CHAPTER 5:
DISCUSSION

This study considered the effect of home-based OT intervention in addition to the existing in and out-patient treatment for patients with RA on the immediate and sustained improvement in subjects’ occupational performance, by teaching patients self-management. The experimental group received an extended intervention in the form of focus groups and a home visit.

In reviewing the results of the OT intervention the subjects received, different measures and research designs are considered in relation to the assessment of functional ability, disease activity and health related quality of life. A review of the extended occupational therapy intervention and the effect on the experimental group is included. The findings after one week of intensive OT intervention and at final follow up are compared and the value of each measure used for this study discussed. Finally the subject’s evaluation of the OT programme is presented as well as the value of using both qualitative and quantitative research as both methods were used in this research project.

The HAQ-DI, SF 36 and DAS28 were chosen as quantitative outcome measures for the study to evaluate the subjects’ functional status and severity of their arthritis and provide a disability index score. Qualitative assessments were also completed to establish subject’s perspectives of their disease and the OT intervention.

Two groups of subjects, a control (n=22) and an experimental group (n=29) were randomly selected from the CHBH arthritis clinic. Their baseline scores according to the HAQ-DI, DAS28 and demographics were not significantly different (Table 3). The groups were comparable in relation to age, period of disease in years and moderate disease activity. Their functional ability as measured by the HAQ-DI reflecting a similar picture of moderate disability. The baseline characteristics of our study population are representative of patients with RA in the public health care sector, in South Africa.\textsuperscript{11,54,72}
5.1 OUTCOME MEASURES

5.1.1 Functional Ability
The measurement of the subjects' functional ability was carried out using the HAQ-DI and qualitative focus groups and interviews. These assessments were the most important measures used in the study as this is where the emphasis in terms of occupational performance is assessed. All subjects were admitted for intensive in-patient occupational therapy and having attended the same intervention, both groups showed a statistically significant improvement in their functional ability (Table 4 and 5) by the end of a one week in-patient rehabilitation programme.

A change of 0.48 points or more in the HAQ-DI scores reflect a significant improvement. One week of OT in this study resulted in an average change of 0.93 (p<0.0001) for the control group and 0.94 (p<0.0001) for the experimental group. All subjects thus improved from “moderate” to “mild” on the HAQ-DI scale. There was however no significant difference (p=0.55) in the HAQ-DI scores between the control and experimental groups at the end of the one week intervention.

The improvement found in this study is supported by other research that shows the improvement from an intensive occupational therapy programme occurs in the initial period. Various studies that have compared intensive in-patient treatment with home follow-up, to intensive out-patient treatment only, have shown the superiority of the first method of intervention. The increase in function attained by an in-patient programme in their opinion outweighs the cost 3 to 2.5. Helewa et al demonstrated that this three fold increase in efficacy gained in in-patient treatment with out-patient follow-up and home follow-up.

Home care programmes have also been studied and showed significant improvement in functional capacity. The evidence for this type of intervention is however limited as only two studies could be found, one done in 1966. Both do provide support for the use of a comprehensive OT intervention programme in improving functional ability and HR-QOL.
Qualitative approaches are particularly suited to access the insider’s view on the way experiences are given meaning with reference to the people’s cultural and social context. For this reason focus groups were offered to the experimental group one month after the initial inpatient treatment. The use of focus groups supported client-centred assessment that assumes clients know what they want in terms of their occupational performance. This assumption allows therapists to trust clients to identify the problems that interfere with optimum occupational performance. This also reflected the second assumption of the client-centred approach is that the only relevant frame of reference for therapy is that of the client and that the therapist must accept the client’s reports as the most relevant source of information.

Results established two themes related to subjects experience. The first related to “Behaviour and self management” and the second to “Problems identified that interfere with occupational performance”. Codes under the first theme included “improvement in function” which was identified as having the greatest impact, with a decrease in effects of disease. Further codes included “better self-management skills” and “task simplification”, “adjusting activities” and the “use of assistive devices”. The second theme related directly to the practical application of new methods learnt and used for activities in the various rooms of the home and personal management task. The third assumption of the client-centred approach that the most valuable role for the therapist is to support the client through the changes he or she wishes to make, with information, ideas, suggestions, resources, and trust in his or her ability to succeed in making the desired change was reinforced by this aspect.

These codes also reflect directly the desired outcomes of OT intervention in facilitating occupational performance and decreasing the consequences of RA in ADL. It further confirms the efficacy of comprehensive intensive in-patient OT for patients with RA in improving functional ability.

