

# **A COMPARISON OF HOSPITAL-BASED AND COMMUNITY BASED MODELS OF CEREBRAL PALSY REHABILITATION**

by

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## Declaration

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## Dedication

I dedicate this project to all children with Cerebral Palsy and their caregivers.

## Abstract

**Purpose:** Cerebral palsy is a disabling and permanent condition which requires sustained rehabilitation over a long period of time. There is much debate as to which model of service delivery is most appropriate for children with cerebral palsy and their mothers. The aim of this study was to compare the efficacy and effectiveness of two models of service delivery currently offered in Harare, Zimbabwe. One of these is a hospital-based and the other a community-based service.

**Method:** A quasi-experimental study was done to determine the efficacy of two service delivery models from the perspective of caregivers and functional gains in children. Questionnaires were distributed to caregivers of children with CP at baseline and after three months. The caregivers were 46 in total, with twenty caregivers having children receiving rehabilitation services under an outreach program and 26 receiving services as outpatients at a central hospital. The caregivers' health-related quality of life was assessed using the EQ-5D, the burden of care was measured using the Caregiver Strain Index, satisfaction with physiotherapy was assessed using the modified Medrisk satisfaction with physiotherapy services questionnaire and compliance was measured as an index of the met appointments from the scheduled appointments. Additionally, motor functional changes in children with CP were assessed at baseline and after three months using the Gross Motor Function Measurement (GMFM-88).

**Results:** Children receiving community based treatment children were significantly older than children in the hospital based group. However, the two groups were comparable in terms of socio-demographics of both children and caregivers at baseline. The correlation between age and change in score was tested and found to be non-significant ( $r = -.103$ ,  $p = .497$ ). Spearman's rho indicated that as the level of severity increased in terms of GMFCS level, so the amount of improvement decreased ( $\rho = -.568$ ,  $p < .000$ ). However, as age was significantly different between the two groups and there were more severely affected children in the community based treatment group, regression analysis was done to establish which factors predicted the amount of change in the GMFM Score. Dummy variables were created for the categorical variable of the group and the ordinal variable of GMFCS was dichotomised into level 3 and above and level 4 and below. The resulting model accounted for 25% of the variance (adjusted  $R^2 = .25$ ) after the score of one child was removed after residual analysis indicated that he/she had improved more than two standard deviations from the mean residual. The results indicate that, once age and category were controlled for, children in the community based treatment group improved 3.5 points more than children receiving hospital based services. Children who were more severely disabled showed 4.7 points less improvement, and for each month of age, children showed .04 less improvement, although this was not significant.

Additionally, changes in GMFM-88 scores were negatively and significantly co-related to level of severity,  $r=-0.57$ ,  $p<0.05$ .

Most of the caregivers experienced a high burden of care as 51% ( $n=23$ ) of the caregivers had scores greater or equal to seven. Seven is a cut-off point for clinical distress/depression. Furthermore, a greater portion of caregivers expressed that they were overwhelmed by caregiving role and this increased with the chronicity of care. Financial burden of caregiver was predictive of caregiver strain, and this was universal across the treatment models.

The two groups of caregivers were comparable in their HRQoL as there were no statistically significant differences in EQ-5D scores, at baseline and after three months. Further, most of the caregivers reported that they suffered from pain/discomfort and anxiety/depression, which increased with chronicity of care.

Caregivers in the community based treatment group seemed to be more satisfied with services and were more compliant ( $p<.001$ ) as compared to recipients of hospital based services. Statistically significant differences were in the following domains: time therapist spends with child ( $p<.001$ ), amount of explanations ( $p=.028$ ), empathy given by therapists ( $p<.001$ ), level of answering of questions by therapists ( $p<.001$ ) and overall satisfaction ( $p=.038$ ). The higher child to therapist ratio may serve to explain the lower satisfaction rating in the hospital based group. Further, caregivers were appreciative of the health promotional talks, and they also expressed the need for improvement in the waiting area and booking schedule.

**Conclusion:** Long term caregiving leads to strain in caregivers and there is a need to design tailor-made interventions to alleviate the burden on caregivers as it may ultimately affect the child's functional prognosis and health outcomes. Findings from this study seem to suggest that the provision of care within a community setting is preferable in that it was associated with a greater improvement in functioning, greater satisfaction with services and better compliance. In addition, care-givers continued to bring in older children for therapy, which was encouraging. It is therefore suggested that this is the preferred method of service delivery. Further research is needed however, to cost the methods of service delivery in order to determine the feasibility cost of transferring the management of children with CP from institutions to the community.

## List of Abbreviations

- ADL – activities of daily living
- AIDS – acquired immunodeficiency syndrome
- ANOVA – analysis of variance
- APDK – Association for the Disabled of Kenya
- CBR – community based rehabilitation
- CCH – Chitungwiza Central Hospital
- CP –cerebral palsy
- CRU – Children Rehabilitation Unit
- CSI – Caregiver Strain Index
- CWDs- children with disabilities
- DVD – digital video disc
- GHQ- general health questionnaire
- GMFCS – Gross Motor Classification System
- GMFM – Gross Motor Function Measure
- HCH – Harare Central Hospital
- HEP – home exercise program
- HIV- Human immunodeficiency virus
- HRQoL – Health related Quality of Life
- IBR – institution based rehabilitation
- ICF – International Classification of Functioning, Disability and Health
- ILO – International Labour Organization
- LBP – low back pain
- MCS – Mental Component Summary
- MOHCWZ – Ministry of Health and Child Welfare Zimbabwe
- MSD – musculoskeletal disorders
- NDT – neurodevelopmental theory
- NECG – non-equivalent control group
- OP – outreach program
- OT – Occupational Therapist
- PCS – Physical Component Summary
- PEDI – Paediatric Evaluation of Disability Inventory
- PODCI – Paediatric Outcomes Data Collection Instrument

- PT – Physiotherapist
- PWDs – people with disabilities
- QOL – Quality of Life
- RCT – random controlled trial
- RT – Rehabilitation Technician
- SCI – spinal cord injuries
- SD – standard deviation
- SES – socio-economic status
- SF-36 – Short Form Health Survey
- SIRAS – Sports Injury Rehabilitation Adherence Scale
- SPSS – Statistical Package for Social Sciences
- TB – tuberculosis
- UK – United Kingdom
- UNDP – United Nations Development Programme
- UNESCO - United Nations Educational, Scientific and Cultural Organization
- USA – United States of America
- VAS – visual analogue scale
- WeeFIM - Paediatric Functional Independence Measure
- WHO – World Health Organization
- WHOQOL-BREF - World Health Organization Quality of Life Instruments

# Table of Contents

Declaration.....	i
Acknowledgements.....	ii
Dedication.....	iii
Abstract.....	iv
List of Abbreviations .....	vi
Table of Contents.....	viii
List of Tables .....	xiv
List of Figures .....	xv
Operational definitions.....	<b>Error! Bookmark not defined.</b>
1 INTRODUCTION.....	1
1.1 Background .....	1
1.2 Rationale .....	2
1.3 Aim .....	3
1.4 Objectives.....	3
1.5 Justification and significance .....	3
2 LITERATURE REVIEW .....	5
2.1 Introduction and definitions .....	5
2.1.1 Incidence.....	5
2.1.2 Aetiology.....	6
2.1.3 Associated impairments.....	6
2.1.4 Diagnosis .....	7
2.1.5 Classification .....	7
2.1.6 Prognosis.....	8
2.1.7 Management.....	8
2.2 The burden of caregiving .....	11
2.2.1 Introduction .....	11
2.2.2 Definition of burden of care.....	11
2.2.3 The burden of caregiving a child with CP.....	12
2.3 Health-related quality of life (HRQoL) of caregivers.....	17
2.3.1 Definition of HRQoL .....	17

2.3.2	Factors influencing HRQoL of caregivers .....	17
2.3.3	Ways of enhancing HRQoL and decreasing the burden of care .....	18
2.4	Satisfaction with rehabilitation services .....	22
2.4.1	Defining patient satisfaction .....	22
2.4.2	Satisfaction with physiotherapy services.....	22
2.4.3	Factors affecting satisfaction .....	22
2.4.4	Surveys on satisfaction with physiotherapy services.....	24
2.4.5	Ways of enhancing satisfaction .....	25
2.5	Compliance with rehabilitation services.....	26
2.5.1	Definition of compliance .....	26
2.5.2	Compliance rates of physiotherapy treatment.....	26
2.5.3	Factors influencing compliance .....	27
2.5.4	Effects of non-compliance .....	28
2.5.5	Barriers to compliance .....	29
2.5.6	Ways of enhancing compliance .....	30
2.6	Models of service delivery .....	33
2.6.1	Introduction .....	33
2.6.2	Outreach based rehabilitation .....	33
2.6.3	Types of outreach programs .....	34
2.6.4	Principles of outreach programs.....	34
2.6.5	Efficacy of outreach programs .....	35
2.6.6	Sustainability of outreach programs.....	37
2.6.7	Community based rehabilitation .....	37
2.6.8	Institution based rehabilitation (IBR).....	39
2.7	Description of services.....	40
2.7.1	The Children Rehabilitation Unit Rehabilitation Services .....	40
2.8	Review of data collection tools/instrumentation .....	42
2.8.1	Introduction .....	42
2.8.2	Tools for measuring physical activity/ motor function .....	42
2.8.3	Tools for measuring the burden of caregiving.....	43
2.8.4	Tools for measuring Health-Related Quality of Life.....	43
2.8.5	Tools for measuring patient satisfaction with service provision .....	45
2.8.6	Tools/ methods of measuring compliance.....	45
2.9	Conclusion of literature review.....	47

3	METHODOLOGY .....	48
3.1	Introduction .....	48
3.2	Research Setting .....	48
3.2.1	Description of the research settings .....	48
3.2.2	Description of services offered in the research settings .....	48
3.2.3	Mabvuku Outreach group.....	48
3.2.4	Outline of Chitungwiza Central Hospital Rehabilitation Services .....	49
3.3	Study design.....	50
3.3.1	Rationale for the study design .....	50
3.4	Study population/ participants .....	51
3.4.1	Inclusion criteria.....	51
3.4.2	Exclusion criteria .....	52
3.4.3	Sample size calculation .....	52
3.4.4	Recruitment and sampling method .....	52
3.4.5	Research personnel.....	53
3.5	Data collection tools/instrumentation .....	53
3.5.1	The GMFM-88 .....	53
3.5.2	Rationale for the use of GMFM-88 .....	54
3.5.3	Caregiver strain index (CSI) .....	54
3.5.4	Rationale for the use of the CSI .....	54
3.5.5	The EQ-5D .....	55
3.5.6	Rationale for the use of the EQ-5D.....	55
3.5.7	MedRisk Instrument for Measuring Patient Satisfaction with Physical Therapy Care (MRPS) 56	
3.5.8	Rationale for use of the MRPS .....	56
3.5.9	Rationale for the selection of the attendance index for measuring compliance in this study 57	
3.5.10	Self-designed data sheet.....	57
3.6	Procedure.....	57
3.6.1	Ethical approval.....	57
3.6.2	Pilot study .....	58
3.6.3	Procedure for the main study .....	59
3.7	Data Management .....	61
3.8	Statistical Analysis.....	61

3.9	Ethical considerations .....	62
3.9.1	Introduction .....	62
3.9.2	Autonomy.....	62
3.9.3	Confidentiality.....	63
3.9.4	Beneficence.....	63
3.9.5	Justice.....	63
4	RESULTS.....	65
4.1	Introduction .....	65
4.2	Overview flow chart for the study .....	66
4.3	Demographic characteristics of the sample .....	68
4.3.1	Gender of the children .....	69
4.3.2	Age of the children.....	69
4.3.3	CP type .....	70
4.3.4	GMFCS levels for children with CP .....	70
4.3.5	Caregiver s' age .....	70
4.3.6	Caregiver relationship status with child.....	71
4.3.7	Caregivers' educational status .....	71
4.3.8	Caregivers' employment status .....	71
4.3.9	Summary of demographic characteristics of the sample .....	71
4.4	Gross motor function scores of children with CP .....	72
4.4.1	Changes in GMFM-88 scores over three months, within groups .....	72
4.4.2	Changes in GMFM-88 scores across groups .....	73
4.4.3	Factors affecting GMFM-88 scores .....	74
4.4.4	Summary of GMFM-88 scores .....	74
4.5	Comparison of the treatment (therapy) sessions.....	75
4.5.1	Summary of treatment sessions details for the duration of the study.....	75
4.6	CSI scores .....	76
4.6.1	Comparison of caregiver's CSI scores at baseline and at three months.....	76
4.6.2	Comparison of caregiver's CSI scores ranges at baseline and at three months .....	77
4.6.3	Comparison of frequencies of reported CSI problems .....	78
	The frequencies of reported problems on the CSI is outlined.....	78
4.6.4	Summary of CSI scores.....	80
4.7	EQ-5D scores for both groups.....	81
4.7.1	Health profiles of caregivers at baseline and at three months.....	81

4.7.2	Summary of proportions of caregivers with problems in the EQ-5D dimensions .....	82
4.7.3	Comparison of utility scores at baseline and at three months for both groups.....	83
4.7.4	Comparison of EQ-5D VAS scores at baseline and at three months for both groups ..	84
4.7.5	Correlations between EQ-5D scores and other variables .....	85
4.7.6	Summary of EQ-5D results .....	85
4.8	Satisfaction with services.....	86
4.8.1	Overview of satisfaction domains for both groups.....	86
4.8.2	Differences in satisfaction between the two groups .....	88
4.8.3	Factors influencing satisfaction – results from the open ended questions .....	89
4.8.4	Summary of satisfaction results .....	90
4.9	Compliance results.....	91
4.9.1	Compliance rates for the two groups .....	91
4.10	Summary of results .....	92
5	DISCUSSION.....	93
5.1	Introduction .....	93
5.1.1	Comparability of the two groups .....	93
5.2	Demographic characteristics of the sample .....	93
5.2.1	Sociodemographics of children with CP.....	93
5.2.2	Caregiver demographic characteristics.....	94
5.3	Discussion of changes in functional (GMFM-88) scores of children with CP.....	94
5.4	Discussion of the burden of caregiving a child with CP on caregivers.....	95
5.4.1	Overview .....	95
5.4.2	Economic burden .....	95
5.4.3	Physical burden .....	96
5.4.4	Psycho-social burden .....	97
5.4.5	Summary of CSI discussion.....	99
5.5	Discussion of HRQoL of caregivers.....	100
5.5.1	Overall comparison .....	100
5.5.2	Mobility, usual activities and self-care.....	101
5.5.3	Pain.....	101
5.5.4	Anxiety/depression .....	102
5.5.5	Effect of severity of CP on caregivers’ burden and HRQoL.....	102
5.5.6	Conclusion of EQ-5D discussion .....	103
5.6	Discussion of satisfaction with services .....	104

5.6.1	Overview .....	104
5.6.2	Effect of external factors to satisfaction.....	104
5.6.3	Effect of internal factors to satisfaction.....	105
5.6.4	Global measures of satisfaction .....	106
5.7	Compliance discussion .....	107
5.7.1	Conclusion of compliance discussion.....	109
5.8	Limitations.....	110
6	CONCLUSION AND RECOMMENDATIONS.....	112
	REFERENCES .....	115
	APPENDICES .....	xvii
	Appendix 1: GMFM-88.....	xvii
	Appendix 2: Caregiver Strain Index - English version.....	xxiii
	Appendix 3: Caregiver Strain Index - Shona version .....	xxiv
	Appendix 4: South African English version of the EQ-5D.....	xxv
	Appendix 5: EQ-5D – Shona version .....	xxvii
	Appendix 6: The original MRPS.....	xxx
	Appendix 7: Modified MRPS – English version .....	xxxi
	Appendix 8: Modified MRPS –Shona version.....	xxxii
	Appendix 9: Self-designed data sheet.....	xxxiv
	Appendix 10: HREC approval letter.....	xxxvi
	Appendix 11: Harare Central Hospital clinical director approval letter.....	xxxvii
	Appendix 12: Harare Central Hospital head of rehabilitation department approval letter ...	xxxviii
	Appendix 13: Harare Central head of CRU approval letter.....	xxxix
	Appendix 14: Chitungwiza Central Hospital clinical director approval letter .....	xl
	Appendix 15: Chitungwiza Central Hospital head of rehabilitation department approval letter	xli
	Appendix 16: Medical Research Council of Zimbabwe approval letter .....	xlii
	Appendix 17: Caregivers information letter – English version .....	xliii
	Appendix 18: Caregivers information letter– Shona version.....	xliv
	Appendix 19: Caregivers consent form – English version .....	xlvii
	Appendix 20: Caregivers consent form – Shona version .....	xlviii
	Appendix 21: Rehabilitation professionals’ information letter .....	xlix
	Appendix 22: Rehabilitation professionals’ consent form.....	li

