ANA	Antinuclear Antibody
ADL	Activities of Daily Living
CEO	Chief Executive Officer
CHAQ	Children Health Assessment Questionnaire
CHBAH	Chris Hani Baragwanath Academic Hospital
CMJAH	Charlotte Maxeke Johannesburg Academic Hospital
HAQ	Health Assessment Questionnaire
HIV	Human Immunodeficiency Virus
HLA	Human Leukocyte Antigens
HOD	Head of Department
HREC	Human Research Ethics Committee
HRQL	Health Related Quality of Life
JAMAR	Juvenile Arthritis Multidimensional Assessment Report
JIA	Juvenile Idiopathic Arthritis
KH	Klerksdorp Hospital
KTHC	Klerksdorp/Tshepong Hospital Complex
RA	Rheumatoid Arthritis

RF	Rheumatoid Factor
RMMCH	Rahima Moosa Mother and Child Hospital
TB	Tuberculosis
TH	Tshepong Hospital
UK	United Kingdom
WHO	World Health Organization
WITS	University of the Witwatersrand

Chapter 1: Introduction

1. INTRODUCTION

Juvenile Idiopathic Arthritis (JIA) is one of the chronic rheumatic diseases experienced in childhood (5). It is an autoimmune disease characterized by chronic inflammatory arthritis of the joints, which results from an immune reaction that can be triggered by various environmental factors (6).

The literature available on therapeutic intervention for this condition in South Africa is limited. The only recent published study conducted in the Western Cape in 2006, assessed characteristics of JIA and functional disability in a sample of clients with JIA, and compared these to international studies in the United Kingdom (UK), India, Europe, United States (US), Japan and Turkey. Results showed that disease profiles for JIA in South Africa differ from developed countries, and often these clients are diagnosed late due to the poor access to specialised paediatric centres (7). In addition, the prevalence of JIA within a South African context is lower when compared to international studies (7).

The decreased prevalence of JIA in South Africa can be attributed to rheumatology services for clients with JIA in South Africa being limited to a few specialised hospitals in large centres. In addition, it is not clear which occupational therapy services are available within these specialised hospitals in comparison to the international standards of best practice, such as those published by the German Society of Paediatric Rheumatology (GKJR) (8).

International standards of best practice recommend a combination of various multi-disciplinary services to address the needs for clients with JIA, with the occupational therapist's role well defined (8). It is important to determine what the outcomes, in terms of occupational performance and condition related factors are, so the needs of parents and clients with JIA in a South African context can be addressed. In addition, which services are used to meet these needs in occupational therapy when assessing and treating clients with JIA, in the specialised rheumatology clinics, in public hospitals in South Africa.

The outcomes in terms of occupational performance and condition related factors in JIA, and the needs of parents and children with this condition, have previously been assessed in developed countries using one of several parent/patient-reported outcome assessment tools. These various assessment tools have been developed over the years to assess clients with JIA and assist the physician/therapist to measure the disease progression and decide on effective therapeutic intervention (9). The Juvenile Arthritis Multidimensional Assessment Report (JAMAR) is an assessment tool that has been proven to assess the needs of parents and clients with JIA and is suitable for use in a clinical setting as it has a quick administration time. Extensive clinical research has been conducted on this assessment tool and it has been adopted in many countries (9).

1.1. Statement of the problem

In most Western countries, the standards of best practice for clients with JIA are well documented and researched, but the same cannot be said for most developing countries. Literature advocates for the expansion of research and services needed to treat this chronic disorder in the contexts of developing counties (10).

Although some advances have been made in providing services for clients with JIA with an increase in the number of paediatric rheumatologists, and the development of specialised services in tertiary hospitals in South Africa, the level of these services offered have not been researched. Limited research on occupational therapy services that are available and the nature in which clients with JIA present in South Africa, means that the best practice to meet the needs of parents and clients with JIA are unknown in this context.

1.2. Purpose of the study

The occupational therapy services currently being offered to clients with JIA, as well as their dysfunction that is of concern to them and their parents, need to be established. The purpose of this study is to determine which services occupational therapists are offering in specialised rheumatology paediatric centres and to use a standardised client and parent report assessment tool, the JAMAR assessment tool, to assess dysfunction in occupational performance, and identify condition related factors to determine the needs for therapy in clients with JIA.

1.3. Aims

The aims of the study are:

- To determine the current occupational therapy services available to clients with JIA in Gauteng, South Africa, and
- To determine the clinical presentations of a South African sample of clients with JIA using the JAMAR assessment tool.

1.4. Objectives

- To determine the current occupational therapy assessment and treatment provided to clients with JIA in specialised paediatric centres in five public hospitals in Gauteng.
- To determine the clinical presentations/needs of clients with JIA which can impact on occupational performance of a Gauteng ~~s~~ample of clients with JIA using the JAMAR assessment tool.

1.5. Justification for the study

A greater understanding is needed of services offered by the public sector, as the challenge faced by health planners, at legislative levels, and service providers, are seeking ways to offer a multi-disciplinary best practice service including rehabilitation, to all children with rheumatic diseases (1). The need for current and intensive research is needed on the services offered by occupational therapists to children with rheumatic diseases, and the occupational therapists' role in the intervention of JIA in South Africa, due to limited literature currently available.

This study will further identify the outcomes for occupational performance and condition related factors, which can be related to the needs of clients with JIA in South African healthcare facilities. This will contribute to the current limited research on JIA in South Africa and will make use of the JAMAR assessment tool as a reliable, valid outcome tool to collect data on a South African population.

Chapter 2: Literature Review

2. LITERATURE REVIEW

This chapter provides insight into the current literature available for Juvenile Idiopathic Arthritis (JIA) in South Africa and internationally. The Information discussed provides an in-depth review of the services offered to these clients and the current treatment approaches used by occupational therapists. Patient reported assessment tools currently available and the selection of an appropriate assessment tool will be discussed to gain an overview of the assessment and treatment of clients with JIA.

2.1. Juvenile Idiopathic Arthritis (JIA)

Juvenile Idiopathic Arthritis (JIA) is an autoimmune disorder that results in the inflammation of multiple joints. The accepted definition for JIA is, “children under the age of 16 years of age who have chronic arthritis (lasting >6 weeks) and in whom no other specific cause of arthritis can be identified” (3: p 1078). Various international studies have noted that JIA was the most common chronic musculoskeletal condition in children and the most common cause leading to musculoskeletal disability (3, 11).

In a review of JIA in 2010, JIA was characterised by excessive inflammation within the joint space, which was the body’s immune response to injury. In addition, it was the body’s defence against infections and it facilitated tissue repair. In normal cases, the inflammatory response stopped after healing was completed to prevent damage to its own cells and tissues, but this was not the case in clients with JIA (12, 13) .

In an update of JIA diagnosis and management in 2015, seven types of JIA have been described (Table 2.1) (3).

Table 2.1: Juvenile Idiopathic Arthritis subtypes (3: p 1077)

JIA subtype	Characteristics
Oligoarticular	Younger child More common in females than in males 1-4 affected joints in first 6 months ANA positive in up to 70% Uveitis – common
Extended oligoarticular	>4 joints after first 6 months
Polyarticular RF negative	≥5 joints in first 6 months RF negative Younger child More common in females than in males ANA positive in ~40%
Polyarticular RF positive	≥5 joints in first 6 months RF positive x 2 (3 months apart) More common in females than in males Adolescents
Enthesitis-related arthritis	HLA B27 positive Sacroiliitis Inflammatory backache Family history of HLA B27 – related disease Usually older boys (>7 years)
Psoriatic arthritis	Psoriasis Dactylitis Psoriasis in 1st degree relative Nail pitting
Systemic arthritis	Fever – daily Rash Hepatosplenomegaly Serositis Raised ferritin Complicated by macrophage activation syndrome
HLA = human leukocyte antigens; ANA = antinuclear antibody; RF = rheumatoid factor	

2.2. Incidence and prevalence of Juvenile Idiopathic Arthritis

In 2009, JIA was described as the sixth most common childhood disease and the focal cause of acquired disability in children, particularly in the developed world (1). Literature on the incidence of JIA, referring to the number of new cases within a given period, suggested an annual incidence of 0.008 to 0.226 per 1000 children (14).

The study conducted in Cape Town, South Africa in 2001, suggested growing incidences of JIA in developing countries, with an equal prevalence amongst males and females. This compared to international literature which regarded the predominance of JIA which displayed a higher predisposition towards females who are twice as likely to be dialogised with JIA than males (3, 15). This study also indicated that the Polyarticular subtype was the most common subtype amongst their population (7).

Prevalence studies of JIA, referring to the number of cases present in a population at a given time, were limited with no current literature available. Literature available ranged from reviews of epidemiology studies conducted in 1966, indicating a prevalence rate of 1-4 per 1000 children, and a 1980 census data conducted in the United States, being 1 case per 1000 children (16).

Research in developed countries suggested that the incidence of JIA may be influenced by environmental factors such as air pollution and weather (6, 17). In addition, northern countries such as Norway had a greater prevalence of JIA within their populations (148/100 000 per year), as opposed to countries nearer to the equator such as Costa Rica (31/100 000 per year) (6, 18, 19).

These differences in prevalence of JIA within different populations showed associations between environmental, geographical and ethnic backgrounds, and children with European descent who had a higher prevalence of JIA (6). This can be seen from a study by Berkun in 2010 Table 2.2 (6).

Table 2.2: Prevalence of Juvenile Idiopathic Arthritis throughout the world (6: p 320)

Country	**Prevalence/100 000**	**Prevalence 95% CI**	**Definition used**	**Year****
Sweden [13]	86.3	77.0-96.0	JCA	1992
USA [9]	86.1	36.9-135.3	JRA	1996
Australia [74]	440	140-664	JCA	1996
Costa Rica [7]	31	25.0-37.0	JCA	1998
Germany [5]	20.3	16.6-24.7	JCA	1998
Turkey [11]	64	43.0-91.0	JCA	1998
Norway [75]	148	115.0-187.0	JCA	1998
Germany [76]	14.8	12.5-27.5	JCA	2001
Canada [77]	35.0		JRA	2005
France [78]	19.8	19.3-20.3	JIA	2006
Estonia [79]	83.7	72.4-95.8	JIA	2007

*CI – confidence interval; **year of publication; JRA – Juvenile Rheumatoid Arthritis; JCA – Juvenile Chronic Arthritis; JIA – Juvenile idiopathic arthritis.

A study conducted in 2002, reviewed epidemiological studies of childhood arthritis between 1966-2002 from 34 various countries. The studies depicted an increase of awareness as JIA occurrence increased in countries, which resulted in revisions in diagnosing criteria and resources being made available (14).

The study noted four main contributing factors for the differences in estimates with regards to incidences and prevalence of JIA amongst varying populations. The first contributing factor was due to new diagnostic criteria being developed with differing definitions for clinical cases and diagnostic difficulties experienced by clinicians. The second factor was the difference in both experience and qualifications of clinicians (community based versus clinical case studies) which affected the definition of study populations. The third factor was the difference of when the studies were undertaken, as standards of living, healthcare resources and knowledge changed over time. The fourth factor which contributed to the differences in incidence and prevalence of JIA was that small studies had a greater chance of fluctuation (14). These factors needed to be considered with regards to the incidence and prevalence of JIA when comparisons were made between international studies and developing countries.

Furthermore, it was noted that Tuberculosis (TB) and Human Immunodeficiency Virus (HIV) complicated the prevalence of JIA within Sub-Saharan Africa (7). In 2005, a study was conducted in South Africa to assess the association of HIV infection and arthritis in children. From their population sample 27% had HIV with a predominance of male to female ratio of 2.5:1 (20). The study concluded that amongst the 27% of clients diagnosed with JIA, a majority of 78% of those children were HIV positive and presented with arthritic symptoms, mainly polyarticular subtypes. In addition, more children presented with ‘spondyloarthopathy-like’ symptoms as opposed to non-infected clients with JIA (20). A review of a similar study emphasised this association of HIV positive children who displayed symptoms similar to JIA but considered these cases as a differential diagnosis (6).

As international literature described fluctuating prevalence and incidence of JIA which was dependent on geographical locations, this was evident when comparing literature from international studies to studies from the African continent, which showed a higher prevalence in countries with European origins (10, 14, 20). With growing prevalence and awareness of JIA, an increase of resources and medical services were made available for these clients.

2.3. Services Available

In children with rheumatic diseases, the optimal standard of care was found to require the involvement of the multi-disciplinary team which included rheumatologists, nurses, occupational therapists, physiotherapists, social services, psychologists and school teacher services (1, 21). This multi-disciplinary team aimed to promote the holistic health care approach for children with rheumatic diseases that were appropriate to their developmental stages. This included adequate exercise programmes, important family or caregiver education and the provision of adequate psychosocial support for the child in both social and schooling environments (1).

The official JIA website provided medical insight, educational campaigns and fundraisers for families that had children with JIA in the United Kingdom(UK). The website suggested the healthcare team, for the treatment of JIA, should include the general paediatrician, clinical nurse specialist, pharmacist, physiotherapist, podiatrist and occupational therapist (22).

The role of the general paediatrician was described as one to assist and guide children and their families through the management of JIA based on clinical judgement and patient preference, who worked alongside adult rheumatologists to monitor symptoms and medication side effects (22).

The clinical nurse specialist's role was described as educating the child and family members about the diagnosis, treatments and therapies that were available, managing medications and emotional support in terms of coping with their long-term condition. The clinical nurse specialist could also manage their own nurse-led clinics, which assessed children, ensured efficiency of treatment and referrals to treatment services, similar to the general paediatrician's role (23).

The role of the pharmacist within this setting, was to provide the child and families with education on the correct use of medications, managed repeat medications and monitored side effects of medications produced for the public market (24).

The physiotherapist's role within this setting aimed to address physical deficits as a result of JIA, which affected the child's ability to lead an active lifestyle. The physiotherapist assessed joints, muscles and range of movements and provided treatment strategies based on stretching exercises, muscle strengthening, endurance training and management of swelling (25).

The podiatrist's role within this setting was to asses, diagnose and treat any problems the child experienced in their feet or ankles which affected their gait. The podiatrist would consider inflamed joints and tendons and prescribed insoles to improve function and decrease load on overused ligaments and tendons (26).

The role of the occupational therapist within this setting, aimed to assess the child's performance of day-to-day activities, provided assistive devices and splints, offered pain management techniques and acted as a liaison between the family, multi-disciplinary team and the school. The occupational therapist promoted and preserved the child's current functioning in order to meet developmental stages and for the child to be as independent as possible (27, 28).

In South Africa, multi-disciplinary teams were often limited to Rheumatologists (Paediatric and Adult), nurses, occupational therapists, physiotherapists, and social workers, who strived to promote holistic healthcare but were often limited due to the lack of therapeutic and human resources available. Institutions could have limited services or multi-disciplinary team members available for the treatment of JIA, thus scopes of professions overlapped, e.g. physiotherapists and occupational therapist's treatment regarding functional exercises and home programmes, if their institutions lacked either service.

2.3. Occupational Therapy

Occupational therapists could be defined as health professionals whose aim was to assist people to achieve independence, meaning and satisfaction in all aspects of their lives (29). These aspects of independence were based on essential occupational performance areas, namely activities of daily living (ADL), instrumental activities of daily living, rest and sleep, education, play, social participation, leisure and work (30). Activities of daily living were activities aimed at caring for one's body in terms of personal management, personal care and functional mobility (30). Instrumental activities of daily living were activities that required advanced home and community self-care activities, while rest and sleep comprised of sleep patterns (30).

Education comprised of school performance while social participation involved interaction between peers and family members, which could be achieved through play (31). Leisure included recreation activities (1) and the work aspect involved productivity and household activities, although it was not considered for children (31).

The ability to perform daily occupations was an indicator of wellbeing and health which provided meaning to an individual (32). A study conducted exclusively for females with JIA and Rheumatoid Arthritis (RA) on their perceptions of good health and the importance of daily occupations, noted that twice as many women had RA as compared to men and 60% of clients with JIA were females (32).

Due to the nature of the disease and its functional limitations which could make individuals dependent for occupations such as self-care, it was noted that providing assistance, either manual or modified, could have a positive effect on the well-being of the individual who found these occupations meaningful (32). For the women that participated in the study, their most important desire was to be either partly or completely independent especially in self-care activities (32).

2.4. Condition related factors affecting occupational performance

Clients with JIA experienced both physical symptoms and associated psychological illnesses which affected their ability to engage in their occupational performance areas independently (33). Physical symptoms included swollen joints, joint stiffness and pain, which could lead to significant limitations in the child's ability to engage in school related activities, extramural activities, and social activities with peers and independence in activities within the home (33).

2.4.1. Physical symptoms

In a qualitative study conducted in Belgium, in which three men and eight women aged 20-30 years old reflected on their experiences of growing up with JIA, the participants noted that physical limitations namely pain, swollen joints and side effects from medication affected their school participation, social and sport activities, home activities and relationships (34). These physical limitations contributed as potential factors for the child's decreased engagement in physical activities (35).

Clients with long standing JIA could have experienced difficulties with endurance sports, as seen in a meta-analysis of five JIA studies in aerobic fitness which found that clients with JIA were 22% less fit compared to their healthy peers (36). Other risk factors should be noted in children with cervical spine arthritis who had a greater risk of spinal injury especially in contact sport, and increased risk of cardiovascular complications with exercise due to myocarditis and pericarditis in systemic arthritis or aortic anomalies in HLA-B27 associated arthritis (36).

A major contributing factor to decreased independence and quality of life was chronic pain. Pain can be defined as, "an unpleasant sensory or emotional experience associated with actual or potential tissue damage" (2: p 1032). In a study of semi-structured interviews conducted in America, a small group of adolescent and young adults between the ages of 14-21 years old with JIA, aimed to identify the perceptions and individual challenges of living with JIA (33). The study noted that amongst the group interviewed the physical challenges mainly reported by the youth were pain and exercising, with pain being a major contributing factor for their decreased activity levels (33).

According to literature, clients with JIA were more likely to report pain as being a contributing factor to functional activity as opposed to clients without chronic disease (33). Literature indicated an association between older aged children with JIA and decreased physical activity (35).

Chronic pain could have implications for those children, not only with physical implications but also in terms of their mental health. With flare ups and chronic pain impeding function, it forced those children to rely on assistive devices to maintain their independence, such as using a crutch to aid walking (33).

Literature further suggested that chronic diseases affected children with regards to varying school performance and absenteeism (37). A study of clients with JIA in Moroccan schools determined a correlation between the disease activity and severity of JIA a child experiences with absenteeism and poor school performance. The study consisted of thirty-three children with JIA with no secondary chronic conditions and a control group of seventy-four healthy children. The measures included were based on disease activity, level of disability, pain, attendance at school and failure rates. The study concluded that 66% of clients with JIA that were assessed still attended schooling, while 12% withdrew from schooling due to the severity of the disease, and 48.5% repeated at least one year of schooling, compared to their healthy counterparts that did not experience the same difficulties (37).

The study also noted an association between absenteeism and tender joints ($p = 0.02$). The disease activity and level of disability, according to the Children Health Assessment Questionnaire (CHAQ), were two significant factors in predicting the number of days missed from school (37).

Absenteeism from class could be attributed to fatigue from sleepless nights because of pain, attending multi-disciplinary team services and joint flare ups. These factors could also contribute to decreased school performance affecting the children's concentration, their ability to write for extended periods of time and engaging in after-school activities (38).

2.4.2. Psychosocial symptoms

The psychosocial impact of the disease on the child could affect their sense of belonging and self-worth within their social groups and their social development. In addition to their physical limitations which affected their quality of life, the disease can lead to psychosocial deficits regarding their body image, self-esteem and feelings of isolation (34).

The affected child also became aware of the financial burden and pressures placed on family members which contributed to the psychosocial impact of the disease. In addition, their physical limitations hindered their engagement in sports and physical education compared to their healthy peers (38).

In a longitudinal case study conducted in Norway, which assessed 84 clients with JIA over a span of 18.3 years after being diagnosed with JIA. The study assessed both the physical and psychosocial health of these clients during their development, in which they received ongoing treatment intervention. This was measured with the use of two outcome measures i.e. the Health Assessment Questionnaire (HAQ) and the Health-Related quality of life (HRQL) (39).

It was noted that the cohort experienced high mental distress on onset but on first follow-up (8.7 years after initial assessment) their psychosocial functioning, mental health and self-worth was comparable to the general Norwegian adolescent population (39). On final assessment by the researcher it was noted that as the clients grew older they had improved self-perceptions and positive coping and adjustment processes (39).

The research study had limitations in which the majority of the participants in the cohort were of a higher educational level and a higher social economic status. This may have indicated responses from clients that had a more favourable outcome with regards to access to specialised health resources and services, thus adding bias to the research. However, emphasis should remain on adolescents' ability for self-growth and acceptance of the condition (39, 40).

In contrast to a study in 2006, conducted in an Indian population of a lower social economic status. This study showed significant relations of JIA affecting self-esteem, self-concept and adjustment in school (41). This in contrast to physical symptoms such as pain, which could have negative effects on these children's mood and lowers one's quality of life, with some instances having associations to higher rates of depression and impaired psychosocial functioning (33, 42-45).

As both physical and psychological symptoms affected these clients with JIA with regards to their quality of life, occupational performance and psychosocial well-being, it became significant for the occupational therapist to perform detailed assessments through various tools as to determine appropriate treatment intervention strategies.

2.5. Assessment of Juvenile Idiopathic Arthritis

The occupational therapist needed to assess clients diagnosed with JIA in order to plan appropriate treatment interventions. Assessments could be conducted through the use of observations or clinical assessment tools, which guide the intervention process as well as assess and monitor progress.

Traditional assessments conducted by occupational therapists, involved assessing symptomatic deficits such as affected joints, joint deformity, range of motion, strength, fine motor skills, pain, and gait, through the use of interviews and checklists (15). Although, these assessments addressed physical deficits, these assessments did not address functional deficits with relevance to occupational performance and limitations to quality of life caused by the disease (15, 46).

A child may experience a combination of physical and psychosocial limitations through different developmental stages during childhood. This could range from a one year old child with affected hip and knee joints that experiences difficulty crawling and walking, to a school aged child who could be independent with their home activities but experienced difficulties in engaging in physically demanding sport, or an adolescent that had difficulty writing for long periods of time, maintaining a part time job or adjusting to life changes such as applying for a disability grant (15, 44).

Although evidence-based practice principles recommended assessment tools to possess definitive psychometric properties, there was limited utilization of psychometric assessment tools and clinical measures for physical, psychological, social functioning and quality of life by occupational therapists (15).

2.6. Clinical Outcome Tools used with Juvenile Idiopathic Arthritis

Clinical Outcome Tools were assessment tools that were designed to improve the clients with JIA individual disease symptoms and provided impartial clinical signs to improve the patients' HRQL (47). Thus, assessment tools had been developed for rheumatic diseases which had been authenticated and recommended by international paediatric rheumatology professional societies to standardise measures in both clinical studies and traditional research (47).

Clinical outcome tools aimed to quantify attributes of an objective or a person's subjective responses with objective data obtained through multiple individual measures and constructs represented in binary or nominal outcomes. Thus the research could assess pain, disease activity and response to therapy in a quantifiable measure (45, 47). This form or measures could be useful within the multi-disciplinary team to provide a standard measure and rating of the client's progression of the disease, which could scientifically note improvements or regressions regarding response to therapeutic interventions (45).

In a study that reviewed the advantages and disadvantages of clinical outcome tools, in which clinical outcome tools were referred to as patient reported outcomes, it was noted that clinical outcome tools were becoming increasingly recognised within clinical studies. The advantage of these assessment tools was that it provided information on the effectiveness of medical and therapeutic interventions, which could not always be assessed through objective clinical measures (48, 49).

The disadvantages of clinical outcome tools were the lack of randomisation which could be used for random clinical trials because of the limited use of control groups to compare data.

In addition, the limited use of blinding to compare the effectiveness for treatment approaches has the potential of confounding results through placebo effect. An additional disadvantage is that the questionnaires could be long or difficult to administer, or may not perform well for the whole range of functioning, especially in extreme cases (48).

There were various clinical outcome tools available for JIA, such as the Children's Health Assessment Questionnaire (CHAQ), Health-related quality of life (HRQOL) Juvenile Arthritis Disease Activity Score (JADAS), Juvenile Arthritis Multidimensional Assessment Report (JAMAR) and Juvenile Arthritis Parent Assessment Index (JAPAI) or Juvenile Arthritis Child Assessment Index (JACAI) (50-52). The two assessment tools that were used at the CMJAH Paediatric Rheumatology clinic, were the CHAQ and JAMAR assessment tool.

The CHAQ was a self-administered questionnaire that comprised of 52 questions that spanned across ADLs, assistive devices/aids, and activities that required external assistance from individuals (53). The questionnaire could be administered to children from at least five years of age, and could be used for other paediatric diseases such as juvenile dermatomyositis, juvenile systemic lupus erythematosus, linear scleroderma and system sclerosis (54).

The CHAQ had been used for a widespread international study in which thirty-two countries participated and the questionnaire was translated to meet cross-cultural and language adaptations and maintained high validity and reliability amongst participants (54, 55).

Literature noted that the CHAQ was an effective instrument which had high validity, reliability and responsiveness to change over time (56). Limitations for the CHAQ included, a lack of measure of an individual's strengths, as the test only focused on negative aspects of their physical ability, a ceiling effect which could influence false-negative outcomes that made the scale less sensitive to milder levels of disability or close to normal end of the scale (56).

Other limitations for the CHAQ were that the scoring system for the CHAQ was complex and the questionnaire was double sided which made it difficult for clinicians to quickly review patient information (53). A modified CHAQ was developed in 2004, in which to combat the ceiling effect and decreased sensitivity for children with relatively good function experienced in the original CHAQ (56, 57). Limitations were experienced as the study was only implemented in one rheumatic clinic, thus children and adults may respond to the changed versions differently due to language nuances (56).

The JAMAR assessment tool was devised by a group of seven paediatric rheumatologists, as a PRO clinical assessment for clients with JIA. The JAMAR assessment tool was developed on an Italian population over the span of two years and all data obtained was two sided. The child and parent questionnaire were compared and initial and follow up questionnaires were compared and found to be statically significant obtaining a p-value of <0.05 (9). The JAMAR assessment tool underwent pilot testing of its questionnaire to ensure its face and content validity (9).

In addition, although the JAMAR assessment tool had been used in limited international studies in a routine clinical environment, it was currently being used in a multinational collaborative research study to study JIA outcomes. This was due to the fact that the JAMAR assessment tool could be translated to meet different national languages and maintain reliability and validity (9, 52, 58-60).

The JAMAR assessment tool consisted of two versions (children's version and parent/caregiver version) (Appendix A1 and A2) and was anticipated for use as both a proxy-report for all ages which could be completed by the parent, and as a client self-report for clients' whose ages fall within the range of 7-18 years. The JAMAR assessment tool had an administration time of less than 15 minutes and was developed specifically for a busy clinical setting as it provided quick and efficient administration (9).

Thus, the JAMAR assessment tool was chosen for this study for its quick administration and the scope of the questionnaire which related to occupational performance outcomes. This was similar to occupational therapy assessments and met the needs for this research study.

The need for these standardised assessments could help occupational therapists and healthcare professionals determine precise treatment interventions to promote independence in occupational performance of their clients (61).

2.7. Treatment of Juvenile Idiopathic Arthritis

Although literature on occupational therapy treatment for JIA was limited, abundant literature on the treatment of adults with RA was available and would be considered in conjunction with available JIA literature, for this study. The common trends that existed for the treatment for JIA were based on splinting, assistive devices, pain management, education, and physical exercise.

2.7.1. Splinting:

Studies showed that the aim of splinting was to provide rest for the affected joints in the functional anatomical position, which aided in decreasing inflammation and resulting pain at the affected joints (62, 63).