Positive family support was reported by 69% of subjects in the experimental group. For RA patients, who often are dependant to some extent on spouses, partners or close relatives for the fulfilment of daily tasks, developing adequate self-
management behaviour is a process that involves social interaction. The perceptions of the patient’s spouse or significant other of the patient’s capacities to cope with the consequences of the disease may be an important factor in the process. The active participation of family members in education programmes can influence their opinions of the patient’s capabilities positively and provide ongoing support for continued self-management behaviour.

The subjects in this study were reassessed 20 weeks (± 1 week) after discharge from their one week of intensive OT rehabilitation. The experimental group had received both a focus group and a home visit intervention in this time. The follow-up shows that the improvement in the functional status, reflected in the HAQ-DI scores between the experimental and control groups were again not significantly different (p=0.67). The significant improvement gained from the one week intervention within both groups was however maintained by both groups. The experimental group maintained the improvement slightly better with a total of 64% compared to the 58% for the control group (Table 11).

There is conflicting evidence regarding the duration benefit after intensive intervention for patients with active RA. An in-patient treatment regimen of 13.6 days on average, led to a significant improvement in “quality of well being” for up to 12 months. The disease activity (Ritchie Scale) and disability index (HAQ-DI) did not maintain the significant improvement after admission for the same period. Helewa et al demonstrated a sustained three fold increase in efficacy with outpatient follow-up and home follow-up, after in-patient rehabilitation. The effect was best maintained up to 35 weeks. The average admission period per patients was approximately three times longer than the one week admission in this study. Our patients also had less regular doctor and OT follow-ups.

The descriptive data recorded during the home visits to experimental groups included the resources within the subject’s home environment. It was found that even though the subject’s were living in under resourced areas they all had access to electricity, running water and a toilet. Other labour saving devices like microwave ovens and vacuum cleaners were rarely found (Table 20). It can be concluded that the subjects in this study have little access to the type of electric...
and electronic appliances that could assist with home maintenance and reduce repetitive and forceful movements used in caring for themselves, their homes and their families.

As resources to improve functional ability were limited, the subjects were happy to use assistive devices for the practical value and purpose it offered. The devices issued most commonly were extended sponges and tap turners. This is because all subjects made them during their in-patient rehabilitation. The second most useful and commonly used were non-slip surface mats and built up handles. A total of 144 assistive devices were issued to the experimental group. Area, tool and task adjustments in most homes were carried out to improve energy conservation, protect joints and increase energy saving and safety for the subjects. These further contributed to the subject’s functional ability in ADL, as they were within their present environment and were cost effective. Patients with low SES have worse health outcomes than patients with high SES. The reality of implementing this type of approach is that it is suitable for this population group as they have no/limited access to structural and technical environmental changes. The current health care system can provide patients with limited AD, as issued during this study. Government health funding can however also not supply structural and technical environmental changes.

It would appear that the major effect on occupational performance of the subjects was as a result of the intensive one week OT intervention and that the added intervention of focus groups and home visits had little effect on the actual functional status of the subjects. Considering the average disease duration was in excess of 12 years for both groups (Table 3), one can expect some level of disability to persist. The maintained improvement in both groups over a period of four months and the initial significant improvement perhaps justify the cost of a week of in-patient treatment. In-patient care is both more efficacious and more costly than an out-patient treatment programme. For the expenditure on intensive in-patient intervention to be economically and clinically worthwhile it is crucial that benefits are maintained for as long as possible. Our study population did maintain their improvement for up to four months. It can be considered a limitation of the study that we did not include further follow-up to establish the
sustainability of the effects of this programme. Maybe another follow-up at eight
and 12 months would have provided better information on that.

The slightly bigger improvement in the experimental group may be a reflection of
the added OT groups and home visits resulting in customisation and further
reinforcement of the joint protection techniques. Although there was no statistically
significant difference between the groups an added improvement in the
experimental group can be seen as a clinical difference with 25% fewer tender
joints. This is supported by the findings of Warsi et al that suggests arthritis self-
management education programmes lead to small but significant added reductions
in pain and disability. It is generally assumed that these programmes are a highly
effective and relatively inexpensive way of providing patients with tools to better
manage their arthritis. Our subjects did not perceive the focus groups in
themselves to have been the extremely helpful. The combination of a focus group
with the follow-up home intervention however was perceived as making an
important contribution. This can still be considered a relatively inexpensive way of
providing client-centred intervention.

From the above it is clear that in terms of functional ability both the experimental
and control groups showed a significant trend of improvement after the intensive
OT intervention at final follow-up, and that the difference in change over time was
never significantly different between the two groups (p=0.37) (Table 10). In hind
sight a third group should have been included, who just followed the normal OT
programme and did not receive the intensive OT programme. Monitoring their
functional disability might have added valuable information to the study.