## List of Tables

Table 4-1: Study population demographic characteristics, n=46 .....	68
Table 4-2: GMFM-88 scores over three months, n=46.....	72
Table 4-3: Predictors Of Changes In Functional Scores .....	74
Table 4-4: Treatment sessions details for the study duration.....	75
Table 4-5: CSI scores comparison at baseline and at three months, n=46.....	76
Table 4-6: Range of CSI scores at baseline and at three months, n=46.....	77
Table 4-7: Frequency of reported problems on the CSI for both groups, n=46. ....	78
Table 4-8: Health states of caregivers, n=46.....	81
Table 4-9: Comparison of EQ-5D utility scores at baseline and at three months, n=46.....	83
Table 4-10: EQ-5D VAS scores over three months, n=46.....	84
Table 4-11: Correlations between EQ-5D scores and other variables.....	85
Table 4-12: Satisfaction with rehabilitation services, n=46.....	86
Table 4-13: Comments on internal variables of satisfaction .....	89
Table 4-14: Comments on external variables to satisfaction .....	90

## List of Figures

Figure 3-1: Study design .....	50
Figure 3-2: Time plan of the study.....	59
Figure 4-1: Overview chart for the study.....	66
Figure 4-2: Age distribution of children with cp, n=46 .....	69
Figure 4-3: GMFCS level classification for the groups, n=46 .....	70
Figure 4-4: GMFM-88 scores over three months, n=46 .....	73
Figure 4-5: CSI scores comparison at baseline and at three months, n=46.....	76
Figure 4-6: Summary of proportion of caregivers reporting problems, n=46 .....	80
Figure 4-7: Summary of proportions of caregivers with problems in the EQ-5D dimensions, n=46 .....	82
Figure 4-8: Comparison of utility scores at baseline and at three months for both groups.....	83
Figure 4-9: EQ-5D VAS scores over three months, n=46 .....	84
Figure 4-10: Differences in satisfaction, n=46 .....	88
Figure 4-11 : Comparison of compliance rates across groups, n=46 .....	91

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# 1 INTRODUCTION

## 1.1 Background

*“Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder”.*<sup>3</sup>(page 572) CP is a global problem<sup>9</sup> with global incidence of 2 to 3 cases per 1 000 births<sup>10</sup> and the exact incidence in Zimbabwe is unknown, however, from extrapolated data; incidence is estimated at 1.55/1000 in rural areas and 3.3/1000 in urban areas.<sup>11</sup> Furthermore, CP is the most common paediatric neurological condition<sup>12</sup> and the principal cause of disability in children.<sup>9</sup>

Children with CP face multiple bio-psychosocial challenges.<sup>13 14</sup> This coupled by the fact that CP is a lifetime condition<sup>15 93</sup>, results in a huge burden on caregivers<sup>13</sup> as *“family caregivers often shoulder the principal, multifaceted responsibilities of long-term disability management”*.<sup>16</sup> (Shillitoe & Christie cited by Raina et al., page e627) Inevitably there is a need for a multi-disciplinary approach for the provision of holistic care.<sup>15 17</sup>

Rehabilitation treatment is an essential component<sup>12 17</sup> of the multi-disciplinary approach to CP management.<sup>15 18</sup> Furthermore, CP accounts for the largest group treated in paediatric rehabilitation<sup>19</sup> and children constitute 30% of attendances at rehabilitation departments in Zimbabwe.<sup>20</sup> Rehabilitation service provision models can be broadly classified as either institution-based or community/outreach-based approaches.<sup>21 22</sup> Additionally, rehabilitation services have been traditionally provided through institutions (hospital-based approach).<sup>23 24</sup> Zimbabwe utilizes a hybrid model of provision of rehabilitation services that is, a blend of hospital-based and community-based approaches and services are provided at district, provincial and central hospitals.<sup>20</sup> However, a decade of socio-economic meltdown has resulted in dilapidation of the health care delivery system.<sup>25</sup> At present, organization of rehabilitation services varies from institution to institution and is mainly governed by resources availability and most institutions are offering hospital-based services only. For instance, out of the 6 state central hospitals in Zimbabwe, only Harare Central Hospital (HCH) is at present running a consistent outreach program through its Children Rehabilitation Unit (CRU).<sup>20</sup> Of note is that, the running of the program has been made possible through donor funding and support.<sup>26</sup> The CRU is a specialized paediatric rehabilitation centre, and it runs a peri urban , community-based outreach program in Harare for the provision of

rehabilitation services which is modelled on the WHO Community Based Rehabilitation (CBR) model

.<sup>26</sup>

To the author's knowledge, nothing is known about the most efficient and effective model of service delivery when it comes to CP rehabilitation i.e. between hospital-based and community-based models. Therefore, there is a need for a comparison and it is reasonable that a model will be judged to be more efficient and effective if it meets the following outcome measures:

- The caregivers exhibit higher health-related quality of life (HRQoL) scores and exhibit less levels of stress
- The caregivers show more satisfaction with the mode of access to rehabilitation services
- The caregivers show more compliance with the associated mode of service delivery
- The children with CP treated show greater changes in motor function

## 1.2 Rationale

Long term caring for a child with CP negatively affects the health and HRQoL of the informal caregiver.<sup>27 28</sup> Therefore, it is essential to assess the health status and HRQoL of caregivers of children with disabilities.<sup>29</sup> Likewise, improvement of quality of life for both child and family is one of the major goals in CP management.<sup>15 20</sup> Consequently, there is a need to establish a more efficacious model of service delivery i.e. the one which offers a holistic approach to management by offering psycho-social support to caregivers<sup>28</sup> in addition to the provision of therapy, to children with CP. More so, compliance with therapeutic activities and subsequently, functional outcomes in children is dependent on the health of caregivers.<sup>27 29 30</sup>

The CRU Outreach program is modelled on a WHO CBR approach.<sup>26</sup> The roots of CBR can be traced back to the Declaration of Alma of Atta which led to the adoption of global primary health care strategy by the WHO. Its main aim was for the provision of primary health care and rehabilitation services to people with disabilities in their communities.<sup>31</sup> Community based rehabilitation has been in existence for more than 3 decades<sup>31 32 33 34</sup> yet little is known about its efficacy, effectiveness, relevance, appropriateness and sustainability as a service delivery model and public health strategy.<sup>35 36 37</sup> Therefore, a comparison with a traditional hospital-based approach is critical in determining the most efficacious and effective mode of rehabilitation service delivery.

The Ministry of Health and Children Welfare Zimbabwe (MOHCWZ) drafted a National Strategic Health Plan to revitalize the health system.<sup>25</sup> Thus, a comparison between community-based and hospital-based models will aid in evidence –based decision making in planning, structuring and provision of rehabilitation services for the realisation of the best treatment outcomes.<sup>17</sup>

### 1.3 Aim

To compare the efficiency and effectiveness of a hospital-based and a community-based service delivery models in CP rehabilitation

### 1.4 Objectives

In two groups of children, one of which was treated as part of the Outreach program and the other at a hospital clinic:

- To determine whether the demographic and clinical characteristics of children with CP treated under the CRU Outreach program and the CCH CP clinic were equivalent.
- To determine if there was a significant difference in improvement over a three month period in Gross Motor Function Measurements (GMFM) for children treated at Outreach points and for children receiving hospital-based treatment and whether either group improved more than the other.
- To determine what factors were related to improvement in children's function over time.
- To investigate the relative impact of the two modes of service delivery on the HRQoL of the caregivers by determining if there was a significant difference in the rank order of scores on the EQ-5D and on Caregiver Strain Index (CSI) before and after a three month period of intervention and between the two groups.
- To determine the degree of caregiver satisfaction with the rehabilitation services that they received and to establish whether both groups were equally satisfied with services by testing whether there was a significant difference in the ranking order of scores on the Medrisk Instrument for Measuring Patient Satisfaction with Physical Therapy Care (MRPS)
- To determine whether caregiver compliance to treatment schedules was associated with mode of service delivery, as measured by the number of appointments kept.

### 1.5 Justification and significance

It is hoped that this study would come up with recommendations of a model of service delivery which provides holistic care and which is built on the strengths of the two models under scrutiny. The postulated "ideal" model should provide caregivers with psycho-social support in addition to therapy for CWDs. This is of paramount importance as the widely used hospital-based approach is biased towards meeting the functional limitations of CWDs, yet not much is done in addressing the plight of caregivers who shoulder most of the burden of care giving. Furthermore, it was the author's view, that a model which met the psychosocial needs of caregivers would be associated with compliance and satisfaction with services which is essential for the rehabilitation of CWDs.

Additionally, because of constraints in human and financial resources in our country, it is essential to come up with an efficient and effective model of service delivery which can be run under lowest possible costs.

## 2 LITERATURE REVIEW

### 2.1 Introduction and definitions

This chapter describes in detail a review of related literature for the variables under scrutiny in this study. As no direct literature was found on the comparison of models of CP rehabilitation, we embarked on an extensive, thematic search of literature pertinent to this study. We utilised the following data bases: MEDLINE, Pedro, CINAHL, PubMed, EBSCO and Google Scholar. The following key words were used in our search : cerebral palsy, the burden of care, quality of life of caregivers of children with CP, satisfaction with physiotherapy, compliance, outreach, CBR, institution based rehabilitation. We considered full journal articles and web articles which were published in the English language and we did not set a time limit for the included articles as evidence in the area was very scarce. The literature review is structured as follows: a review of variables related to the study will be presented first. A review of data collection tools will then precede a review of the methodology utilised.

There have been several attempts in the past to define the term cerebral palsy.<sup>3</sup> However universal to the proposed definitions is that CP is a motor disorder, causative agent is static, presents with diverse and dynamic impairments and is a result of damage to the developing brain and is a result of damage to the developing brain and that deficits become more apparent with time.<sup>38 39 153</sup>

*“Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder.”<sup>3</sup> (page e627)*

#### 2.1.1 Incidence

The exact incidence of CP worldwide is unknown, however, literature reports of incidence rates in different settings. For instance, incidence in the USA is estimated at 2 per 1000 live births,<sup>17</sup> whilst that of the European region is pegged at 2.5 per 1000 live births.<sup>19</sup> The exact incidence in Zimbabwe is unknown, however from extrapolated data, incidence is estimated at 1.55/1000 in rural areas and 3.3/1000 in urban areas.<sup>11</sup>

### 2.1.2 Aetiology

From the definition, CP is as a result of damage to the developing brain<sup>3 17</sup> and the damage can occur prenatal, perinatal or postnatal.<sup>13 15 38 39 40 41</sup> Further, “*the causal pathways for CP are believed to be numerous and the etiology multifactorial*”.<sup>39</sup> (page 446)

The most common prenatal causes include placental abnormalities, restricted intrauterine growth, multiple births, congenital abnormalities, genetic disorders and intrauterine infection and inflammation.<sup>13 17 41</sup> Additionally, gestational age can be a risk factor, with the risk of acquiring CP more in pre-term and post-term deliveries as compared to normal term deliveries.<sup>13 40 41</sup>

Perinatally, the most common causes include complications such as breech presentations, low Apgar score, meconium aspiration, prolonged labour and low birth weight.<sup>13 40 41</sup> Studies at two central hospitals in Zimbabwe revealed a high incidence of birth asphyxia in infants compared to high income countries.<sup>42</sup> Further, the National Health Strategy for Zimbabwe (2009-2013) stipulates that birth-related trauma such as birth asphyxia is the leading cause of CP.<sup>25</sup> Increases in birth-related trauma have been attributed to the dilapidation of the health care system in the last decade.<sup>25</sup> Further, infections such as HIV and encephalopathy may also lead to CP.<sup>41 43</sup>

Postnatal, the most common causes include neonatal jaundice, kernicterus, meningitis, encephalopathy and trauma.<sup>17 40 41</sup> There is a paucity of research on the aetiology of CP in the Zimbabwean context. However, a study at a central hospital revealed that hyperbilirubinaemia is a risk factor for developmental delay, and it is associated with choreo-athetoid CP.<sup>42</sup>

### 2.1.3 Associated impairments

Although motor impairments are the hallmark feature of CP, other impairments such as feeding problems, seizures, visual, auditory, mental retardation, and learning disability are part of CP.<sup>17 19 44</sup> Motor problems include, delay in movement initiation, poor force production, poor timing of force generation, difficulty with postural control and increase in co-contraction.<sup>45</sup>

Approximately 30% of persons with cerebral palsy have a seizure disorder.<sup>17</sup> The onset and manifestation of seizures is variable.<sup>38</sup> Seizures are particularly common in children with CP as embroiled in most of the definitions of the syndrome itself.<sup>17 39</sup> The prevalence of seizures is higher in children with spastic quadriplegia and hemiparesis, as opposed to those with spastic diplegia and ataxic CP.<sup>38</sup>

Pain is also prevalent in children with CP.<sup>17</sup> The causal pathways are multifactorial as CP is associated with multiple impairments.<sup>17</sup> For instance, muscle spasms and neurological impairments may lead to increase in pain in children in CP.<sup>17</sup>

Cerebral palsy is as a result of damage to the infantile brain and is invariably associated with impairment of learning and cognition.<sup>17 19 38</sup> It is estimated that 23-44 % of CP cases have impaired cognition ,and the concurrent presence of epilepsy increases cognitive deficits.<sup>19</sup> The extent of brain damage and the inherent CP type is predictive of the extent of cognitive impairment.<sup>38</sup> For instance, it is expected for children with hemiplegic CP to have a higher IQ, as opposed to quadriplegic CP.<sup>38</sup>

Sleep problems are very prevalent in children with CP.<sup>46 47 48</sup> The most common sleep disorders in children with CP include : sleeping anxiety, night waking and parasomnias and sleep-disordered breathing caregivers.<sup>48</sup>

#### **2.1.4 Diagnosis**

Despite CP being a well-known phenomenon for years, it remains a clinical diagnosis.<sup>15 17 38 49</sup>

Diagnosis is mainly based on neurological examination, observation of persistent neurological signs and symptoms and absence of genetic disease.<sup>17 49</sup> The classical diagnostic signs and symptoms are delayed milestones, abnormal muscle tone, hyperreflexia, persistent primitive reflexes, abnormal postural reactions and absence of regression or evidence of a more specific diagnosis.<sup>15 38 49</sup>

The neurological manifestations somewhat correlate with the locality of structural damage in the developing brain.<sup>15 17</sup> As CP is a developmental disorder resulting from damage to the infantile brain, the clinic signs are detectable any time before 3 years of age.<sup>17</sup> Clinically, feeding problems are usually the first detectable signs before delay in the attainment of developmental milestones becomes apparent.<sup>17</sup>

#### **2.1.5 Classification**

Although CP is the most common neurologically physically disabling condition,<sup>39</sup> coming up with a standardized definition and diagnosis criteria has proven to be elusive.<sup>38 39</sup> Consequently, various classification systems for CP have been postulated.<sup>39 50 49</sup> Generally, CP can be grouped according to nature of motor impairment, assumed area of cerebral dysfunction or number of extremities affected.<sup>17 49</sup>

##### **2.1.5.1 Physiologic classification**

This classification system categorises CP into either pyramidal or extrapyramidal types.<sup>17 39</sup> Pyramidal lesions are associated with increased tone, deep tendon and overflow reflexes.<sup>17 39 50</sup> Spasticity is the hallmark of pyramidal variant of CP and its clinical manifestation is persistent whilst in extrapyramidal, tone fluctuations is movement/activity and emotional dependent.<sup>39</sup> Further, extra pyramidal variants are characterised by abnormalities in tone regulation, postural control and coordination.<sup>17 51</sup> Physiologic variants of CP are further classified into spastic, ataxic and dyskinetic.