Splinting was considered a form of conservative management for chronic synovitis, joint inflammation and stiffness, prevention of tendon ruptures, before surgical intervention was required (64). Limited literature was available regarding clients with JIA and splinting, although there was literature available regarding splinting of adult RA.

A study conducted in 1980, stated that common deficits noted in clients with JIA with regards to the loss of extension of the wrist with ulnar deviation present, found wrist extension splints and steroid injections an effective form of treatment (65). Clinicians agreed that splinting the hand in a neutral wrist position was beneficial to prevent malformation of the anatomical structures of the juvenile hand, but the duration of use and degree of support warranted further research (66).

A systemic review conducted in 2007, concluded that splints were noted to reduce pain immediately after wearing the splint and was sustained for a period of time. This was even though the use of splints had negative effects after being used, in which clients had a decreased hand dexterity and grip strength (67). Literature also stated that resting the hand following inter-articular injections may be more harmful to the hand following immobilisation with splinting (68).

Supporting evidence regarding splint use was noted in an article in 2009, in the non-drug treatment of RA, in which resting splints were recommended for flare-ups involving inflammation of the hands. It was noted that continuing studies examining the efficacy of splints for individuals with RA and systemic reviews were needed to show more conclusive evidence (68, 69).

Occupational Therapists might use splints as a form of intervention for the treatment of clients with JIA. The Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) occupational therapy department made use of splinting as a modality for both paediatric and adult clients with rheumatic conditions, to prevent joint deformity, decrease joint inflammation, decrease pain, and maintain/increase joint range and function. Evidence was mainly based on adults and caution should therefore be exercised when this information was applied to clients with JIA.

2.7.2. Assistive devices and pain management:

Occupational Therapists might provide assistive devices and joint protection techniques to rheumatic clients which assisted with pain management and to independently perform ADLs regarding their occupational performance (70). These devices included dressing or feeding aids or adapted devices such as Velcro fasteners and enlarged handles (71, 72).

A systematic review conducted in 2009, displayed strong evidence that joint protection programmes were effective in the management of morning stiffness, pain and functional capacity, which aimed to promote daily occupations, reduce pain and prevent deformities. In addition, the information given to clients was used in conjunction with information on assistive devices, methods of adapting the environment and use of orthoses, to help improve pain management and function (67, 69).

The combination of low intensity weight bearing and aerobic exercises accompanied by home programmes had shown positive effects on pain management and decreased joint symptoms (73). Thus, combination therapy of active exercises in conjunction with assistive devices and home programmes could prove to be a great asset for the occupational therapist in the intervention for JIA.

2.7.3. Education:

JIA being a chronic disease with symptoms of pain, swelling and limitations on movement could be a disrupting factor to a child's school performance and social relationships (37). Considerations should also be made regarding the psychological and social implications of the child's ability to engage in age-related activities within the school environment (38). As part of the treatment intervention process for children with rheumatic conditions, the occupational therapist’s role within the school environment was to assist the child to meet the expected demands for their educational level. This was achieved through use of adapted devices to assist within the classroom, treatment of learning disabilities and assessment for remedial schooling (15).

The treatment intervention focus of occupational therapy for clients with JIA within the school setting would address major factors contributing to a child's poor school performance. These factors included physical symptoms, developmental milestones and psychosocial support (38).

The occupational therapist could provide recommendations regarding extended time for tests, the use of assistive devices to aid writing or compensatory methods such as using a laptop. In addition, to assessing the school environment so the child could mobilise easily taking physical limitations and fatigue into account.

2.7.4. Physical exercise:

Research suggests that physical activity or exercise programmes for clients with JIA had positive biological effects by reducing cartilage damage, loss of proteoglycans, optimizing bone density and lowering obesity risks which could worsen joint load (36).

The severity of disease symptoms of clients with JIA and treatment related side effects could however contribute to reduced physical activity which has showed to contribute to muscle atrophy, weakness and reduced fitness (36).

A recent systematic review suggested that a combined physical activity programme with pharmacotherapy had showed to have numerous health benefits. These benefits included a decreased number of actively inflamed joints, decreased pain intensity, improved joint range of motion and muscle strength leading to an increased functional status and quality of life (74).

Literature stated that clients with JIA that engaged in exercise programmes for a minimum of six weeks improved aerobic fitness, muscle strength, decreased disease activity, encouraging joint range, improved energy levels and reduced medication use for pain management (36). Physical exercise might however have potential risks or constraints as clients with JIA were advised to limit strain on joints for fear of injury or increased diseased activity (36).

This notion was supported by a systematic review conducted in 2014 on RA patients, which found strong evidence that resistive exercises, general body strengthening, isometric, active strengthening and moderate to high resisted strengthening exercises, were most effective to all the various stages of RA when adapted to the individuals' functional capacity and joint integrity (69, 75-77).

Strong evidence regarding aerobic exercises performed at 50% to 90% of individuals' maximum heart rate, has improvements in quality of life, aerobic capacity, and function and reduced pain (69, 75-77). Dynamic exercises, such as dance exercises, proved to be most beneficial for early onset, active RA and inactive RA, which combined intensive aerobic exercises and muscle strengthening (77).

The occupational therapist incorporated the use of functional activities applicable to these clients and graded these activities through activity analysis to incorporate both muscle strengthening and joint range exercises to aid in joint protection and support (78). The occupational therapist would incorporate physical exercise with leisure, play or sport activities to improve sport readiness and reduce gross motor delays (36).

The treatment intervention strategies used by the occupational therapists should incorporate all aspects of modalities discussed namely, splints, assistive devices, pain management, home programmes, school considerations and physical exercise to ensure effective intervention for clients with JIA.

Clients with JIA often presented with similar clinical presentations associated with the condition which contributed to both physical and psychosocial impairments. These impairments decrease one's quality of life and independence in occupational performance areas. Health resources should include a comprehensive multi-disciplinary team that could provide specialised treatment to clients with JIA.

Chapter 3: Methodology

3. METHOLODOLGY

This chapter discusses the motivation for research techniques, research design and research procedure that the researcher has undertaken to conduct the research study. In addition, this chapter provides information on statistical methods used for data analysis and ethical considerations for the research study.

The researcher conducted the study in two phases. The research design and procedure, selection of subjects and measurement techniques used for each phase will be discussed.

3.1. Study design

The researcher chose a quantitative approach to conduct the study as this research approach allowed the researcher to collect and analyse structured data through the use of surveys, being both efficient and cost effective (79). Both phases of the research study used a descriptive cross-sectional design.

In phase one of the study, a questionnaire that was completed by occupational therapists in specialised paediatric centres at five public hospitals (Appendix B). The researcher aimed to obtain information on the current occupational therapy assessment and treatment services implemented at their institutions for the management of clients with JIA. The use of a survey method provided the researcher with the benefit of numeric description items to assess trends of occupational therapists working within these institutions (80). In addition, this study method was also chosen for the ability to analyse data from a specific population, namely employed occupational therapists within chosen institutions, in an efficient and cost effective manner (81).

In phase two, the study used a demographic questionnaire to obtain information (Appendix C) regarding the personal background of clients with JIA who attended two specialised rheumatic clinics. The demographic questionnaire included information on the client's gender, age, ethnicity, diagnosis, precautions and the medical services attended by the client at the institution. The clients with JIA were further assessed using the JAMAR assessment tool (Appendix A1 and A2) to determine the clinical presentations/needs related to occupational performance and condition related factors.

3.2. Population and research site

The population for the first phase of the study comprised of occupational therapists involved in the assessment and treatment of clients diagnosed with JIA practicing in specialised paediatric centres at four public hospitals. These hospitals included Charlotte Maxeke Johannesburg Academic Hospital (CMJAH), Chris Hani Baragwanath Academic Hospital (CHBAH), Klerksdorp/Tshepong Hospital Complex (KTHC) and Rahima Moosa Mother and Child Hospital (RMMCH). For this study, KTHC was considered as two separate hospitals, namely Klerksdorp Hospital (KH) and Tshepong Hospital (TH), as the occupational therapy department was split between the two hospitals but were managed by the same Head of Department (HOD). Therefore, the researcher referred to five public hospitals which constituted the population.

The population for the second phase of the study consisted of clients with JIA that received health care from two specialised rheumatic clinics namely CMJAH and CHBAH.

3.3. Sampling procedure

3.3.1. Selection of subjects

Total population sampling is a sampling technique that includes a specific group of people with unique characteristics from the entire population and constitutes the selection of all of whom meet the inclusion criteria (82). This sampling technique was used in both phases of the study. For the first phase of the study total population sampling was used, as there was a scarce population of occupational therapists working in the above-mentioned hospitals who were involved in the assessment and treatment of clients diagnosed with JIA.

The advantage of this sampling technique was that it provided the researcher with the opportunity to obtain generalisations about the population being studied. The disadvantage of this technique was the development of the list of participants who met the inclusion criteria for the study which proved to be time consuming (82).

For the second phase of the study, total population sampling was used because of the limited number of clients diagnosed with JIA that attend the clinics at CMJAH and CHBAH.

3.3.2. The inclusion criteria

Phase one:

The inclusion criteria:

- All occupational therapists employed within the participating hospitals.

The exclusion criteria:

- Occupational therapists who did not assess or treat clients with JIA.
- Occupational therapy technicians and assistants.

Phase two:

The inclusion criteria:

- All clients diagnosed with JIA between the ages of one month and 18 years of age that attended CMJAH and CHBAH rheumatology clinics.
- For clients with JIA under the age of seven, their parents/guardians completed the parent version of the JAMAR assessment tool.

The exclusion criteria:

- Clients that were already assessed previously and clients who had a dual diagnosis were not considered for reassessment.

3.3.3. Sample size

During the first phase of data collection, the researcher approached forty-five occupational therapists who were employed at the five institutions. The sample population was reduced to participants that met the inclusion criteria, namely occupational therapists who assessed/treated clients with JIA, therefore only nine participants were selected.

For the second phase of the study the sample size was calculated as being 80 participants, having assumed an attendance of 100 clients at the rheumatology clinics in a 10 month period, based on Cochrane's formula with a margin of error set at 0.50 (83).

After 10 months of data collection for phase two, a total sample population of 37 participants were assessed, which included 34 children and three parents, as three children were under the age of seven.

Although the research study had 37 participants, which did not meet the ideal sample size, clients diagnosed with other rheumatic conditions, such as Juvenile dermatomyositis, Juvenile Lupus, Juvenile Scleroderma and Mixed connective tissue disease, that also attended the rheumatology clinic, were not considered when calculating the sample size.

3.4. Measurement tools

Phase one

For phase one, the researcher developed a self-administered questionnaire (Appendix B) which consisted of both quantitative and qualitative elements. The items of the questionnaire were developed through the testing of common trends and facts that had been established from the literature review and could be expected from the responses of the recipients, to ensure questions were related to the scope of the study (84). The questionnaire consisted of 17 items and the average time to complete the questionnaire was 15 minutes. The questionnaire focused on four main aspects: demographics, multi-disciplinary team treatment approaches and referrals, occupational therapy assessments and treatment services.

The first aspect focused on demographics. Items 1-4 determined demographics of occupational therapists, in terms of type of institution, field of occupational therapy and the assessment or treatment of clients with JIA using quantifiable categories. Item 4 determined the inclusion criteria, thus only occupational therapists who assessed or treated clients with JIA continued to complete the questionnaire.

Items 5-8 determined the JIA demographic profile that occupational therapists treated at their institutions, with item 6 using a Linkert scale to rate most common age groups that were seen by occupational therapists.

The second aspect focused on the multi-disciplinary team treatment and referrals to occupational therapists. Questionnaire items 9-12 used quantifiable measures and allowed participants to comment on the quantifiable measure that they chose. The third aspect focused on occupational therapy assessments in item 13. The fourth aspect provided an overview of occupational therapy services and perceptions of occupational therapy treatment, through item 14-17, where participants used quantifiable measures and participants commented regarding occupational therapy services.

The questionnaire underwent pre-testing and pilot testing prior to it being used in the main study to ensure the questions were related to the scope of the study. Pre-testing allowed the researcher to review and revise questions in the questionnaire that were vague through either language skills or culture (85). Lecturers of the occupational therapy department from the University of the Witwatersrand (WITS) (who were not specialising in arthritis), were invited to participate in the pretesting of the questionnaire (Appendix D).

The lecturers provided written feedback on the ambiguity, clarity, and layout of the questionnaire. The purpose was to examine the questionnaire with regards to the flow, salience, suitability, and organizational ease (86). The questionnaire was revised in terms of additional options for questions, clarity within the questions and information sheet for the reader. It also included the option for the participant to end the questionnaire at item 4 if they did not assess/treat clients with JIA. All revisions were made before the questionnaire underwent pilot testing.

Pilot testing involved presenting the questionnaire to occupational therapists who were experienced in rheumatology. The pilot study judged the appropriateness of the questions and the scope of the questionnaire in keeping with the literature (86).

Two occupational therapists employed at Red Cross War Memorial Children's Hospital (Cape Town), with a minimum of three years' experience in the field of paediatric rheumatology were invited to participate in the pilot study. The therapists who agreed to participate in the pilot study were not included in the main research study. Recommendations for revisions of the questionnaire included clarity of questions for the participants and the addition of options for suggested treatment services. On completion of the pilot study revisions were made to the final questionnaire (Appendix E).

Phase two:

The second phase of data collection consisted of two parts. Part one included a demographic questionnaire (Appendix C) which described personal information of clients with JIA that were assessed by the researcher. The second part included the JAMAR assessment tool (Appendix A1 and A2) that was used to obtain information from clients and/or parents/caregivers of clients with JIA, regarding the disease activity and functional limitations of clients with JIA.

Demographic Survey:

The demographic questionnaire was completed by the researcher before commencing with the JAMAR assessment tool. The questionnaire obtained demographic information regarding the client's, age, date of birth, gender and ethnic background.

The questionnaire also obtained the primary diagnosis and secondary diagnosis for the client. Only children with a primary diagnosis of JIA were considered for the study. Medical services that clients with JIA received at the time of the assessment were also obtained from the questionnaire.

Juvenile Arthritis Multidimensional Assessment Report (JAMAR):

The JAMAR assessment tool consisted of two versions, a client version and a parents/caregiver version (Appendix A1 and A2). The JAMAR assessment tool could have been used as both a proxy-report for all ages, which could have been completed by the parent and as a client self-report for clients whose ages fall within the range of 7-18 years.

The JAMAR assessment tool was a practical and feasible measurement tool which was completed in less than 15 minutes on average. (9). The JAMAR assessment tool possessed both face and content validity and the reliability of the outcome measure was found to be statistically significant with a p value <0.05 (9).

The JAMAR assessment tool consisted of 15 measurements: 1. Assessment of functional ability; 2. Rating of the intensity of the client's pain; 3. Assessment of HRQL; 4. Rating of the client's overall well-being; 6. Assessment of morning stiffness; 7. Assessment of extra-articular symptoms (fever and rash); 8. Rating of the level of disease activity; 9. Rating of disease status at the time of the visit; 10. Rating of disease course from previous visit; 11. Listing of medications the client is taking; 12. Description of side effects of medications; 13. Report of difficulties with medication administration; 14. Report of school problems caused by the disease; 15. A question about the satisfaction with the outcome of the illness (9).

3.5. Research procedure

The research procedure is illustrated below in Figure 3.1.

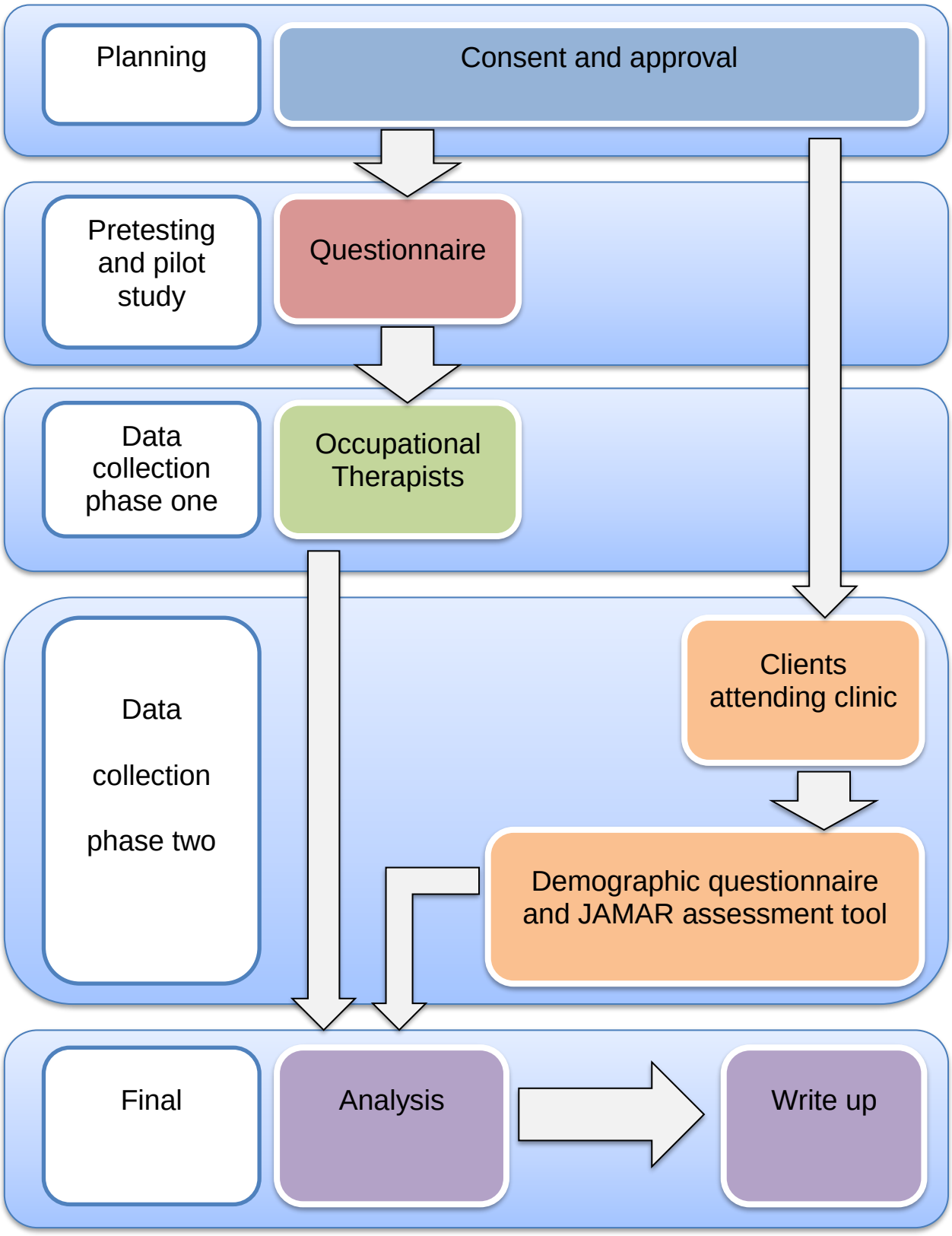


Figure 3.1: Flow diagram of research design

Phase one

Ethical clearance and permission for the study was obtained (Appendix F) and a draft questionnaire was compiled.

The questionnaire underwent pre-testing and pilot testing prior to it being used in the main study.

The researcher contacted the head of each occupational therapy department and arranged a date for the researcher to distribute and collect the questionnaires at each of the five institutions.

Data collection for phase one was carried out over a period of two months. The researcher attended one of the participating hospitals each day of the week for the period of data collection and invited occupational therapists to participate in the study and distributed the questionnaires to occupational therapists who agreed to participate in the study. Questionnaires were placed in sealed envelopes to ensure confidentiality. The participants completed the questionnaire during their lunch or tea breaks and the researcher collected the questionnaire in person from each hospital on the same day which ensured a high return rate for the study.

Phase two

Once permission for the study was obtained from the two institutions (CMJAH and CHBAH), the researcher collected data for a period of 10 months by attending the rheumatology clinics which were held every second week on a Monday at CMJAH, and every week on a Thursday at CHBAH. The researcher only attended the CMJAH and CHBAH clinic for two hours per day due to work constraints.

The researcher invited clinic attendees to participate in the study when participants attended their clinic appointments, and questionnaires were completed at the clinic. Clients over the age of seven years who had signed consent from the parents/caregivers completed the JAMAR assessment tool independently. For clients under the age of seven years, only a parent JAMAR assessment tool was completed. The researcher explained the nature of the research study to the applicable participants and provided information sheets which detailed the research study. Participants were informed verbally and through the information sheets provided, that participation in the study was voluntary and that they could have withdrawn from the study with no consequences. The completion of the questionnaire was an agreement to participate in the study.

3.2. Data analysis

Data analysis commenced once data collection had been completed. The first phase of the study used descriptive statistics which described the demographic information of clients with JIA treated by occupational therapists. Data was illustrated in graphs to show the different trends in each institution. Frequency tables were used to demonstrate occupational therapy services used in the intervention of clients diagnosed with JIA. Although some questions were open-ended, these questions were quantitatively analysed i.e. counting the number of similar responses. Frequency tables were used to display the analysed data regarding assessment and treatment by occupational therapists, multi-disciplinary team members, and services offered to clients with JIA.

The second phase of the study used descriptive statistics to represent results obtained from the demographic questionnaire of clients with JIA and the JAMAR assessment tool. Clients' perceptions of disease activity and functional limitations were represented in frequency tables.

3.3. Ethical principles

The researcher applied to the Human Research Ethics Committee (HREC) of the University of Witwatersrand and permission was granted to conduct the study (Appendix F). Approval from the Department of Health (Appendix G), the Chief Executive Officer (CEO) of each of the participating hospitals (Appendix H-K) and Heads of occupational therapy departments (Appendix L-O) were obtained prior to data collection. The researcher applied for individual ethical clearance from CHBAH as part of their research procedure (Appendix P). The authors of the JAMAR assessment tool were approached, and emailed permission was obtained to use the JAMAR assessment tool for the study (Appendix Q).

For phase two of the study approval was obtained from the occupational therapy HOD and CEO for CMJAH (Appendix R-S). Approval was obtained from the occupational therapy HOD, CEO and ethical clearance was granted for CHBAH (Appendix T-U).

The questionnaire used for the first phase of the study was accompanied by a cover letter and information sheet (Appendix V) which described the details and intention of the research study and consent was assumed through the completion of the questionnaire. Participants who chose to refrain from the study could choose not to complete the questionnaire.

All participants remained anonymous and confidentiality was ensured throughout the study by placing completed questionnaires in sealed envelopes with no identifying information provided on the envelopes or the questionnaires (87). The questionnaires were given index codes to maintain patient confidentiality for data analyses.

For the second phase of the study written consent was obtained from the clients' parents/guardians and verbal assent was obtained from the clients (Appendix W-X). Participants of the study remained anonymous through index coding. The data obtained from the JAMAR assessment tool was stored separately from the coding list.

All data obtained for the research study, namely the JAMAR assessment tool and coding list were stored in a secure location, and password protected, in which only the researcher and the supervisor had access to the data.

Chapter 4: Results

4. RESULTS

This chapter describes the results that were obtained in the two phases of this research study. Results obtained from phase one will be discussed according to the demographics of occupational therapists working at the participating hospitals, occupational therapists who assessed and treated clients with JIA. Furthermore, referrals and barriers experienced by the multi-disciplinary team members, current assessment and treatment services offered to clients with JIA, will be discussed.

The results obtained from phase two will be discussed according to the demographic profile of children attending the JIA clinics and assessment results of the JAMAR assessment tool, with regards to clinical presentations of the condition related to physical, psychosocial symptoms and functional capabilities.

4.1. Phase One results

4.1.1. Occupational therapists assessing and treating clients with Juvenile Idiopathic Arthritis

Forty-five occupational therapists from the five institutions agreed to participate in phase one of the study. Of the 45 occupational therapists, 40% (n=18) worked in the Paediatric domain. The sample was reduced as only 20% (n=9) of 45 participants met the inclusion criteria of occupational therapists who assessed and treated clients with JIA.

Occupational therapists who worked at RMMCH, did not assess/treat clients with JIA and are not included in further results. References shall be made to only the four institutions that had participants that met the inclusion criteria, namely CHBAH, CMJAH, KH, and TH.

The distribution of occupational therapists who assessed/treated clients with JIA can be seen in Figure 4.1, with TH having the most therapists who attend to these clients (44%, n=4).

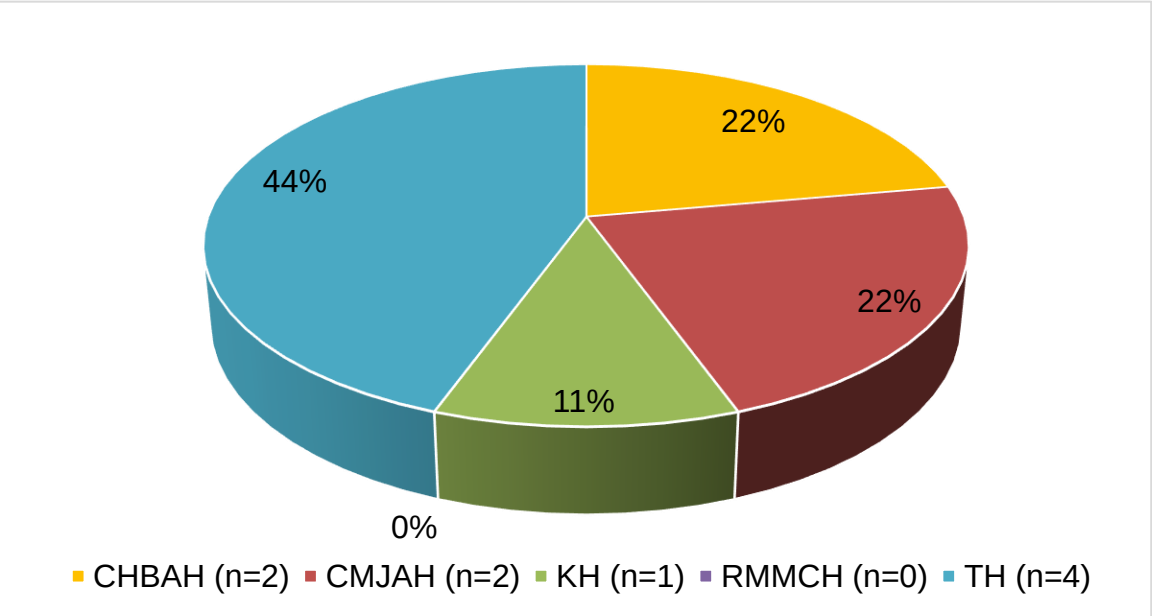


Figure 4.1: Occupational therapists who assess/treat clients with Juvenile Idiopathic Arthritis (n=9)

Most participants (89%; n=8) stated that they assessed/treated an average of one to ten clients with JIA a month, while one participant stated 11-20 clients with JIA were seen at their institution (Table 4.1). It was noted that no institution assessed/treated more than twenty clients with JIA a month.

Table 4.1: Average number of clients with Juvenile Idiopathic Arthritis seen by occupational therapists at each institution per month (n=9)

Clients with JIA	CMJAH	KH	TH	RMMCH	CHBAH	Total
1-10 Clients	2	1	4	0	1	89% (8)
11-20 Clients	0	0	0	0	1	11% (1)

Participants were asked to rank age groups of clients with JIA assessed/treated from most to least common. Only the most common age groups as identified by each participant are represented in Figure 4.2. Fifty-six percent (n=5) of the participants indicated that the most common age group they assessed/treated was between the ages of 11-18 years.