As in other studies, as in this one, it has been found that the HAQ-DI is a valuable,
effective and sensitive tool for measurement of functional disability in RA that
correlates well with duration of the disease rather than age related loss of function
43. The use of this tool also allowed for the comparison of results to previous
research 3. It has allowed us to compare our study results with various other OT
studies 12 – 23, 75. Although the value of using the HAQ-DI in measuring
occupational performance has been described 47, combining the outcome measure
with OT specific occupational performance measure ⁶⁹, might have been more sensitive to change.

### 5.1.2 Disease Activity

In order to establish whether the improvement found in the functional ability of the subject’s related to the number of joints affected by their disease and related pain, the level of disease activity was measured using the DAS28. Both groups had a significant improvement from baseline to final follow-up with the experimental group having an improvement of 23% (p=0.0001) when compared to the control groups change of 15% (p=0.03). The level of disease activity did however remain “moderate” for both groups and thus the significant change seen is within the moderate level of the disease activity ⁵⁶.

Since both groups’ subjects continued to receive their normal medical care, the change in the DAS28 cannot only be accounted for by that. Accepting the limitations of what an OT intervention programme can contribute to decreased disease activity, one can argue that the increased awareness of how to look after their joints, use assistive devices and self-manage the disease emphasised in the OT intervention contributed to less painful joints, thus the lower scores on the 28 tender joint count DAS28. This is even more evident in the experimental group who had additional treatment that lead to significantly fewer tender joints than in the control group.

The study by Nunez et al who found that a therapeutic education and functional re-adaptation (TEFR) programme which combined individual and group treatment sessions plus pharmacological therapy significantly improved disability (measured by the HAQ) and disease activity, with respect to baseline, also reflects similar findings ²⁷.

It is however clear that the great gain achieved by the OT intervention in this study was in the area of functional ability where the DI moved from moderate to mild. This indicates that patients can have mild disability in the presence of moderate disease activity.
As reported in the literature the measurement of disease activity is used to assess change over time as an effect of treatment. It is a clinical index of disease activity that combines information from swollen joints, tender joints, the acute phase response and general health. It has been extensively validated and is used both in RA clinical trials and for monitoring individual RA patients. The DAS28 with 3 variables was used because it has been proposed that in established RA (our subjects had an average disease duration of 12.05 and 12.85 years respectively), it is better to use the DAS index with 3 variables as global health or patient global assessment of disease activity can be considered in relation to mixed variables that combine the effects of the disease process and damage. This scale was found to be effective in this study and sensitive to changes in the subject’s disease activity and is important to the occupational therapist as it allows her to monitor joint damage and customise joint protection programmes and adapt the environment especially to the needs of the patients with RA.

5.1.3 Health Related Quality of Life

The SF 36 was the health related quality of life measurement used after the one week of intensive OT intervention. Findings showed that the two groups differed significantly in three of the eight categories: Physical Functioning (PF), Role Physical (RP) and Role Emotional (RE). The control group scored very poorly with 9.09 for RP and 4.55 for RE (scale 1 – 100). The result of RP in the control group is not supported by their DAS28 scores that indicated moderate disease activity and the mild HAQ-DI scores they had reported at this time.

The control group (who had no intervention after discharge from the one week intensive OT intervention) showed significant improvement in five of the eight categories: Physical Functioning (PF), Role Physical (RP), Role Emotional (RE), Social Functioning (SF), and Mental Health (MH) at the 20 week (± 1 week) follow up. The experimental group showed only slight improvement in six of the eight categories, at this final follow-up. The ANCOVA however showed that the change over time at the end of the follow up period between the two groups was not statistically different.
It can be argued that with the very low RP and RE scores in the control group at baseline, there was a lot of room for improvement thus leading to significant changes in these areas. This does however not account for the significant improvement in PF, SF, and MH seen in the control group but not in the experimental group.

A possible explanation may be that as the experimental group knew they were coming back for a focus group in a month’s time, they would have the opportunity to discuss their problems and progress. They also knew they were to receive further support resulting in a more positive evaluation of their quality of life in the initial assessment. The control group however only received further attention after 20 weeks and although their initial view of their quality of life was significantly less in the physical and emotional areas, they had time to implement the knowledge and skills they learned in OT which resulted in the development self-efficacy. In studies based on the self-efficacy approach which considered both the short and long term effects, Taal noted that self-efficacy in subjects is related to their perceptions of their health status.

The improvement in self efficacy in this study population appears to have led to a perceived improvement in their quality of life which extended to social and mental health aspects as well. Change occurred more slowly in the control group but over a 20 week period they caught up with the experimental group. One can argue therefore that the additional OT intervention of focus groups offered to the experimental group had the effect of speeding up the group’s self-efficacy and their positive perception of their quality of life.