### 2.1.5.2 Spastic / Hypertonic

Is the most common variant of CP as it accounts for 83 % of cases.<sup>44 49</sup> The variation in tone is posture and movement –dependent and there may be loss or absence of tone in lying.<sup>44</sup>

### 2.1.5.3 Dyskinetic

Accounts for 12% of the cases and is subdivided into athetoid/hyperkinetic and dystonic subtypes.<sup>44</sup>  
<sup>49</sup> Clinically, athetoid variant is characterised by involuntary movements and slow powerful, localized or generalized co-contractions are observed in the dystonic variant. Further, athetoid movements can evolve into dystonic and athetosis and dystonic movements can manifest simultaneously.<sup>44</sup>

### 2.1.5.4 Ataxia

It accounts for 4% of the cases and impairment of equilibrium and coordination are the hallmark of this protégé.<sup>44 49</sup> Clinically, spasticity in legs, hypermetric movements and incoordination are observable. Of note, is that children with ataxia achieve walking a bit late, and they do often require a walking aid.<sup>44</sup>

### 2.1.6 Prognosis

According to the parents' point of view, the ability to walk is the most important functional prognostic outcome/indicator.<sup>38</sup> The type and severity of CP inherently serves as a predictor of the likelihood for achieving the walking milestone.<sup>38 49</sup> For instance, children with hemiplegia and diplegia CP are at greater odds of attaining the milestone of walking as opposed to children with quadriplegia.<sup>38</sup> Further, those who sit by 2 years are likely to walk with the odds of walking diminish for children who would not have achieved independent sitting by 4 years.<sup>38</sup> Further, *“ambulation status, intelligence quotient, quality of speech, and hand function together are predictive of employment status”*.<sup>49</sup> (page 6)

### 2.1.7 Management

Cerebral palsy is not curable and management is directed at maximizing the child's functional capacity as well as optimizing their QOL.<sup>15</sup> Given the diverse impairments CP presents,<sup>13</sup> there is a need for a multi-disciplinary approach for the provision of holistic care.<sup>3 15 17 19 44</sup> Treatment should meet the unique developmental needs of the child as well as meeting family expectations.<sup>17 44</sup> An optimal team, would include a paediatrician, neurologist, physiotherapist, occupational therapist, a nurse, a social worker and a school teacher.<sup>17</sup>

### 2.1.7.1 Rehabilitation

Rehabilitation treatment is an essential component<sup>12 17 49</sup> of the multi-disciplinary approach to CP management.<sup>15 18 49</sup> The ultimate goal is for the child to achieve optimal functionality in adulthood.<sup>44</sup> Different therapies have different, yet complimentary and at times overlapping roles.<sup>38</sup> For instance physiotherapy focuses on posture and mobility, occupational therapy on activities of daily living (ADLs) training and adaptive equipment whilst speech and language therapists on communication.<sup>17</sup>  
<sup>38</sup> The broad goals of rehabilitation are<sup>17</sup>;

- Health education and promotion on CP, its associated impairments and management
- Strengthening activities using a task-specific, functional approach
- Educating patient and family to promote functional activities at home and in the community
- Influencing tone to enhance function and to prevent effects of immobilization
- Provision of neuropsychological, occupational therapy and speech therapy for patients with psychosocial disorders and cognitive impairments
- Provision of occupational and speech therapy for patients with oromotor impairment<sup>17</sup>

#### 2.1.7.1.1 Determinants of efficacy of rehabilitation treatments

Various factors determine the efficacy of rehabilitation treatments. However, there is a paucity in high level trials (RCTs) done to measure efficacy of rehabilitation treatments.<sup>49 52</sup> Treatment dosage and frequency determines functional outcomes in children with CP.<sup>18 45 53</sup> However, the optimal treatment dosage is unknown.<sup>18 53</sup> Findings from a study by Law et al. suggest an optimal frequency of three to four treatments per month.<sup>18</sup> Elsewhere, Tordis et al. set to determine the effects of intensive physiotherapy over changes in motor function in children with CP as measured on the GMFM-66, and GMFM-88. The children were treated five times a week over a period of four weeks and their results were inconclusive.<sup>45</sup> Needless to say, the sample size of 5 children limits the generalizability of their findings. In a separate study, Christiansen & Lange (2008)<sup>53</sup> carried out a prospective randomized control trial to investigate effects intermittent dosage of therapy against continuous dosage of therapy sessions. Their sample included 25 children with CP of all levels of severity as measured by the GMFCS and of age range one to 10 years. Children in the experimental group received 45 minute physiotherapy sessions, four times a week followed by six weeks of rest without physiotherapy sessions. This cycle was repeated twice for the duration of the study period (30 weeks). The control group received 45 minute physiotherapy sessions, once or twice per week for 30 weeks. The results indicated that both groups improved significantly from baseline scores as measured by the GMFM-66. Further, they were statistically significant differences between the two groups.<sup>53</sup> The median compliance rate was greater in the experimental group as compared to the

control group i.e. 93% vs. 83%. Additionally, their results revealed that severity was correlated to changes in functional scores with the least affected children improving more.<sup>53</sup> By and large, there is no consensus as to the optimal treatment frequency/dosage.<sup>18 45 53</sup>

Age of children can also determine the extent of functional/motor changes in children with CP, with greater changes in younger children.<sup>18</sup> This is substantiated by Debusse and Brace (2011) who postulated that the sensitivity of the GMFM-88 is greater in children younger than 6 months.<sup>54</sup> Further, the GMFM-88 has ceiling effects for children older than 7 years.<sup>54</sup> Additionally, the level of severity also affects the magnitude of functional gains. Least affected individuals tend to attain greater functional gains.<sup>52</sup> This may be accounted for by their greater functional capacity, and consequently are able to practise functional patterns more.<sup>52</sup>

The treatment approach may also influence the magnitude of changes in motor function.<sup>52 55</sup> However, there is no consensus as to the “gold standard” of treatment approach and or techniques.<sup>55</sup> Desloovere et al.<sup>55</sup> compared the impact of the neurodevelopmental treatment (NDT) against conventional physiotherapy post Botulinum Toxin A. Their sample consisted of 76 children, age range: 4 to 18 years and within levels I-III as measured on the GMFCS. The outcome measures were 3-D gait analysis and the Goal Attainment Scale. The groups were equivalent in clinical characteristics as they were matched in terms of age, diagnosis and level of severity. Outcomes of the study indicated better functional outcomes in the NDT group. Further the most commonly used techniques included: tone reduction, mobilization, muscle strengthening and functional training.<sup>55</sup> However, the sample consisted of children who could ambulate and this limits the generalizability of their findings.

Elsewhere, Bar-Haim et al.<sup>52</sup> carried out a RCT across three sites comparing the efficacy of motor learning coaching to neurodevelopmental approach. Their sample included 78 children with CP, age range 6-12 and of GMFCS levels II and III. The children received intensive treatments for three months i.e. three, one hour sessions per week. The outcome measures were the GMFM-66, mechanical efficiency and parental rating of mobility performance. Their results revealed that all children showed improvements over the three months period. However; there was significantly greater retention of motor skills for children at 9 months for children under the motor learning arm.<sup>52</sup> Further, findings from the study also substantiate the hypothesis that intensive treatment sessions lead to increases in functional gains in children with CP.<sup>52</sup> However, their inclusion criterion limits the generalizability of their findings across children with CP of all ages and severity.

Another RCT by Law et al<sup>18</sup> adds to the debate on the effect of type of interventions on functional gains. They compared the efficacy of child-focused interventions against context-focused approach to therapy. Their sample consisted of 128 children, age range 1 to 6 years and of all levels of severity as measured by the GMFCS. The outcome measurements were: the PEDI, GMFM-66 and the Preschool Children's Participation scale. Their results revealed a non-significant difference in the two approaches. Further, children in both treatments improved over the 6 months study period. However, there were declines in functional gains at three months follow-up period.<sup>18</sup> To that end, there seems to be no evidence to a more superior treatment approach which results in greater functional gains in children with CP.<sup>18 52 55</sup>

Other factors such as the nature of therapist-child relationship may influence changes in functional outcomes. A good relationship characterised by mutual understanding and cooperation enhances treatment efficacy.<sup>45</sup>

## 2.2 The burden of caregiving

### 2.2.1 Introduction

Traditionally, rehabilitation services have been provided within institutions. However, due to advances in health care delivery systems<sup>28 56</sup>, escalating health-care costs and changes in societal attitudes<sup>28</sup>, there is now emphasis on shifting care from institutions to the community.<sup>28 56 57 58 59</sup> This paradigm shift has led to the transfer of burden of informal caregiving to the family.<sup>28 56 59</sup> The inherent burden on caregivers is testimonial to the activity limitations and participation restrictions children with CP face.<sup>29</sup> Furthermore, the level of dependency is correlated to the level of severity, and this can translate to long care giving hours for caregivers.<sup>60 61 62</sup> Additionally, as CP is a lifetime condition, it can place a huge strain on the caregiver as some of the children require life-time assistance.<sup>1 3 9 15 29 49 63</sup>

### 2.2.2 Definition of burden of care

Burden of care is a complex and multi-dimensional concept, and as such, it is not universally conceptualised and defined. Some authors define it as the physical, psychological, emotional, social and financial stress that results from caregiving.<sup>64</sup> According to Floyd and Gallagher, caregiver burden is defined as "*strain or load borne by a person who cares for a family member with a disability.*"<sup>1</sup> Universal to the diverse definitions is that long term caregiving has an effect on the physical, psychological, emotional, social and financial strain on the caregiver.<sup>1 61 64</sup>

### 2.2.3 The burden of caregiving a child with CP

*Even under ideal circumstances, caregiving can bring with it challenges, strain, and stress.*<sup>65</sup> (page 137) More so, raising a child with a disability has been recognised for some time as a major source of burden and distress.<sup>1 59</sup> As informal caregivers, parents provide long-term care that often requires extraordinary physical, emotional, social and financial resources.<sup>61</sup> *“A (primary) caregiver is defined as the person responsible for most of the day-to-day decision-making and cares for the child”*<sup>17 63 66</sup> and are mothers in most cases.<sup>61 63</sup> As such, informal caregiving can be regarded as a form of a “career” which is not normally entered on free will, not driven by ambition and is neither recognised by society as worth pursuing.<sup>64</sup> It is a career with multiple roles such as being the hands-on care provider, trusted companion, surrogate decision maker and patient’s advocate.<sup>67</sup>

Likewise, in spite of the positive effects caregiving has, long term care has been demonstrated to negatively impact health of caregivers.<sup>67</sup> It can lead to strain in physical and psychological health of caregivers.<sup>66</sup> Therefore, given the multidimensionality of caregiving, the burden of care can be categorically classified into the following classes; financial/economic, physical and psychosocial burden.<sup>1</sup>

#### 2.2.3.1 Economic burden of caregiving a child with CP

In the context of CP, economic burden can be defined as the additional expenditure borne by the patient, the family and society that is attributable to CP.<sup>49 68</sup> There is a paucity of economic cost of CP in low income countries as the scarce data available finds its origin in high income countries.<sup>68 69</sup> Estimates of the financial cost of CP in Australia in 2007 were around \$1.47 billion (0.14% of GDP)<sup>70</sup> ,and that of China stood at estimated two to four billion dollars as of 2003.<sup>68</sup>

Economic costs can be categorised into health-care, social and productivity costs.<sup>69</sup> Productivity costs on the part of caregivers emanate from the caregiver leaving employment or reducing employment time.<sup>69</sup> As caregiving is time consuming, it leads to conflict between caregiving and occupational roles. This subsequently jeopardises employment opportunities thus resulting in financial burden.<sup>28 59 63 66 67 71</sup> Further, unemployed caregivers cannot contribute towards national coffers in the form of taxes.<sup>70</sup> In the context of adults with CP, productivity costs are incurred if the individual does not enter the labour market at all.<sup>69</sup>

Disability-related costs are classified under health-care and social costs.<sup>69</sup> These have been demonstrated to be highly predictive of caregiver burden and to affect all regardless of the socio-economic status.<sup>1</sup> Some countries provide with some form of financial assistance to families of CWDs. For instance, in South Korea, CWDs receive a tuition waiver and low income families with a

CWD receive a monthly grant. Nevertheless, a study revealed that most caregivers in South Korea expressed dissatisfaction with the inadequacy of the financial aid.<sup>1</sup> Elsewhere, a report on the financial impact of CP in Australia stipulated, “*people with cerebral palsy in Australia are marginalised and services to support them are underfunded*”.<sup>70</sup> (page 1) This is of particular concern as one wonders what caregivers in low-income countries go through. This is also echoed by the sentiments of caregivers of children with intellectual disability in Kenya. In spite of the reported financial burden, they do not receive any assistance from the government given that most of them are of lower socio-economic status.<sup>72</sup>

Furthermore, factors such as long life expectancy, life-long and high dependency on caregivers’ support, progressive deterioration of motor function, and recurrent use of rehabilitation services contribute towards economic burden.<sup>68</sup> All in all, there is an intertwining correlation between caregiving and bio-psychosocial health of caregivers. In essence, care giving a CWDs results in the long term economic burden.<sup>61 66</sup> This subsequently leads to poor mental health in caregivers.<sup>62</sup> Further, the increased health care costs on the part of the caregiver and inherent productivity costs loss, leads to the financial burden to the caregivers and society at large.<sup>69</sup>

#### **2.2.3.2 Physical burden of caregiving a child with CP**

Various factors predispose caregivers to the risk of developing physical health problems, e.g. the amount of assistance offered in ADLs such as feeding, bathing among others.<sup>61 73</sup> The risk is even more in caregiving a child with severe physical and cognitive impairments.<sup>17</sup> Further, advances in health-care have resulted in increased life-spans for children for who may require lifetime assistance.<sup>17</sup> Additionally, as these children grow, they become heavier to lift, and this predisposes caregivers to musculoskeletal problems such as LBP.<sup>73</sup> However, there is a paucity in literature on prevalence and risk factors of musculoskeletal problems and LBP in caregivers of children with physical disabilities.<sup>14 73</sup> Literature concurs that caregivers are at the risk of suffering from chronic physical health problems such as chronic fatigue, sleep deprivation, pain, especially shoulder and low back pain and osteoarthritis in the long run.<sup>28 61 74</sup>

Sharan and colleagues<sup>14</sup> conducted a cross sectional study on the prevalence musculoskeletal disorders (MSDs). They compared outcomes in 257 caregivers of children with CP who had undergone a multi-level surgery against 117 caregivers of ambulatory CP children with orthopaedic problems. The outcome measures were: the Borg CR-10 for measuring physical exertion during lifting/carrying child and fatigue and the CSI for measuring the burden of care. Their results revealed that MSD were more common in the control group. The most common MSDs included myofascial pain syndrome, fibromyalgia and thoracic outlet syndrome. Additionally, caregivers in the control

group exhibited greater signs of distress.<sup>14</sup> The burden was mainly due to financial problems with most caregivers failing to secure money for transportation to the hospital.<sup>14</sup>

Likewise, findings by Kaya and colleagues<sup>30</sup> concur with results Sharan and colleagues.<sup>14</sup> In their study, Kaya et al. compared the prevalence of musculoskeletal problems (MSP) and LBP in 81 Turkish caregivers of children with CP against 60 caregivers of children without health problems. They utilised the following outcome measures: SF-36- QOL, Beck Depression Inventory- depression-, VAS – pain intensity and GMFCS – severity of CP. Although the two groups were comparable in their demographics, MSP and LBP were more prevalent in caregivers of children with CP. The predictors of LBP were child's BMI, age of child, depression and poorer QOL. Furthermore, caregivers of children with CP suffered significantly higher pain levels which were of chronic duration. Caregivers of children with CP also exhibited poorer QOL as depicted by lower scores in all SF-36 with the exception of social functioning.<sup>30</sup> Additionally, caregivers of children with CP exhibited signs of depression and their findings point to an association between LBP and depression. Furthermore, LBP was not associated with severity of CP and this corroborates the hypothesis that psychosocial factors may be stronger predictors of LBP development in caregivers. They hypothesized that physical strain leads to LBP and subsequent activity limitations and participation restrictions in caregivers. This leads to poorer health and QOL in caregivers. The inherent depression perpetuates the LBP and creates a vicious cycle.<sup>30</sup>

Findings from a study by Tong and colleagues<sup>73</sup> also concur that caregiving a child with CP leads to physical strain. Tong et al.<sup>73</sup> conducted a cross sectional study to evaluate the prevalence of LBP in female caregivers of children with physical disabilities (n=90) as compared to caregivers of children with medical conditions, n=23. They utilised the following outcome measurements: modified Nordic questionnaire for measuring LBP, Center for Epidemiological Studies Depression Scale for measuring mood, the US Department of Labour Classification which measures the amount of physical lifting and WeeFIM for evaluating children functioning. Additionally, BMI measurements were also recorded for both children and caregivers. Mothers constituted most of the caregivers, and their age range was 20-65 years and that of children was 25-237 months. Children with CP constituted most of children with physical disabilities, n=59 (65.6%). Their findings revealed that LBP was more prevalent in caregivers of children with physical disabilities. Further, LBP was more prevalent in caregivers of children who required physical assistance across diagnoses. The predictive factors for LBP were: presence of LBP prior birth of child with physical disability, increase in age of child and increased depression in caregivers.<sup>73</sup>

Methodologically, the cross sectional nature of the studies above limits generalizability of findings and causality cannot also be inferred. However, available evidence points that caregiving a child with CP predisposes caregivers to musculoskeletal disorders.<sup>14 30 73</sup> The magnitude of physical burden is dependent on the severity of CP and the presence of additional impairments such as visual and hearing problems.<sup>63 66 75</sup> Consequently, with chronicity of care, caregivers may exhibit poorer physical health status and face problems in activity limitations and participation restrictions.<sup>74</sup>

### 2.2.3.3 Psycho-social burden of caregiving a child with CP

Long term caregiving has been shown to predispose caregivers to strain, stress, depression which is of chronic duration relative to the rest of the population.<sup>62 66 67 74</sup> Parental stress has been demonstrated to be comparably higher in parents of children with CP and various factors account for this.<sup>76</sup> For instance, a Canadian population-based study revealed that caregivers of children with health problems were more likely to be smokers as compared to parents of children without health problems as a way to deal with the associated stress.<sup>74</sup> This was regardless of equivalency in social support, family function or marital satisfaction between the two groups.<sup>74</sup>

Further, parental stress secondary to caregiving, may lead to disruption in family relationships.<sup>1 65</sup> This is because of lack of contact with other siblings or family members as most time is spent in caregiving.<sup>61</sup> Consequently, strain of care has a negative effect on parenting skills thus affecting care for the child with CP and quality of care for other siblings.<sup>62</sup> Likewise, other studies postulate that strain in caregiving can lead to inconsistent parenting skills which may in term lead to/compound behavioural problems in children with CP.<sup>77</sup>

Furthermore, child emotional and behavioural problems lead to parental stress<sup>60 78 77</sup>, of which maladaptive behaviour has been cited as the strongest predictor of parental stress.<sup>46 76</sup> Child behavioural problems are associated with situational stress. Situational stress is dependent on factors such as income, health status and job satisfaction which all contribute towards caregiver well-being.<sup>77</sup> Other authors postulated that stress in parents leads to child behaviour problems<sup>77</sup>, this can be partly explained by the fact that stress can result in inconsistent and inadequate parenting skills.<sup>62</sup> Therefore, it is evident that there is an interplay between behavioural problems and parental stress.<sup>76</sup>