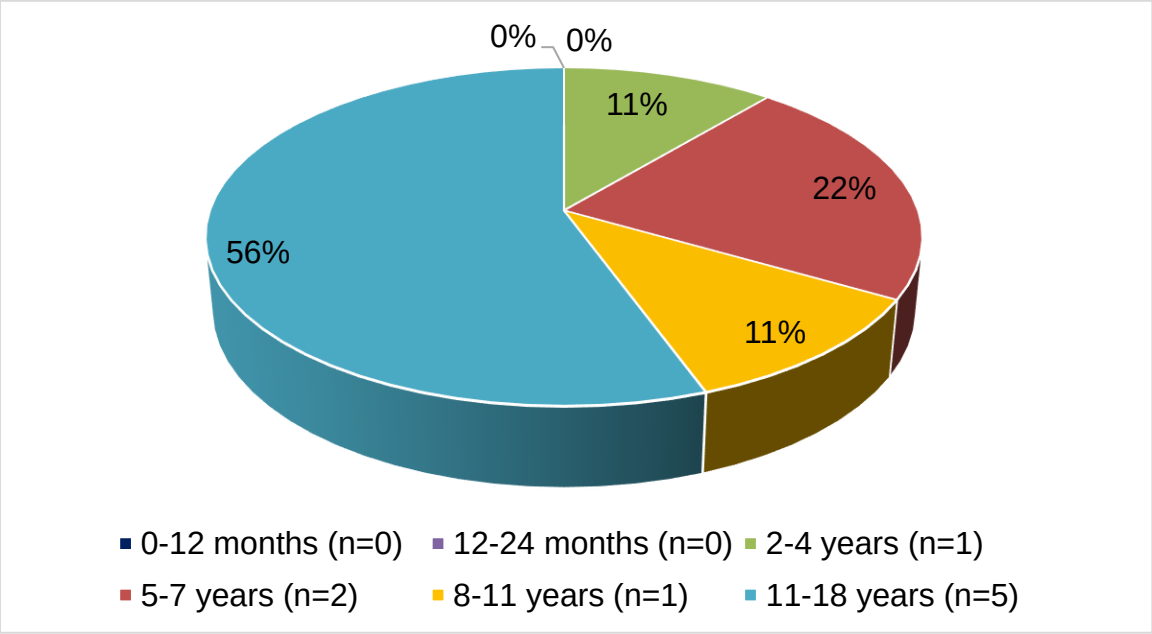


Figure 4.2: Most common age groups of clients with Juvenile Idiopathic Arthritis seen by occupational therapists (n=9)

4.1.2. Gender of clients with Juvenile Idiopathic Arthritis seen by occupational therapists

More than half the participants stated that mainly female clients with JIA (56%, n=5) were seen at their institutions while 22% (n=2) stated that more male clients with JIA were seen at their institution (Figure 4.3). Two (22%, n=2) occupational therapists were not sure which was the most common gender group seen within their institution.

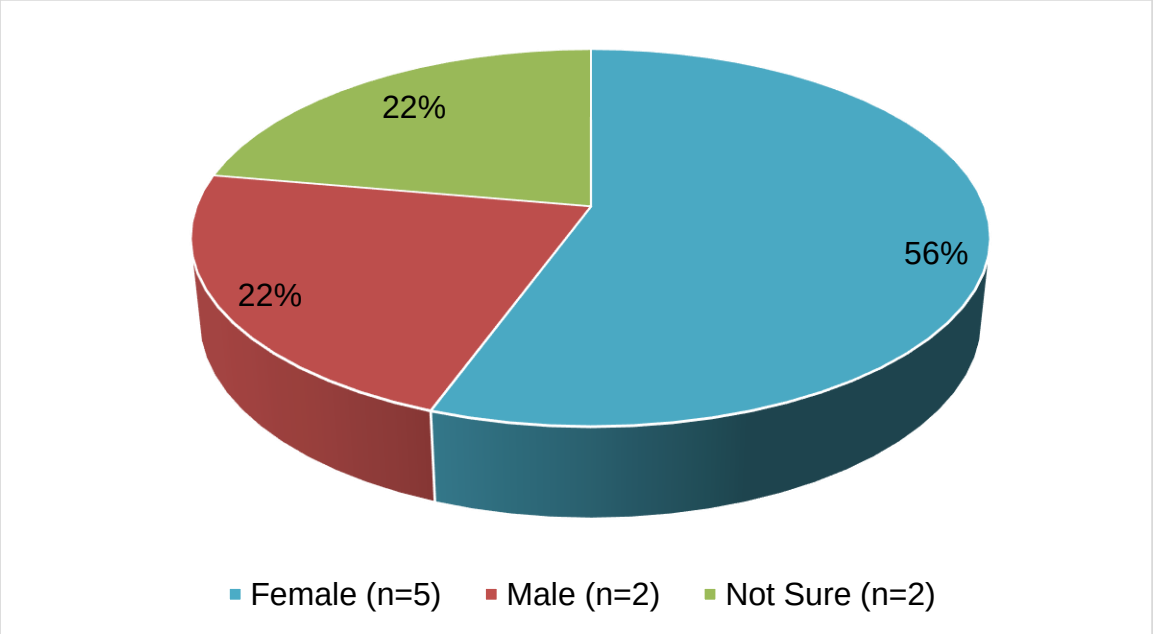


Figure 4.3: Most common gender groups of clients with Juvenile Idiopathic Arthritis seen by occupational therapists (n=9)

4.1.3. Referral to multi-disciplinary team members

Seven of the nine occupational therapist (78%) referred to other multi-disciplinary team members, while two (22%) of the occupational therapist did not refer to their multi-disciplinary team.

The most common multi-disciplinary team referrals made by occupational therapists were indicated through use of multiple options which could be selected by the occupational therapist. A total of 19 responses were recorded. The most common response for multi-disciplinary team referrals by occupational therapists were for physiotherapist (78%, n=7), followed by social services (44%, n=4) and rheumatologist (44%, n=4). Referrals were also made to other multi-disciplinary team members such as the podiatrist (22%, n=2), dietician (11%, n=1) and orthotist (11%, n=1). No referrals were made to nursing, psychologist and school teacher services (Figure 4.4).

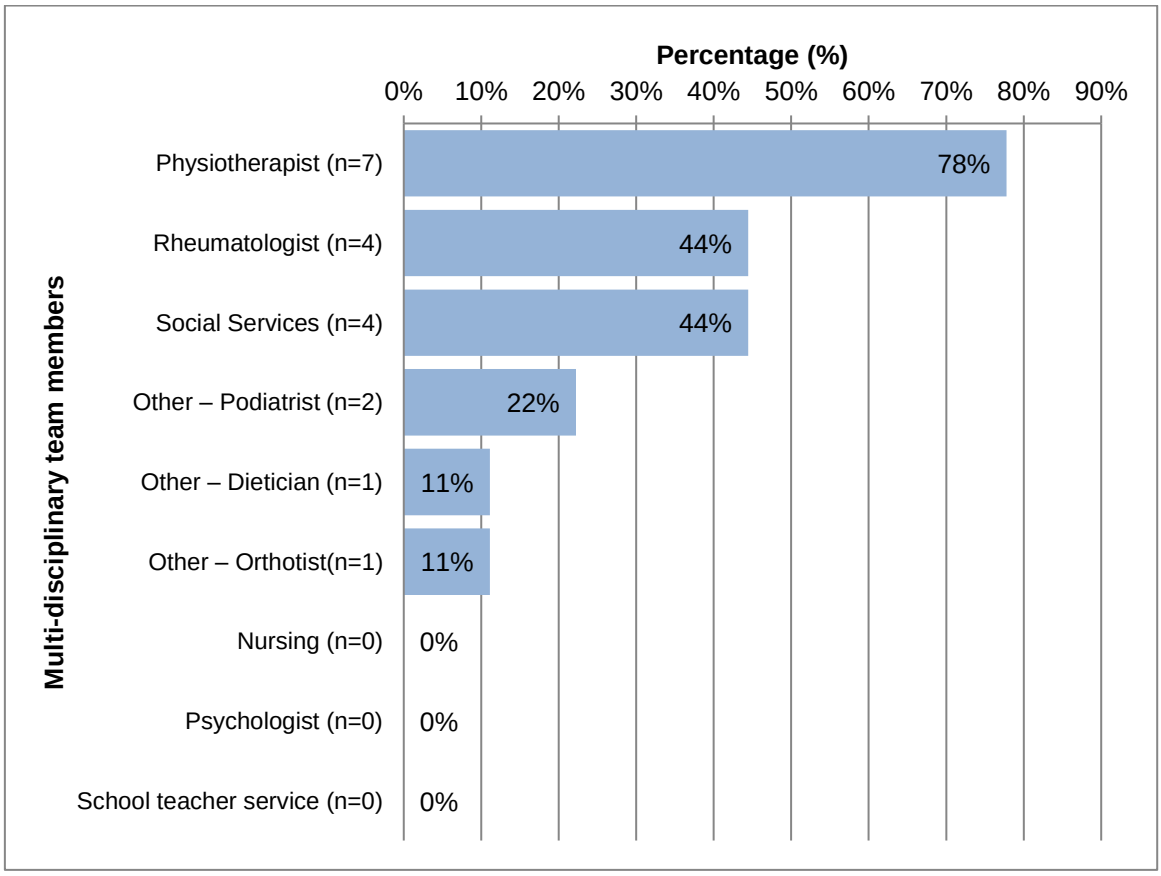


Figure 4.4: Referral of clients with Juvenile Idiopathic Arthritis to multi-disciplinary team members by occupational therapists (n=9)

4.1.4. Barriers related to working in a multi-disciplinary team

Participants were asked to comment on barriers that could affect working within a multi-disciplinary team. From the sample of nine participants, four responses were obtained which related to barriers. These included the difficulty of arranging suitable times for joint treatments and the multi-disciplinary team having a poor understanding of the occupational therapist's role, which was noted at CMJAH. Klerksdorp Hospital occupational therapists noted a poor understanding of the condition and its functional implications, and CHBAH occupational therapists noted that physiotherapists are unable to attend the JIA clinic due to staff shortages

4.1.5. Reasons for referral to occupational therapy

A total of 23 responses were made by the nine participants as multiple options could be chosen by the occupational therapist. The most common reason for referrals to occupational therapy were for assistive devices (89%, n=8) followed by splints (78%, n=7) (Figure 4.5). The least common referrals were for functional exercise, educational assessments, joint protection, pain management and task adaptation each respectively being 11% (n=1). No referrals were made for learning disabilities and psycho-social problems.

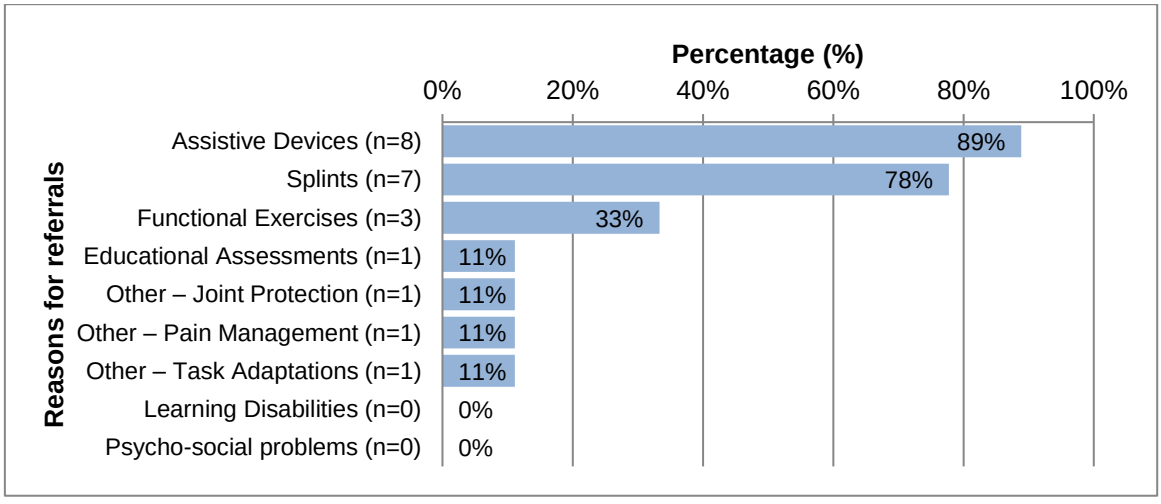


Figure 4.5: Common reasons for referral to occupational therapy (n=9)

4.1.6. Multi-disciplinary team understanding the role of occupational therapy for the treatment of Juvenile Idiopathic Arthritis

Of the nine participants, 67% (n=6) noted that multi-disciplinary team members did not understand the role of occupational therapy in the treatment of JIA. The participants expressed their opinions with regards to the barriers related to the role of the occupational therapist in the treatment of clients with JIA through use of an open-ended question.

Content analysis was used to categorise the responses and categories were then quantitatively analysed by counting the frequency of responses. The five categories that the responses were divided into were: No responses; referred only for splints and assistive devices; clients not referred early to occupational therapy; standardised treatment protocols not available; and no outpatient clinics were available.

The participants noted that the most common barrier related to the role of the occupational therapist in the treatment of clients with JIA were that multi-disciplinary team members only referred clients to occupational therapy for splints and assistive devices (56%, n=5), followed by clients who were not being referred early to occupational therapy (33%, n=3) and no outpatient clinics and no standardise treatment protocols being available both scoring 11% (n=1) (Figure 4.6).

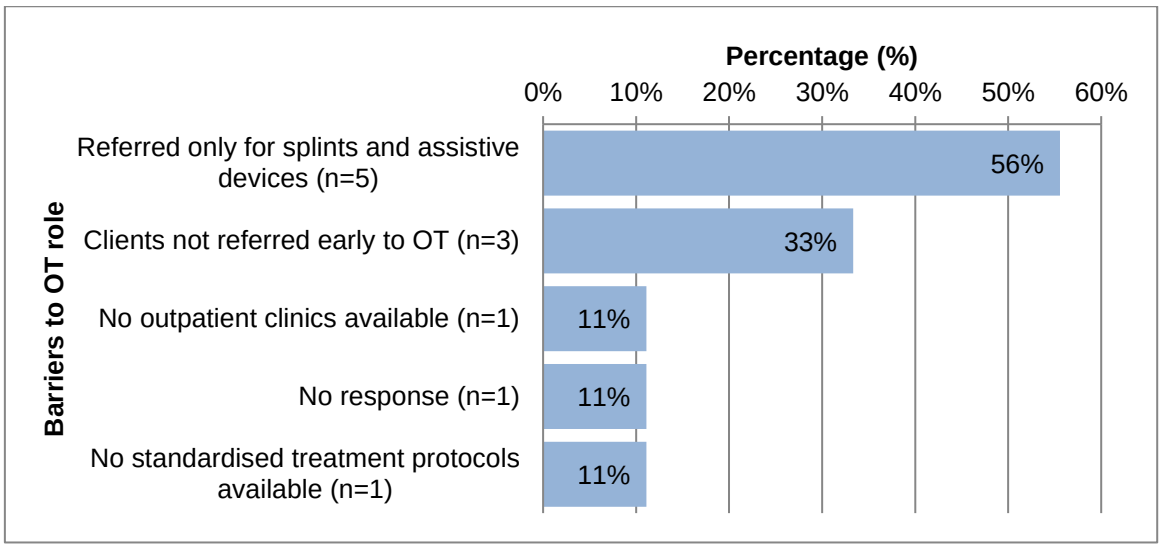


Figure 4.6: Barriers related to the occupational therapist's role in the treatment of Juvenile Idiopathic Arthritis (n=9)

4.1.7. Assessment tools used to evaluate clients with Juvenile Idiopathic Arthritis

Most participants (89%, n=8) stated that they did not use any form of formal screening tools or assessments for assessing clients with JIA within their institutions. Only one participant from CHBAH noted that they created their own assessment tool.

4.1.8. Current occupational therapy services and treatment offered to clients with Juvenile Idiopathic Arthritis

Participants noted the occupational therapy services and treatment offered by their institutions included splints, assistive devices, pain management, functional exercise, home programmes and occupational therapy services related to education. Each participant could choose multiple options for each occupational therapy service provided.

4.1.8.1. Splints

All participants agreed that resting splints (100%, n=9) were the most common splint provided. Neoprene wrist splints and thumb wrap splints were the least common (11%, n=1) (Figure 4.7).

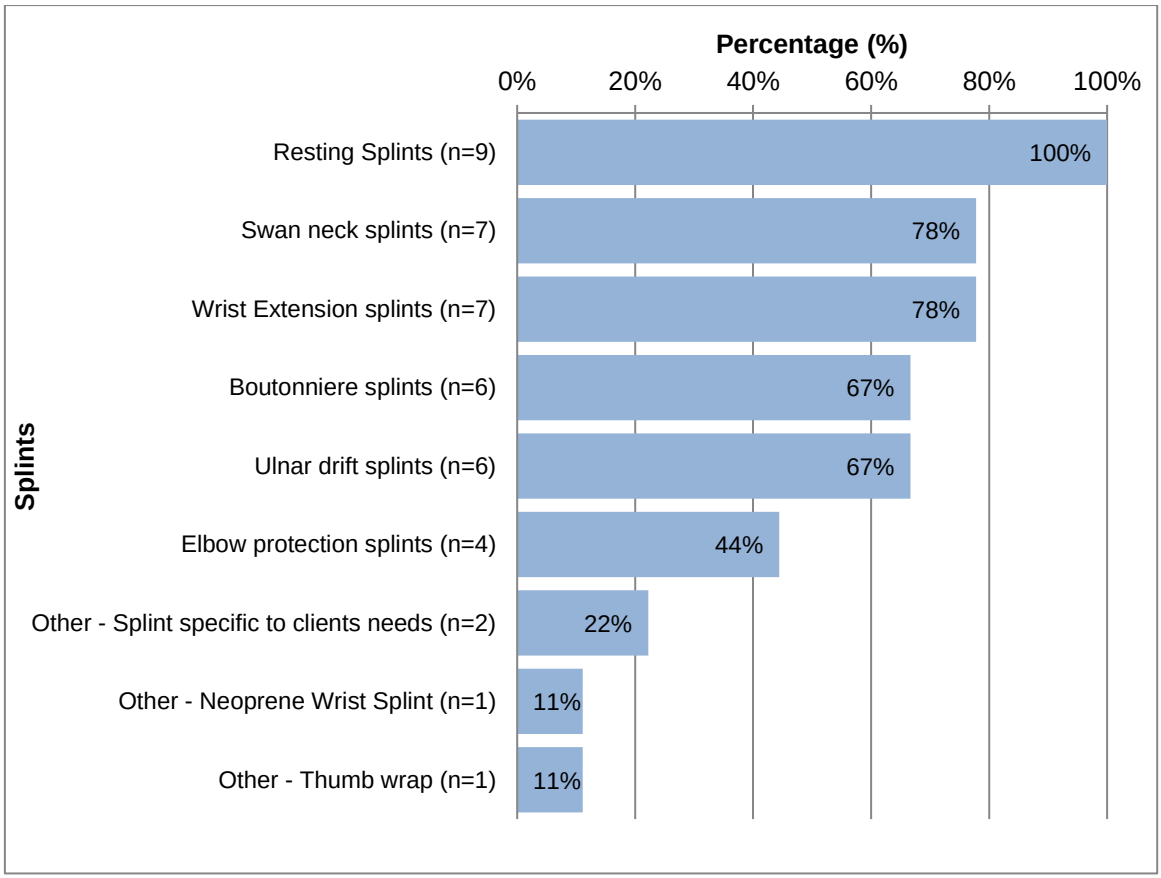


Figure 4.7: Occupational therapy services: Splints (n=9)

4.1.8.2. Assistive devices

Participants noted that wheelchairs/seating devices and personal management aids were the most common assistive devices that were used for treatment by occupational therapists. (78%, n=7) (Figure 4.8).

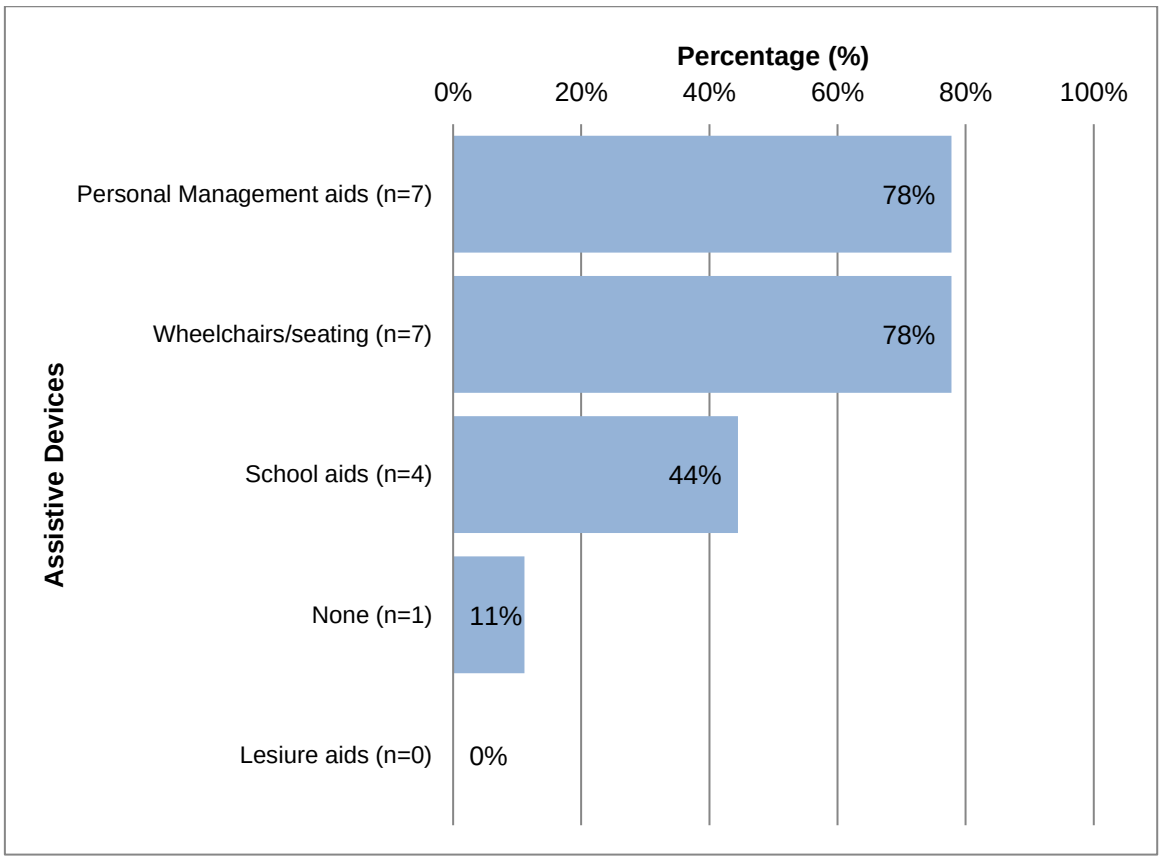


Figure 4.8: Occupational therapy services: Assistive devices (n=9)

Participants were asked to list the specific assistive devices that were made and issued to clients with JIA at their institutions (Figure 4.9). The most common assistive devices made for clients with JIA were pencil grips (56%, n=5) followed by built up handles (44%, n=4) and wash mitts (33%, n=3). It was noted that tap openers, built up utensils, adapted handles for plugs and extended brushes/sponges were the least common assistive devices issued.

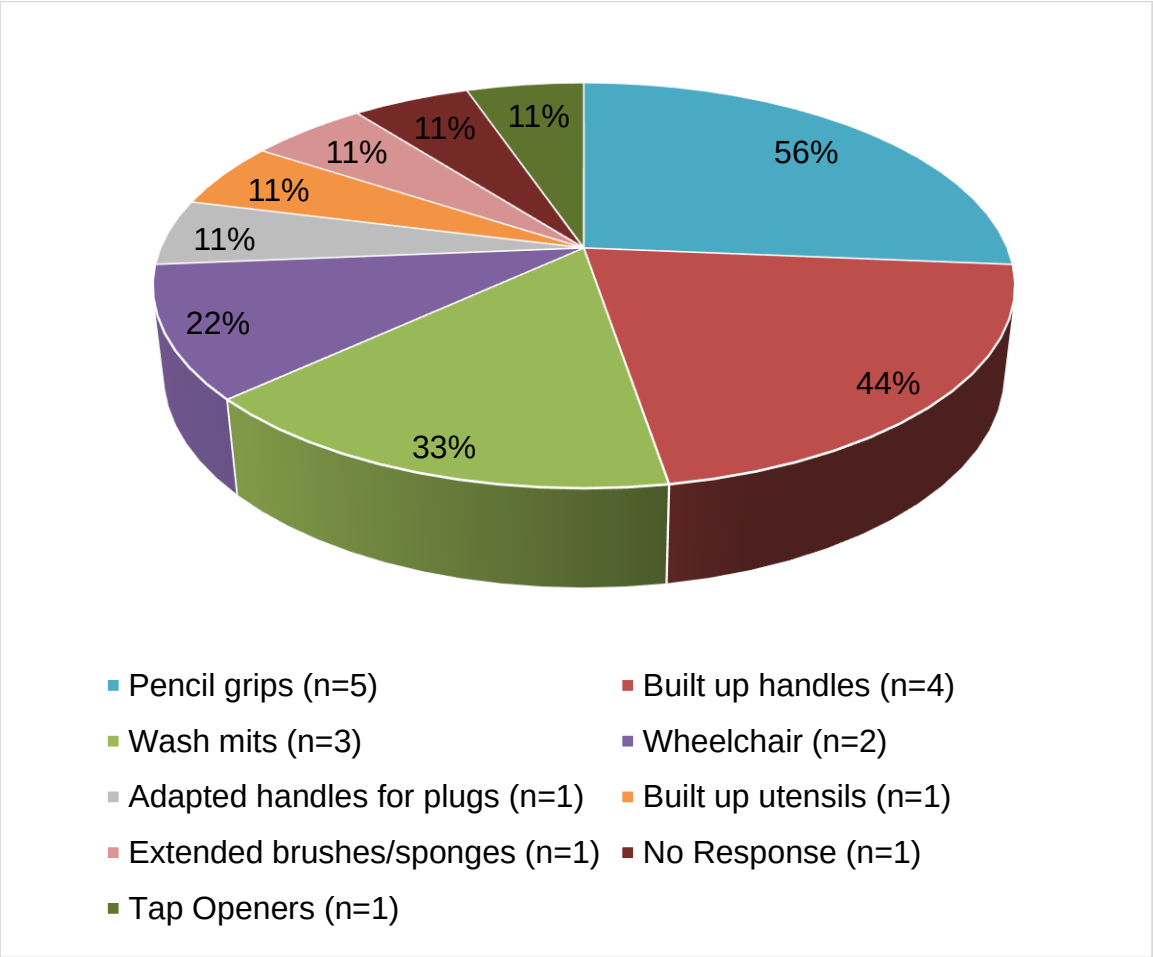


Figure 4.9: Type of assistive devices issued by occupational therapists (n=9)

4.1.8.3. Pain management techniques

All the participants used joint protection techniques to manage pain symptoms (100%, n=9). Of the nine participants 56% (n=5) preferred using heat packs and 22% (n=2) preferred using wax baths for pain management (Figure 4.10). Other pain management techniques included ice 11% (n=1) and splinting 11.11% (n=1).