A further limitation of the study was that the SF 36 was not administered at baseline. Considering that the subjects had undergone one week intensive OT intervention already at the first assessment, a baseline assessment could have helped to clarify the results found in the study.

The SF 36 is a generic instrument and has been reviewed in over a hundred publications. It has been extensively researched and standardised in over ten countries in order to make cross country comparisons is available. A local study
noted that the SF 20 domains, PF and GH have a high degree of internal consistency and reliability in SA population and that there is a high correlation between the HAQ-DI and SF 36 sub-scales that indicates high content/construct validity in the SF 36\textsuperscript{54}. The inclusion of physical and mental components in the SF-36 compliments to the holistic approach used in OT.

The results of the SF 36 for both groups over time in this study were not consistent with the results from the HAQ-DI and DAS28. We found the SF-36 to be a very difficult and not a user friendly tool to administer and score. Financially the scoring software is very expensive and probably not the best choice for a resource poor setting. Another generic health related QOL tool, e.g. the World Health Organization QOL questionnaire (WHOQOL) that is readily available might be a better tool.

5.2 SUBJECT’S EVALUATION OCCUPATIONAL THERAPY INTERVENTION

The programme was based on the OT’s management of RA where the patients’ participation in their everyday activities is the focus of attention. When the body functions and structures are impaired for whatever reason, activity participation or OP will be interrupted\textsuperscript{35}. It is this interruption of OP that is the prime concern, as well as the impact that a dysfunction has on a person, rather than the dysfunction itself. When OP has been limited by dysfunction and the OT considers that intervention to restore adaptive skills is not feasible, she/he may feel that the most appropriate method of restoring the performance is through adaptation not of the person’s skills but the way in which the activity is performed\textsuperscript{58}. In the extended intervention self-management was highlighted using a client centred approach by problem solving within the focus groups and the home environments\textsuperscript{20, 29, 44, 68}.

Evaluation of the role and range of OT intervention by the experimental group indicated that subjects did not perceive the additional focus group to have been very important as a contributing factor to their improvement (4%). The information gathered during the focus groups did however lead to the changes suggested to improve function at the home visit, which was perceived as important by 38% of the experimental group. During the focus groups positive themes on behaviour
and self-management emerged and the subjects in these groups indicated that there was a decrease in effects of the disease (67%), they had improved function (75%), were using task simplification (63%) and assistive devices (50%) and were adjusting difficult activities (60%).

At final follow-up all subjects in the study felt that the intervention helped them cope better with their condition. Both groups evaluated daily exercise as the biggest contributor to their improvement (75% - experimental group, 82% - control group) with 100% of the experimental group and 90% of the control group still performing exercise at three times per week (Table 22).

Why did both groups score the daily exercise as most important? Patients commented that following the exercise programme as taught during their hospital stay, made them feel more mobile “I can get up and walk without having to hold on to furniture all the way”, less stiff “The stiffness is better after exercising in the morning” and sore “My pain is better, I can even cook porridge again”. They also felt they had more energy to get through the day “Now I can do my washing all in one day”. As exercise is a very concrete part of the intervention with an immediate effect and the other components of the intervention are more behavioural and it takes time to produce an effect. This information leads the researcher to believe that daily exercise is indeed a very important component in the comprehensive OT treatment.

The home visit was indicated by 38% of the experimental group as being the second most important aspect in helping them. As the control group had fewer options, they rated their admission and hospital stay as second biggest contributor to their improvement - 36% as opposed to the 21% for the experimental group. The issuing and use AD was allocated third place by both groups (33% experimental and 18% control) although the control group was exposed to much less assistive devices than the experimental group. Other issues like the issuing and use assistive devices, joint protection and learning about the condition were all considered less important by the control group indicating that the reinforcement of these concepts in the focus groups and home visits consolidated the application of these aspects and their effects in the subjects in the experimental group.
5.3 RESEARCH DESIGN

The intervention programme aimed to improve the occupational performance of patients with RA, by using a comprehensive OT approach with qualitative and quantitative measures. Patients were educated on their disease, taught joint protection, energy saving principles and how to exercise. Splints were made and assistive devices issued. The programme involved active learning opportunities and both group and individual treatment sessions for both the control and experimental groups. This programme supports the silver standard of Occupational Therapy treatment as supported by evidence based practice in the Cochrane review.Various studies using a quantitative approach have failed to prove a change in functional status but indicate a positive change in HR-QOL or attitude of the patient. Others were able to prove great differences in functional status by only using this approach. The use of a pure quantitative approach led Furst et al to observe no changes in functional status. They concluded that the changes were too subtle and was not reflected in the assessment tool. This conclusion could have been different if a qualitative approach was included. In this study the use of both a quantitative and qualitative design allowed for the initial change in functional ability to be clearly demonstrated as well as the more subtle changes in self-efficacy and internalisation of the various techniques taught in the extended OT intervention to be recognised.