Furthermore, children behavioural problems such as sleep problems are known to increase parental stress.<sup>46 48</sup> *"A number of factors associated with cerebral palsy could affect the sleep of a child with the condition, including pain and orthopaedic problems, spinal curvature, bowel problems, upper airway obstruction, epilepsy, and psychological issue"*.<sup>47</sup> (page 1) Wayte et al.<sup>48</sup> conducted a

cross sectional study in the UK to ascertain the relationship between sleep problems in children with CP and maternal depression. Their sample included 40 children age range: 4-12 years and the control group constituted of 102 typically developing children. The outcome measures included a demographic questionnaire, the Pittsburgh Sleep Quality Index and Major Depression Inventory for measuring sleep quality and depression respectively and the Child Sleep Habits Questionnaire. The results revealed that sleep problems were prevalent in children with CP and interrupted sleep led to depression in caregivers. Associated impairments such as visual and cognitive impairments and epilepsy were associated with greater sleep disruption. Additionally, compared to typically developing children, children with CP exhibited the following sleep disorders: sleeping anxiety, night waking and parasomnias and sleep-disordered breathing. They recommended the screening and treatment of sleep problems in children with CP given their negative effect on caregivers.<sup>48</sup>

Caregiving also leads to increase in depression, guilt, recurrent anxiety and dissatisfaction with life<sup>61</sup><sup>71</sup><sup>78</sup><sup>79</sup> and these are high risk factors of clinically anxious and depressive moods.<sup>71</sup> A study in Kenya revealed that 79% of caregivers of children with intellectual disability were at a risk of clinical depression, and this was mostly as a result of financial lack and social isolation because of the stigmatization associated with this disability.<sup>72</sup> Other identified risk factors in this study included; gender (females more predisposed), unemployment, primary education, married status and age of caregivers (younger caregivers were at a greater risk).<sup>72</sup>

The amount of time spent caregiving has a bearing on the caregiver's health. Spending more time in caring for a child with CP leads to poorer mental health levels, and this is even worse in females as they bear greater responsibility in caregiving.<sup>61</sup><sup>75</sup> Studies revealed that caregivers of children with health problems experience poorer physical and psychological health levels as compared to caregivers of children without health problems.<sup>59</sup><sup>74</sup> Mothers are responsible for most of the caregiving and as a result, female caregivers are of poor health as compared to male caregivers.<sup>75</sup> Needless to say, in Africa, the responsibility of caregiving is almost "entirely" left to the mother.<sup>72</sup> Furthermore, caregivers who already suffer from underlying chronic conditions exhibit even poorer health as they have limited time to look at their own personal needs and health.<sup>61</sup>

Other stress outcomes of long term caregiving include deteriorating self-concept, cognitive problems, altered self-efficacy and decline in emotional well-being.<sup>59</sup><sup>66</sup><sup>79</sup> This can lead to difficulties in marital and social relationships as caregivers have constrained social opportunities<sup>80</sup> and limited freedom because of long hours consumed by caregiving.<sup>28</sup> Further, unpredictable caregiving demands results in stress and anxiety in caregivers<sup>61</sup> and ultimately leads to poor psychological health.<sup>66</sup> Perceived time pressure is associated with negative maternal mental health. The strain of

caregiving, affects the mother's self-efficacy, and this ultimately affects parenting skills.<sup>62</sup> This in turn can propagate/perpetuate behavioural problems in children with CP.<sup>62 77</sup>

Child's characteristics may influence the level of burden. A study revealed that the strongest predictors in caregivers' health in caregiving a child with intellectual disability in Kenyan were: child behaviour, child's temperament, severity of disability, low self-esteem and poor social support.<sup>72</sup>

## 2.3 Health-related quality of life (HRQoL) of caregivers

### 2.3.1 Definition of HRQoL

Caring for a child with CP has been shown to impact the health and HRQoL of caregivers.<sup>28 65</sup>

According to the WHO, "quality of life is defined as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concern".<sup>7</sup> (page 5)

### 2.3.2 Factors influencing HRQoL of caregivers

HRQoL is multifactorial and according to Yilmaz et al (2013), "...factors concerning HRQoL and related factors are controversial".<sup>81</sup> (pages 3-4) However, there is concordance in literature that caring for a child with a disability impacts on various aspects of a parent's life thus influencing their HRQoL. These include physical, social and emotional health and well-being, marital relationships, and employment and financial status.<sup>28 67 81</sup> Further, caregiving can have both positive and negative impact on QOL.<sup>28</sup> For instance, in the process of providing care, informal caregivers are faced with the threat of deterioration of their own health and subsequently QOL.<sup>28 67</sup> This is partly explained by the fact that more attention has been given to children with CP, yet the health and HRQoL of the caregivers has been overlooked yet they are affected by long term care.<sup>28 29</sup> Higher stress levels are associated with low reported levels of well-being and poorer QOL.<sup>80</sup> A meta-analysis by Pinquart and Sorensen revealed that higher age, lower socioeconomic status and lower levels of informal support were related to poorer health of caregivers. Patient status, caregiver status and social factors are the most salient factors related to caregiver burden.<sup>79</sup>

A comparative study on 137 caregivers of mothers of children with CP and 140 mothers of healthy children revealed that caregiving a child with CP is associated with poorer HRQoL.<sup>81</sup> The mean age of mothers of children with CP was 36.0 (SD 9.0) years whilst that of children was 9.3 (SD 5.3) years. They recruited only the spastic sub-variant of all levels of severity as measured by the GMFCS. Although mothers in the two groups were equivalent in demographics, mothers of children with CP exhibited poorer HRQoL and showed more signs of depression. Furthermore, they had poorer: social

functioning, mental health, emotional health, and generally lower perceived health. Results from the study revealed that HRQoL was independent of severity of CP.<sup>81</sup>

Compared to the general population, caregivers of children with CP have been found to experience poorer health levels with female caregiver's health levels even lower as compared to their male counterparts.<sup>75</sup> This is because caregiver QOL is variable and dependent on factors such as the number of hours spent in caregiving, current level of health of the child and the amount of social support<sup>28</sup> among other factors. On the same wavelength, a Cambodian study done to explore the determinants of QOL in caregivers of children with CP revealed that caregivers scored lower in the domains of health and satisfaction on the ComQOL-AS.<sup>82</sup> These low scores were associated with poorer material and emotional well-being<sup>82</sup> and these findings concur to the proposition that long term caregiving is associated with a decline in caregiver QOL.<sup>28 67</sup>

In a qualitative study to explore the impact of caring for a child with cerebral palsy on QOL for mothers and fathers, parents attributed the following factors as positively contributing to their QOL: their personality, amount of support they receive and attitudes.<sup>28</sup> Likewise, mothers of children with CP who have extensive social support networks, have a greater perceived QOL, low levels of depression and parental stress i.e. there is a positive correlation between well-being and social support.<sup>80</sup> Furthermore, perceived severity of disability has been reported to affect the health of the caregiver than the actual disability.<sup>74</sup>

### **2.3.3 Ways of enhancing HRQoL and decreasing the burden of care**

There is need for a holistic approach to CP management i.e. protocols which looks into the health and welfare of caregivers as well in addition to meeting the health-care and functional needs of children with CP.<sup>75</sup> Further, there is a great need to design tailor-made interventions to alleviate the burden on caregivers as it ultimately affects the child's functional prognosis and health outcomes.<sup>58</sup><sup>71</sup> More so, informal caregivers are a very important resource to the health care delivery system and care of children with disabilities and their welfare warrants special attention.<sup>62 63 67</sup> Therefore, there is urgent need for therapeutic interventions to enhance HRQoL of parents/caregivers.<sup>71 76</sup> Additionally, caregiver strain in its extreme, can lead to inhumane or cruel treatment or even murder of disabled people by the caregiver<sup>79</sup> thus the need to deal with it.

Given the multi-dimensionality of burden of care, there is need to consider multiple strategies to combat the effects of caregiving. Factors affecting buffering ability include: characteristics of the caregiver, caregiver shared history and social, economic and cultural circumstances.<sup>59</sup> As such if these are addressed, it can result in relief of burden of care and improvement of HRQoL.<sup>59</sup>

Improved access to services to services has been shown to alleviate the burden of care.<sup>28</sup> Service providers should strategically work on technical issues such as booking schedules i.e. appointments should be made in consultation with caregivers so that they are also convenient to their schedules.<sup>62</sup> Health professionals should take into cognoscente that lack of time is cited strongest predictor to non-compliance with treatment<sup>28 62</sup> thus the great need to consult caregivers on booking schedules. This is especially important considering the shift is now towards family centred approach especially when it comes to management of children with physical disabilities as “...in the past 50 years, family-centred practice has become the gold standard as an approach to the provision of services to children with CP”.<sup>83</sup> (page 476) Furthermore, adoption of the family-centred approach as opposed to the traditional medical model of service delivery which focuses more on meeting the functional limitations of children with CP without looking at the plight of the caregiver, helps in improving HrQOL of caregivers.<sup>1 28 66 76 78 80</sup> This highlights the need for policy makers to look into implementing this model of care.

As long term caregiving is associated with MSDs and LBP,<sup>14 84</sup> ergonomic training and advice on lifting, transfers and carrying techniques becomes paramount.<sup>14</sup> Furthermore, provision of low cost aids would also help to alleviate physical and financial burden in caregivers.<sup>46</sup> Likewise, timely access to therapy and assistive devices can lessen the burden on caregivers.<sup>70</sup> More so, encouraging facilitation of functional independence in children with CP to lessen the burden on the caregivers. This is essential as poor health and HrQOL in caregivers may lead to decreased compliance with therapeutic procedures and this may compromise functional outcomes in children with CP.<sup>30</sup>

Service providers should provide platform for social interaction and social support for caregivers<sup>1 79</sup> as this has been demonstrated to alleviate the effects of stress.<sup>62 77 80</sup> Social support can be informal or formal<sup>46</sup> with informal care is mainly provided by relatives and friends whereas formal support is provided by professionals, home support services and respite care options.<sup>60</sup> A qualitative study by Davis et al revealed that caregivers attributed their high QOL to their personality and available social support.<sup>28</sup> Social support is needed and can be offered in various ways for instance emotionally or instrumentally.<sup>79</sup>

Furthermore, social interaction and social support are essential if social connectedness is to be achieved. Social connection refers to “a feeling of social acceptance or group membership, as well as the feelings that individuals have for those in their social groups”.<sup>65</sup> (page 138) Social connections are factors such as social support from family, friends, community, support groups, religious connections and sense of community belonging.<sup>61</sup> This also entails the involvement of the extended family so as to lessen the burden on the primary caregiver.<sup>1</sup> Palamaro Munsell et al hypothesized that social

connectedness mediates caregiver strain thus resulting in improved or positive caregiver well-being and this results in positive child adjustment and family cohesion. The results from their study showed that caregiver well-being is significantly associated with caregiver social connections and caregiver strain.<sup>65</sup> Therefore, health education and promotion in caregivers is essential to encourage them to engage in more social activities<sup>81</sup> as this also increases informal support<sup>46</sup>. This substantiates the need for professional social and emotional support for caregivers.<sup>81 70</sup> Psycho-social support can be provided in form of counselling and stress management in caregivers of children with CP.<sup>14</sup> For this to be attained, early screening and treatment of depression and LBP in caregivers becomes paramount.<sup>30 73</sup>

Provision of essential information to families<sup>80</sup> is important in improving HRQoL and decreasing the burden of care. Educating the caregiver on the disability, stress management and counselling can assist in this regard.<sup>1 75</sup> It is also important to provide responsive respite options and therefore it's the obligation of therapists to also provide caregiver with information on the available respite options<sup>62</sup> as health education and promotion are mandatory to therapists.

Parenting training has the potential of alleviating stress in parents/caregivers of children with CP.<sup>83</sup> In essence, incidence of behavioural problems is very high in children with CP.<sup>17 38</sup> As such, behaviour modification has the potential impact of alleviating stress in parents/caregivers of children with CP.<sup>83</sup> Furthermore, greater caregiver involvement in mental health programs is associated with better functional/treatment outcomes for the child as well as with improved child behaviour and emotional health.<sup>85</sup> Therefore, provision of mental health programs assists caregivers in adjusting thus easing the burden of care.

One of the associated impairments of CP is communication difficulties.<sup>3</sup> Difficulty in communication can make the caregiving process burdensome. Therefore interventions for caregivers should also focus on improving communication skills.<sup>75</sup> Additionally, improved communication skills increases perception of parental sense of control and improve parenting skills. This is essential as parenting style affects the behaviour of child with CP which can in turn can result in stress in caregivers.<sup>75 86</sup>

Long term caregiving is associated with physical burden<sup>66 75</sup> and caregiver's fitness levels has been demonstrated to co-related with caregiver's well-being.<sup>79</sup> Therefore, provision of fitness training programs can help in alleviating physical burden among caregivers. Furthermore, motor fitness is associated with a higher self-efficacy in caregivers as it enables them to meet the physical demands of the caregiving role.<sup>79</sup>

Long term caregiving can lead to financial burden, this is as a result of compromised working opportunities and health-care related costs among other costs related to caregiving a child with CP.<sup>28</sup><sup>59 66 67</sup> As such, financial assistance schemes and increased availability of financial resources assists in the alleviation of financial burden.<sup>1 28 75</sup> This can be in form of government grants for children with disabilities and waivers in accessing certain services such as health and education.<sup>1</sup> Governments should finance people with CP patients so as to improve their QOL.<sup>68</sup>

On the same wavelength, economic costing of diseases is essential to inform policy.<sup>68</sup> There is need for national surveillance system for planning and budgeting purposes so as to improve therapeutic outcomes and consequently improving the plight of their caregivers.<sup>70</sup> The following strategies can be used at national level to decrease economic burden<sup>68</sup>:

- research into the definitive aetiology of CP so as to prevent its sequel
- preventive strategies in the form of health education and promotion
- provision of treatments and rehabilitation to optimise function, thus creating independence
- vocational training for people with CP<sup>70</sup>

#### **2.3.3.1 Conclusion of review of burden of caregiving and HRQoL of caregivers**

Research on HRQoL and strain in caregivers has produced contrasting findings and various factors seem to account for this variation. Firstly, the difference in research settings with most of the research emanating from high-income countries. Further, there is dearth in HRQoL research in low-income countries<sup>82</sup> and HRQoL is contextual and culturally sensitive.<sup>87 88</sup>

Secondly, the heterogeneity in samples as some studies have utilised broad range of disabilities<sup>1</sup>, some recruited children with CP only<sup>28 66</sup>, some included children with CP and other comorbidities<sup>75</sup> thus strain due to caregiving cannot be attributed entirely to CP. Further, every condition has its unique demands. As CP is associated with a vast array of impairments, it seems defensible to include children with other comorbidities, but the confounding effect of comorbidities cannot be accounted for thus discrepancies in findings.

Thirdly, the selective inclusion of children with certain level of severity. In essence, some studies only included ambulatory children only (GMFCS levels I to III)<sup>75</sup> or severely affected children<sup>1</sup> which limits the generalization of the findings.

Fourthly, the differences in comparison groups, in essence, one study utilized caregivers of children without long term health condition as the control group<sup>75</sup> and another used caregivers of children with minor health problems<sup>66</sup> and some only recruited caregivers of children with CP only.<sup>28</sup>

Lastly, methodological differences i.e. different sample sizes with most studies having small sizes and differences in study designs, with cross sectional studies constituting the majority of the studies. It must be reiterated that RCTs are the gold standard and therefore, because of the designs employed in this field, causality cannot be inferred and confounders are not accounted for either. Further, use of different tools employed with different psychometric properties limits the generalisability and comparability of the studies. Notwithstanding the contextual and methodological variations, there is concordance from various studies that long-term caregiving leads to poor health and HRQoL in caregivers.