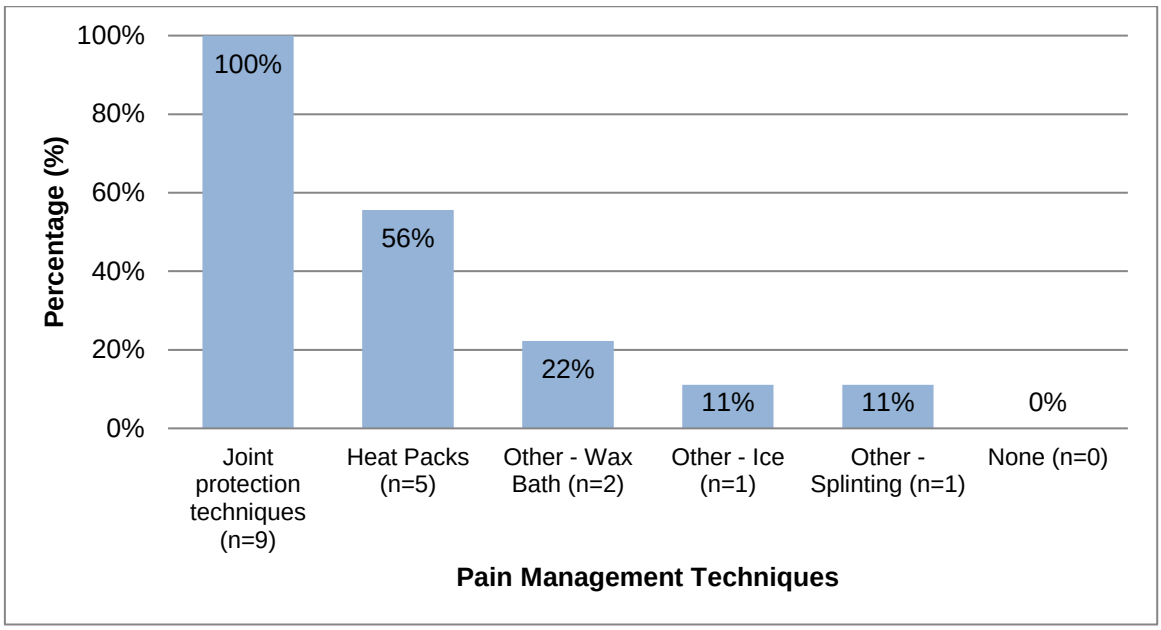


Figure 4.10: Occupational therapy services: Pain management techniques (n=9)

4.1.9.4. Functional exercises

Participants noted that the most common form of functional exercises they used for the treatment of JIA were joint range exercises (89%, n=8), followed by muscle strengthening (67%, n=6) and endurance type exercises (44%, n=4) (Figure 4.11).

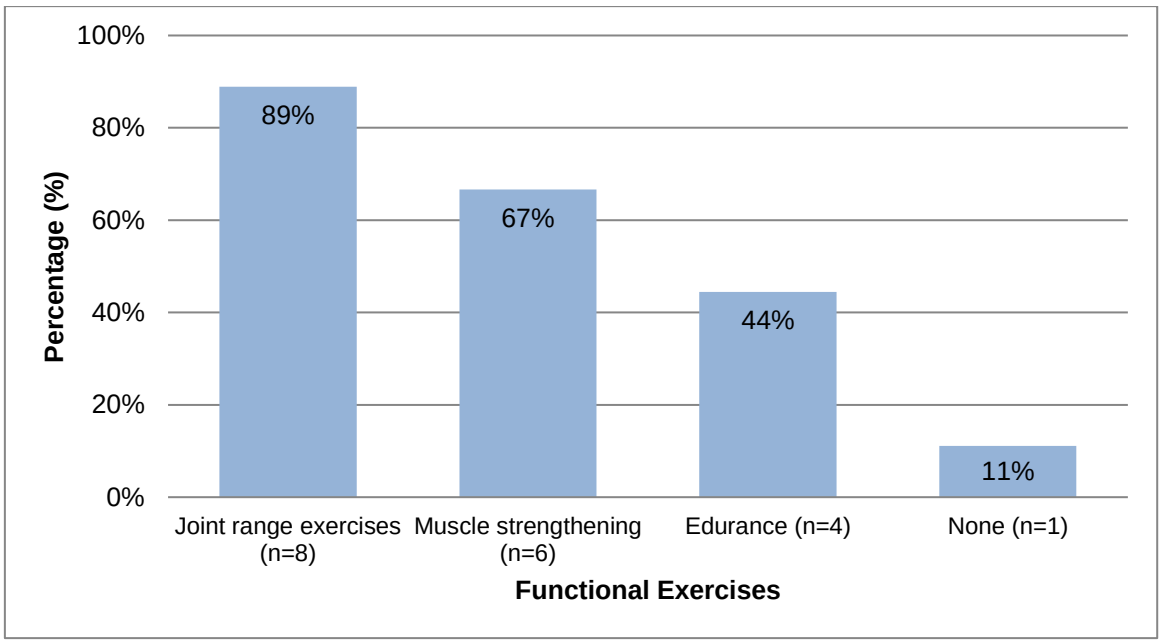


Figure 4.11: Occupational therapy services: functional exercises (n=9)

The majority of participants did not comment on the most common form of functional exercise they use for treatment (44%, n=4), while play-dough for hand strengthening was the most common exercise (22%, n=2) used by occupational therapists (Figure 4.12).

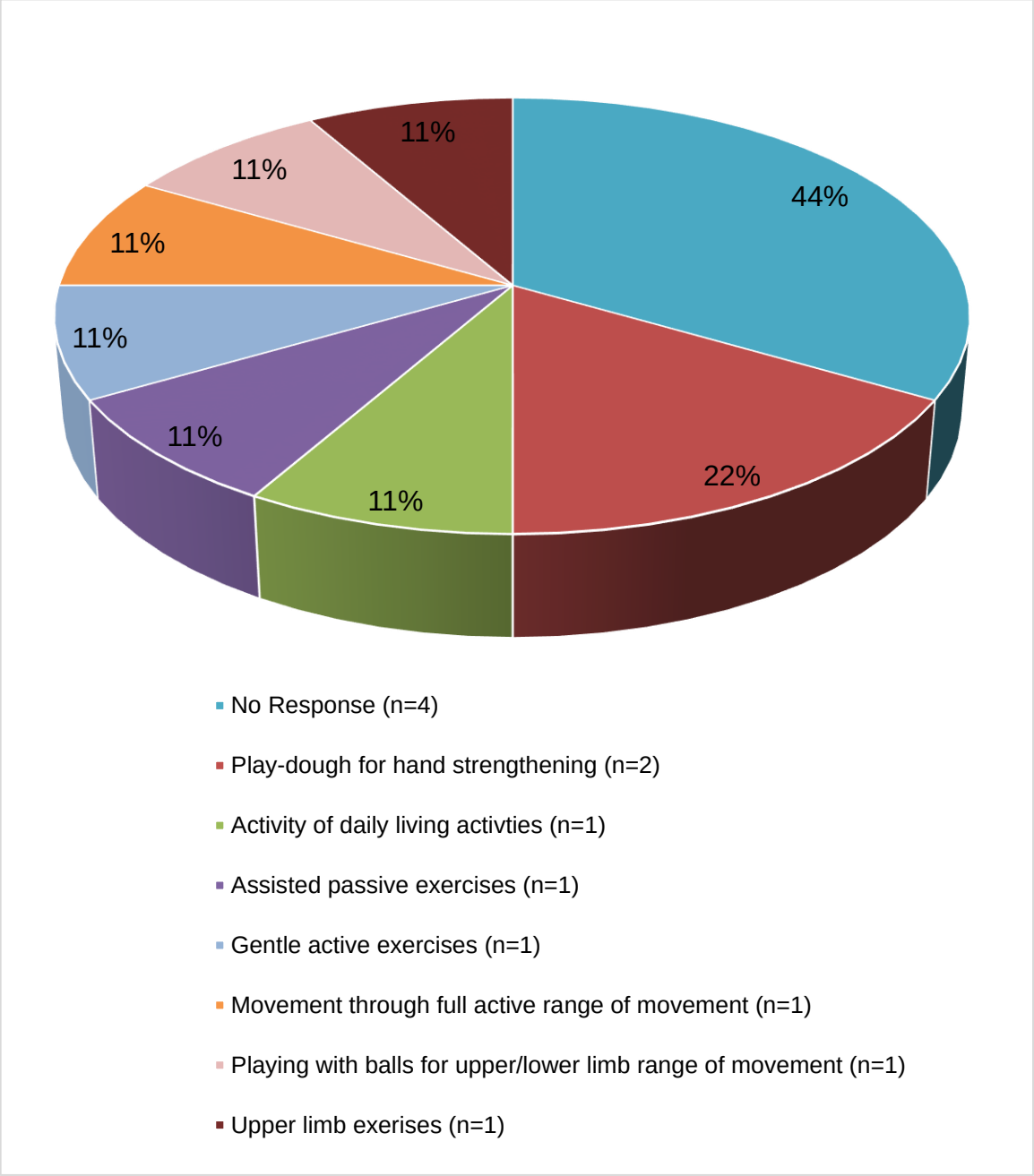


Figure 4.12 Forms of functional exercises commonly used by occupational therapists (n=9)

4.1.8.4. Home programmes

Participants noted that joint protection principles were the most common home programme used for the treatment of clients with JIA (89%, n=8), followed by functional exercise home programmes (78%, n=7). Play home programmes were the least used by participants (22%, n=2), while no home programmes related to social participation and leisure were issued by the occupational therapists (Figure 4.13).

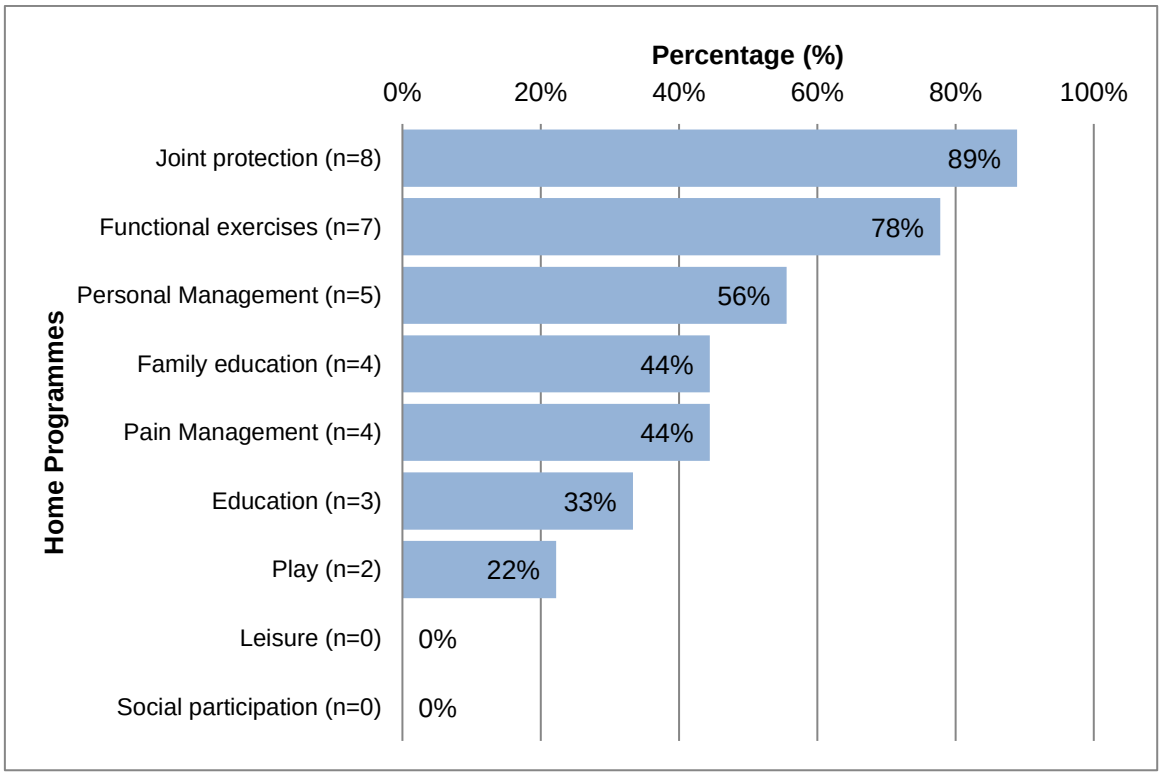


Figure 4.13: Occupational therapy services: home programmes (n=9)

4.1.8.5. Occupational therapy services related to education

Of the various school related services occupational therapists provided, 33% (n=3) of the participants indicated that they were involved in school performance assessments. Almost half of the participants however stated that they were not involved in educational services (44%, n=4) (Figure 4.14).

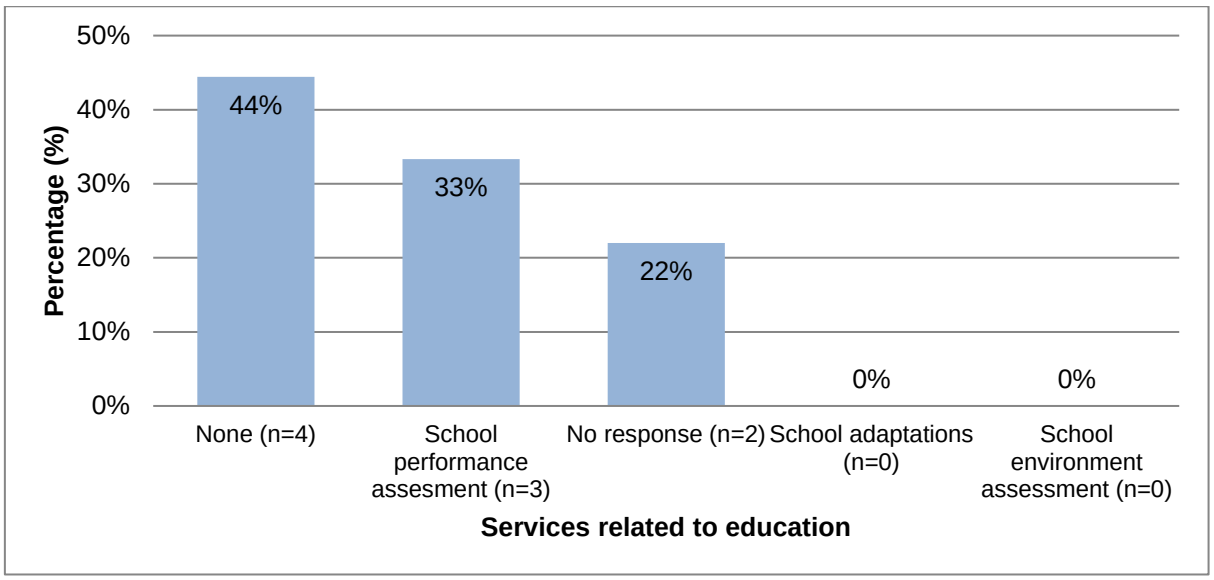


Figure 4.14: Occupational therapy services related to education (n=9)

4.1.9. Main treatment focus of occupational therapists

Participants noted that the most common occupational performance areas they focussed on for the treatment of clients with JIA were personal management (89%, n=8), followed by education (56%, n=5). Social participation and leisure were the least common areas of focus (11%; n=1 respectively) (Figure 4.15).

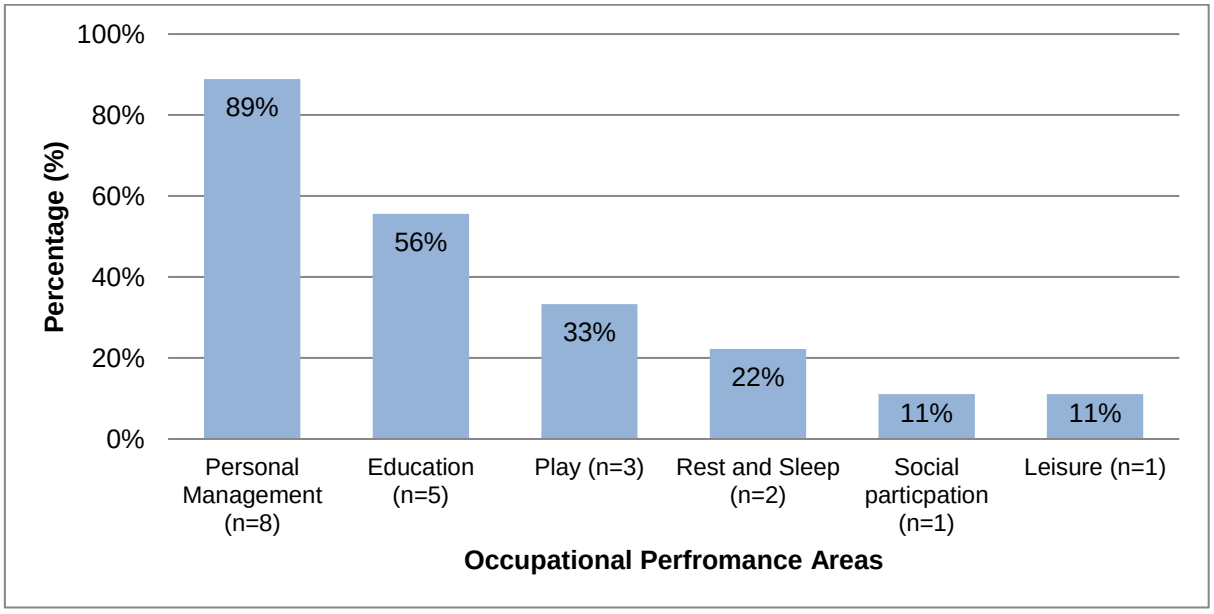


Figure 4.15: Main treatment areas focused by occupational therapists (n=9)

4.1.10. Optimal services for clients with Juvenile Idiopathic Arthritis

Of the nine participants, six (67%) agreed that the occupational therapy services were not optimal for clients (Table 4.2). For participants that agreed that services were optimal. It was noted that these participants agreed that their departments were well equipped to treat these clients and that their services were optimal for treating clients with JIA.

Table 4.2: Optimal occupational therapy services for clients with Juvenile Idiopathic Arthritis (n=9)

Are occupational therapy services offered optimal for clients with JIA?	CMJAH	KH	TH	CHBAH	Total (n=9)
Yes	0	0	2	1	3 (33%)
No	2	1	2	1	6 (67%)

Participants who disagreed with services being optimal stated their reasons were that referrals were not early enough and that clients with JIA needed more focus on education and insight training (Table 4.3).

In addition, participants also commented on services they would have liked to have offered to clients with JIA at their institutions (Table 4.4). Although three participants did not comment, participants from CHBAH only commented on earlier referrals, while participants from CMJAH noted improvements that should be made in attendance to JIA clinics, specialised assessment forms and increased education on JIA by the universities and for insight training. Participants from KH and TH also noted more education on insight training and earlier referrals, but also added the development of treatment protocols and establishing outpatient clinics.

Table 4.3: Responses of how services could improve for Juvenile Idiopathic Arthritis clients (n=9**)**

How services can improve?	CMJAH	KH	TH	CHBAH	Total Responses (9)
Attendance of JIA clinics	1	0	0	0	1 (11%)
Specialised assessment forms	1	0	0	0	1 (11%)
Not enough education of treatment of this condition in universities	1	0	0	0	1 (11%)
Not enough focus on education and insight training	1	0	1	0	2 (22%)
Develop treatment protocols	0	1	0	0	1 (11%)
Establish outpatient clinics	0	1	0	0	1 (11%)
Earlier referrals	0	0	1	1	2 (22%)

Table 4.4: Other treatment occupational therapists would like to offer Juvenile Idiopathic Arthritis clients in their institutions (n=9)

Other treatments occupational therapists would like to offer clients with JIA	CMJAH	KH	TH	CHBAH	Total Responses (10)
Support groups for clients with JIA/family/caregivers	1	0	0	0	1
Education groups	1	0	0	0	1
Tai Chi as a form of exercise	1	0	0	0	1
No response	0	1	2	0	3
Unable to suggest any other treatment for clients with JIA	0	0	1	0	1
Group based treatment activities	0	0	1	0	1
Comprehensive exercises to increase hand function and ADLS	0	0	0	1	1
School Adaptations	0	0	0	1	1

4.2. Phase Two results

Information represented below consists of data collected from CMJAH and CHBAH Rheumatology Clinics. The JAMAR assessment tool consisted of two questionnaires for clients to complete with the first questionnaire completed only by children over the age of seven years. For clients under the age of seven years, only parent questionnaires for the JAMAR were completed.

A total sample population of 37 participants were assessed, which included 34 children and three parents. Questionnaires collected from CMJAH consisted of ten children. Three children were under the age of seven in which parent questionnaires were only completed. Twenty-four questionnaires were collected from CHBAH that were completed by children only. Four children at CHBAH attended the clinic without parent/caregiver supervision and were 17-18 years of age completing their Grade 12.

4.2.1. Demographics of sample population

The demographics for the sample from each clinic were determined using demographic questionnaires. The demographic questionnaire included questions on gender, ethnic group, age and medical services attended.

4.2.1.1. Gender distribution

The gender distribution of the sample population for both institutions indicated a total of 38% (n=14) males and 62% (n=23) females. More male participants were seen at CMJAH (62%, n=8), while more female participants were seen at CHBAH (75%, n=18). (Table 4.5)

Table 4.5: Gender and ethnic distribution of sample population (n=37)

Gender	CMJAH n=13	CHBAH n=24	Total n=37
Male	62% (8)	25% (6)	38% (14)
Female	38% (5)	75% (18)	62% (23)
Ethnic Group	CMJAH n=13	CHBAH n=24	Total n=37
Black African	69% (9)	88% (21)	81% (30)
White	8% (1)	8% (2)	8 % (3)
Asian	8% (1)	0% (0)	3% (1)
Coloured	8% (1)	4% (1)	5% (2)
Other – Indian	8% (1)	0% (0)	3% (1)

4.2.1.2. Ethnic distribution

The ethnic distribution of the sample population of the two institutions are represented in Table 4.5. The majority of participants for both institutions were Black African (81%, n=30).

4.2.1.3. Age distribution

The most common age group for the sample population for both institutions were 11-12 years (18.92%, n=7) and 13-14 years (18.92%, n=7) (Figure 4.16). No participants were in the age groups of 0-2 years and 5-6 years, with most of the sample population being of school going age.

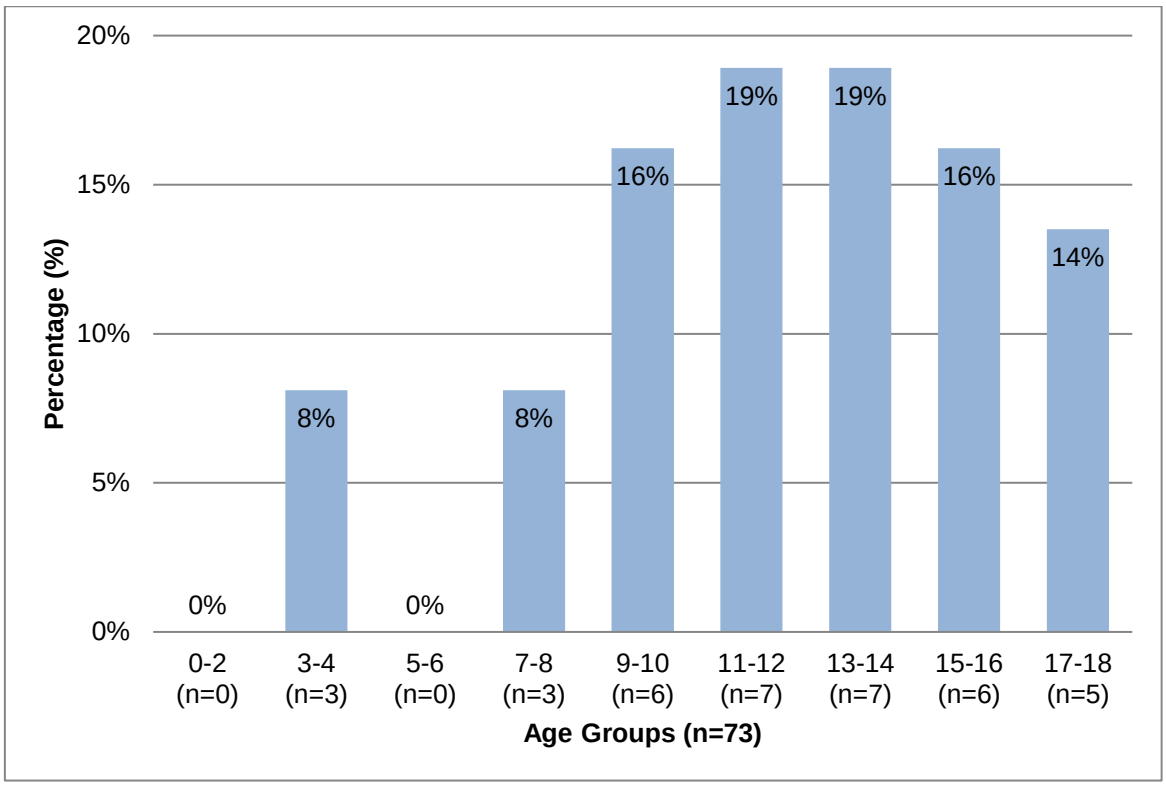


Figure 4.16: Age distribution of sample population (n=37)

4.2.1.4. Multi-disciplinary services

The most common multi-disciplinary services attended by the sample population were rheumatologists (Figure 4.17). Participants from CMJAH noted the three most common multi-disciplinary services being utilised were rheumatologists (100%, n= 13), school teacher services (69%, n=9), physiotherapists (38%, n=5).

Participants from CHBAH noted the three most common multi-disciplinary services being utilised were rheumatologists (100%, n= 13), nursing (58%, n=14) and school teacher services (50%, n=12) (Figure 4.17).

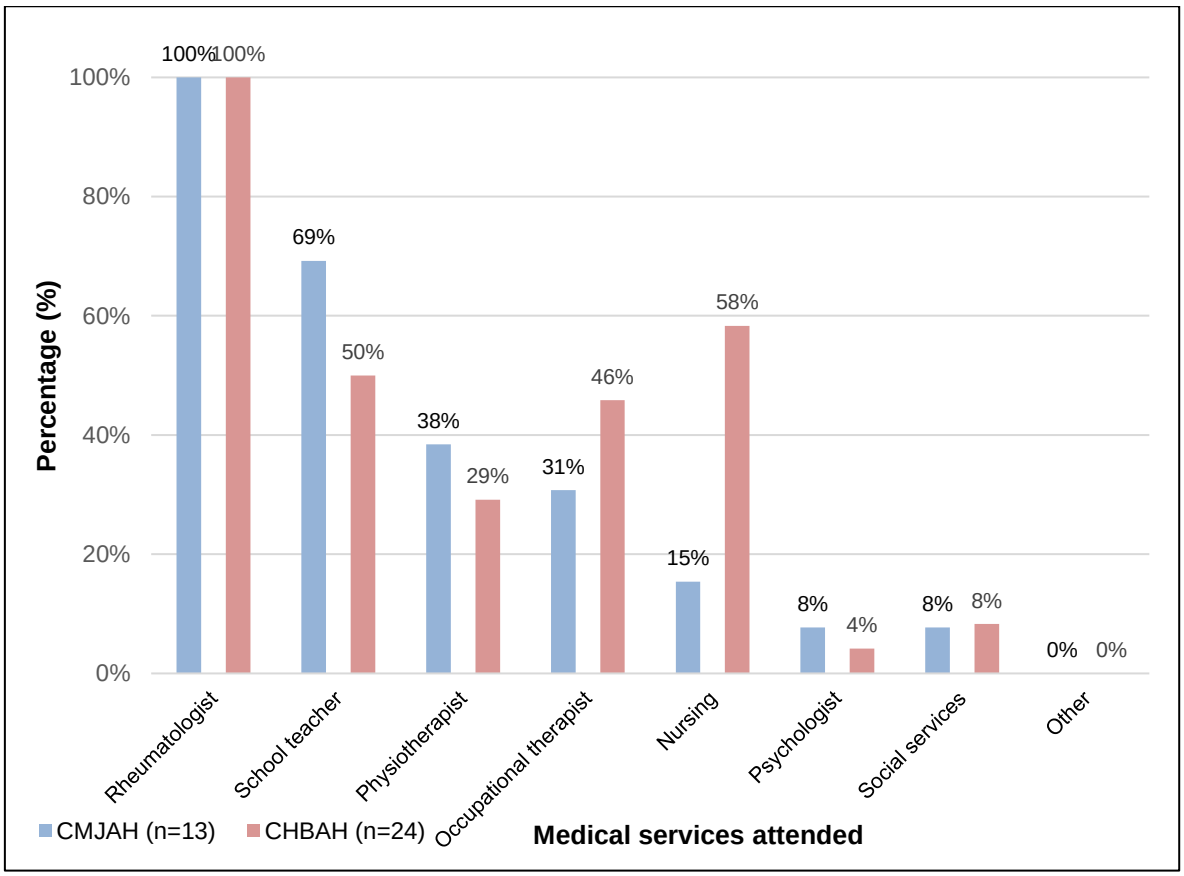


Figure 4.17: Medical services attended by clients with Juvenile Idiopathic Arthritis

4.2.2. Assessment results

The JAMAR tool consisted of 15 items but only the following were extracted that related to the study: Evaluation of functional ability, pain rating scale, Joint pain and swelling, joint stiffness, disease activity rating, disease activity at clinic visit and disease course from previous visit, school deficits, and quality of life assessment. Items 5, 9-12 concerning associated symptoms, medication and side effects were not included for the purpose of this study (Appendix A1, A2). This was to ensure that clinical presentations/needs of clients with JIA that impacted on their physical and functional limitations were of direct cause from the condition.