The combination of qualitative and quantitative approaches used in this study appears to have provided positive results with descriptive data confirming and explaining the changes observed. Subjects’ reporting of their own perceptions of functional improvement help to direct the OT programme in a much more client centred way than the standardised tests do. Taal et al reported that programmes that consist only of lectures or discussions that do not include behavioural methods, are ineffective in improving physical health. It appears that changes in health outcomes are not mediated by behavioural changes only, but also by cognitive factors and self-efficacy.
The context of this study in a lower socioeconomic group of subjects meant they have limited resources to adapt their environments, so customised tailor made intervention is very important, using what is within the existing environment.

The positive change in self-efficacy observed in both the control and the experimental groups indicate that the one week intensive OT programme without focus groups and home based intervention is effective. The fact that the experimental group achieved an improved quality of life score sooner (SF 36 scores) and understood the value of other techniques taught to them justifies the use of qualitative intervention methods.

Qualitative approaches are particularly suited to access the insider’s view of his or her social world because their prime focus is on the way experiences are given meaning with reference to the people’s cultural and social context. They help understand the experience of living with specific musculoskeletal conditions of RA and chronic pain. Qualitative methods have also been employed to provide context and depth to epidemiological surveys. The contribution to qualitative approaches to musculoskeletal research is wide-ranging: in-depth studies have brought to the surface the complex experiences of living with pain and disability, and thus allow an understanding of how these are shaped by people’s social and cultural context.

Only one study reviewed used only qualitative approach. Dubouloz et al demonstrated the transformation of meaning perspectives, learning process and growth in their study.

There is a growing recognition that assessing an intervention’s effect should not only focus on the statistical significance of the differences in health outcome between the experimental care and control group, but should also focus on the relevance or importance of these outcomes.

Interplay between quantitative and qualitative research approaches appears to have greater success. Ong et al suggest that the therapeutic processes that can
lead to agreed outcomes, also demonstrate that a discordant relationship can still deliver effective intervention.

5.4 SUMMARY

In this study the effectiveness of OT in terms of a programme based on the silver standard according to evidence based practice was instituted for a group of subjects attending RA clinic at CHBH. A one week initial in-patient OT intervention using these guidelines showed a significant difference in the subject’s functional ability as assessed using quantitative measures. This intervention aimed to control disease and disability and improve occupational performance by teaching the subject’s self management and adapted techniques.

An extended intervention in terms of a focus group and a home visit was offered to the experimental group. This was to offer a client centred approach in addressing the subjects individual needs in terms of their functional ability and occupational performance. The need for an overall approach that looked at the individual as well in their environmental context was very important. Including qualitative data ensured that patients’ perception of what helped them the most was addressed and these interventions were measured using both quantitative and qualitative methods.

At the final follow-up both groups had maintained the improvement in both their functional ability and their DI. It appears as though the focus groups and home visits had a subtle effect on the experimental group which was not reflected in the quantitative tests but was found in their higher evaluation of all the various OT techniques covered in their intervention, in improving their condition. The experimental group may be applying these techniques more effectively as is evidenced in the decrease in the number of tender joints when compared to the control group. These clinical important changes indicate the value of future client centred support after an initial intervention.

The HR-QOL scores obtained for both groups after the initial one week intervention was lower for the control group who were not to receive further OT
intervention. The self efficacy of the experimental group appears to have improved by the anticipation of further individual support in terms of the proposed extended intervention planned for them. The control group's HR-QOL scores improved over the 20 weeks, when they had a chance to try out and use what was taught in the OT intervention.

In this study both improvements in functional ability and the disability index as well as QOL was maintained over a 20 week period for both groups, indicating that OT intervention has an effect not only on functional ability (HAQ-DI) and disease activity (DAS28) but in HR-QOL as well. Although the greatest improvement was seen in functional ability, where the subjects rating changed from moderate to mild, all three of these factors play a role in improving the subject's involvement in their occupational performance, and are important to consider in OT intervention. In this study this improvement was achieved in the context of the environment and resources available to the subjects living in Soweto. Research has shown that the quality of life improvement lasts longer than the functional improvements\textsuperscript{15,62}. This study's participant's maintained their improvement in Disability Index as well as QOL over 20 weeks.