## **2.4 Satisfaction with rehabilitation services**

With the shift from the biomedical model of care to patient-centred care, comes the need to assess patient satisfaction with services.<sup>89</sup> Satisfaction in itself is an indicator of the quality of service delivery and it can be used as a clinical audit tool.<sup>8 89 90 91</sup> More so, it's essential to evaluate patient satisfaction with services delivery as satisfaction is inter-rated to treatment compliance and outcomes.<sup>89 92</sup>

### **2.4.1 Defining patient satisfaction**

Patient satisfaction is a multi-factorial concept<sup>8 91</sup> and it is dependent on technical, interpersonal aspects of care and amenities of care.<sup>8</sup> As such, several definitions on satisfaction have been postulated. Satisfaction can be defined as the extent to which a program fulfils patient's expectations.<sup>8</sup>

### **2.4.2 Satisfaction with physiotherapy services**

Surveys on patients' satisfaction with physiotherapy have taken a centre stage in the past few years. This drive has been stimulated by the shift towards a client-centred approach, competition for limited resources and the correlation between satisfaction, quality of care and treatment efficacy.<sup>93</sup> Generally, literature reports of high satisfaction rates with physiotherapy services.<sup>89 93 94</sup> Satisfaction with physiotherapy surveys have been predominantly done in North America<sup>95 96</sup>, Australia<sup>89 93 97</sup>, the UK<sup>90 94 98</sup> and a few in Brazil<sup>91</sup> and the Middle East<sup>99</sup>. There is a paucity of published surveys of patient satisfaction with physiotherapy services in Africa and in paediatric neurology. Proxy studies have been done in children with cystic fibrosis.<sup>94</sup> Evidently, most of the outcome tools were developed for use in private physiotherapy settings.<sup>91 93 95 97</sup> Additionally, most of the respondents were patients with orthopaedic or musculoskeletal problems.<sup>89 91 97 98</sup>

### **2.4.3 Factors affecting satisfaction**

Satisfaction with physiotherapy services is a multi-dimensional construct and there has been no consensus as to what variables exclusively measure this attribute.<sup>95</sup> This is reflected in diversity of

surveys thus have been developed thus far to measure satisfaction.<sup>90 91 93 95 97</sup> Beattie et al.<sup>95</sup> proposed a dichotomization of factors into external and internal factors. Internal factors relate to patient/therapist interaction and treatment process. External factors relate to logistical and environmental factors such as the processes of making bookings and the comfort of the waiting area.<sup>95</sup>

#### **2.4.3.1 Internal factors to patient satisfaction**

The patient-therapist interaction affects satisfaction with treatment.<sup>91 95</sup> Therapists' friendliness and communication skills have been identified as the most important predictors of patient satisfaction.<sup>91 97</sup> This relationship is affected by the nature of the treatment sessions. For instance, availability of services and amount of time spent with the therapist.<sup>90 93</sup> Time spent with therapist is a strong predictor of satisfaction with more time spent during treatment sessions is associated with greater satisfaction.<sup>89</sup> Harding and Taylor (2010), carried out a survey on 165 outpatient physiotherapy and occupational therapy patients at three metropolitan health sites in Australia.<sup>89</sup> They utilised the MedRisk Instrument for Patient Satisfaction with Physical Therapy and additional two open ended questions. Most of the patients were receiving treatment for musculoskeletal/orthopaedic conditions, and there was a spread of respondents' age. Results revealed a very high rate of satisfaction with overall satisfaction of 96%. Furthermore, their results revealed significant high scores on internal items (therapist-patient interaction and treatment-related factors) as compared to external factors (booking process and environment). Patients indicated that the most positive experiences were related to staff attitude, therapist communication and attitude, therapist technical skills, effect of treatment and the process of care. This cements the predictive power of internal factors to satisfaction.<sup>89</sup>

Psychological indices such as perceptions and expectations also affect satisfaction with physiotherapy.<sup>90 91</sup> Patients with extremely high, unmet expectations are more likely to be dissatisfied with services and relationship with therapist and would ultimately tend to change healthcare providers according to the consumer model.<sup>90</sup> Further, if patients perceive that interventions by therapists are going to assist them in recovery, they are more likely to be satisfied with treatment.<sup>90 91</sup>

The amount of explanation and information given can also have a bearing on patient satisfaction. Having more insight with regards the impairment(s)/health condition and treatment process are associated with greater satisfaction.<sup>8 90</sup> Additionally, continuity of care also affects satisfaction as most patients normally prefer to be treated by the same therapist. This promotes a better patient-therapist relationship and this also assists in the attainment of continuity of care.<sup>90</sup>

### 2.4.3.2 External factors to patient satisfaction

Logistical issues such as booking process and organization of the treatment sessions affect patient satisfaction.<sup>89 90</sup> The booking system affects the waiting times<sup>90</sup> and research reveals the link between short waiting times and patient satisfaction.<sup>89</sup> Therefore, scheduling of treatment sessions in such a way that they fit into the client's schedule affects the level of satisfaction.<sup>90</sup> Furthermore, the comfort of the waiting area also affects patient satisfaction; this is in terms of comfort of the sitting area, décor and lightning.<sup>91</sup>

### 2.4.4 Surveys on satisfaction with physiotherapy services

Stiller, Cains and Drury<sup>93</sup> carried out a purpose- designed survey on 122 out of the 154 eligible patients at a rehabilitation centre in South Australia. The sample consisted of patients of diverse diagnoses, with orthopaedic patients and the 60-79 age bands constituting the majority of the clients who completed the survey questionnaire. The survey revealed a high satisfaction with physiotherapy services especially in the domains of therapists' interpersonal skills and the treatment facilities. Satisfaction was independent of age, gender and diagnosis. Patients expressed the desire to be more involved in the drafting of the treatment plan, more treatment time, being consulted on appointment scheduling and effective communication especially on explanations and instructions.<sup>93</sup> The strengths of this study were in the fact that the survey was designed with input from other clinicians and physiotherapists. Furthermore, the survey was administered by a volunteer and this helped in promoting the honesty of responses by decreasing desirability bias. A sample size of 106/154 also gave the sample size an adequate power. The data was dichotomised for data analysis, thus presenting the threat of losing data properties by converting data from an ordinal scale to a nominal scale. Lastly, neutral responses were discarded for analysis. This is a form of bias in reporting satisfaction findings given that neutral responses can imply a form of "dissatisfaction", which warrants further investigation.<sup>100</sup>

Byrne and Hardy<sup>94</sup> carried a postal survey on the family satisfaction with community physiotherapy for children with cystic fibrosis. They mailed the questionnaire adapted from the Chartered Society of Physiotherapy to all recipients of services at Royal Victoria Infirmary, Newcastle upon Tyne in the UK. Their results revealed a very high satisfaction rate with physiotherapy services with an overall satisfaction rate of 83% and a 83-94% satisfaction range for the domains on the questionnaire.<sup>94</sup>

Devreux et al.<sup>99</sup> carried out a survey on patient satisfaction with physical rehabilitation services in Jeddah, Saudi Arabia. They distributed the adapted scale to measure satisfaction with physical therapy to 3960 physiotherapy, occupational therapy and respiratory therapy patients. The patients were drawn from a public, private and a teaching hospital. The scale to measure satisfaction with

physical therapy is a validated tool to measure patient with physiotherapy services and was developed in Switzerland. It has 14 items which are rated on a 5-point Likert scale. The response rate was 18.9% (725/3609) and the sample consisted of 70.9% outpatients. Of note is that, 40% of the questionnaires were completed by close relatives who were more critical as compared to responses given by patients. The overall satisfaction across the three settings ranged from 69.2% to 84.3%. There were significant differences in satisfaction across the hospital categories except for the reassurance in therapy especially in the domains of quality of information given, explanations on treatment and well as in the feeling of security domain.<sup>99</sup>

#### **2.4.5 Ways of enhancing satisfaction**

According to Mendoca and Guerra, three essential components are to be considered for the effective delivery of services. These are technical assistance, interpersonal relationship and the physical environment.<sup>91</sup>

##### **2.4.5.1 Technical assistance**

Technical issues such as booking schedules, staffing levels, nature of treatment facilities and equipment all affect satisfaction with treatment. Improving booking procedures results in increased patients' satisfaction.<sup>89</sup> It is essential to consider the patient's preferences and working schedule if to enhance satisfaction and compliance with services<sup>89</sup>. All in all, patients who are actively involved in decision-making with regards to their treatment plan are more likely to be more compliant and satisfied with services.<sup>91</sup>

Parameters such as the perceived quality of care received and waiting times all affect patient satisfaction. As such, staffing levels are essential in the delivering of quality services. More staffing levels would decrease patient waiting times and this increases patient satisfaction.<sup>89</sup> Furthermore, quality facilities and equipment are essential for delivering quality care. Thus improving on the facilities and acquisition of equipment all work towards improving satisfaction.<sup>93</sup>

##### **2.4.5.2 Interpersonal relationship**

A good rapport is essential if patients are to be satisfied with treatment.<sup>89</sup> There is also need to involve the patient in goal setting and treatment progression.<sup>93</sup> A client-centred approach, based on the provision of essential information, empathy and making the patient feel more secure during treatment contributes towards client satisfaction.<sup>99</sup>

Additionally, improving on the amount of time spent per client also results in more satisfied patients.<sup>93</sup> However the economic implications of lengthy treatment sessions also need to be considered. Also, offering patients the opportunity to express dissatisfaction or platform to suggest

areas of improvement in service delivery can help in improving service delivery and ultimately on improving satisfaction.<sup>89</sup>

### 2.4.5.3 Physical environment

Adjustment of the physical environment is also essential in attainment of patient satisfaction. Thus, the need to improve the waiting area in terms of comfort, lighting among other issues.<sup>89</sup>

Additionally, availability of parking space<sup>89</sup> for clients is essential in improving accessibility thus ultimately affects the extent of satisfaction.

## 2.5 Compliance with rehabilitation services

### 2.5.1 Definition of compliance

Compliance is a complex issue<sup>101</sup> and is a multidimensional concept<sup>102 103</sup> with neither a single theory to explain nor measure it.<sup>104</sup> Even though it has been a subject of research for more than four decades now, its definition and strategies to combat it have remained elusive.<sup>105</sup> Furthermore, given its negative implications on treatment efficacy and strain on resources<sup>4 104 105 106</sup>, there is a great need assess it.<sup>107 108</sup>

Complexity of compliance is reflected in the multiple definitions that have been postulated. The generic definition of compliance is “...the extent to which a person's behaviour in terms of taking medication, following diets, or executing life-style changes coincides with medical or health advice”.<sup>104</sup> (page 332). In the context of physiotherapy, compliance would therefore imply the extent of adherence to prescribed appointments, educational activities, following advice from treating physiotherapist and/or a home exercise regimen.<sup>4 5</sup> On the contrary, non-compliance can be defined as “not adhering to prescribed physical therapy appointments, educational activities, and/or a home exercise regimen” .<sup>102</sup> (page 87). Compliance and adherence are used interchangeably in literature<sup>102 105</sup> and as such, the two terms will be used interchangeably in this text .

### 2.5.2 Compliance rates of physiotherapy treatment

Research points at high rates non-compliance with physiotherapy treatments, and this is also universal to other health care disciplines.<sup>4 109</sup> This is vibrantly expressed by Vermeire et al who stipulated that “poor compliance is to be expected in 30±50% of all patients, irrespective of disease, prognosis or setting.”<sup>104</sup> (page 334) Literature reports of 34-51% compliance rate with physiotherapy treatment for neck and low back pain.<sup>102 107</sup> This variability in non-compliance rates has been partially attributed to a lack of a standardized definition of compliance.<sup>102</sup>

Not much is known about adherence rates in paediatric physiotherapy.<sup>101</sup> A qualitative study by Chappell and Williams (2002), revealed a 54.4% non-compliance rate in patients with cystic fibrosis.

<sup>101</sup> Furthermore, other authors postulated that non-adherence with physiotherapy treatment regime and exercise performance could be as high as 70% and could be worse in unsupervised home exercise programs.<sup>4</sup> It therefore warrants the assessment of compliance with physiotherapy appointments as adherence ultimately affects the efficacy of therapeutic interventions.<sup>101</sup> Therefore it becomes paramount to explore the factors affecting compliance rates.

### **2.5.3 Factors influencing compliance**

Compliance is a multi-dimensional concept and its determinant factors can be classified into the following categories: psychological, social and personal factors, disease related factors, economic factors and health care related factors.<sup>4 101 102 105</sup>

#### **2.5.3.1 Psychological factors**

Psychological variables such as emotional state of patient affect compliance with treatment. Literature states that anticipated difficulty in home exercise program is the strongest predictor in compliance.<sup>102 103</sup> This perceived difficulty is also affected by variables such as pain tolerance and self-efficacy.<sup>103 109</sup> In the same vein, highly perceived functional gain and or pain relief is positively correlated to compliance.<sup>109</sup>

Personal motivation also affects compliance rates as patients who are motivated are more likely to be compliant.<sup>109 110</sup> Additionally, patients' beliefs and attitude can also impact compliance.<sup>104 105 109</sup> In essence, perceived improvement is associated with compliance with treatment<sup>5 109</sup> as this also improves the self-efficacy of the clients. Furthermore, perceived efficacy of interventions can also increase compliance.<sup>109</sup> However, a research by Alexandra et al revealed that compliance was not associated with depression or health locus of control in low back pain patients.<sup>102</sup>

#### **2.5.3.2 Social and personal factors**

Availability of social supports and family lifestyle may influence on the rate of compliance.<sup>104 110</sup> Research in LBP patients has shown that married patients are more likely to be more compliant with the home exercise program (HEP).<sup>104</sup> This is more so if the spouses are physically active.<sup>110</sup>

Patient age<sup>101</sup> also affects compliance and older age has been shown to be associated with a lower rate of compliance.<sup>104</sup> This is partly explained by cognitive changes such as loss of memory which increases the incidence of forgetting the prescribed HEP or missing scheduled appointments.<sup>66 104 111</sup>

#### **2.5.3.3 Treatment-related factors**

Complexity of exercises may affect the rate of adherence to the home exercise program. Complex exercise routines may lead to non-compliance<sup>112</sup> as highly perceived difficulty exercises are associated with high rates of non-compliance.<sup>110</sup> Further, the length of treatment also affects

compliance rates, for instance, lower rate of compliance has been demonstrated to be associated with longer treatment periods in LBP patients.<sup>102</sup> Additionally, the nature of relationship between health-care professional also affects compliance. Therefore, effective communication and a trustworthy relationship are essential in this regard, i.e. a relationship which is characterised by shared decision making especially in the area of booking appointments and goal setting.<sup>104</sup> A systematic review on the barriers of adherence in physiotherapy in outpatient states that low in-treatment adherence is a very strong predictor of non-compliance.<sup>103</sup> This reiterates the need for professionals to constantly monitor, provide feedback and assess compliance with prescribed exercises during the treatment sessions.<sup>113</sup>

#### **2.5.3.4 Disease-related factors**

Patient condition affects long-term compliance<sup>101</sup>, in essence, compliance is poor in chronic conditions such as LBP, arthritis and motor disorders in children.<sup>102 104 110 112</sup> The severity and prognosis of a condition may also affect compliance with treatment. For example, patients with mild back pain are more likely to be compliant as their symptoms may resolve in a shorter period of time.<sup>102</sup> This is a different in motor disorders<sup>110</sup> such as CP which may require a lifetime commitment to therapy.

#### **2.5.3.5 Economic factors**

Lack of financial resources can affect compliance with appointments and HEP.<sup>114</sup> Patients may fail to turn up for scheduled appointments because of financial strain.<sup>114</sup> Secondly patients may fail to comply with HEP especially for HEP which require the purchase of equipment to utilize at home as part of the HEP.<sup>102</sup>

In summary, a survey of Ontario chiropractors to assess their views on the maximization of patient compliance, the following variables were found to be strong predictors of non-compliance<sup>111</sup>:

- low level of motivation
- sedentary fitness levels
- low level of pain tolerance
- low self-esteem levels
- inexperience with exercises<sup>111</sup>

#### **2.5.4 Effects of non-compliance**

Non-adherence affects the treatment outcomes, the caregiver, professionals delivering the treatments and consequently leads to a strain on the health care delivery system.<sup>101 102 104</sup> Non-compliance can lead to delayed progress<sup>104</sup> as treatment outcomes may depend on the intensity

and frequency of treatment which are all affected by rate of compliance. It can also lead to unnecessary alteration of treatment regimens<sup>102 104 105</sup>. This leads to wastage of resources (both human and financial) and may prolong treatment time<sup>105</sup> and this can be a source of frustration to healthcare practitioners.<sup>102 104 105</sup>

Further, prolonged treatment time will result in economic burden on the part of caregivers as treatment becomes costly<sup>104 105</sup> given that non-compliance also leads to diminished clinical outcome/efficacy.<sup>101 102 104</sup> It can be seen therefore that non-compliance perpetuates a vicious cycle.<sup>105</sup>

### 2.5.5 Barriers to compliance

It's essential to identify barriers to compliance so as to come up with resolutions to combat non-compliance.<sup>105</sup> Lack of time is the most cited barrier to compliance.<sup>102 104 111 112</sup> In a qualitative study to explore non-compliance with home exercises in paediatric physiotherapy, lack of time was cited as the major stumbling block. On the same wavelength, a survey of chiropractors' perceived barriers to compliance revealed that 91.4 % of non-compliance can be attributed to lack of time. Additionally, lack of time makes it hard to integrate home exercise programs into the patient's busy schedule<sup>102 112</sup> and a busy schedule and inherent forgetting<sup>111</sup> leads to non-compliance. In the same vein, a working schedule can also act as a barrier to compliance.<sup>102</sup>

Patient's belief systems<sup>104 112</sup>, attitude towards therapy<sup>105</sup> and motivation<sup>109</sup> have a bearing on compliance. For instance, in LBP patients, perceived efficacy of interventions has been demonstrated to impact compliance. Highly perceived/anticipated benefit from exercise is associated with compliance with keeping appointments and adhering to the HEP.<sup>102 109</sup> Furthermore, "wrong beliefs" due to inadequate knowledge may also act as a barrier to compliance.<sup>105</sup>

Perceived severity of condition also affects compliance. In a qualitative study exploring compliance with exercise in knee pain patients, those experiencing severe pain and or loss of mobility were the ones who were more likely to be compliant.<sup>109</sup> Additionally, beliefs towards causes of a condition affect subsequent compliance with exercise. In essence, for patients who suffered from arthritis of the knee, those who believed it to be cause by immutable factors such as age, obesity had a more resigned attitude towards arthritis and were less likely to be compliant.<sup>112</sup> Perceived difficulty with exercises has been shown to lead to non-adherence with HEP.<sup>102</sup>

Logistical issues also can lead to non-compliance, for instance, transport problems<sup>102 115</sup> are cited as one of the barriers to compliance with appointments. This is very important to note especially in the context of low income nations where there is no adapted public transportation for people with

disabilities.<sup>115</sup> In the same vein, lack of financial resources for instance lack of bus fare is also a barrier to compliance.<sup>102 105</sup>

Pain has also been shown to hinder the progression of exercises.<sup>111</sup> This can be during treatment sessions or in executing home exercise programs.<sup>103 111</sup> Likewise, complex exercises with potential negative effects such as pain and swelling decrease the likelihood of compliance.<sup>109 112 116</sup> Pain can lead to a child becoming irritable during exercises forcing the caregiver to abandon the session<sup>101</sup> thus affecting compliance with HEP. On the contrary, positive effects such as increase in QOL can result in increased compliance.<sup>112</sup>

The nature of the patient/practitioner relationship also affects the extent of compliance and a poor relationship may lead to non-compliance.<sup>105</sup> This relationship is affected by factors such as perceived ownership. For instance, lack of ownership of the program can lead to non-compliance i.e. if goals of exercise are not clearly stated, understood and agreed upon between the service provider and client.<sup>112</sup> More so, lack of feedback and monitoring by the professionals may also lead to non-compliance.<sup>112</sup>

Characteristics of the patient/caregiver also affect compliance. In essence, patient's self-efficacy, locus of control, and level of motivation<sup>107</sup> all have a bearing on compliance. For instance patient with low self-efficacy, diminished locus of control and demotivated are likely to be non-compliant with treatment.<sup>107 109</sup>

Other factors such as lack of clinical knowledge about the disease<sup>112</sup>, lack of social support<sup>107</sup>, patient finding the exercises boring and monotonous<sup>111</sup> and burnout<sup>101</sup> may all lead to non-compliance with treatment.