4.2.2.1. Evaluation of functional ability

The evaluation of functional activity for participants is represented in Figure 4.18. The most difficult activity noted by participants were squats (Activity 4), which scored the highest (35%; n=13), followed by opening and closing a tap or opening a previously opened jar (Activity 10) with 27% (n=10) no difficulty responses.

The least difficult activities noted by participants were opening a door by lowering the handle (Activity 9), bending their head back and looking at the ceiling (Activity 14) and biting into a sandwich or an apple (Activity 15), which scored the highest no difficulty responses (92%; n=34) and some difficulty responses (8%, n=3).

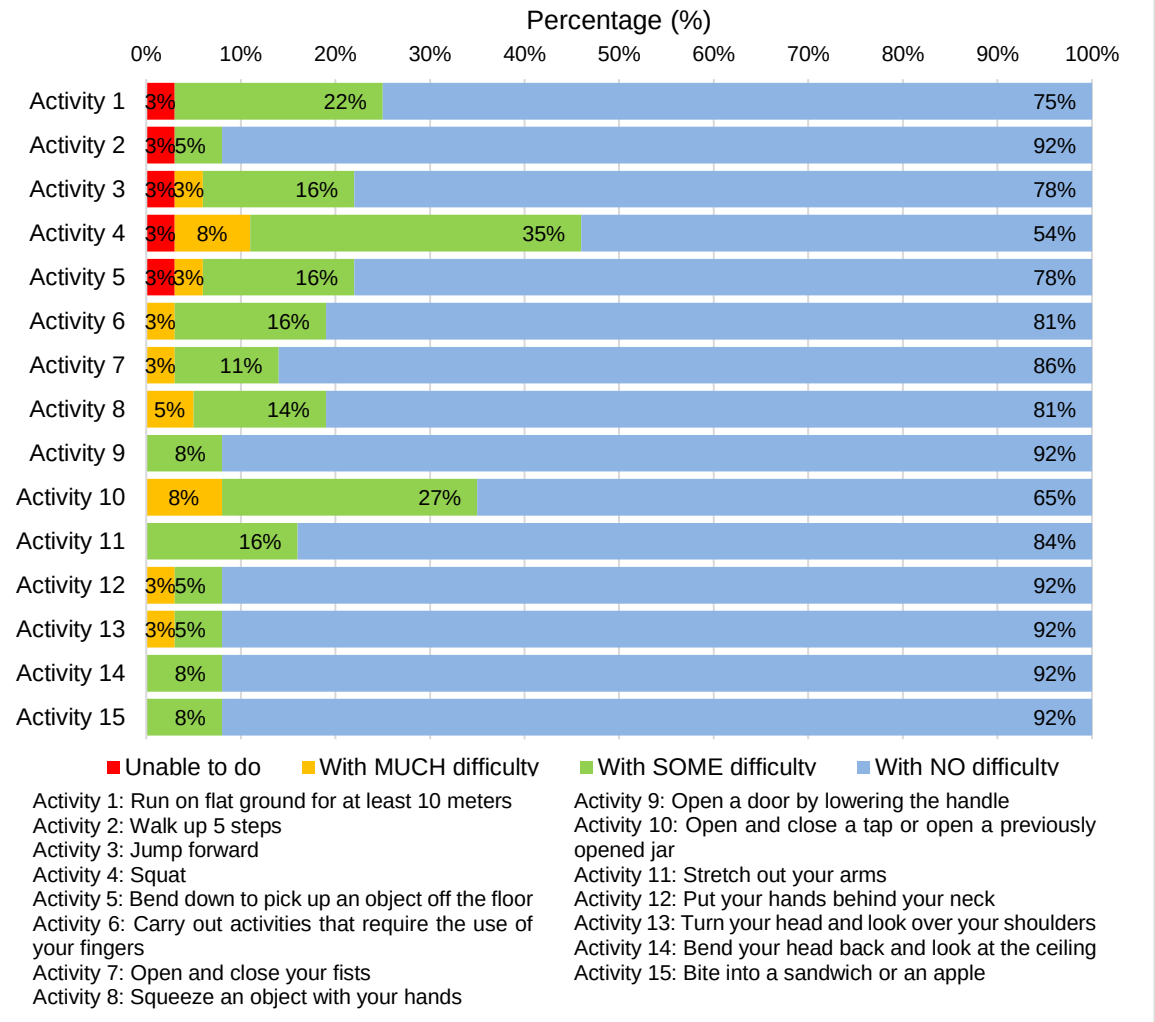


Figure 4.18 Evaluation of functional activity – responses from participants (n=37)

4.2.2.2. Pain rating scale

The results of the pain scale completed by participants, which referred to general pain experienced, are represented in Figure 4.19. It was noted that 46% (n=17) of the participants experienced no pain (pain rating 0/10) for the week prior to their clinic visit, 11% (n=4) participants rated their pain being mild (5/10) and 5% (n=2) rated their pain as severe (10/10).

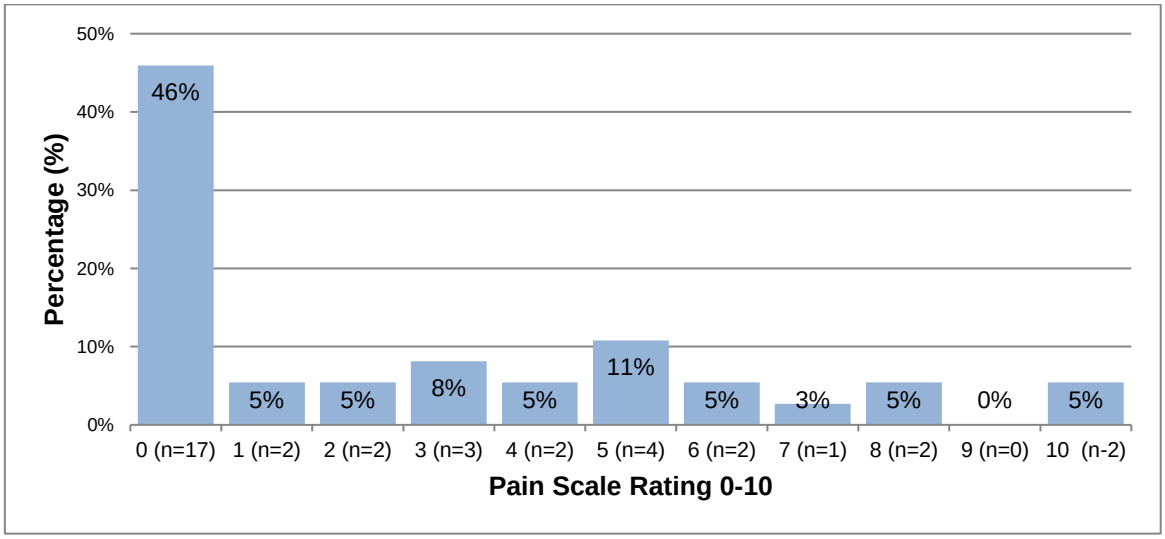


Figure 4.19: Evaluation of Pain (n=37)

4.2.2.3. Joint pain and swelling

Just under half of the participants indicated that they experienced no joint pain or swelling on the day of their clinic visit (41%; n=15) (Figure 4.20). Participants who experienced joint pain and swelling on the day of their clinic visit reported that their right knee was most affected (22%; n=8) followed by the right ankle (16%, n=6) and left and right fingers (16%, n=6 respectively).

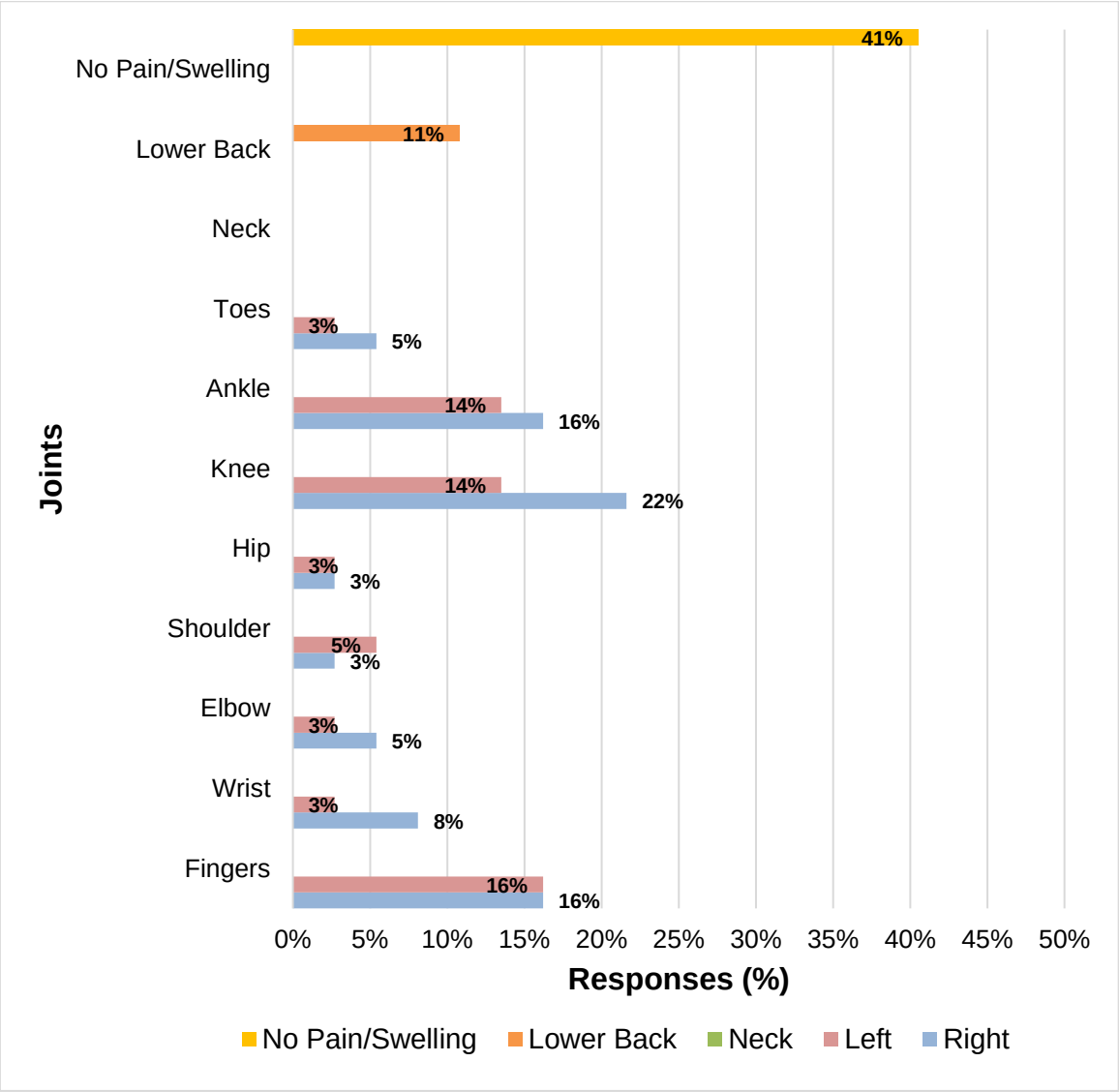


Figure 4.20: Evaluation of joint pain and swelling (n=37)

4.2.2.4. Joint stiffness

The evaluation of joint stiffness noted in Figure 4.21, in which only 49% (n=18) participants stated they experienced joint stiffness in the morning for the past week. Of the 18 participants 50% (n=9) reported the joint stiffness lasted <15 minutes, while the minority 11% (n=2) reported joint stiffness lasting > 2 hours.

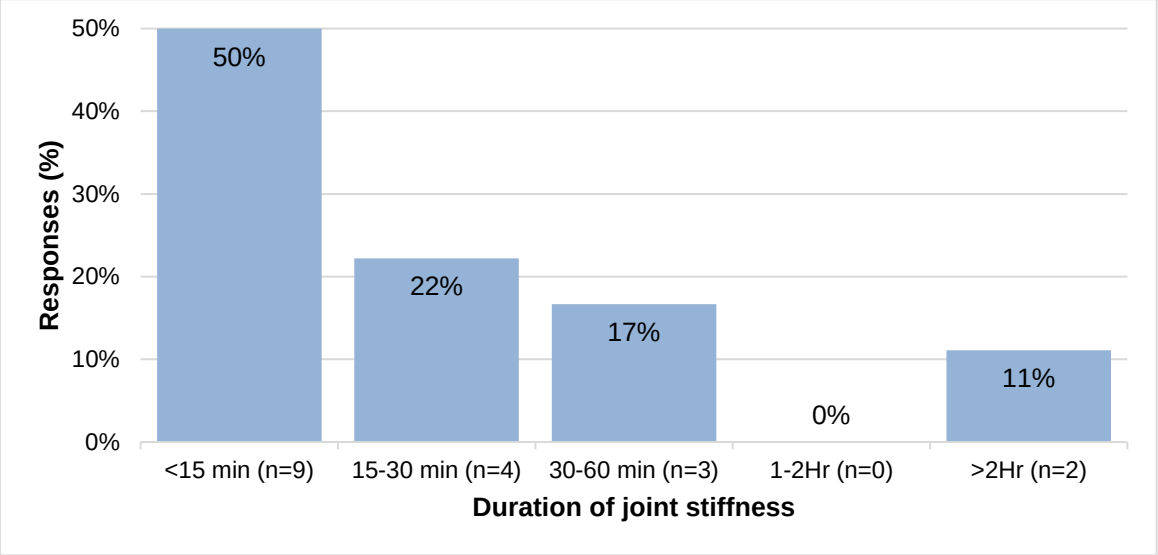


Figure 4.21: Evaluation of joint stiffness (n=18)

4.2.2.5. Disease activity rating

The level of disease activity was rated on a scale of 0-10 (Figure 4.22). Fourteen participants (38%) reported no disease activity (0/10), 11% (n=4) rated their level of activity as mild (5/10) and 3% (n=1) rated their level of disease activity as severe (10/10).

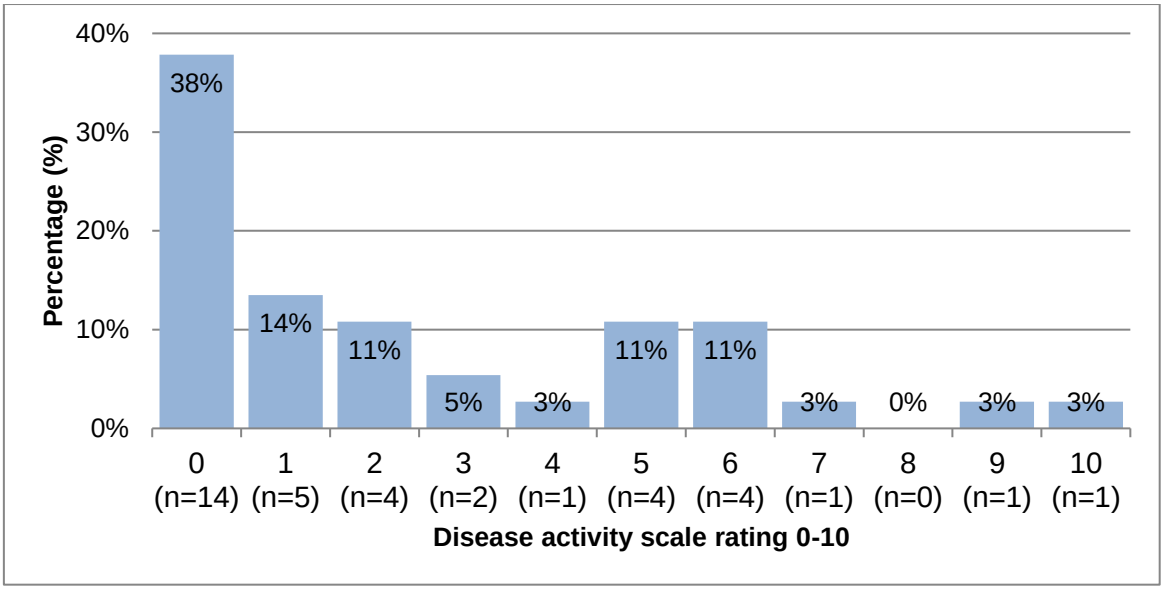


Figure 4.22: Evaluation of level of disease activity (n=37)

4.2.2.6. Disease state at clinic visit and disease course from previous visit

Three of the JAMAR assessment tool questions were related to the participants' disease state on the day of their clinic visit. The first question inquired about their current disease state upon the clinic visit. The JAMAR assessment tool noted that 59% (n=22) of participants displayed relapsed and persistent disease activity (Table 4.6).

The second question was related to the participant's opinion of the course of the disease comparing the current clinic visit to the previous visit. Participants agreed that there had been an improvement since their last clinic visit, with 43% (n=16) indicating "much improved" and 32% (n=12) indicating "slightly improved." It was noted that 24% (n=9) of the participants noticed no changes since their last visit (Table 4.6).

The third question assessed if participants would be satisfied if their condition remained unchanged for the next few months. It was noted that 57% (n=21) of participants agreed that their condition can remain the same, while 43% (n=16) were not satisfied for their condition to remain the same (Table 4.6).

Table 4.6: Responses noted of current disease state at clinic visit (n=37)

Questions:	Remission		Persistent Activity	Relapse	
Current state of child's illness (n=37)	41% (15)		27% (10)	32% (12)	
Questions:	Much Improved	Slightly Improved	Stable / Unchanged	Slightly Worsened	Much Worsened
Compared to last visit (n=37)	43% (16)	32% (12)	24% (9)	0% (0)	0% (0)
Questions:		Yes		No	
Satisfied if condition remain the same/unchanged for the next few months (n=37)		57% (21)		43% (16)	

4.2.2.7. School deficits

The JAMAR assessment tool included a question on school related problems. Each participant could choose multiple options, 57% (n=21) participants, reported no school problems related to JIA. Some school related problems identified by participants related to difficulty remaining seated for a long time (22%; n=8) and absenteeism (19%; n=7). In addition, some children, parents and caregivers noted additional problems such as body pain after physical exercise and not being able to take part in sport (Table 4.7).

Table 4.7: Participant responses for school related problems (n=37)

School Related Problems:	Responses (n=37)	Percentage
None	21	57%
Numerous absences	7	19%
Difficulty remaining seated for a long time	8	22%
Difficulty in his/her relationships with teachers	2	5%
Decrease in performance	2	5%
Other: Body pain after physical exercise	2	5%
Other: Not taking part in sport	3	8%

4.2.2.8. Quality of life assessment

The quality of life JAMAR assessment tool consisted of 10 items that were related to quality of life (Figure 4.23). More than 80% of the participants reported that their quality of life was either never affected or sometimes affected with the exception of the item QL8 (getting along with other children) which only 13% of the participants indicated as affected sometimes or often. The factors that affect the quality of life of almost half the participants sometimes, often or every day, were QL2 (walk or walking up a flight of stairs), QL3 (activities that required a lot of energy), QL5 (pain), QL 6 (sad/depressed), QL7 (nervous or anxious) and QL9 (difficulty concentrating or paying attention). Very few participants reported that their quality of life was affected often or every day.

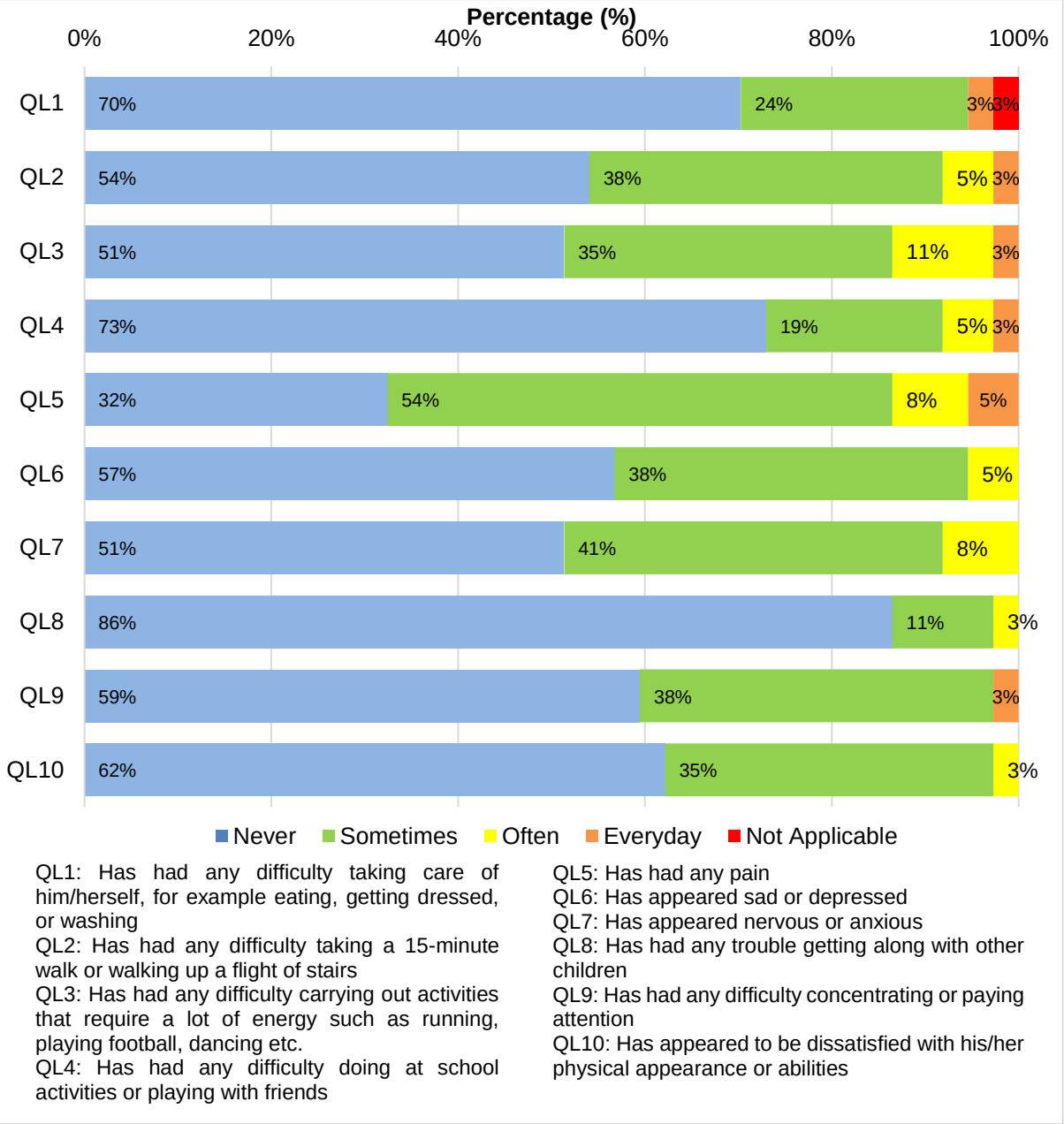


Figure 4.23: Evaluation of quality of life (n=37)

The data collected in phase one and phase two, which represented occupational therapy assessment and treatment services, referral to multi-disciplinary team members and condition related factors obtained from the JAMAR assessment tool will be discussed in chapter 5 and compared to literature available.

Chapter 5: Discussion

5. DISCUSSION:

This chapter answered the aims and objectives proposed by the research study. The discussion included the two phases of the research study. Phase one of the study related to the current occupational therapy assessment and treatment services available to clients with JIA in Gauteng. Phase two of the study focused on condition related factors, as identified by JIA clients or their caregivers, which impacted on the occupational performance of these clients. Services provided in South Africa for clients with JIA will be compared to international studies. Lastly services provided to clients with JIA will be compared to the clients' self-reported occupational performance.

5.1. Demographics

Participants for phase one included nine occupational therapists from specialised institutions within Gauteng who provided services to clients with JIA. This is similar to local and international literature, which referred to specialised paediatric rheumatology clinics being created to address this condition with specialised staff and resources (7, 8). The specialised institutions that employed the occupational therapists for phase one, consisted of CHBAH, CMJAH, KTHC and RMMCH.

RMMCH had no therapists who assessed or treated clients with JIA within their institution. RMMCH is considered a regional hospital, and clients with specialised conditions, such as JIA, were referred to tertiary/central institutions which offered dedicated paediatric rheumatology clinics.

The limited number of occupational therapists who treated clients with JIA reflected the speciality of the disease, with limited staff and resources being available to address this condition at each of the institutions.

Although JIA was considered as the sixth most common childhood disease internationally with prevalence rates between 1-4 cases per 1000 children, the prevalence of clients with JIA who attended the two specialised paediatric clinics in Gauteng, for phase two of the research study, were not reflective of international prevalence rates, as a sample population of only 37 participants were assessed (1, 16). These 37 participants only included participants on their initial consultation at the specialised paediatric clinics and did not include follow up appointments, as this provided a true reflection of the prevalence of JIA within the clinic.

The limited number of occupational therapists who treated clients with JIA and the number of participants in phase two that attended these clinics, reflected the speciality of the disease, with staff and resources being sufficient to address this condition at each of the institutions. Although the number of clients with JIA seen by institutions are not in relation to international prevalence rates, these clients could be diagnosed late or missed by clinics or attended clinics that did not provide these necessary services.

5.1.1. Age groups

Participants in phase one noted the average age group of children assessed within their institutions were children of school going ages between 11-18 years (Figure 4.2). These averages were consistent with the ages of participants assessed in phase two of the research study which ranged between the ages of 9-18 years (Figure 4.16).

International literature indicated the most common onset for the disease is school going age, which correlated with the data obtained in phase one and phase two (12). This is important when considering the services occupational therapists provide in the specialised clinics.

5.1.2. Gender

The demographic questionnaire in phase two noted overall, that the majority of participants attending the JIA clinics were females as opposed to males, although CMJAH had a higher attendance of males to females as compared to CHBAH (Table 4.5). The notion that females have a higher prevalence of JIA than males were similar to results from phase one of the study, in which more than half of the occupational therapists agreed that more female clients with JIA attended their institutions as opposed to male clients with JIA (Figure 4.3).

The results of this study are in line with international and local research in which female clients have a higher predisposition to develop JIA (3, 15). Local literature indicate mixed reviews with either showing an equal predominance amongst male and female gender distributions (7), or agreeing with a higher predominance of females to males (20).

5.1.3. Ethnic diversity

The ethnic distribution of clients with JIA noted in participants of phase two, displayed a higher predisposition of Black African children being diagnosed with JIA as opposed to White children (Table 4.5). International literature showed a trend of European based populations, namely Caucasians, having a higher predisposition to JIA, as opposed to Sub-Saharan countries (6, 10, 14, 20).

The provincial profile for Gauteng (2004) had a population density of 520 people per a square meter, with Gauteng being the most densely populated province in South Africa (88). In addition, it was noted in Gauteng that the population groups consisted of Black African (73.8%), White (19.9%), Coloured (3.8%) and Indian (2.5%) (88).

The higher representation of Black African children being predisposed to JIA in this study could therefore be linked to the higher percentage of Black African children who utilised these specialised government institutions.

5.2. Multidisciplinary team members and referrals:

The multi-disciplinary team most commonly providing services in the Gauteng public sector included the: Paediatric rheumatologist, physiotherapist, occupational therapist, nursing staff, social worker, dietician, podiatrist and orthotist. All clients with JIA in phase two of this study attended medical services offered by the paediatric rheumatologists at both CMJAH and CHBAH (Figure 4.17). The utilisation of nursing services was noted to be higher at CHBAH compared to CMJAH (Figure 4.17). This could be attributed to the referral process and services rendered at each of the institutions.

Participants also utilised the occupational therapy services greater than physiotherapy at CHBAH, as opposed to CMJAH where physiotherapy was utilised more than occupational therapy services (Figure 4.17). This could also be attributed to the different referral systems at each institution and the establishment of the role for each scope of practice in the treatment of clients with JIA.

The referrals to occupational therapy at CHBAH was higher, possibly due to an occupational therapist having a physical presence in the JIA clinic, as opposed to CMJAH where occupational therapists and physiotherapists did not attend the clinic, and referrals were dependent on the rheumatologist's discretion and understanding of their roles.

Multi-disciplinary team members in the public sector catered services for clients with JIA through a referral basis amongst team members. Most participants in the sample for phase one agreed that multi-disciplinary team members did not understand the role of the occupational therapist and thus referred these clients later to occupational therapy. Participants from phase one, noted that the most common referrals to the occupational therapist from multi-disciplinary team members were for assistive devices followed by splints and functional exercises (Figure 4.5).

The multi-disciplinary team members often had fixed ideals of the role of occupational therapist's intervention, with the main reason for referrals being solely for splints and assistive devices. Therefore the full scope of the occupational therapy services was not utilised, in terms of school assessments, play therapy and achieving developmental milestones (28, 36, 69, 71).

The majority of occupational therapists were noted to refer more to physiotherapists than other multi-disciplinary team members (Figure 4.4). The higher referral percentage to the physiotherapist could be attributed to their role in treating physical deficits regarding biomechanics and the musculoskeletal systems. Furthermore, combined sessions with the occupational therapist that occurred in some institutions adopted a multi-disciplinary team approach, which is similar to international literature regarding multi-disciplinary team approaches (1, 21, 25).

The occupational therapists from the sample noted four barriers that prevented a multi-disciplinary team approach to treatment which occurred within their institution (Figure 4.6). Firstly, difficulty arranging combined treatment sessions suitable for other multi-disciplinary team members. Secondly, a poor understanding of the occupational therapist's role in the treatment of JIA, which contributed to the poor referral rate to occupational therapy from main referral structures such as doctors. Thirdly, multi-disciplinary team members had a poor understanding of the condition and functional implications with regards to JIA, which affected referrals to the appropriate multi-disciplinary team members. Lastly, some institutions reported that physiotherapists were unable to join the JIA clinic due to staff shortages at the time. These barriers work against the ideal multi-disciplinary team and referral process set by the British society of paediatric and adolescent rheumatology standards of care for clients with JIA (21).

The role of the occupational therapist for rheumatic conditions extends to both acute and chronic management, with regards to splinting, joint protection education, pain management, home and school assessments, and improving independence in occupational performance areas (28). Although occupational therapists feel that the role of occupational therapy is not well established for the intervention of clients with JIA, multi-disciplinary members referrals to occupational therapy are in keeping with international guidelines. Emphasis should be placed on commination within the multi-disciplinary team as to establish efficient and comprehensive services to clients with JIA and improving the referral procedure.

5.3. Occupational therapy assessments

Literature indicated that limited psychometric assessment tools for physical, psychological, social functioning and quality of life were used by occupational therapists for assessing clients with JIA (15). Occupational therapists often made use of individual assessments which determined joints affected, joint deformity, range of motion, strength, fine motor skills, pain, and gait, as a measure of physical functioning of clients (15).

This was confirmed by occupational therapists in the sample population when they stated they did not use any specific screening tools or assessments for clients with JIA. The assessments they used often had limited relevance to occupational performance and condition related factors caused by the disease (15, 46). The lack of comprehensive occupational therapy assessment tools for clients with JIA makes it difficult to obtain a holistic overview of these clients' functioning and to monitor progress on follow up appointments.

The JAMAR assessment tool can be used as an indicator and possible screening tool that occupational therapists could utilise within the clinic setting. Items on the JAMAR assessment tool ranges from assessing physical symptoms, disease activity and level of function. This is in agreement with occupational therapy's philosophy to enable and facilitate independence to individuals with disabilities (28, 29). For the purpose of this study the JAMAR assessment tool was used as a measure for occupational performance and condition related factors for clients with JIA. The results from the JAMAR assessment tool were then compared to current occupational therapy services offered at specialised institutions.

Amongst the results obtained from the JAMAR assessment tool, children with JIA, parents and caregivers reported physical symptoms and functional limitations experienced due to the condition. Common areas of concern were based on functional limitations related to general pain, joint pain, swelling, joint stiffness, disease activity, disease status, school deficits and quality of life.

The JAMAR assessment tool provides a fair overview of these condition related factors and occupational performance areas affected by the condition and could form part of the assessment tools that occupational therapists could use to monitor clients progress upon follow-up appointments.

5.4. Occupational therapy treatment modalities:

The common JIA treatment modalities identified by the occupational therapists in this study included: splinting, assistive devices, pain management, education, and physical exercise.

5.4.1. Splinting

All occupational therapists from phase one of the research study, used splinting as part of their intervention programme for clients with JIA at their respective institutions. These services focused mainly on splints for the upper limbs (Figure 4.7), although the clients with JIA from phase two of the study commented that their joint pain and swelling were mainly related to their lower limbs. Some of the participants further commented on pain in their fingers (Figure 4.20).

Literature indicated the use of the resting splint as a form of treatment modality for swollen and painful joints, aiming to provide rest for the affected joints in the most functional anatomical position (62, 65, 66). The resting splint aided the decrease of inflammation and resultant pain at the affected joints (62). Although only a small percentage of the sample of clients with JIA mentioned pain symptoms, a few participants experienced swollen joints, joint stiffness, active disease activity and disease status (Figure 4.19-22, Table 4.6). The occupational therapy participants from phase one of this study all noted that they issued resting splints to clients with JIA (Figure 4.7).

There appears to be a need by clients with JIA that required splinting as part of the treatment modality for JIA and was being addressed by the occupational therapy services provided at the Gauteng institutions.

5.4.2. Assistive devices

Assistive devices were often used by occupational therapists in phase one of this study, as a treatment modality for JIA, which assisted clients with pain management and enabled clients to perform ADLs independently in keeping with international literature (69, 72). Occupational therapy participants in the sample population noted that wheelchairs/seating and personal management assistive devices such as built up handles, wash mitts, extended toothbrushes and tap openers were common assistive devices, issued by occupational therapists for clients with JIA (Figure 4.8-9).

This linked to literature that indicated health professionals considered mobility, physical engagement in occupations and personal management activities for self-care as priorities in treatment planning, when assistive devices were issued (33, 71). These results linked to participants who noted that opening and closing taps or jars was strenuous, as these activities incorporated smaller joints which could have been swollen or inflamed, thus impacted on their function for daily activities (Figure 4.18).

A small number of the occupational therapy participants also agreed that school aids, such as pencil grips was one of the most common assistive devices issued by occupational therapists (Figure 4.8-9). Although results from the JAMAR assessment tool did not comment on physical limitations that would require school aids by the participants, international literature suggested that occupational therapists should consider school assessments for school aids as part of their treatment planning (15).

Thus, the common areas of concern identified by clients with JIA, included engaging in functional mobility, personal management and school aids. These concerns were considered a treatment focus by occupational therapists and were included as part of the occupational therapy services provided at the Gauteng institutions.

5.4.3. Pain management

Pain can be a limiting factor, both physically and psychosocially, for clients with JIA. It negatively affects occupational performance, leading to poor engagement in sports or leisure activities and absenteeism from school with chronic pain having relations to depression (34, 35, 37, 42-45). The occupational therapists commented on pain management modalities they used at their institution with joint protection techniques being the most common followed by the use of heat packs (Figure 4.10).

Occupational therapists also noted alternative methods for pain management such as wax bath treatment and splints. Just under half of the participants from phase two noted they did not experience joint pain or stiffness, while those who experienced pain indicated their knees, ankles and fingers were the most common joints affected (Figure 4.20). The current home programmes prescribed by occupational therapists identified in phase one were not joint specific but focused on functional exercises utilised in treatment.

Literature indicated that joint protection techniques accompanied by home programmes showed improvements in functional outcomes and pain management for adult clients with RA (69). This was similar to the types of home programmes that occupational therapists in this study issued to clients with JIA i.e. joint protection and functional exercise home programmes (Figure 4.13). Almost half of the occupational therapy participants provided pain management home programmes to clients with JIA, which was similar to literature for adults with RA, regarding a balanced programme of functional exercise, assistive devices and joint protection for the best possible outcome for clients with JIA (Figure 4.13) (69).

Occupational therapists in this study did not issue many education and play home programmes, as some occupational therapists noted that they did not provide school assessment/services for clients with JIA (Figure 4.13-14). However, the clients with JIA in phase two noted that their main school related problems were absenteeism, school performance and participation in sport (Table 4.7). This shows concern that occupational therapists in hospitals, did not consider the need for school services as a higher priority in treatment planning so as to assist these clients to integrate into a schooling environment.

However, a gap could be present regarding education services, as they may not be enough occupational therapists in the education sector to deliver these services at schools that clients with JIA attend.

The JAMAR assessed the quality of life for clients with JIA through everyday tasks from self-care to social engagement. Responses from participants (Figure 4.23), noted that QL1 (Has had any difficulty taking care of him/herself), QL2 (Has had difficulty taking a 15-minute walk or walking up a flight of stairs), QL3 (Has had difficulty carrying out activities that require a lot of energy), QL4 (Has had any difficulty doing at school activities or playing with friends), were items that scored moderate difficulty, and QL5 (Has had any pain) which was the most affected in the four weeks prior to the clinic appointment. This was supported by literature which highlighted the association between pain and level of engagement (36).

Literature also noted that clients with JIA had trouble in engaging in everyday activities due to physical and psychological deficits, such as depression. Various studies indicated that decreased physical functioning and pain had been associated with higher rates of depression and high mental distress in adolescents (34,35), which was evident from participants opinions in this research study, in terms of quality of life (Figure 4.23).

The treatment modalities used by occupational therapists in this study for pain management comprised of joint protection techniques and accompanied with functional exercises of the upper limb and home programmes. Although these forms of treatment for pain management offered by occupational therapy services provided at Gauteng institutions may address general pain symptoms experienced by clients with JIA, further research is required to address specific joints as identified by these children.

5.4.4. Education

Clients with JIA learn to cope with the disease on a daily basis, but often experience physical limitations as a result of pain, joint stiffness and swelling which could disrupt their school performance (37). The majority of children that were seen in phase two were of school going age, thus the occupational therapist should play a role in guiding the development of these clients, so that they can meet their developmental milestones and educational requirements. However, almost half of the occupational therapists in phase one stated they did not engage in school educational services (Figure 4.14).

The main reason for this could be attributed to the fact that these clients usually utilised health services at central or academic health institutions up to the age of six years. These clients are then referred down to primary healthcare community clinics for management of general physical symptoms and educational needs are referred to the department of education occupational therapists from school going ages of seven years and over.

The occupational therapists who stated they were involved in educational services however, conducted school performance assessments as their main service and prescribed assistive devices, such as pencil grips. Although international studies suggested a greater role for the occupational therapist in school environments, in terms of assisted aids for writing, assessing the school environment and application for extended time for exams (38), this was not evident from the services currently provided by occupational therapists within the health institutions.

In phase two of the study, just over half of the participants indicated on the JAMAR assessment tool that they experienced no school related problems because of JIA. Participants who experienced school rated problems noted absenteeism and difficulty remaining seated for a long period, as their main difficulties (Table 4.7). Literature stated that chronic diseases affected children with regards to varying school performance and absenteeism. An increased disease activity and the severity of JIA a child experienced, had a direct relation to the child's absenteeism and poor school performance (37).

Results from the JAMAR assessment tool highlighted disease activity and absenteeism, but further investigations are needed to show a relationship between these two factors with quality of life and school performance. In addition, the clients with JIA in the study indicated the duration of time they experienced joint stiffness in the week prior to their clinic appointment. Almost 90% of the participants noted that they/their child experienced joint stiffness in the morning which lasted less than an hour (Figure 4.21). This could be an additional factor that could have contributed to a child's poor performance at school as a result of fatigue (38), as simple tasks such as getting ready for school become more effortful due to joint stiffness thus exerting more energy into these activities before going to school.

These children further noted other school related deficits such as body pains after physical exercise, disruptive in class, fluctuating school performance, difficulty concentrating and not taking part in sport because of the disease (Table 4.7). In a study looking at children with arthritis in a school setting, it was also found that alternative reasons for absenteeism from class can be associated to fatigue from sleepless nights because of pain, attending multi-disciplinary team services and joint flares.

These factors could also lead to decreased school performance affecting the children's concentration, the ability to write for extended periods of time and engaging in after school activities (37, 38).

Although nearly half of the occupational therapists in phase one stated that education should be a main area of focus for clients with JIA (Figure 4.15), this was not reflective in the study results for occupational therapy services related to education (Figure 4.14).

Establishing the role of the occupational therapist with regards to assisting clients with JIA in the educational sector is of great importance and the scope should not only consider addressing physical symptoms experienced by these clients, but also psychosocial deficits.

The occupational therapist has clear roles in the management of RA in adults, with references made to counselling, adaptations to leisure activities, assisting with life skills and coping strategies (28). Clients with JIA noted in the JAMAR assessment tool that they sometimes experienced feelings of nervousness, anxiousness, sadness or depression, which could affect their ability to cope with the condition as their physical limitations increase (Figure 4.23) (38). This could further affect their body image, hinder their ability to engage in sports at school, and influence their adjustment from primary to high school (34, 38, 40). These are all areas the occupational therapist could address.

In conclusion, occupational therapy services provided by Gauteng institutions showed varied approaches to treatment services with regards to education, as these clients were referred to either community clinics or received treatment from department of education occupational therapists at school.

The role of the occupational therapist, especially from health institutions, was not established within the school environment. Apparent shortfalls in treatment services related to psychosocial needs of school going clients with JIA were identified.

5.4.5. Physical exercise

Reduced physical activity of clients with JIA due to physical limitation, has an impact on their ability to cope with everyday tasks (36). International literature showed a correlation between physical exercises and reduced joint inflammation, decreased pain, improvements in range of motion and better quality of life (74). Most occupational therapists in phase one agreed with using functional exercises as a modality for the treatment of clients with JIA, with the majority using joint range exercises followed by muscle strengthening and endurance exercises (Figure 4.11).

This form of intervention correlated with international literature in which physical activity or exercise programmes for clients with JIA had positive biological effects such as reducing cartilage damage, optimizing bone density and lowering joint load by reducing the risk of obesity, which contribute to improved function (36). Some clients however indicated having body pain after engaging in sports (Table 4.7).

The association between clients with JIA and a lack of participation in physically strenuous activities as compared to their healthy peers was evident in international literature (36). The possible risk of injury during these activities could also be a preventative measure taken by clients with JIA and their parents/caregivers. Contributing co-morbid complication could further affect their level of engagement, such as myocarditis and pericarditis in systemic arthritis or aortic anomalies in HLA-B27 associated arthritis (36).

Literature suggested that JIA subtypes, disease duration, pain, stiffness and fatigue contributed as potential factors for decreased engagement in physical activities (35). This was evident from the JAMAR assessment tool results (Figure 4.18), in which physical intensive activities, such as running (Activity 1), jumping (Activity 3), squats (Activity 4) and bending down to pick up an object off the floor (Activity 5), were highlighted by participants who showed some degree of difficulty, much difficulty or unable to do.

Although almost half of the occupational therapists in phase one did not comment on the most common form of exercises used in treatment, the rest of the participants indicated a general focus on hand strengthening, ADL activities, general strengthening with passive and gentle mobilisation for upper and lower limbs, as well as range of motion exercises (Figure 4.12).

The focus of hand strengthening or upper and lower limb strengthening could be linked to the occupational therapist's role in achieving independence in ADLs and meeting developmental milestones.

In addition, occupational therapists in phase one were inclined to choose more than one approach for functional exercises. This agreed with international literature regarding the use of tailored, balanced, multi-treatment programmes of joint range exercises and muscle strengthening to improve these clients' quality of life (69, 75-77).

Occupational therapy services provided by Gauteng institutions addressed the needs of clients with JIA through the use of functional exercise programmes in order for these clients to lead more active and engaging lifestyles both at home and at school.

5.5. Optimization of occupational therapy services and recommendations:

In phase one, occupational therapists were asked to assess how optimal occupational therapy services were within their institutions for the treatment of JIA. More than half of the participants agreed that these services were not optimal for clients with JIA, although some participants felt that their services were optimal due to their departments being well equipped and being able to access resources (Table 4.2).

Participants who disagreed with services being optimal mentioned possible solutions to improve occupational therapy services within their institutions. These possible solutions included: the occupational therapist's attendance to JIA clinics and more JIA outpatient clinics being established, developing standardised assessment and treatment protocols for clients with JIA. Furthermore, earlier referrals to occupational therapy by the multi-disciplinary team, increased emphasis on JIA as a condition in university curriculums, and treatment focusing on school performance could also be possible solutions (Table4.3).

In addition, participants also commented on services they would like to offer clients with JIA at their institutions. These included the use of support groups and education groups for clients with JIA/parents and caregivers, alternative forms of treatment such as Tai Chi, comprehensive exercises for hand function and ADLs, increased focus on school adaptations and group-based treatment (Table 4.4).

5.6. Summary:

The data obtained from occupational therapists and from the clients with JIA indicate common trends to functional deficits these children experience, and general occupational therapy services being offered that were similar to international treatment standards. However, occupational therapists expressed their concerns of not having access to standardised treatment protocols and outpatient clinics which negatively influenced the role of the occupational therapist in the management of JIA (Table 4.3).

Thus, the need to explore the relevance of clinical assessment tools is needed in order to provide evidence-based practice for occupational therapy intervention for clients with JIA. In addition, the diversity in occupational therapy services within institutions needs to be consolidated to a standardised treatment protocol to ensure that service delivery and resources are equal to all areas of the public, with emphasis on developing occupational therapy services in the school setting.

Gauteng occupational therapists and clients with JIA who participated in the research study provided insight on both occupational services rendered and the needs of these children related to factors affecting their occupational performance. It could be seen that most services provided by occupational therapists in Gauteng institutions were comprehensive in addressing physical symptoms, but greater care is needed in the management of psychosocial factors and school related deficits.

Chapter 6: Conclusion

6. CONCLUSION:

This chapter will provide an overview of the undertaken research study, with conclusions regarding the aims and objectives of the research study, objective findings from data collection, limitations and possible future research opportunities regarding occupational therapy intervention for clients with JIA.

JIA was described as the sixth most common childhood disease and the main cause of acquired disability in children, in the developed world, according to international literature (1). Literature for JIA in South Africa was limited when compared to developed countries, and disease profiles for JIA in South Africa differed from developed countries. Furthermore, clients were often diagnosed late due to the poor access to specialised paediatric centres (7). This was a result of JIA services being restricted to specialised institutions and limited human resources were available to implement services in accordance with international standards.

The aim of the research study was to determine current occupational therapy assessment and treatment services provided to clients with JIA and to determine the condition related factors influencing the occupational performance of these clients.

The occupational therapists, who were involved in the management of JIA, indicated the occupational therapy services they provide were in accordance with international treatment standards for clients with JIA, apart from the occupational therapist's role within the education sector.

This was due to the fact that most occupational therapists did not engage in school educational services. In addition, multi-disciplinary team members did not understand the role of the occupational therapist, which affected the referrals to occupational therapy within the acute stage of the condition.

Although a limited sample of clients with JIA was obtained from the two main JIA clinics within the Southern Gauteng District, it was noted overall that female clients with JIA showed a higher predominance than males, which is in keeping with the literature (3, 15). JIA was more prevalent in Black African clients when compared to their White counterparts. This is not aligned with international literature, which stated that there is a higher prevalence of JIA in Caucasian European based populations as opposed to South Africa (6). The reason for this was probably related to the groups of populations that attend these two specialised clinics service in the southern Gauteng district.

Occupational performance and condition related factors for physical intensive activities displayed a degree of difficulty for clients that experienced active disease states. Less than half of these clients were in relapse or experienced persistent activity. These participants noted pain symptoms, joint pain and swelling and feelings of dissatisfaction with the disease progression. Although most participants experienced no school difficulties, some participants did note that absenteeism from school, school performance and difficulty in engaging in physical activities were affected by the condition. Almost half of the participants noted psychosocial deficits linked to depression and anxiousness.

The research study noted that current occupational therapy services did address most of the needs identified by clients with JIA, which was in keeping with international literature (1, 21). Deficits in services provided were the lack of involvement in educational services, psychosocial deficits not being addressed and the absence of the use of a standardised assessment for clients with JIA specific to occupational therapy treatment focus areas.

Although occupational therapist agreed that current services for clients with JIA were not optimal, resources and staffing within the different institutions should be considered when planning to develop standardised treatment protocols and guidelines for clients with JIA.

Although some recommendations could include occupational therapists providing services in the education sector to address the deficits in treatment provided by occupational therapists within the health sector, and the development of standardised protocols for the assessment and treatment of JIA to ensure consistent service delivery within institutions.

6.1. Limitations of research

The limitation of using a survey for a research study is often the poor response rates (89). A low response rate has the possibility of lowering the reliability of the research study which might result in study bias (90). The researcher attempted to counter this by ensuring that all questionnaires for phase one, were issued and collected in person from each of the four participating institutions.

Limitations were experienced in phase two as the sample size was dependent on the number of clients with JIA who attended the clinics and did not include clients who attended the clinic for follow up appointments. In addition, only clients who met the inclusion criteria, having a primary diagnosis of JIA, were invited to participate in the research study. Clients who had co-morbid conditions and other rheumatic conditions were not considered which resulted in a smaller sample size. Considerations can be made for expanding the inclusion criteria to include newly diagnosed, previously diagnosed and clients with JIA that have co-morbidities as to yield a larger sample size.

Other reasons for the small sample of clients with JIA in phase two were: The researcher's limited time in the clinics (being two hours per day for each clinic); clients arriving late for the scheduled appointments and the irregularity of the rheumatology clinics (CHBAH had weekly clinics as opposed to CMJAH which had bi-monthly clinics).

6.2. Suggestions for future research

The research study highlighted potential areas for future studies. It is recommended that the associations between active disease states, joint swelling, absenteeism and school performance, and level of engagement in activities of children with JIA be investigated. As this could further support the need for occupational therapy services within the school setting. The research study also highlighted the poor understanding of the role of the occupational therapist in the treatment of clients with JIA.

This is however the opinion of the occupational therapists who participated in this study and it is recommended that future research be conducted to clarify this by obtaining information from the multi-disciplinary team and information could be provided to the multi-disciplinary team with regards to the role of the occupational therapist.

Lastly, the review of occupational therapy services highlighted the growing need for a standardised assessment for clients with JIA that is specific to occupational therapy as no standardised assessment tool is currently being used. A standardised assessment tool would provide a clinical picture of these clients' functioning and occupational performance and in addition provide a constant measure as to monitor these client's progress from intervention. Thus, a standardised treatment protocol should be implemented in all government institutions, which provides guidelines to treating occupational performance deficits through recommended activities as to provide equal access to resources at each institution.

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APPENDIX A1

Juvenile Arthritis Multidimensional Assessment Report (JAMAR): Parent's Version (9: pp 946-9)

Patient Identification Code: _____ **Date:_____**

Parent filling in the questionnaire: Mother ☐ Father ☐

The aim of this questionnaire is to gather information on the current state of your child's illness. Your answers will help us improve our clinical evaluation. Please read the questions below carefully and choose the answers that best apply to your child. If you have doubts or need any clarification, please ask for our help. There are no right or wrong answers. We simply ask that you answer exactly as you feel.

1. Evaluation of functional ability

Please choose the answer that best describes your child's ability to carry out the activities listed below with particular reference to the **past four weeks**. Please indicate only the difficulties or limitations **caused by the illness**. If your child has difficulty carrying out any of these activities because he/she is too young and **not because of the illness**, indicate "**Not applicable**".

	With NO difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do	Not applicable
1. Run on flat ground for at least 10 metres	☐	☐	☐	☐	☐
2. Walk up 5 steps	☐	☐	☐	☐	☐
3. Jump forward	☐	☐	☐	☐	☐
4. Squat	☐	☐	☐	☐	☐
5. Bend down to pick up an object off the floor	☐	☐	☐	☐	☐
6. Carry out activities that require the use of his/her fingers	☐	☐	☐	☐	☐
7. Open and close his/her fists	☐	☐	☐	☐	☐
8. Squeeze an object with his/her hands	☐	☐	☐	☐	☐
9. Open a door by lowering the handle	☐	☐	☐	☐	☐
10. Open and close a tap or open a previously opened jar	☐	☐	☐	☐	☐
11. Stretch out his/her arms	☐	☐	☐	☐	☐
12. Put his/her hands behind his/her neck	☐	☐	☐	☐	☐
13. Turn his/her head and look over his/her shoulders	☐	☐	☐	☐	☐
14. Bend his/her head back and look at the ceiling	☐	☐	☐	☐	☐
15. Bite into a sandwich or an apple	☐	☐	☐	☐	☐

2. How much pain has your child had because of the illness over the past week? (choose the most accurate score)

NO PAIN ○ **EXTREME PAIN**



0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10



3. Please indicate if <u>today</u> your child is feeling <u>pain</u> or has <u>swelling</u> in any of the joints listed below

LEFT SIDE	Presence of pain or swelling	RIGHT SIDE	Presence of pain or swelling
Fingers	☐	Fingers	☐
Wrist	☐	Wrist	☐
Elbow	☐	Elbow	☐
Shoulder	☐	Shoulder	☐
Hip	☐	Hip	☐
Knee	☐	Knee	☐
Ankle	☐	Ankle	☐
Toes	☐	Toes	☐
	Neck	☐	
	Lower back	☐	
My child has no joints with pain or swelling	☐		

4. Has your child had <u>joint stiffness</u> upon waking up <u>over the past week</u>? Yes ☐ No ☐

If you answered "yes", how long does it last?