#### **2.5.6 Ways of enhancing compliance**

It's essential that multiple interventions/strategies be considered to enhance compliance, given its multidimensionality.<sup>4 103</sup> These multi-interventions should combine educational and behavioural strategies.<sup>104</sup> Additionally, it's paramount to formulate specific strategies to combat short and long-term compliance, as they are two distinct constructs<sup>102</sup> especially considering that long-term compliance is notoriously difficult to achieve and maintain.<sup>4</sup> In a survey of Ontario chiropractors to assess their views on the maximization of patient compliance, the following variables were found to be strong predictors of compliance, high levels of motivation, self-esteem, fitness and pain tolerance as well as experience with exercises.<sup>111</sup> As such, it can be hypothesized that working on these and other variables is crucial in attaining compliance.

Working on the psychological indices can help in enhancing compliance with treatment. This can be achieved by strategies such as exercise counselling<sup>105 107</sup> especially on the benefits and the importance of exercise.<sup>111</sup> Motivating the patients<sup>4 110 111</sup> also helps to improve compliance. The practitioner can motivate clients by explaining the exercises in a positive and enthusiastic manner.<sup>111</sup> Motivation can be used with other behavioural strategies<sup>104</sup> such as encouragement, support and praise to enhance compliance.<sup>111</sup>

Patient education is essential in increasing compliance and satisfaction.<sup>8 90</sup> Therefore, knowledge about the impairment and how therapy will help to ameliorate the impairments is very essential. In essence, caregivers of children with CP should thus be counselled on the importance of compliance with appointment and home exercise programs.<sup>5 104</sup>

Improving the self-efficacy of a patient also helps in improving compliance. Health beliefs have an impact on patient adherence behaviour according to the health beliefs model.<sup>110</sup> For instance in LBP, perceived benefits of exercise in reducing pain has been demonstrated to lead to higher compliance with prescribed exercises.<sup>112</sup> Behavioural techniques such as positive reinforcement, goal setting and contracting between patient and therapist have been shown to enhance compliance.<sup>113</sup>

The attitude of the health care professionals is also essential if patients are to be compliant with treatment. A good professional-patient relationship enhances compliance<sup>104 105</sup> thus it is essential to build a solid rapport with patients.<sup>111</sup> This therefore entails a paradigm shift from a biomedical approach to a bio-psychosocial approach to care to enhance attainment of compliance. This is vividly expressed by the following statement by Vermeire et al (2001) that there is need “... to abandon the paternalistic approach to the patient and to consider him as a partner, sharing decisions after being appropriately informed”<sup>104</sup> (page 340) Furthermore, health care professionals should recognise that adherence barriers are unique to every patient which warrants collaboration with the patient in drafting a realistic treatment plan.<sup>103 109</sup> This reiterates the need to involve the client in scheduling appointments so that they can be in line with their schedules.<sup>101</sup> Over and above, the patient should be involved in the prescription of the HEP in such a way that exercises can be integrated into the patient’s daily routines taking into cognisance the fact that lack of time is one of the chief barriers to non-compliance.<sup>109 112</sup>

The therapists’ clinical and interpersonal skills are also essential in promoting adherence.<sup>105 112</sup> Proper instruction<sup>110</sup>, keeping instructions simple<sup>111</sup> and more input/feedback and supervision from physiotherapists during treatment sessions also<sup>109 111 112 113</sup> helps to improve variables such as self-efficacy thus ultimately improves patient compliance. Findings from a study on measuring adherence

to rehabilitation in LBP patients (n=105)<sup>113</sup>, points at a significant, positive correlation between compliance with HEP and in-treatment adherence. Furthermore, at 4 weeks, there was a significantly positive correlation between in-treatment adherence and the physiotherapists' perceived efficacy of rehabilitation treatment.<sup>113</sup> It thus becomes essential that professionals should monitor treatment outcomes and adherence to exercises<sup>112</sup> so as to early detect non-compliance and mitigate it. This may imply limiting the number of exercises in a program<sup>112</sup> or altering the HEP especially modifying the most difficult components of the HEP.<sup>113</sup>

Home exercise programs are essential for attainment of optimal treatment outcomes and this is very important to consider in CP rehabilitation.<sup>101</sup> As such, it becomes paramount to assess the patient's understanding and correct performance of exercises. This can be achieved by demonstrating the exercises and asking the patient to demonstrate back on the first and subsequent visits.<sup>111</sup> Monotony is one of the causes of non-compliance, therefore regular reviewing of home programs is crucial to avoid monotony.<sup>101</sup> Furthermore, as lack of time is one of the chief barriers to compliance, limiting number of exercises and graduated progression of exercise prescription can also aid compliance.<sup>111 112</sup>

The economic implications of treatment on the patient should also be considered in drafting a treatment program.<sup>105</sup> Therefore, client should be consulted on the affordability when scheduling appointments and drafting HEP. For instance, prescribing exercises that require low-cost equipment such as gym-balls<sup>111</sup> has been demonstrated to enhance compliance.

Literature cites that the usage of reminders especially in a written format helps to enhance compliance.<sup>112</sup> Additionally, use of complementary, multimedia methodologies such as DVD<sup>110 111</sup> as opposed to traditional instructional sheets only may help in improving adherence. A pilot study to assess compliance and utility of a home exercise DVD for caregivers of children and adolescents with brachial plexus palsy revealed the following:<sup>110</sup>

- the DVD increased the caregivers motivation to perform the exercises
- use of the DVD is cost efficient and effective strategy of increasing compliance
- was a more popular alternative to the written hand-out
- resulted in increased confidence in the correctness of exercises performed

Results from another study produced contrasting results from the fore mentioned study. Lysack et al (2005) carried out a comparison study to measure compliance and satisfaction with home exercise between computer-assisted video instruction and routine rehabilitation. Forty patients were randomly assigned into the experiment group (n=18) which received additional exercise instruction

and the control group (n=22) which received routine rehabilitation. At 4 weeks, there were no statistically significant differences between the groups in terms of satisfaction and adherence to home exercise programs. This trial thus negates the hypothesis that videos can enhance compliance with home exercise programs as compared to conventional methods such as use of instructional sheets and demonstrations.<sup>117</sup> The contrast in findings may warrant further probing into the utility of use of multi-media strategies in enhancing compliance.

## 2.6 Models of service delivery

### 2.6.1 Introduction

As the purpose of this study is to compare the impact of IBR with CBR, in the form of an outreach programme (OP) this section discusses different models of service provision with regards to CP rehabilitation. There is little consensus as to the model in which OPs should be situated. Some authors classify OP under IBR,<sup>118 119</sup> whilst others place these programs under CBR.<sup>24</sup> Literature reports on service delivery models which are a blend of IBR and CBR, for instance The Association for the Disabled of Kenya (APDK) which works in hand with the Ministry of Medical Services Kenya in the provision of rehabilitation services.<sup>120</sup> The APDK sources funds whilst the government provides therapists and technicians as well as paying their salaries. Services are provided at hospitals, outreach centres and within the community. For instance, clients identified during community visits are referred either to the outreach centres or hospitals. This referral system depicts integration of IBR, CBR and OPs.<sup>120</sup> Furthermore, CBR is an exceedingly broad phenomenon, and as such there is no universal conceptualization of CBR<sup>24</sup>, and its implementation varies markedly from country to country.<sup>32</sup> Some CBR projects, for example, are reported to be “...*expert-based, outreach programmes from local hospitals*”<sup>24</sup> (page 247). On the contrary, other CBR solely involves community work for instance the Kwale District Eye Centre program in Kenya.<sup>120</sup> The aim of the program is to sensitize communities and advocate for rights of children with albinism.<sup>120</sup>

### 2.6.2 Outreach based rehabilitation

Partapuri, Steinglass, & Sequeira (2012) defined outreach as , “...*planned, regular, and periodic single-day visits by qualified staff from a health facility to populations located 5–15 km from the facility...*” .<sup>121</sup>(page 20). Bowman et al (2008) further defines specialist OP as “...*a model of health care, whereby a specialist health service is provided to a community on a visiting basis*”.<sup>6</sup>(page237) The essence of outreach in terms of rehabilitation is therefore a system/model wherein rehabilitation professionals based at specialized centres travel to perform rehabilitation treatments in the community.<sup>122</sup>

### 2.6.3 Types of outreach programs

Organization and structuring of outreach service provision, is markedly different in diverse settings.<sup>6</sup> However, according to Citters and Bartels (2004), *“The primary elements of outreach services include case finding, assessment, referral, treatment, and consultation”*.<sup>123</sup> (page 1238) Outreach visits can be specifically be designed to meet a particular health service need, for instance immunization.<sup>121</sup> In addition, OPs can be used for other complimentary functions thus maximizing resources utilization.<sup>121</sup> This is of uttermost importance in low income countries like Zimbabwe which faces formidable challenges in financing the health delivery system. Other outreach programs are characterised by a team of healthcare practitioners providing various services.<sup>124</sup> For example, the SOS program in Australia which provides medical, gynaecological, ophthalmology services to marginalised populations 124

Elsewhere, Lemaire et al.<sup>125</sup> describe a Canadian physical rehabilitation outreach program for adults with disabilities. The goal of the OP was for the provision of rehabilitation services, health education and promotion and advocacy for PWDs by educating and mobilising the community.<sup>125</sup>

Literature also describes a form of outreach “camps”. This is a system whereby a team of professionals from a base hospital goes into the community and camps there and provide services for some days before returning to base station. This model is described as the Aravind model in Nepal and has been used in the provision of ophthalmologic services.<sup>119</sup>

Daiski (2008) describes a health bus outreach model of health services provision to the poor and marginalized population of downtown Toronto, Canada. A specialised bus moves from one part to the other and is staffed by nurses who provide basic primary health care. The recipients of the services showed appreciation in focal group discussions on this innovate yet flexible way of service provision.<sup>126</sup> It can be seen that organisation and aims of outreach programs vary from setting to setting.

### 2.6.4 Principles of outreach programs

Access to health care is a determinant to health<sup>31</sup> and as outreach is done within the service recipients’ community, it helps to increase geographical access.<sup>122 127 128</sup> Outreach has also been found to improve service access to remote and underserved populations<sup>128</sup> as it saves recipients from the costs<sup>122 129</sup> and time of travelling.<sup>121 122 130</sup> Outreach can also be integrated with local services thus increasing their sustainability.<sup>6</sup>

Compared to outpatient clinics, outreach clinics are more cost efficient to the patient in terms of lower costs and time used for travelling to access services.<sup>122 131</sup> The use and mobilization of

community resources, for instance, in the utilization of community volunteers, lowers operational costs thus making outreach cost effective.<sup>32</sup>

According to Bowling & Bond (2001),<sup>131</sup> outreach has better outcomes in terms of patient satisfaction, service delivery efficiency and higher compliance compared to outpatient services. In contrast, , Bowmen et al. (2008),<sup>6</sup> carried out a retrospective descriptive study to compare rehabilitation outcomes of patients receiving treatment under a rural outreach program and those receiving care at a city rehabilitation institution. The results revealed comparable functional outcomes were achieved by clients who received care under the rural outreach thus demonstrating that outreach is equally effective as a service delivery model.<sup>6</sup>

Social support is essential in alleviating the burden of caregiving.<sup>28</sup> Since outreach is held within the clients' neighbourhood and there are no travelling costs involved ,it affords the family an opportunity to accompany the patients for treatment.<sup>124 130</sup> Furthermore, as outreach is done in the service recipients' community, familiarity with treatment environment and having family support<sup>124</sup> may serve as enhancers to compliance.

Outreach also increases health practitioners' understanding of patients' socio-economic barriers to compliance to health care advice and utilization.<sup>128</sup> This improved understanding of barriers facing clients, gives the practitioners the capacity to adjust treatment schedules accordingly.<sup>128</sup> Over and above, the essence of outreach can be summarised in the following statement by Gruel et al. (2006, page ),*"Overcoming travel-related difficulties, having familiar surroundings, family, and staff available at on-site consultations, and improved communication between all parties were perceived to be important benefits of outreach clinics"*.<sup>124</sup>

On the contrary, operational costs such as staffing travelling and reimbursement costs are unique to outreach, thus rendering it expensive as compared to the outpatient model.<sup>132</sup> Contrastingly, results from the evaluation of a specialist outreach program to improve access and equity for indigenous people in remote Australia, indicated outreach resulted in decrease in costs of up to A\$173 per single consultation.<sup>128</sup> This therefore warrants further exploration into the efficacy of OPs.

### **2.6.5 Efficacy of outreach programs**

Evaluation is essential to ascertain the extent to which a program meets the needs of targeted recipients.<sup>133</sup> Further, evaluations help in the accounting of resources utilization as well as serving as a baseline for future planning.<sup>125 133</sup> Our search for literature did not yield any reports on the evaluation of outreach programs for children with CP/ physical disabilities. Further, Bowman et al. cites that there is a paucity in the efficacy of rehabilitation outreach programs.<sup>6</sup> However, evidence

from a systematic review on the efficacy of community-based , outreach programs for the provision of mental health services in the geriatric population points to the efficacy of outreach services in increasing access to services and improved therapeutic outcomes.<sup>123</sup>

McGovern et al.<sup>132</sup> evaluated the efficacy of a mental health outreach program for the elderly in rural parts of the USA. Their outcome measures included: the Government Performance and Results Act Instrument which measures life satisfaction, independence, overall health and psychosocial functioning.<sup>132</sup> Additionally, the Geriatric Depression Scale, Mini-Mental State Examination and Instrumental Activities of Daily Living Scale were also administered. Data collected from the 720 participants revealed that as compared to baseline, the subjects exhibited decline in depression, improved functioning in instrumental ADLs, greater satisfaction. Even though, they were no apparent changes in overall health status, outreach seemed to improve the quality of life of elders with mental health problems. Further, the program also managed to advocate for the health and quality of life of the elderly with mental health problems in the community. However, the relatively higher operational costs, posed a threat to the sustainability of the outreach program.<sup>132</sup>

Outreach programs have also been demonstrated to be efficacious in the provision of specialist surgery<sup>124</sup>. Gruen et al.<sup>124</sup> conducted an evaluation of the effect of outreach on access and treatment outcomes. They reviewed records of 2368 patients attended to at remote three sites in Northern Australia. Under the program, a team of specialists visited the sites between one to four times annually. The specialists would perform some minor surgical procedures with complicated cases being referred to the regional hospital. Results indicated that outreach improved access and utilization of specialist services which inherently led to improved health outcomes in the marginalised communities. Further, it also improved the identification/screening of cases that required specialist treatment as outreach facilitated their referral to specialist centres. Moreover, outreach also *"... led to opportunistic attendances by patients who had not been referred, and in many cases had not previously been seen at the clinic for that problem"*.<sup>124</sup>(page 136)

As, the organization and execution of outreach programs varies, the type of outreach program may serve as an indicator for economic efficacy.<sup>119</sup> Kendal et al.<sup>119</sup> carried out an economic evaluation of two ophthalmic outreach programs in Nepal. For the first model, healthcare practitioners visit the community, screen patients, offer basic ocular services and refer more complicated cases to the base hospital. In the bid to reduce operational costs, the hospital reduced the number of outreach outings, number of sites and introduced a new outreach model. Under the new camp model, the outreach team would "camp" in the community for a couple of days before returning to the base hospital. A comparison was made of the "orthodox" program with that of the new model and

efficacy was based on program costs, services utilisation and extent of access to services. Findings from the study revealed that, concentrated camps were associated with decline in operational costs.<sup>119</sup> Furthermore, coverage remained relatively the same compared to the “orthodox” model.<sup>119</sup>

Further, Bowman et al.(2008)<sup>6</sup> compared the outcomes of patients treated under an outreach program against an IBR. The results indicated that recipients of outreach services exhibited comparable functional gains as measured by the FIM. Further length of stay was shorter in outreach model of care. This reiterates the efficacy of outreach as a model of service delivery.<sup>6</sup>

### **2.6.6 Sustainability of outreach programs**

Given the potential benefits and costs associated in running programs, there is need to ensure the sustainability and continuity of care in outreach programs.<sup>128</sup> Firstly, there is great need to integrate services so as to minimise costs and avoid duplication and completion for services.<sup>121 128</sup> For instance, literature reports of outreach programs which combine various primary health services such as immunization and nutrition.<sup>121</sup> However, the inherent challenge is that this can lead to the decreased efficacy of services as the staff may be overwhelmed with responsibilities.<sup>121</sup>

For outreach program to be successful, they need to be fully resourced.<sup>125 128</sup> This is in terms of human and financial resources.<sup>125 128</sup> One of the inherent conflicts arises from the need to balance roles of health care practitioners at the base institution and for the outreach programs.<sup>128</sup> Therefore careful planning becomes paramount.<sup>128</sup> Furthermore, there is need to regularly evaluate the outreach programs.<sup>128</sup>

One of the greatest challenges to community based treatment programs is the high attrition rate of community volunteers and it's essential to put in place measures to minimize it. As such incentives become paramount and they present another cost if the community-based programs are to be sustainable.<sup>31</sup> Given all this, community-based care is overall cost effective as compared to IBR as expenses are inevitable in both models. Additionally, literature reports that most services recipients preferred community-based interventions to hospital-based interventions.<sup>24</sup>

### **2.6.7 Community based rehabilitation**

As the CRU Outreach is modelled on the CBR approach<sup>26</sup> it is relevant to discuss how CBR principles are upheld in this model of service provision.