Less than 15 minutes	15 to 30 minutes	30 minutes to 1 hour	1 to 2 hours	More than 2 hours
☐	☐	☐	☐	☐

5. Please indicate if your child has had either or both of the symptoms listed below <u>over the past week</u>

Fever > 38°C (if due to arthritis)	Yes ☐	No ☐
Skin rash (if due to arthritis)	Yes ☐	No ☐

6. Considering all the symptoms, such as pain, joint swelling, morning stiffness, fever (if due to arthritis), and skin rash (if due to arthritis), please evaluate the <u>level of activity</u> of your child's illness <u>at the moment</u> (choose the most accurate score)

NO ACTIVITY ○ **MAXIMUM ACTIVITY**



0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10



7. How would you evaluate the <u>current state</u> of your child's illness?

Complete absence of symptoms (**remission**)	Continuing presence of symptoms (**persistent activity**)	Recurrence of symptoms after a period of complete well-being (**relapse**)
☐	☐	☐

8. Compared to his/her last visit, how would you evaluate the <u>course</u> of your child's illness?

Much improved	Slightly improved	Stable/unchanged	Slightly worsened	Much worsened
☐	☐	☐	☐	☐

9. Is your child taking any medication to treat arthritis? Yes ☐ No ☐

If you answered "no", please go directly to question 13
If "yes", please also answer questions 10, 11, and 12

10. Which medication is your child currently taking?

NSAIDs (e.g._____) ☐	Please specify_____	
Steroids (e.g._____) ☐	Please specify_____	
Methotrexate (e.g._____) ☐	*Oral* ☐	*Subcutaneous* ☐ *Intramuscular* ☐
Salazopyrin (e.g. _____) ☐	Cyclosporine (e.g. _____) ☐	
Etanercept (Enbrel) ☐	Infliximab (Remicade) ☐	Adalimumab (Humira) ☐
Golimumab (Simponi) ☐	Certolizumab (Cimzia) ☐	Abatacept (Orencia) ☐
Anakinra (Kineret) ☐	Canakinumab (Ilaris) ☐	Rilonacept (Arcalyst) ☐
Tocilizumab (Actemra) ☐	Other (please specify_____) ☐	
Other (please specify _____) ☐	Other (please specify_____) ☐	

11. Since your child's last visit, has he/she had any disturbances which may be caused by the medication he/she is taking? Yes ☐ No ☐

If you answered "yes", please specify which in the table below

Fever ☐	Pain or burning feeling in the stomach ☐
Headache ☐	Nausea ☐
Skin rash ☐	Vomiting ☐
Mouth sores ☐	Constipation ☐
Swollen/bleeding gums ☐	Diarrhoea ☐
Increased body hair ☐	Black or bloody stools ☐
Weight gain ☐	Blood in the urine ☐
Weight loss ☐	Swelling, bruising, pain, redness, etc., at the injection site ☐
Mood swings (excitement, depression, anxiety) ☐	Other (please describe)_____ ☐
Sleep disturbances ☐	Other (please describe)_____ ☐

12. Does your child take his/her medication regularly (as prescribed by the doctor) at home? Yes ☐ No ☐

If "no", why not?

He/she refuses to ☐	Too many administrations during the day ☐
Organisational difficulty (for example, problems taking medication at school) ☐	Fear of side effects ☐
The child takes too much medication ☐	Other (please specify) _____ ☐

Which medication is most difficult to give on a regular basis? _____

13. Does your child attend school? Yes ☐ No ☐

If you answered "yes", what school-related problems does the illness cause?

None ☐	Difficulty in his/her relationships with teachers ☐
Numerous absences ☐	Decrease in performance ☐
Difficulty in remaining seated for a long time ☐	Other (please specify) _____ ☐

14. Evaluation of Quality of Life

Please choose the answer that best describes your child's overall health.
If a question is not applicable because your child is **too young**, choose "**Not applicable**".
Considering the **past four weeks**, we would like to know if your child:

	Never	Some-times	Often	Every day	Not applicable
1. Has had any difficulty taking care of him/herself, for example eating, getting dressed, or washing	☐	☐	☐	☐	☐
2. Has had any difficulty taking a 15 minute walk or walking up a flight of stairs	☐	☐	☐	☐	☐
3. Has had any difficulty carrying out activities that require a lot of energy such as running, playing football, dancing etc.	☐	☐	☐	☐	☐
4. Has had any difficulty doing at-school activities or playing with friends	☐	☐	☐	☐	☐
5. Has had any pain	☐	☐	☐	☐	☐
6. Has appeared sad or depressed	☐	☐	☐	☐	☐
7. Has appeared nervous or anxious	☐	☐	☐	☐	☐
8. Has had any trouble getting along with other children	☐	☐	☐	☐	☐
9. Has had any difficulty concentrating or paying attention	☐	☐	☐	☐	☐
10. Has appeared to be dissatisfied with his/her physical appearance or abilities	☐	☐	☐	☐	☐

15. Considering all the ways the illness affects your child, please evaluate how he/she feels at the moment (choose the most accurate score)

VERY WELL ○ **VERY POORLY**



0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10



16. Considering all the ways the illness affects your child, would you be satisfied if his/her condition remained stable/unchanged for the next few months?

Yes ☐	No ☐

APPENDIX A2

Juvenile Arthritis Multidimensional Assessment Report (JAMAR): Child's Version (9: pp 950-3)

Patient Identification Code: _____ Date:_____

The aim of this questionnaire is to gather information on the current state of your illness. Your answers will help us improve our clinical evaluation. Please read the questions below carefully and choose the answers that best apply to you. If you have doubts or need any clarification, please ask for our help. There are no right or wrong answers. We simply ask that you answer exactly as you feel.

1. Evaluation of functional ability

Please choose the answer that best describes your ability to carry out the activities listed below with particular reference to the **past four weeks**. Please indicate only the difficulties or limitations **caused by the illness**.

	With NO difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do
1. Run on flat ground for at least 10 metres	☐	☐	☐	☐
2. Walk up 5 steps	☐	☐	☐	☐
3. Jump forward	☐	☐	☐	☐
4. Squat	☐	☐	☐	☐
5. Bend down to pick up an object off the floor	☐	☐	☐	☐
6. Carry out activities that require the use of your fingers	☐	☐	☐	☐
7. Open and close your fists	☐	☐	☐	☐
8. Squeeze an object with your hands	☐	☐	☐	☐
9. Open a door by lowering the handle	☐	☐	☐	☐
10. Open and close a tap or open a previously opened jar	☐	☐	☐	☐
11. Stretch out your arms	☐	☐	☐	☐
12. Put your hands behind your neck	☐	☐	☐	☐
13. Turn your head and look over your shoulders	☐	☐	☐	☐
14. Bend your head back and look at the ceiling	☐	☐	☐	☐
15. Bite into a sandwich or an apple	☐	☐	☐	☐

2. How much pain have you had because of the illness over the past week? (choose the most accurate score)

NO PAIN ○ **EXTREME PAIN**



0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10



3. Please indicate if <u>today</u> you are feeling <u>pain</u> or have <u>swelling</u> in any of the joints listed below

LEFT SIDE	Presence of pain or swelling	RIGHT SIDE	Presence of pain or swelling
Fingers	☐	Fingers	☐
Wrist	☐	Wrist	☐
Elbow	☐	Elbow	☐
Shoulder	☐	Shoulder	☐
Hip	☐	Hip	☐
Knee	☐	Knee	☐
Ankle	☐	Ankle	☐
Toes	☐	Toes	☐
	Neck	☐	
	Lower back	☐	

I have no joints with pain or swelling ☐

4. Have you had <u>joint stiffness</u> upon waking up <u>over the past week</u>? Yes ☐ No ☐

If you answered "yes", how long does it last?

Less than 15 minutes	15 to 30 minutes	30 minutes to 1 hour	1 to 2 hours	More than 2 hours
☐	☐	☐	☐	☐

5. Please indicate if you have had either or both of the symptoms listed below <u>over the past week</u>

Fever > 38°C (if due to arthritis)	Yes ☐	No ☐
Skin rash (if due to arthritis)	Yes ☐	No ☐

6. Considering all the symptoms, such as pain, joint swelling, morning stiffness, fever (if due to arthritis), and skin rash (if due to arthritis), please evaluate the <u>level of activity</u> of your illness <u>at the moment</u> (choose the most accurate score)

NO ACTIVITY — **MAXIMUM ACTIVITY**



0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10



7. How would you evaluate the <u>current state</u> of your illness?

Complete absence of symptoms (**remission**)	Continuing presence of symptoms (**persistent activity**)	Recurrence of symptoms after a period of complete well-being (**relapse**)
☐	☐	☐

8. Compared to your last visit, how would you evaluate the <u>course</u> of your illness?

Much improved	Slightly improved	Stable/unchanged	Slightly worsened	Much worsened
☐	☐	☐	☐	☐

9. Are you taking any medication to treat arthritis? Yes ☐ No ☐

If you answered "no", please go directly to question 13
If "yes", please also answer questions 10, 11 and, 12

10. Which medication are you currently taking?

NSAIDs (e.g._____) ☐		Please specify_____	
Steroids (e.g._____) ☐		Please specify_____	
Methotrexate (e.g._____) ☐	*Oral* ☐	*Subcutaneous* ☐	*Intramuscular* ☐
Salazopyrin (e.g. _____) ☐		Cyclosporine (e.g. _____) ☐	
Etanercept (Enbrel) ☐	Infliximab (Remicade) ☐	Adalimumab (Humira) ☐	
Golimumab (Simponi) ☐	Certolizumab (Cimzia) ☐	Abatacept (Orencia) ☐	
Anakinra (Kineret) ☐	Canakinumab (Ilaris) ☐	Rilonacept (Arcalyst) ☐	
Tocilizumab (Actemra) ☐	Other (please specify_____) ☐		
Other (please specify _____) ☐	Other (please specify_____) ☐		

11. Since your last visit, have you had any disturbances which may be caused by the medication you are taking? Yes ☐ No ☐

If you answered "yes", please specify which in the table below

Fever	☐	Pain or burning feeling in the stomach	☐
Headache	☐	Nausea	☐
Skin rash	☐	Vomiting	☐
Mouth sores	☐	Constipation	☐
Swollen/bleeding gums	☐	Diarrhoea	☐
Increased body hair	☐	Black or bloody stools	☐
Weight gain	☐	Blood in the urine	☐
Weight loss	☐	Swelling, bruising, pain, redness, etc., at the injection site	☐
Mood swings (excitement, depression, anxiety)	☐	Other (please describe)_____	☐
Sleep disturbances	☐	Other (please describe)_____	☐

12. Do you take your medication regularly (as prescribed by the doctor) at home? Yes ☐ No ☐

If "no", why not?

I refuse to	☐	Too many administrations during the day	☐
Organisational difficulty (for example, problems taking medication at school)	☐	Fear of side effects	☐
I take too much medication	☐	Other (please specify) _____	☐

Which medication is most difficult to take on a regular basis? _____

13. Do you attend school? Yes ☐ No ☐

If you answered "yes", what school-related problems does the illness cause?

None	☐	Difficulty in my relationships with teachers	☐
Numerous absences	☐	Decrease in performance	☐
Difficulty in remaining seated for a long time	☐	Other (please specify) _____	☐

14. Evaluation of Quality of Life

Please choose the answer that best describes your overall health.
Considering the **past four weeks**, we would like to know if you:

	Never	Some-times	Often	Every day
1. Have had any difficulty taking care of yourself, for example eating, getting dressed, or washing	☐	☐	☐	☐
2. Have had any difficulty taking a 15 minute walk or walking up a flight of stairs	☐	☐	☐	☐
3. Have had any difficulty carrying out activities that require a lot of energy such as running, playing football, dancing etc.	☐	☐	☐	☐
4. Have had any difficulty doing at-school activities or playing with friends	☐	☐	☐	☐
5. Have had any pain	☐	☐	☐	☐
6. Have felt sad or depressed	☐	☐	☐	☐
7. Have felt nervous or anxious	☐	☐	☐	☐
8. Have had any trouble getting along with other children	☐	☐	☐	☐
9. Have had any difficulty concentrating or paying attention	☐	☐	☐	☐
10. Have felt dissatisfied with your physical appearance or abilities	☐	☐	☐	☐

15. Considering all the ways the illness affects you, please evaluate how you feel at the moment (choose the most accurate score)

VERY WELL — **VERY POORLY**



0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10



16. Considering all the ways the illness affects you, would you be satisfied if your condition remained stable/unchanged for the next few months?

Yes ☐	No ☐

Thank you very much for having taken the time to fill in this questionnaire. The information you have provided will be very useful for following the changes in the course of your illness in the best possible way.

APPENDIX B

INFORMATION SHEET

A review of the current Occupational Therapy management for clients with Juvenile Idiopathic Arthritis in five hospitals in South Africa.

Good Day Sir/Madam

I, Darrel Moodley, am currently an occupational therapy Master of Science student at the University of Witwatersrand. And I will be completing a study that will focus on the occupational therapy management for Juvenile Idiopathic Arthritis (JIA) in five hospital establishments in South Africa.

I an inviting you to participate in the study.

Why am I doing this?

Literature on JIA is limited in South Africa compared to developed countries that have well documented studies regarding prevalence, intervention and environmental causations for JIA. In addition, the role of Occupational Therapy in the intervention of JIA in South Africa is limited and not clearly defined. The study will be conducted through the use of a questionnaire which will be distributed to occupational therapists working in the follow hospitals: Charlotte Maxeke Johannesburg Academic Hospital, Chris Hani Baragwanath Hospital, Donald Gordon Hospital, Klerksdorp Hospital and Raheema Moosa Mother and Child Hospital.

What is expected from the participants in the study?

You are kindly invited to take part in this research study by completing the questionnaire. Occupational Therapists working in both the public and private sector, in the above-mentioned hospitals, are encouraged to participate in this study as there is often a discrepancy between services available to clients in these two different sectors

Are there benefits to the participants?

No. This research aims to determine the current occupational therapy services available to clients with JIA in both the private and public sector. The objective of the study is to identify the current occupational therapy treatment interventions and services provided to these clients. All participants will have access to the results obtained from this questionnaire once the study has been completed.

May you withdraw from the study?

You may withdraw from the study at any time without having to give a reason. This study is completely voluntary and not taking part in it, or withdrawing from it.

What about confidentiality?

Confidentiality will be maintained as all completed questionnaires will be placed in a sealed envelope.

If you have any queries, more information may be obtained from Darrel Moodley at telephone number (011) 488 4609. Any ethical queries or reporting of study-related adverse events should be made to the chairperson of the Wits Human Research Ethics Committee, Prof. P. Cleaton-Jones at 011 717 1234.

Thank you

Darrel Moodley

SURVEY QUESTIONNAIRE

Please place a cross (x) for your selection in each question. Please note that you can only choose one option unless otherwise stated in the question.

1. Which field/domain of Occupational Therapy do you practice in?

Physical	Paediatrics	Psychiatry	Public Health	Other

If Other, please explain:

_____

2.1 What sector do you work in?

Government	Private	Other

If Other, please explain:

_____

2.2 If government, what type/level of establishment are you currently working in?

Tertiary Hospital	Regional Hospital	District Hospital	Other

If Other, please explain:

_____

3. For how many years have you been practicing as an Occupational Therapist?

1	2-5	6-10	11-15	16-20	21-25	26+

4. Do you assess and/or treat clients with Juvenile Idiopathic Arthritis (JIA) in your facility?

Yes	No	Not sure / Unknown

If YES, please continue with the questionnaire.

5. Approximately how many clients with JIA do you assess/treat on a monthly basis?

0	1-10	11-20	21-30	31-40	41-50	50+

6. Rank which age group the majority of your clients with JIA fall into from most to least by numbering 1-6.
   1 = Most common and 6 = least common.

0-12 months	12-24 months	2-4 years	5-7 years	8-11 years	12-18 years

7. At your facility, which gender is most common among clients with JIA?

Male	Female	Not sure / Unknown

8. Do you refer clients with JIA to other facilities/hospitals to receive specialised occupational therapy?

Yes	No	Not sure / Unknown

If yes, to which facilities and why?

_____
_____
_____
_____

9. Do you refer clients with JIA to any other multidisciplinary team members?

Yes	No	Not sure / Unknown

9.2 If yes, to which multidisciplinary team members/services do you refer?

Physiotherapy	Nursing	Social services	Other
Medical personnel (Doctors, Specialists)	Psychology	School liaison services	

If other please explain:

_____

_____

_____

10. What are the most common reasons for referral to occupational therapy for clients with JIA?

Please note you can select more than one option for this question

Splints	Learning disabilities	Functional exercises	Not sure / Unknown
Assistive Devices	Psycho- social problems	Educational Assessments	Other

If other please explain:

_____

_____

_____

11. Do you practice as part of a multidisciplinary team in the treatment of JIA?

Yes	No	Not sure / Unknown

11.2 If No, describe the barriers preventing MDT work?

_____

_____

_____

11.3 If yes, which disciplines are involved?

Physiotherapy	Nursing	Social services	Other
Medical personnel (Doctors, Specialists)	Psychology	School liaison services	

If other please explain:

_____

_____

_____

12. As part of a multidisciplinary team, do you feel that the role of the Occupational Therapist is established in the treatment of clients with JIA?

Yes	No

Please explain:

_____

_____

_____

13. Do you use any specific screening tools or assessments for these clients?

Yes	No

If yes, which screening tools or assessments do you use?

_____

_____

_____

_____

14. What OT services do you currently offer clients with JIA within your facility?

- Splints:

Boutonniere splints	Swan neck splints
Ulnar drift splints	Wrist extension splints
Resting splints	Elbow protection splints
None	Other

If other please explain:

_____

_____

_____

- Assistive Devices:

School aids	Personal management aids	Wheelchairs/ Seating	Leisure aids	None	Other

Please list the assistive devices you most often provide:

_____

_____

_____

- Pain Management:

Heat packs	Joint protection techniques	None	Other

If other please explain:

_____

_____

_____

- Functional Exercise:

Joint range exercises	Muscle strengthening	Endurance	None	Other

Please list functional exercises you would most commonly use:

_____

_____

_____

_____

- Home Programmes related to the following:

Personal management	Education	Pain management	Joint protection	Social participation	Other
Family education	Play	Leisure	Functional exercise	None	

If other please explain:

_____

_____

_____

- OT services related to education:

School performance assessment	School adaptations	Other
School environment assessment	None	

If other please explain:

_____

_____

_____

15. Which occupational performance areas is your main focus for these clients?

Personal management	Rest and sleep	Education	Other
Social participation	Play	Leisure	

If other please explain:

_____

_____

_____

16. Do you think that the OT services currently offered to these clients are optimal to clients with JIA?

Yes	No

16.2 If Yes, please explain your answer:

_____

_____

16.3 If NO, how do you think these OT services can be improved?

_____

_____

_____

_____

17. Is there other treatment you would like to offer to clients with JIA?

_____

_____

_____

_____

_____

Thank you for your participation.

APPENDIX C

Demographic Questionnaire:

Index Code:_____ Date:_____

Personal Information:			
Gender:	□ Male □ Female	Child's Date of Birth:	
Ethnic Group:	□ Black African □ White □ Asian □ Coloured Other: _____	Child's Age:	
Medical Information:			
Primary Diagnosis:			
Secondary Diagnosis:			
Precautions:			
Medical services attending:	□ Medical □ Occupational Therapist □ Physiotherapist □ Nursing	□ Psychology □ Social Services □ School liaison (Teacher) Other: _____	

APPENDIX D

Pretesting questionnaire following changes

INFORMATION SHEET

A review of the current Occupational Therapy management for clients with Juvenile Idiopathic Arthritis in five hospitals in South Africa.

Good Day Sir/Madam

I, Darrel Moodley, am currently an occupational therapy Master of Science student at the University of Witwatersrand. And I will be completing a study that will focus on the occupational therapy management for Juvenile Idiopathic Arthritis (JIA) in five hospital establishments in South Africa.

I an inviting you to participate in the study.

Why am I doing this?

Literature on JIA is limited in South Africa compared to developed countries that have well documented studies regarding prevalence, intervention and environmental causations for JIA. In addition, the role of Occupational Therapy in the intervention of JIA in South Africa is limited and not clearly defined. The study will be conducted through the use of a questionnaire which will be distributed to occupational therapists working in the follow hospitals: Charlotte Maxeke Johannesburg Academic Hospital, Chris Hani Baragwanath Hospital, Donald Gordon Hospital, Klerksdorp Hospital and Raheema Moosa Mother and Child Hospital.

What is expected from the participants in the study?

You are kindly invited to take part in this research study by completing the questionnaire. Occupational Therapists working in both the public and private sector, in the above-mentioned hospitals, are encouraged to participate in this study as there is often a discrepancy between services available to clients in these two different sectors

Are there benefits to the participants?

No. This research aims to determine the current occupational therapy services available to clients with JIA in both the private and public sector. The objective of the study is to identify the current occupational therapy treatment interventions and services provided to these clients. All participants will have access to the results obtained from this questionnaire once the study has been completed.

May you withdraw from the study?

You may withdraw from the study at any time without having to give a reason. This study is completely voluntary and not taking part in it, or withdrawing from it.

What about confidentiality?

Confidentiality will be maintained as all completed questionnaires will be placed in a sealed envelope.

If you have any queries, more information may be obtained from Darrel Moodley at telephone number (011) 488 4609. Any ethical queries or reporting of study-related adverse events should be made to the chairperson of the Wits Human Research Ethics Committee, Prof. P. Cleaton-Jones at 011 717 1234.

Thank you

Darrel Moodley

QUESTIONNAIRE

1. Do you treat clients with juvenile idiopathic arthritis in your facility?

Yes	No

2. What type of establishment are you currently working in?

Tertiary Hospital	Regional Hospital	District Hospital	Private Practice

3. For how many years have you been practicing as an Occupational Therapist?

1	2-5	6-10	11-15	15-20	21-25	26+

4. Approximately how many clients with JIA do you assess/treat on a monthly basis?

0	1-10	11-20	21-30	31-40	41-50	50+

5. What is the most common age group of clients with JIA that you treat in your facility?

0-12 months	12-24 months	2-4 years	5-7 years	8-11 years	11-18 years

6. At your facility, which gender is most common among clients with JIA?

Male	Female

7. Do you refer these clients to other facilities/hospitals to receive occupational therapy?

Yes	No

If yes, to which facilities: _____

_____

_____

_____

8. What are the most common reasons these clients are referred to occupational therapy?

Splints	Learning disabilities	Functional exercises
Assistive Devices	Psycho- social	Educational Assessments

Other: _____

_____

_____

9. Do you practice as part of a multidisciplinary team?

Yes	No

9.1 If No, please explain why you are not able to practice as part of o multi-disciplinary team at your facility?

_____

_____

_____

9.2 If yes, which disciplines are involved?

Physiotherapist	Medical	Nursing	Psychology	Social Services	School liaison

Other: _____

_____

_____

10. As part of a multidisciplinary team, do you feel that the role of the Occupational Therapist is established in the treatment of clients with JIA?(Explain)

Yes	No

Explain: _____

_____

_____

_____

_____

11. Do you refer these clients to any other multidisciplinary members?

Yes	No

11.1 If yes, to whom do you refer to?

Physiotherapist	Medical	Nursing	Psychology	Social services	School liaison

12. Do you use any screening tools or assessments for these clients?

Yes	No

If yes, which screening tool do you use? _____

_____

_____

_____

13. What services do you currently offer for clients with JIA within your facility?

- Splints:

Boutonniere splints	Swan neck splints
Ulnar drift splints	Wrist extension splints
Resting splints	Elbow protection splints

Other:_____

_____

_____

_____

- Assistive Devices:

School aids	Personal management aids	Leisure aids	Other

Please list a few examples:

_____

_____

_____

_____

- Pain Management:

Heat packs	Joint protection techniques

Other: _____

_____

_____

- Physical Exercise:

Joint range exercises	Functional exercises	Other

Please list a few examples: _____

_____

_____

_____

- Home Programmes related to the following:

Personal management	Survival skills	Pain management	Joint protection
Family education	Play	Leisure	Physical exercise

Other: _____

_____

_____

_____

- Education:

School assessment	School adaptations	Learning disabilities

Other: _____

_____

_____

_____

14. Which occupational performance areas do you focus on mainly for these clients?

Personal management	Survival skills	Rest and sleep	Education
Social participation	Play	Leisure	Work

15. Do you think that the services that are currently offered for these clients are beneficial to clients with JIA?

Yes	No

Explain: _____

_____

_____

_____

16. Where do you feel the deficits in treatment lie?

APPENDIX E

Pilot study questionnaire following changes

INFORMATION SHEET

A review of the current Occupational Therapy management for clients with Juvenile Idiopathic Arthritis in five hospitals in South Africa.

Good Day Sir/Madam

I, Darrel Moodley an occupational therapy Master of Science student at the University of Witwatersrand, will be completing a study that will focus on the occupational therapy management for Juvenile Idiopathic Arthritis (JIA) in five hospitals in South Africa.

I would like to invite you to participate in the study.

Why am I doing this?

Literature on JIA in South Africa is limited compared to developed countries that have well documented studies regarding prevalence, intervention and environmental causations for JIA. In addition, the role of occupational therapy in the intervention of JIA in South Africa is limited and not clearly defined. The objective of the study is to identify the current occupational therapy treatment interventions and services provided to these clients in both the private and public sector.

What is expected from the participants in the study?

The study will be conducted through the use of a questionnaire which will be distributed to occupational therapists working in the following hospitals: Charlotte Maxeke Johannesburg Academic Hospital, Chris Hani Baragwanath Hospital, Donald Gordon Hospital, Klerksdorp Hospital and Raheema Moosa Mother and Child Hospital.

You are kindly invited to take part in this research study by completing the questionnaire, which will be distributed and collected manually. Occupational therapists working in both the public and private sector, in the above-mentioned hospitals, are invited to participate in this study, as there is often a discrepancy between services available to clients in these two different sectors. Once the questionnaire is completed nothing further will be required of the participants.

Are there benefits to the participants?

There are no direct benefits for participants. However, all participants will have access to the results obtained from this questionnaire once the study has been completed.

May I decline participation?

Participation is voluntary and anonymous, and by completing the questionnaire you are agreeing to participate in the study.

What about confidentiality?

Confidentiality will be maintained, as all completed questionnaires will be placed in a sealed envelope. Please fill out the questionnaires anonymously without any identifying information.

Please return completed questionnaires to your head of department.

If you have any queries, more information may be obtained from Darrel Moodley at telephone number (011) 488 4609. Any ethical queries or reporting of study-related adverse events should be made to the chairperson of the Wits Human Research Ethics Committee, Prof. P. Cleaton-Jones at 011 717 1234.

Thank you

Darrel Moodley

QUESTIONNAIRE

Please place a cross (X) for your selection in each question. Please note that you can only choose one option unless otherwise stated in the question.

1. Which field/DOMAIN of Occupational Therapy do you practice in?

Physical	Paediatrics	Psychiatry	Public Health	Other

If other, please explain: _____

2. What type/level of establishment are you currently working in?

Tertiary Hospital	Regional Hospital	District Hospital	Private Practice	Other

If other, please explain: _____

3. For how many years have you been practicing as an Occupational Therapist?

1	2-5	6-10	11-15	15-20	21-25	26+

4. Do you assess and/or treat clients with juvenile idiopathic arthritis (JIA) in your facility?

Yes	No	Not sure / Unknown

If YES, please continue with the questionnaire.

5. Approximately how many clients with JIA do you assess/treat on a monthly basis?

0	1-10	11-20	21-30	31-40	41-50	50+

6. Rank which age group the majority of your clients with JIA fall into from most to least by numbering 1-6.

   1 = Most common and 6 = least common.

0-12 months	12-24 months	2-4 years	5-7 years	8-11 years	11-18 years

7. At your facility, which gender is most common among clients with JIA?

Male	Female	Not sure / Unknown

8. Do you refer clients with JIA to other facilities/hospitals to receive specialised occupational therapy?

Yes	No	Not sure / Unknown

If yes, to which facilities and why? _____

_____

_____

_____

_____

9. Do you refer clients with JIA to any other multidisciplinary team members?

Yes	No	Not sure / Unknown

9.1 If yes, to which multidisciplinary team members/services do you refer?

Physiotherapy	Nursing	Social services	Other
Medical personnel (Doctors, Specialists)	Psychology	School liaison services	

If other, please explain: _____

_____

_____

10. What are the most common reasons for referral to occupational therapy for clients with JIA?

Please note you can select more than one option for this question

Splints	Learning disabilities	Functional exercises	Not sure / Unknown
Assistive Devices	Psycho- social problems	Educational Assessments	Other

If other, please explain: _____

_____

_____

_____

11. Do you practice as part of a multidisciplinary team in the treatment of JIA?

Yes	No	Not sure / Unknown

11.1 If No, describe the barriers preventing MDT work?

_____

_____

_____

_____

11.2 If yes, which disciplines are involved?

Physiotherapy	Nursing	Social services	Other
Medical personnel (Doctors, Specialists)	Psychology	School liaison services	

Please explain other: _____

_____

_____

_____

12. As part of a multidisciplinary team, do you feel that the role of the Occupational Therapist is established in the treatment of clients with JIA?