#### **2.6.7.1 Definition of CBR**

According to ILO, UNESCO & WHO (2010), “*CBR is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their*

*families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services".*"<sup>2</sup>(page 2)

The roots of CBR can be traced back to the Declaration of Alma of Atta<sup>134</sup>, the initial thrust was for provision of rehabilitation services as a situation analysis revealed that only 10 % of people in need of rehabilitation services in the developing countries actually had access to the required services.<sup>135</sup> Since its inception three decades ago, CBR has greatly evolved in terms of scope.<sup>2 31 32 33 34</sup>

#### **2.6.7.2 Principles/characteristics of CBR**

One of the aims of CBR is to provide regular access to services.<sup>2</sup> The thrust of the Outreach program is to provide regular therapeutic services to CWDs within their community.<sup>26</sup> The International Classification of Functioning, Disability and Health (ICF) takes into cognisance environmental factors that limit participation.<sup>57</sup> One of the goals of CBR is to sensitize communities in the bid to remove participation barriers for people with disabilities.<sup>2</sup> The CRU Outreach program strives for inclusion of CWDs in the communities and one of the strategies has in holding stakeholders meeting in various suburbs for the benefit of CWDs and their caregivers.<sup>26</sup>

CBR strives to promote the rights of people with disabilities, for instance its emphasis on the right to education for CWDs.<sup>2</sup> Further, CBR programs work in hand with organizations lobbying for the rights and inclusion of PWDs.<sup>34</sup> The CRU works in conjunction with ministry of education and relevant partners in the bid to lobby for inclusive education for CWDs.<sup>26</sup> On the same wavelength, inclusion is one of the fundamental concept of CBR.<sup>2</sup>

Community involvement is key to the success and sustainability of CBR programs.<sup>2 34</sup> At the community level, there are community volunteers whose role is to identify and refer early CWDs in the community for rehabilitation. They also make follow up visits to the cases identified within the community.<sup>26</sup>

CBR programmes can facilitate access to health care for people with disabilities by working with primary health care in the local community, providing the much needed link between people with disabilities and the health-care system.<sup>120</sup> The CRU utilises some of the local primary health care clinics as sites for outreach. This assists in increasing the efficiency of the referral system.<sup>26</sup> Further, this is also an illustration of the use of local resources in CBR programs to ensure sustainability.<sup>2 31 32</sup>

33 34

CBR strives towards improving QOL of service recipients<sup>32</sup>. Some CBR programs aim at income generation for PWDs thus empowering them and delivering them from the vicious cycle of poverty-disability. According to the WHO,<sup>31</sup> there is a correlation between disability and poverty and as such

the disabled are among the poorest, and they live in poor conditions which exposes them further to other comorbidities and disabilities. The CRU has managed to sponsor some of the caregivers to start income generating projects to relieve them of the financial burden associated with long term care.<sup>26</sup>

Boyce and Paterson<sup>136</sup> report of various CBR programs for CWDs in Nepal with very divergent scope and focus. For instance some focus on CWDs, some on CWDs and their families. Common to the programs is that funding for the programs is mostly by foreign donors. The general scope of the programs can be summarised as follows:<sup>136</sup>

- advocacy and awareness promotion activities
- provision of medical and rehabilitation services
- provision of aids and appliances
- networking and parent support groups
- promotion of inclusive communities e.g. integration of CWDs into mainstream education
- home visits

### **2.6.7.3 The efficacy of CBR programs**

Community based rehabilitation has been in existence for more than 3 decades<sup>31 32 33 34</sup> yet little is known about its efficacy, effectiveness, relevance, appropriateness and sustainability as a service delivery model and public health strategy.<sup>35 36 37</sup> this has been attributed to the following:

- Differences in the conceptualization and implementation of CBR in different settings<sup>37</sup>
- Since its inception three decades ago, CBR has greatly evolved in terms of scope<sup>2</sup>
- Lack of standardized evaluation methods and techniques<sup>36</sup>

### **2.6.8 Institution based rehabilitation (IBR)**

#### **2.6.8.1 Definition of IBR**

Rehabilitation services have been traditionally provided through institutions.<sup>23 24</sup> Institutions range from hospitals to specialized rehabilitation centres and homes for the disabled.<sup>22 120</sup> IBR services can be further be divided into inpatient and outpatient services.<sup>22</sup>

#### **2.6.8.2 Efficacy of IBR services**

Availability of specialised equipment and services gives IBR services an edge against outreach services.<sup>137</sup> Likewise, IBR is advantageous for medically unstable patients<sup>137</sup>. Further, only minor procedures or less complicated cases can be attended during outreach services.<sup>124 125</sup> The referral to specialised can be viewed as form of “burden” on the part of patients. Whereas, IBR ensures a more

smooth referral pathway.<sup>137</sup> This also improves the interdisciplinary networking thus IBR may lead to more efficient services as it enables sharing of experiences among practitioners within the same institution.<sup>137</sup> Contrastingly, immediate consultations with other members of the medical team may be hard to achieve as the outreach team may not constitute all members of the interdisciplinary team.<sup>119</sup>

However, literature reports that IBR is generally expensive.<sup>24 135</sup> According to Mitchell<sup>32</sup>, *“Institution-based rehabilitation is very costly and provides no more than about 3% of the rehabilitation needs of individuals and populations”*<sup>32</sup>. Likewise, a qualitative study carried out by Hams and Kobusingye (2009) in exploring the factors influencing the utilization of outpatient rehabilitation services in Uganda revealed that transport costs were cited as the most stumbling block for patients in accessing services.<sup>138</sup> Further, they reported that coverage of services is low in institution based rehabilitation services.<sup>22</sup>

## 2.7 Description of services

### 2.7.1 The Children Rehabilitation Unit Rehabilitation Services

The Children Rehabilitation Unit (CRU) is a specialized paediatric rehabilitation centre and is the largest paediatric rehabilitation referral centre in Zimbabwe. It is located at Harare Central hospital which is the largest referral centre in Zimbabwe.<sup>20 139</sup> It was established in 1986 as a joint project between the University of Zimbabwe, Harare Central Hospital and Ministry of Health and Child Welfare Zimbabwe (MOHCWZ). The primary objective was to support and compliment the MOHCWZ CBR policy.

The MOHCWZ provides the unit with human resources and at the time of writing of this article the unit was staffed with 1 PT, 2 OTs, 4 RTs, 1 counsellor, a visiting paediatrician as well as administrative staff. The JF Kapneck Trust mobilises financial resources for the financing of the unit's activities. This is an example of a private sector/ government partnership in the provision of health services.<sup>120 139</sup>

Services offered at the CRU range from treatment services, advocacy workshops, health care students teaching program, workshops and facilitation of support groups for various paediatric conditions to financial assistance schemes.<sup>26</sup>

Once a child is diagnosed with CP, they are referred for therapy as they concurrently get medical assistance. Ideally the child receives treatment from rehabilitation professionals within the unit, until the caregiver has fully comprehended the home exercise program and has been empowered with knowledge of the child's condition. Thereafter, they are discharged to the nearest outreach group. In

case of those who reside outside the outreach coverage zones, they are booked for treatments on Fridays at the unit.<sup>26</sup>

## 2.8 Review of data collection tools/instrumentation

### 2.8.1 Introduction

The efficacy of a particular service model is an extremely broad issue thus it was deemed appropriate to consider multiple outcome measures for the comparison of the models under scrutiny. This section presents the review of the tools we utilised for data collection. Where applicable, we discussed the merits and the disadvantages of some of the commonly used outcome measurements and then concluded by justification of the selection of a particular tool.

### 2.8.2 Tools for measuring physical activity/ motor function

There is great need to come up with valid functional outcome measures for children with CP. Although various assessment tools are at disposal, most of them do not capture the impact of CP on functional outcomes.<sup>54</sup> Most of the tools measure developmental performance, gross motor function and postural control.<sup>140</sup>

#### 2.8.2.1 Gross Motor Function Measure-88 (GMFM-88)

The GMFM is a condition specific,<sup>54</sup> standardized and validated ordinal scale which measures changes in motor function in children with CP.<sup>54 141 142</sup> It is applicable for CP children between ages of 5 months and 16 years.<sup>54</sup> The GMFM-88 is a criterion-referenced, 88-items scale which is scored on a 4 point Likert scale. It is scored in five dimensions i.e. lying and rolling; sitting; crawling and kneeling; standing and walking, running and jumping.<sup>142 143</sup> In terms of its psychometric properties, the GMFM-88 has an excellent reliability, has good responsiveness to change and high internal consistency.<sup>54 142</sup> It can be administered by Physiotherapist or a trained health professional. The following items are required for the measurement of GMFM: a mat, bench, toys, stairs and a smooth surface.<sup>54</sup> The weaknesses of the GMFM-88 are that it takes a lot of time to complete and has ceiling and floor effects.<sup>54</sup>

#### 2.8.2.2 Paediatric Functional Independence Measure (WeeFIM)

The WeeFIM is a valid and reliable, generic paediatric functional outcome measure which is modelled on the FIM.<sup>144</sup> It consists of 18 items that assess functional performance in the domains of self-care, mobility and cognition.<sup>145</sup> The specific domains are: self-care (3 items), sphincter control (2 items), transfers (3 items), locomotion (2 items), communication (2 items) and social cognition (3 items).<sup>144</sup> Performance is rated on a 7-ordinal scale and the ratings are as follows<sup>108</sup> :

- 1 - total assistance, subject exerts 0% - 24% effort
- 2 - maximal assistance , subject exerts 25% - 49% effort
- 3- moderate assistance , subject exerts 50% or more effort

- 4 - minimal assistance , subject exerts = 75% or more effort
- 5 - supervision
- 6 - complete Independence
- 7 - modified Independence

The WeeFIM instrument can be administered through direct observation, interview, or a combination of observation and interview. It takes 20 minutes or less to administer the WeeFIM. All the items on the 18-item ordinal scale have to be rated to come up with a score, which ranges from 18 to 126. The WeeFIM instrument is designed for use by a variety of professional and training is essential for accuracy in ratings.<sup>144</sup>

### 2.8.3 Tools for measuring the burden of caregiving

Cerebral palsy is a lifetime condition<sup>3</sup> and caregivers are involved on a daily basis in the management of these children. Prolonged care giving has been found to have a straining effect on the caregivers<sup>146 147</sup> thus the need for measuring the extend of burden. A systematic review revealed that there are more than 74 tools measuring the burden of care and these tools have been utilised in different settings.<sup>148</sup> Given, the extensive base of tools, we only reviewed the CSI which we used for data collection as it seem to cover all the facets of burden of care as discussed in the literature review section on burden of care.

#### 2.8.3.1 Caregiver Strain Index (CSI)

The CSI is a validated and reliable tool for measuring the burden of care giving.<sup>147</sup> The respondents are required to respond with yes or a no. A yes is given a score of 1 and a no a score of zero. Summation of yes responses gives the total score which ranges from 0 to 12. A score of 7 or more signifies a high level of stress.<sup>149</sup>

### 2.8.4 Tools for measuring Health-Related Quality of Life

There is no universal definition for health related quality of life.<sup>150</sup> According to the WHO, quality of life is defined as *“individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concern”*.

<sup>7</sup>(page 5) HRQoL is a more holistic and contemporary outcome measure of the effects of caregiving.<sup>28</sup> Various tools can be used to measure changes in families QOL as an outcome measure for evaluations.<sup>151</sup> The most commonly used tools include the SF-36 and EQ-5D and these have been used in previous studies measuring the HRQoL in caregivers of children with CP. <sup>58 84 152 153155 157</sup>

#### 2.8.4.1 The EQ-5D

The EQ-5D is a standardized and validated tool to assess Health Related Quality of Life (HrQOL) in adults and was developed by the EuroQol Group.<sup>154</sup> In the first section of the tool, respondents rate their own health in the following 5 domains:

- mobility
- self-care
- usual activities (work, study, housework, family/leisure)
- pain/discomfort
- anxiety and depression

The ratings are based on a three-point Likert scale i.e. no problem, a moderate problem or extreme problem and they are rated as 1, 2, and 3 respectively. Utility scores are then used to transform the 5-digit number obtained from scoring the five dimensions into a discrete figure.<sup>154</sup> Utility scores for the Zimbabwean population are available.<sup>87</sup>

The second section of the tool is the EQ-5D visual analogue scale; respondents rate their health by marking on a linear scale which ranges from 0 to 100.<sup>154</sup> The tool has been translated into several languages including Shona, a Zimbabwean native language. The Shona version of the EQ-5D has been found to be a valid and reliable tool in measuring HrQOL in the Zimbabwean adult population.<sup>87</sup> Further, it has been proven to have high test-retest reliability in the Zimbabwean population.<sup>87</sup>

#### 2.8.4.2 Short form Health Survey (SF-36)

The SF-36 is one of the widely used, generic QOL assessment tools.<sup>153</sup> It consists of 36 items which are grouped into the following 8 groups: functional capacity, physical conditions, pain, general health status, vitality, social conditions, emotional conditions and mental health. Three scores can be obtained from scoring i.e. a summative score and 2 aggregate scores. A single-item measure of health change can be deduced with the total scores range from 0 to 100, a score of 0 signifying the worst health status and 100 signifying the best health status.<sup>58 152 155 156</sup> The scores can also be divided into two aggregate scores i.e. Physical Component Summary (PCS) and Mental Component Summary (MCS).<sup>156</sup> The SF-36 takes about 5-10 minutes to complete.<sup>152 156</sup> In terms of psychometric properties, it has high internal consistency<sup>152 156</sup>, high discriminative power<sup>152 156</sup>, adequate test-retest reliability (Cronbach's alpha for PCS= 0.92 and MCS=0.91)<sup>156</sup>, sturdy construct and criterion validity<sup>152 156</sup>, adequate sensitivity to change and strong correlation with other measures such as the WHOQOL-BREF<sup>156</sup>. It can be administered in various ways i.e. through mail-out surveys, telephone

interviews or through the computerised format.<sup>156</sup> The SF-36 has been used in various studies investigating different aspects of QOL of caregivers of children with CP.<sup>58 84 155 157</sup>

### **2.8.5 Tools for measuring patient satisfaction with service provision**

It's essential to evaluate patient satisfaction with services delivery as satisfaction is inter-rated to treatment compliance and outcomes.<sup>92</sup> Patient satisfaction is a multi-factorial concept and there are various tools that have been developed to measure it.<sup>159</sup> Further, there are no standardized tools which are applicable to various settings.<sup>91</sup> Methods of measurement of patient satisfaction include self-administered questionnaires (the most popular), focal groups, informal visits with clients by support staff, client suggestion boxes and client hotlines.<sup>8</sup>

From the search of literature, different questionnaires were found which assess patient satisfaction with physiotherapy services. The tools were not condition specific and have been validated in large populations.<sup>89 90 91 93</sup> These tools were designed to meet the specific objectives of the studies. Most of the questionnaires were rated on a five point Likert scale with ratings phrased from “strongly disagree” to “strongly agree”.<sup>89 90 91 93</sup> The questionnaires consisted of a combination of closed and open ended questions<sup>89 90 91 93</sup> and a combination of positively and negatively phrased questions<sup>91 93</sup>. The range of questions was from 12 to 35 questions.<sup>89 90 91 93</sup> Some of the tools had additional open ended questions where by respondents were requested to comment on the positive aspects of care and areas for improvement.<sup>90 91 93</sup> As there is are “no gold standardised” questionnaire(s), the MedRisk Instrument for Measuring Patient Satisfaction With Physical Therapy Care (MRPS) which is one of the widely used tools in the outpatient setting will be reviewed.