Yes	No

Please explain:_____

_____

_____

_____

13. Do you use any specific screening tools or assessments for these clients?

Yes	No

If yes, which screening tools or assessments do you use?

_____

_____

_____

14. What OT services do you currently offer clients with JIA within your facility?

- Splints:

Boutonniere splints	Swan neck splints
Ulnar drift splints	Wrist extension splints
Resting splints	Elbow protection splints
None	Other

If other, please explain:_____

_____

_____

_____

- Assistive Devices:

School aids	Personal management aids	Leisure aids	None	Other

Please list the assistive devices you most often provide:

_____

_____

_____

_____

- Pain Management:

Heat packs	Joint protection techniques	None	Other

If other, please explain: _____

_____

_____

_____

- Functional Exercise:

Joint range exercises	Muscle strengthening	Endurance	None	Other

Please list functional exercises you would most commonly use:

_____

_____

_____

_____

- Home Programmes related to the following:

Personal management	Education	Pain management	Joint protection	Social participation	Other
Family education	Play	Leisure	Functional exercise	None	

If other, please explain: _____

_____

_____

_____

_____

- OT services related to education:

School performance assessment	School adaptations	Other
School environment assessment	None	

If other, please explain:_____

_____

_____

_____

15. Which occupational performance areas is your main focus for these clients?

Personal management	Rest and sleep	Education	Other
Social participation	Play	Leisure	

If other, please explain:_____

_____

_____

_____

16. Do you think that the OT services currently offered to these clients are optimal to clients with JIA?

Yes	No

16.1 If Yes, please explain your answer:

_____

_____

_____

16.2 If NO, how do you think these OT services can be improved?

_____

_____

_____

17. Is there other treatment you would like to offer to clients with JIA?

_____

_____

_____

_____

_____

Thank you for your participation.

APPENDIX F

R14/49 Mr Darrel Dhaneshin Moodley

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140829

NAME: (Principal Investigator)	Mr Darrel Dhaneshin Moodley
DEPARTMENT:	Occupational Therapy CMJAH, CHBAH,RMH and Klerksdorp Hospital
PROJECT TITLE:	A Review of Occupational Therapy Services in South Africa for Children with Juvenile Idiopathic Arthritis
DATE CONSIDERED:	29/08/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Lizelle Jacobs
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	23/03/2015

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature _____ Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX G

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

OUTCOME OF PROVINCIAL PROTOCOL REVIEW COMMITTEE (PPRC)

Researcher's Name (Principal investigator)	Darrel Moodley
Organization / Institution	University of the Witwatersrand
Research Title	A review of the current Occupational Therapy management for clients with Juvenile Idiopathic Arthritis in five hospitals in South Africa
Protocol number	P010713
Date submitted	10/07/2013
Date reviewed	17/07/2013
Outcome	Approved
Date resubmitted	N/A
Date of second review	N/A
Final outcome	N/A
Date of final outcome	N/A

Provincial Protocol Review Committee (PPRC) comments:

- Recommended unconditionally.

It is a pleasure to inform that the Gauteng Health Department has approved your research (Protocol P010713).

Dr Bridget **Ikalafeng (PhD)**
PPRC: Chairperson

Date 26/07/2013

APPENDIX H

Phase 1 – CEO Consent - CMJAH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Mr. J. Maepa
Office of the Clinical Director
Tell: (011): 488-3365
Email:Johannes.maepa@gauteng.gov.za
10 April 2017

Dear Mr. Darrel D. Moodley

STUDY TITLE: Review of the current Occupational Therapy Management for Clients with Juvenile Idiopathic Arthritis in Five Hospitals in South Africa.

Permission is granted for you to conduct the above recruitment activities as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic Hospital will not anyway incur or inherit costs as result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

Please liaise with the HOD and Unit Manager or sister in charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Supported / not ~~supported~~

Dr. M.I. Mofokeng
Clinical Director
DATE: 11/04/2017

Approved/not approved

Ms G.J Bogoshi
Chief Executive Officer
Date: 12.04.2017

APPENDIX I

Phase 1 – CEO Consent – CHBAH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL
OCCUPATIONAL THERAPY DEPARTMENT

Tel: 011 933 8294 / 9054 **Fax**: 086 605 8212 **Email**: otbara@webmail.co.za

4 October 2013

Prof Jeenah

Re: Research in Occupational Therapy (OT) department by Darrel Moodley

Darrel Moodley is currently an MSc student at WITS University. He is requesting that permission be obtained to do research into the OT Management of patients with Juvenile Idiopathic Arthritis.

Permission has been granted by the HOD of OT, pending approval by the MAC.

Thank you.

Kind regards

Lynn Soulsby
Assistant Director
Occupational Therapy Department
CHBAH
011 933 8187
#6468

4/10/2013.

Approved/ not approved
Prof Jeenah
Head of Psychiatry Unit
CHBAH

Approved/ not approved
Dr Maseko
Deputy CEO
CHBAH

APPENDIX J

Phase 1 – CEO Consent – Klerksdorp/Tshepong Hospital Complex (KTHC)

health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

All correspondence to be directed to:
The Clinical Manager
Dr. David Leburu
K/T Hospital Complex
Private Bag A14
KLERKSDORP
2570

Tel: (018) 406 4740
Fax: (018) 462 1923
DLeburu@nwpg.gov.za
Enq: Sbooi@nwpg.gov.za

CLINICAL MANAGER'S OFFICE

24th May 2017

To : Mr. Darrel Moodley

Dear Sir/ Madam

RE : A REVIEW OF THE CURRENT OCCUPATIONAL THERAPY MANAGEMENT FOR CLIENTS WITH JUVENILE IDIOPATHIC ARTHRITIS IN FIVE HOSPITALS IN SOUTH AFRICA

Presenter – Mr. Darrel Moodley
Date – 15th August 2016

This letter serves to confirm that permission has been granted by K/T Hospital Complex Patient Safety Group (PSG) for a review of the current Occupational Therapy management for clients with Juvenile Idiopathic Arthritis in five hospitals in South Africa study in Klerksdorp/Tshepong Hospital Complex. The researcher is requested to submit regular study progress reports and final study report upon completion of the study.

Kind Regards

.....
Dr. N.D. Leburu
Clinical Manager
K/T Hospital Complex

APPENDIX K

Phase 1 – CEO Consent - RMMCH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

RAHIMA MOOSA MOTHER AND CHILD HOSPITAL
Enquiries: Mrs. S. Jordaan
Tel: (011) 470 – 9030/4
Fax: (011) 477 4117

UNIVERSITY OF THE WITWATERSRAND
Department of Occupational Therapy
JOHANNESBURG
2001

Re: "A review of the current Occupational Therapy management for client with Juvenile Idiopathic Arthritis in five hospitals in SA"

Dear Mr.Darrel Moodley,

Permission is granted for you to conduct the above survey as indicated in your request:

1. The Rahima Moosa hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study site.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.
5. NO file should leave the records department and/or the hospital premises.

Arrangement will be made with recordkeeping clerks so that you could occupy space in their department.

Kindly forward this office with the results of your research on completion of it.

I Darrel D Moodley accept the terms and conditions set-in this document

sign _____ date 29/09/2013

Yours sincerely,

CHIEF EXECUTIVE OFFICER
SJ/cj. 2013-09-18

ADDRESS: cnr. FUEL & OUDSTHOORN STREET CORONATIONVILLE 2093/PRIVATE BAG X20 NEWCLARE 2112

APPENDIX L

Phase 1 – HOD Consent – CMJAH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Dear Mrs Bogoshi

Re: Mr Darrel Moodley's research project (as part of his master's degree)

Mr Darrel Moodley is currently an occupational therapist employed at the Charlotte Maxeke Johannesburg Academic Hospital. He has requested permission to carry out his research at the hospital. I have read his research protocol. He has already obtained the ethical clearance certificate as well as the approval by Gauteng Health Department. Please see attached documents

The title of his project is – "A review of the current Occupational Therapy management for clients with Juvenile Idiopathic Arthritis in five hospitals in South Africa." This research is to look at the difference in services offered by both the public and private sector Occupational Therapists and to determine if there is adequate treatment and management being offered to children with rheumatic diseases. There has been little research in this area and I believe that this would be a worthwhile research. Mr Moodley's research require him to give a questionnaire for the occupational therapists here to fill in and then he will analyse the data.
As this is a quick and easy method which will not have any financial nor human resource implication on the department, I would like to support this research and to request that he should be given permission to carry out his research here.

Best regards

Veda Yip
Assistant Director
Occupational Therapy Department
Charlotte Maxeke Johannesburg Academic Hospital
011 488 4458
011 488 4609
082 447 9591
vedafrancoiseyip@yahoo.com

APPENDIX M

Phase 1 – HOD Consent – CHBAH

Permission letter to Head of Occupational Therapy Department

Department of Occupational Therapy
University of Witwatersrand
7 York Rd
Parktown
2193
(011) 717 – 3701

Dear Sir/Madam

I, Darrel Moodley, am currently an occupational therapy Master of Science student at the University of Witwatersrand. As part of my studies, I am required to compile a research report. The study will focus on the occupational therapy management for Juvenile Idiopathic Arthritis (JIA) in five hospital establishments in South Africa, namely: Charlotte Maxeke Johannesburg Academic Hospital, Chris Hani Baragwanath Hospital, Donald Gordon Hospital, Klerksdorp Hospital and RaheemaMoosa Mother and Child Hospital. I would be most grateful if your department would consider participating in this work.

Title of research project:
A review of the current Occupational Therapy management for clients with Juvenile Idiopathic Arthritis in five hospital establishments in South Africa.

Objectives of study:
This research aims to determine the current occupational therapy services available to JIA clients in both the private and public sector. The objective of the study is to identify and compare the current occupational therapy treatment interventions provided to these clients in both public and private hospitals. Occupational Therapists working in both government hospitals and private hospitals are encouraged to participate in this study, as there is often a discrepancy between services available to clients in these two different sectors.

Methodology:
The research will be conducted at five hospital facilities: Charlotte Maxeke Johannesburg Academic Hospital, Chris Hani Baragwanath Hospital, Donald Gordon Hospital, Klerksdorp Hospital and RaheemaMoosa Mother and Child Hospital. The occupational therapists working at these facilities will be approached to participate in the study. If the therapists agree to participate, they will be required to complete a self-administered questionnaire. This will take approximately 20 minutes. The questionnaire will gather the number of JIA clients seen by occupational therapists working within these facilities and review current

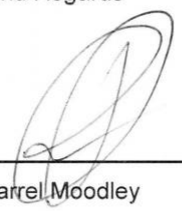
occupational therapy services available for these clients. The occupational therapists will remain anonymous throughout the research process and there will be no cost to be incurred by your department.

I am asking for permission to approach occupational therapists working in your department to be included in the research study.

If you have any queries, more information may be obtained from Darrel Moodley at telephone number (011) 488 4609.Any ethical queries or reporting of study-related adverse events should be made to the chairperson of the Wits Human Research Ethics Committee, Prof. P. Cleaton-Jones at 011 717 1234.

Thank you for your time.

Kind Regards



Darrel Moodley

Approved by: Lynn Saulsby.

Signature: 

APPENDIX N

Phase 1 – HOD Consent – KTHC

Permission letter to Head of Occupational Therapy Department

Department of Occupational Therapy
University of Witwatersrand
7 York Rd
Parktown
2193
(011) 717 – 3701

Dear Sir/Madam

I, Darrel Moodley, am currently an occupational therapy Master of Science student at the University of Witwatersrand. As part of my studies, I am required to compile a research report. The study will focus on the occupational therapy management for Juvenile Idiopathic Arthritis (JIA) in five hospital establishments in South Africa, namely: Charlotte Maxeke Johannesburg Academic Hospital, Chris Hani Baragwanath Hospital, Donald Gordon Hospital, Klerksdorp Hospital and Raheema Moosa Mother and Child Hospital. I would be most grateful if your department would consider participating in this work.

Title of research project:

A review of the current Occupational Therapy management for clients with Juvenile Idiopathic Arthritis in five hospital establishments in South Africa.

Objectives of study:

This research aims to determine the current occupational therapy services available to JIA clients in both the private and public sector. The objective of the study is to identify and compare the current occupational therapy treatment interventions provided to these clients in both public and private hospitals. Occupational Therapists working in both government hospitals and private hospitals are encouraged to participate in this study, as there is often a discrepancy between services available to clients in these two different sectors.

Methodology:

The research will be conducted at five hospital facilities: Charlotte Maxeke Johannesburg Academic Hospital, Chris Hani Baragwanath Hospital, Donald Gordon Hospital, Klerksdorp Hospital and Raheema Moosa Mother and Child Hospital. The occupational therapists working at these facilities will be approached to participate in the study. If the therapists agree to participate, they will be required to complete a self-administered questionnaire. This will take approximately 20 minutes. The questionnaire will gather the number of JIA clients seen by occupational therapists working within these facilities and review current

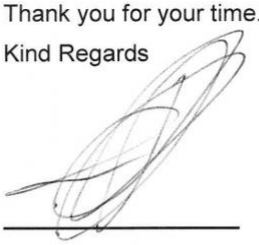
occupational therapy services available for these clients. The occupational therapists will remain anonymous throughout the research process and there will be no cost to be incurred by your department.

I am asking for permission to approach occupational therapists working in your department to be included in the research study.

If you have any queries, more information may be obtained from Darrel Moodley at telephone number (011) 488 4609.Any ethical queries or reporting of study-related adverse events should be made to the chairperson of the Wits Human Research Ethics Committee, Prof. P. Cleaton-Jones at 011 717 1234.

Thank you for your time.

Kind Regards



Darrel Moodley

Permission granted by:

Name: _____

Signature: _____



APPENDIX O

Phase 1 – HOD Consent - RMMCH

Permission letter to Head of Occupational Therapy Department

Department of Occupational Therapy
University of Witwatersrand
7 York Rd
Parktown
2193
(011) 717 – 3701

Dear Sir/Madam

I, Darrel Moodley, am currently an occupational therapy Master of Science student at the University of Witwatersrand. As part of my studies, I am required to compile a research report. The study will focus on the occupational therapy management for Juvenile Idiopathic Arthritis (JIA) in five hospital establishments in South Africa, namely: Charlotte Maxeke Johannesburg Academic Hospital, Chris Hani Baragwanath Hospital, Donald Gordon Hospital, Klerksdorp Hospital and Raheema Moosa Mother and Child Hospital. I would be most grateful if your department would consider participating in this work.

Title of research project:

A review of the current Occupational Therapy management for clients with Juvenile Idiopathic Arthritis in five hospital establishments in South Africa.

Objectives of study:

This research aims to determine the current occupational therapy services available to JIA clients in both the private and public sector. The objective of the study is to identify and compare the current occupational therapy treatment interventions provided to these clients in both public and private hospitals. Occupational Therapists working in both government hospitals and private hospitals are encouraged to participate in this study, as there is often a discrepancy between services available to clients in these two different sectors.

Methodology:

The research will be conducted at five hospital facilities: Charlotte Maxeke Johannesburg Academic Hospital, Chris Hani Baragwanath Hospital, Donald Gordon Hospital, Klerksdorp Hospital and Raheema Moosa Mother and Child Hospital. The occupational therapists working at these facilities will be approached to participate in the study. If the therapists agree to participate, they will be required to complete a self-administered questionnaire. This will take approximately 20 minutes. The questionnaire will gather the number of JIA clients seen by occupational therapists working within these facilities and review current

occupational therapy services available for these clients. The occupational therapists will remain anonymous throughout the research process and there will be no cost to be incurred by your department.

I am asking for permission to approach occupational therapists working in your department to be included in the research study.

If you have any queries, more information may be obtained from Darrel Moodley at telephone number (011) 488 4609.Any ethical queries or reporting of study-related adverse events should be made to the chairperson of the Wits Human Research Ethics Committee, Prof. P. Cleaton-Jones at 011 717 1234.

Thank you for your time.
Kind Regards

Darrel Moodley

Permission granted by:
Name: LORI SNOYMAN

Signature:

APPENDIX P

Phase 1 – Ethical Clearance – CHBAH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 28 October 2013

TITLE OF PROJECT: Review of the current occupational therapy management for clients with juvenile idiopathic arthritis in five hospitals in South Africa

UNIVERSITY: Witwatersrand

Principal Investigator: DD Moodley

Department: Occupational Therapy

Supervisor (If relevant):

Permission Head Department (where research conducted): Yes

Date of start of proposed study: October 2013
Date of completion of data collection: December 2014

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

.....
Recommended
(On behalf of the MAC)
Date: 28 October 2013

.....
Approved/Not Approved
Hospital Management
Date: 31/10/13

APPENDIX Q

Email Consent from JAMAR Author

Subject: R: Research Study
To: darrelmoodley@hotmail.co.uk; angeloravelli@ospedale-gaslini.ge.it
From: angeloravelli@ospedale-gaslini.ge.it
Date: Sun, 26 Jan 2014 10:05:20 +0000

Dear Darrel, thank you very much for your interest in our work. I'm certainly happy to grant you the full permission for the use the JAMAR for your research. Wish you the best of luck in your studies.
Kind regards,
Angelo

Angelo Ravelli, MD
Associate Professor of Pediatrics
Department of Pediatrics, University of Genova
Pediatria II-Reumatologia, Istituto G. Gaslini
EULAR Centre of Excellence in Rheumatology 2008-2013
Largo G. Gaslini, 5
16147 Genova, Italy
Tel.: +39-010-5636729
Fax: +39-010-5636211 or +39-010-393324
E-mail: angeloravelli@ospedale-gaslini.ge.it

APPENDIX R

Phase 2 – HOD Consent – CMJAH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Occupational Therapy Department
CMJAH
Private Bag x39
Parktown
Johannesburg

To: Mrs Gladys Bogoshi
CEO
CMJAH

15/1/2015

Dear Mrs Bogoshi

Mr Darrel Moodley (who is currently a production level 1 Occupational Therapist at CMJAH) would like to get your permission to carry out their research project at Charlotte Maxeke Johannesburg Academic Hospital. He is currently doing his masters degree and this research is part of his requirements. I have read through their research document and I do believe that the project would not cause any harm to the patients and therefore would like to support their request for permission. The title of their project is "A review of Occupational Therapy Services in the province of Gauteng on children with Juvenile Idiopathic Arthritis." This project is used to highlight what services are currently offered in the province. I hope that this will lead to a development of a standardize protocol for patient treatment.

Thank you for your understanding in this matter

Veda Yip
Assistant Director
Occupational Therapy Department
Charlotte Maxeke Johannesburg Academic Hospital
011 488 4458/4609
vedafrancoiseyip@yahoo.com

APPENDIX S

Phase 2 – CEO Consent – CMJAH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries: Mrs. Lefentse Mapaisa
Office of the Clinical Executives
Tel: (011)488-3710
Fax: (011)488-3947
23 January 2015

Mr. Darrel Moodley
Department of Occupational Therapy
University of the Witwatersrand

Dear Mr. Moodley

RE: **A Review of Occupational Therapy Services in South Africa for Children with Juvenile Idiopathic Arthritis**

Permission is granted for you to conduct the above recruitment activities as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Supported / ~~not supported~~

Dr. M.I. Mofokeng
Director: Clinical Services
DATE: 27/1/2015

Approved / not approved

Ms. G. Bogoshi
Chief Executive Officer
DATE: 28/01/2015

APPENDIX T

Phase 2 – HOD Consent – CHBAH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL
OCCUPATIONAL THERAPY DEPARTMENT
Tel: 011 933 8294 / 8187

20 January 2015

Prof Jeenah

Re: Research in Occupational Therapy (OT) department by MSc student

Mr Darrel Moodley is a student at the University of the Witwatersrand. He is currently doing his Master's in OT.

In 2013, he obtained permission from CHBAH to complete phase 1 of his research into the assessment of children with Juvenile Idiopathic Arthritis. His research involved Occupational Therapists completing a self-administered questionnaire. Please see the attached copy of the permission letter from MAC, dated 28 October 2013.

Mr Moodley is requesting permission to complete phase 2 of his research. This would involve administering the JAMAR standardized assessment on children with Juvenile Idiopathic Arthritis. The Medical Human Research Ethics Committee at WITS is requesting written approval from myself and the MAC at CHBAH, in order to issue a clearance certificate. Please see the attached memorandum, dated 19 September 2014, addressed to the CEO.

Permission has been granted by the HOD of OT, with the following conditions:

- The receipt of an ethical clearance certificate from WITS
- Approval obtained by the CHBAH MAC
- All conditions put forward by the WITS University ethics committee need to be fulfilled (see attached memorandum dated 19 September 2014)

Thank you.

Kind regards

Lynn Soulsby
Assistant Director
Occupational Therapy Department
CHBAH
011 933 8187
#6468

APPENDIX U

Phase 2 – Ethical Clearance – CHBAH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 30 January 2015

TITLE OF PROJECT: A review of occupational therapy services in the province of Gauteng for children with juvenile idiopathic arthritis

UNIVERSITY: Witwatersrand

Principal Investigator: D Moodley

Department: Occupational Therapy

Supervisor (If relevant):

Permission Head Department (where research conducted): Yes

Date of start of proposed study: Jan 2015
Date of completion of data collection: Dec 2017

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

.....
Recommended
(On behalf of the MAC)
Date: 30 January 2015

.....
Approved/Not Approved
Hospital Management
Date: 03/02/15

APPENDIX V

INFORMATION SHEET

A review of Occupational Therapy services in the province of Gauteng for children with Juvenile Idiopathic Arthritis

Good Day

I, Darrel Moodley, am currently an occupational therapy Master of Science student at the University of Witwatersrand. I will be completing a study that will focus on reviewing current occupational therapy assessment and services for children with Juvenile Idiopathic Arthritis (JIA) and determining the health outcomes of these children as compared to international literature. This study will be completed in two phases. In phase one, a questionnaire will be distributed to occupational therapists at the participating hospitals to determine current assessments and interventions for children with JIA. In phase two, the researcher will administer the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) clinical assessment at two specialised Rheumatic clinics as to compare the results obtained from international studies.

I am inviting you to participate in the study:

Why am I doing this?

Literature on the prevalence, intervention, and environmental causations for JIA in South Africa is limited in comparison to developed countries. This study aims to find current occupational therapy assessments and services available for children with JIA in public hospitals. The study will administer the JAMAR to a group of children with JIA that attend two rheumatic clinics as to compare the data obtained to international literature. The first phase of the study will be conducted through the

use of a questionnaire that will be distributed to occupational therapists working in the follow hospitals: Charlotte Maxeke Johannesburg Academic Hospital (CMJAH), Chris Hani Baragwanath Academic Hospital (CHBAH), Klerksdorp/Tshepong Hospital Complex (KTHC) and Rahima Moosa Mother and Child Hospital (RMMCH).

What is expected from the participants in the study?

You are kindly invited to take part in phase one of this research study by completing the questionnaire. Occupational Therapists working in the above-mentioned hospitals are encouraged to participate in this study, as to identify current assessments and interventions for JIA.

Are there benefits to the participants?

No. This research aims to increase the current literature on JIA in South Africa, through the review of current assessments and services available for children with JIA and comparing the results of the JAMAR test against available international literature.

The objective of the study:

- To determine the current occupational therapy assessments and services provided to children with JIA in specialised paediatric centres in four public hospitals in South Africa.
- To determine the outcomes for occupational performance and condition related factors of a South African sample of children with JIA using the JAMAR and to compare these outcomes reported in the international literature.

- To determine the match between patient-reported outcomes for occupational performance and condition related factors as given by parents and children with JIA using the JAMAR and current OT services provided.

All participants will have access to the results obtained from this questionnaire once the study has been completed upon request

May you withdraw from the study?

This study is completely voluntary, and completion of the questionnaire is the agreement of the participant to partake in the study. The participant can choose not to complete the questionnaire. Once the questionnaire is completed the participant will not be allowed to withdraw from the study.

What about confidentiality?

Confidentiality will be maintained, as all completed questionnaires will be placed in a sealed envelope.

If you have any queries, more information may be obtained from Darrel Moodley at telephone number (011) 488 4609. Any ethical queries or reporting of study-related adverse events should be made to the chairperson of the Wits Human Research Ethics Committee, Prof. P. Cleaton-Jones at 011 717 1234.

Thank you

_____

Darrel Moodley

BSC – Occupational Therapy

APPENDIX W

Parent/caregiver information sheet

A review of Occupational Therapy services in the province of Gauteng for children with Juvenile Idiopathic Arthritis

Good Day

I, Darrel Moodley, am currently an occupational therapy Master of Science student at the University of Witwatersrand. I will be completing a study that will focus on reviewing current occupational therapy assessment and services for children with Juvenile Idiopathic Arthritis (JIA) and determining the health outcomes of these children as compared to international literature. This study will be completed in two phases. In phase one, a questionnaire will be distributed to occupational therapists at the participating hospitals to determine current assessments and interventions for clients with JIA. In phase two, the researcher will administer the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) clinical assessment at two specialised Rheumatic clinics as to compare the results obtained from international studies.

I am inviting you to participate in the study:

Why am I doing this?

Literature on the prevalence, intervention, and environmental causations for JIA in South Africa is limited in comparison to developed countries. This study aims to find current occupational therapy assessments and services available for children with JIA in public hospitals. The study will administer the JAMAR to a group of children with JIA attended two rheumatic clinics as to compare the data obtained to international and current South African literature.

The study will be conducted through the use the JAMAR that will be implemented in the Rheumatic clinics of Charlotte Maxeke Johannesburg Academic Hospital and Chris Hani Baragwanath Hospital. This will be analysed children with JIA and compare the results obtained to international studies.

What is expected from the participants in the study?

You are kindly invited to take part in phase two of this research study by allowing the researcher to administer the JAMAR on children with JIA between the ages of 0-18 years. There are two versions of the test. Parents/caregivers of children with JIA can complete the parent version. Children between the ages of 7-18 years can complete the children's version independently. The questionnaire will take 20 minutes to complete.

Are there benefits to the participants?

No. This research aims to increase the current literature on JIA in South Africa, through the review of current assessments and services available for children with JIA and comparing the results of the JAMAR test against available international literature.

The objective of the study:

- To determine the current occupational therapy assessments and services provided to children with JIA in specialised paediatric centres in four public hospitals in South Africa.

- To determine the outcomes for occupational performance and condition related factors of a South African sample of children with JIA using the JAMAR and to compare these outcomes reported in the international literature.

- To determine the match between patient-reported outcomes for occupational performance and condition related factors as given by parents and children with JIA using the JAMAR and current OT services provided.

May you withdraw from the study?

The study is voluntary, and participants can choose not to partake in the study. Informed consent will be given to participants to ensure that they are aware of the particulars of the study.

What about confidentiality?

Confidentiality will be maintained, as all personal information will be coded into a database that the researcher and the researcher's supervisor will have access to view. In addition, no personal information shall be disclosed in the results.

If you have any queries, more information may be obtained from Darrel Moodley at telephone number (011) 488 4609. Any ethical queries or reporting of study-related adverse events should be made to the chairperson of the Wits Human Research Ethics Committee, Prof. P. Cleaton-Jones at 011 717 1234.

Thank you

_____

Darrel Moodley
BSC – Occupational Therapy

Informed Consent

I _____ (Childs' Name) agree to participate in the study **A review of Occupational Therapy services in the province of Gauteng for children with Juvenile Idiopathic Arthritis** and agree to allow my child of 7 years and above to participate as well.

Date: _____

Parent/Caregiver: Name: _____ Signature: _____

APPENDIX X

Child Verbal Assent

Hello (Client's Name)

My name is Darrel Moodley and I am here to see how well your joints are doing and what problems you are having at school and at home.

I will ask you some questions and show you some pictures to see how well you are doing. Is it all right, if I do this with you?

You can say no if you want to.

Assent from Child

Child's Name: _____ Child's Signature: _____

Witness: _____ Date: _____