#### **2.8.5.1 MedRisk Instrument for Measuring Patient Satisfaction with Physical Therapy Care (MRPS)**

The MRPS is 12-item questionnaires for measuring patient satisfaction with physical therapy services. The questions are rated on a 5 Likert scale; from strongly disagree to strongly agree. It discriminates between internal factors and external factors which affect patient satisfaction.<sup>89</sup> Internal factors relate to patient –therapist interaction. Whereas external factors relate to factors relate to issues such as booking process and comfort of waiting area and internal factors relate to patient-therapist interaction.<sup>89 96</sup> The MRPS has been proven to be reliable and valid tool which is very easy to administer.<sup>96</sup>

### **2.8.6 Tools/ methods of measuring compliance**

The exact non-compliance rates with physiotherapy are unknown as diverse methodologies have been applied in measuring this variable.<sup>106</sup> More so, there is no gold standard in measuring

compliance<sup>102</sup> and given its multi-dimensionality, various methods need to be considered when measuring compliance<sup>103 106 113 160</sup>. Adherence measures can be classified into clinic-based<sup>103 106 4 113</sup>, home-based<sup>103 106 4 113</sup> and in-treatment based measures<sup>103 4 113</sup>.

### 2.8.6.1 Clinic based measures

One of the most commonly used methods is percentage of met appointments as measured by sessions attended over scheduled sessions.<sup>4 102 103 106</sup> This is a very simple and valid index in measuring adherence. However, attendance to appointment may not necessarily translate to compliance with treatment regimens.

### 2.8.6.2 Home based measures

Subjective measures such as diaries and self-report questionnaires can also be used to measure adherence.<sup>102 106</sup> The patient reports the exercises and the frequency of performed exercises after every exercise session. Subjective measures are less accurate<sup>117</sup> as they are prone to recall bias.<sup>113</sup>

### 2.8.6.3 In-treatment based measures

In treatment measures can either be subjective or objective. These include, questionnaires, verbal feedback from patient, asking the patient to demonstrate exercises given.<sup>111</sup> One of the commonly used objective measures is the Sports Injury Rehabilitation Adherence Scale (SIRAS).<sup>160</sup>

#### 2.8.6.3.1 SIRAS

The SIRAS was developed to measure patient adherence during treatment sessions.<sup>160</sup> The therapist rates how the patient adherence on a 5-point Likert scale in the following three dimensions:

- intensity of performance of exercises
- following instructions during treatment session
- receptiveness of patient to adjustments during treatment

A three phase study to evaluate its psychometric properties revealed the SIRAS is internally consistent (Cronbach's alpha=0.82), has adequate discriminatory validity i.e. scores significantly correlated to attendance at sessions ( $r=0.21$ ,  $p<0.05$ ) and that it has a high test-retest reliability. Further, the developers of the tool recommend the use of SIRAS in conjunction with other adherence measures to capture the multidimensionality of adherence.<sup>160</sup>

## 2.9 Conclusion of literature review

CP is the most common paediatric neurological condition<sup>12</sup> and the principal cause of disability in children.<sup>9</sup> Children with CP face multiple bio-psychosocial challenges.<sup>13 14</sup> This coupled by the fact that CP is a lifetime condition<sup>15 93</sup>, results in a huge burden on caregivers.<sup>13 16</sup>

Long term caregiving leads to financial, social and emotional burden in caregivers.<sup>1 3 9 15 29 49 63 65</sup>

Further, it leads to a decline in the HRQoL of caregivers.<sup>28 67 81</sup> Therefore there is need to provide tailor-made interventions to alleviate the burden of care.<sup>62 63 67</sup> This calls for a model of service delivery which looks into the health and welfare of caregivers with CP.<sup>28</sup> This is essential as rehabilitation have been traditionally provided within institutions. However, in low income settings, coverage and access to rehabilitation services is low.<sup>31</sup> Henceforth, innovative models of care such as CBR and outreach have been shown to be effective in increasing access and equity.<sup>122 129</sup>

However, community based models result in the transference of costs from the caregivers to service providers thus the need to assess their efficacy.<sup>122 127 128</sup> As the goal of rehabilitation is to improve QoL in clients with disabilities, evaluations on HRQoL<sup>154</sup>, compliance and satisfaction<sup>92</sup> can be used as benchmarks for the efficacy of health care.

## 3 METHODOLOGY

### 3.1 Introduction

This section outlines the methodology utilized in carrying out this research. A brief description of the study setting precedes the description of the sample and outline of data collection. The methodology was designed to answer the following research questions:

- Are the demographic and clinical characteristics of children with CP treated under the community-based program and the hospital-based group equivalent?
- Is there a significant difference in improvement over a three month period in GMFM scores for children treated under the community-based program and for children receiving hospital-based treatment and whether either group improved more than the other?
- To determine what factors were related to improvement in children's function over time?
- To investigate the relative impact of the two modes of service delivery on the HRQoL of the caregivers by determining if there was a significant difference in the rank order of scores on the EQ-5D and on Caregiver Strain Index (CSI) before and after a three month period of intervention and between the two groups?
- To determine the degree of caregiver satisfaction with the rehabilitation services that they received and to establish whether both groups were equally satisfied with services by testing whether there was a significant difference in the ranking order of scores on the MRPS?
- To determine whether caregiver compliance to treatment schedules was associated with mode of service delivery?

### 3.2 Research Setting

#### 3.2.1 Description of the research settings

Chitungwiza is a satellite town located 30 km away from Harare. The comparison, Mabvuku is a high density suburb of Harare which is located 17 km, east of the city centre. Both consist of an aggregation of several high density suburbs.

#### 3.2.2 Description of services offered in the research settings

#### 3.2.3 Mabvuku Outreach group

The CRU runs a peri-urban , community-based outreach program in Harare for provision of rehabilitation services in high density areas which is modelled on the WHO CBR model.<sup>26 139</sup> To date, the outreach program coverage extends to 13 high density suburbs in Harare.<sup>139</sup> A team of

rehabilitation professionals i.e. physiotherapists (PTs), occupational therapists (OTs), rehabilitation technicians (RTs) and occasionally a counsellor visits each of the 13 outreach centres once a fortnight. Interventions are done at the local clinics, community centres or day care centres. Treatments are done in the afternoons, and caregivers are expected to be by the outreach points before the outreach team arrives. For the physical treatment regimes, the CWDs are treated either by the PTs, OTs or RTs and interdisciplinary referrals are a common feature. The caregivers and children are given mahewu (a traditional energy drink) at the end of treatment sessions i.e. when all have received therapy, and this gives them an excellent platform for interaction. Besides therapy, the outreach team also runs some health promotional talks on key issues affecting the welfare of the caregivers and CWDs in a bid for the provision of holistic services. If need arises, the outreach manager invites other health care professionals to educate the caregivers on various issues pertinent to the welfare of the CWDs.<sup>26</sup>

### 3.2.4 Outline of Chitungwiza Central Hospital Rehabilitation Services

Chitungwiza Central Hospital (CCH) is one of the 6 central hospitals (tertiary-care institutions) in Zimbabwe (Madondo, Personal Communication<sup>1</sup>) and is located in Chitungwiza which is a high density dormitory town located 30 km out of Harare. It has a bed capacity of 600. Rehabilitation services are provided on in-patient and outpatient basis. The rehabilitation establishment consists of 5 PTs, 3 OTs and 4 RTs. All the professionals are assigned into various specialities and are rotated after 3 months. As such they have an equal chance to work in all domains and there is no “specialization” of professions as such. (Madondo, Personal Communication<sup>2</sup>)

Children with CP receive rehabilitation treatment on an outpatient basis. The rehabilitation department conducts an outpatient CP Clinic every Wednesday of the week. The CP clinic is done in the mornings, children receive individual treatments from either a PT/OT or an RT and interdisciplinary referrals are also a common feature. Caregivers can depart as soon as their child has been treated. Presently the institution is not carrying out any community based treatments. (Madondo, Personal Communication<sup>3</sup>)

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<sup>1</sup> Madondo M, Mayida C, Sithole B. *Outline of Chitungwiza Central Hospital rehabilitation service provision- Interviewed at Chitungwiza Central Hospital, 04 December 2011*. Chitungwiza; 2011.

<sup>2</sup> Madondo M, Mayida C, Sithole B. *Outline of Chitungwiza Central Hospital rehabilitation service provision- Interviewed at Chitungwiza Central Hospital, 04 December 2011*. Chitungwiza; 2011.

<sup>3</sup> Madondo M, Mayida C, Sithole B. *Outline of Chitungwiza Central Hospital rehabilitation service provision- Interviewed at Chitungwiza Central Hospital, 04 December 2011*. Chitungwiza; 2011.

### 3.3 Study design

A non-equivalent control group quasi-experimental design (NECG) was utilized for this study as depicted in Figure 3-1 below.

Group	Pre-response measures	Treatment type	Post-treatment measures
Experimental (Mabvuku)	Y	X	Y
-----			
Control (CCH)	Y	X	Y

Figure 3-1: Study design

A NECG design has both experimental and control groups. There is no randomization and involves pre-test and post-test measurements.<sup>161</sup> The control group should match the experimental group as much as possible and comparability can be assessed by the pre-test scores of the two groups.<sup>162</sup>

In our study, the community-based group (Outreach group) was the experimental group and those receiving hospital based treatment at CCH acted as the non-equivalent control/comparison group. The dotted line depicts the non-equivalence between the two groups.<sup>166</sup> In this study, the independent variable was mode of access to rehabilitation service i.e. hospital or outreach-based. The dependent variables were caregivers': strain levels (burden of caregiving), HRQoL, satisfaction with rehabilitation services, compliance with appointments, and changes in motor function of children with CP.

#### 3.3.1 Rationale for the study design

Quasi-experimental design is “an experimental design that does not meet all requirements necessary for controlling influences of extraneous variables”.<sup>161</sup> (page 4) Quasi-experimental designs provide a moderate level of scientific validity and are prone to bias and confounding and results cannot be generalized.<sup>163</sup> Quasi-experimental designs lack one or two characteristics of true experiments i.e. randomization, control and manipulation.<sup>163</sup> This design is often used when randomization is not practical, unethical<sup>162</sup> or when they are the only realistic option of carrying out the study.<sup>163</sup>

Randomization was not possible as they are no other central hospitals offering outreach services. Secondly, as the outreach points have different numbers of children Mabvuku presented the best chance of attaining the minimal sample size thus the use of convenience sampling method.

Furthermore, the study settings are in different geographical locations and randomization was not practical. The scope of our study did not require manipulation of variables, thus a quasi-experimental design was adequate in answering the study aim and objectives.

This study set to compare the efficiency and effectiveness of community based and hospital-based treatment models in CP rehabilitation, and in the medical field, RCTs are considered to be the “gold standard” for evaluating the efficacy of interventions.<sup>164</sup> Random controlled trials (RCTs) require complete randomization and use of a control group<sup>165</sup> which could not be achieved thus use of a quasi-experimental design. Confounding variables cannot be controlled under these circumstances; however matching between the control and experimental groups helps to achieve comparability thus helps to minimize confound variables between the two groups.<sup>162</sup> Foreseen extraneous variables could include concurrent access to other treatment services for instance traditional healers, among other unseen confounders. The selection of two groups of the same socio-economic backgrounds ensured comparability of the two groups at baseline.

Furthermore, quasi-experimental designs can be the best and most valid design in answering a specific question and can assist in validating a certain treatment approach.<sup>163</sup> Additionally, RCTs require significant resources<sup>162 163</sup> and the researcher has a limited financial budget thus a quasi-experiment was deemed an appropriate design as quasi-experimental designs are generally less expensive.<sup>163</sup>

### **3.4 Study population/ participants**

The participants in this study were; children with CP, caregivers of children with CP, and rehabilitation professionals administering the treatments. In this study a caregiver implied a person who was responsible for day to day care of the child with CP. The target population was drawn from the children treated under the CRU Outreach program and CCH CP clinics. The following selection criterion was applied:

#### **3.4.1 Inclusion criteria**

- diagnosis of CP according to the patient notes
- age range of 0-12 years. The GMFM has good content and face validity for children in the age range 0.5 to 13 years<sup>54</sup> and the discharge age for the CRU Outreach program is 12 years of age thus the choice of 0-12 years range.

- absence of planned surgery , of significant medical and nutritional problems or other clinical factors that might have biased the rehabilitation program <sup>167 168</sup>
- children with CP who attended CRU Outreach program and CCH CP clinics for the first four weeks of the study

#### 3.4.2 Exclusion criteria

- presence of other co-morbid neurological conditions e.g. Spinal Bifida
- clients also receiving other forms of therapeutic interventions

#### 3.4.3 Sample size calculation

The burden of care was one of the major variables under scrutiny in this study and the Caregiver Strain Index (CSI) was used to measure the burden of care. Therefore, assuming mean CSI scores of 7 and 9 (SD=2) for both groups<sup>56</sup>, the expected minimal number of cases per group was 16 at 95% confidence interval and 95% goal power. The sample size was calculated using the sample size calculator function of Statistica software package. Oversampling was done to counteract effects of attrition due to drop-outs, sickness and non-compliance among other unforeseen issues.

#### 3.4.4 Recruitment and sampling method

Convenience sampling method was used to derive the study sample. According to the Outreach records, approximately 30 children with CP attend Mabvuku outreach point; all who consented were to be included in the sample if they met the inclusion criteria. For the experimental group, Mabvuku was chosen from the possible 13 Outreach points. It was reasonable to assume that Mabvuku matches Chitungwiza as both are high density suburbs/areas and the caregivers were likely to be of the same socio-economic status. Additionally, they both have similar catchment areas i.e. they also service nearby communal areas in addition to the urban clientele. Mabvuku is one of the outreach groups with a large number of clients; therefore, we were most likely to meet the minimum sample size requirement from the group. Likewise, CCH was also chosen as a comparison group as it does not have outreach services.

According to Chitungwiza physiotherapy department outpatient records/statistics, approximately 15-27 clients attend per week. All caregivers who had children with CP who met the inclusion criteria and consented were to be recruited .To control for confounding variables; both groups were to be matched in terms of GMFCS levels, socio-economic status (SES) and demographic characteristics to achieve equivalency. However, this was not achieved as this would have yielded a very small population with very low power. Furthermore, matching was hard to achieve given the significant

differences in the average age for both groups and this posed an inherent threat to the comparability of the two groups.

The final sample consisted of all children whose parents/legal guardians who consented to take part in the study. The rehabilitation professionals already involved in Outreach and CCH CP clinics administered the treatments throughout the research.

#### **3.4.5 Research personnel**

The research team consisted of the principal researcher and two research assistants. The roles of research assistants were to assist in the administration and completion of questionnaires and distributing snacks after the completion of questionnaires. The training of research assistants was done before the pilot study. The purpose of the training was to familiarize them with the completion of the data sheet and the scoring of the questionnaires and for the standardization of the recruitment process for the data collection phase. This was essential as they were expected to assist illiterate caregivers in filling in the questionnaires. Moreover, they were to also help in clarifying any queries from caregivers during the process of filling in the questionnaires.

The initial plan was to engage an experienced Physiotherapist to assist in carrying out GMFM measurements, however her schedule did not allow her to be available on all days of data collection. Henceforth, the researcher decided to carry out all the GMFM and one of the inherent challenges is a possibility of systemic errors in the observations. However, the researcher had been trained to use tools from under-graduate training as well in his years of clinical practice.

### **3.5 Data collection tools/instrumentation**

#### **3.5.1 The GMFM-88**

The GMFM is a condition specific,<sup>54</sup> standardized and validated ordinal scale which measures changes in motor function in children with CP.<sup>54 141 142</sup> It is applicable for CP children between ages of 5 months and 16 years.<sup>54</sup> The GMFM-88 is a criterion-referenced, 88-items scale which is scored on a 4 point Likert scale. It is scored in five dimensions i.e. lying and rolling; sitting; crawling and kneeling; standing and walking, running and jumping.<sup>142 143</sup> In terms of its psychometric properties, the GMFM-88 has an excellent reliability, has good responsiveness to change and high internal consistency.<sup>54 142</sup> It can be administered by Physiotherapist or a trained health professional. The following items are required for the measurement of GMFM: a mat, bench, toys, stairs and a smooth surface.<sup>54</sup> For the sake of consistency, the same testing kit were used for both groups. The kit was hired from the Department of Rehabilitation at the University of Zimbabwe (See appendix 1 for GMFM-88)

### 3.5.2 Rationale for the use of GMFM-88

The GMFM-88 was chosen for the following reasons;

- It is condition specific i.e. it was designed to measure changes in motor function of children with CP<sup>54 141</sup> and the study is about comparison of two models of CP Rehabilitation hence its suitability as an outcome measure. Other tools such as the WeeFIM ,PEDI and PODCI are generic measurements of motor function
- the GMFM-88 has high completion rates<sup>142</sup>
- extensively used in the measurement of motor function for children with CP
- has the highest discriminatory validity when compared to the Pediatric Evaluation of Disability Inventory (PEDI) and Paediatric Outcomes Data Collection Instrument (PODCI)<sup>142</sup>
- ease to administer and does not require use of software like the GMFM-66, which makes it cheaper to use

However it must be mentioned that the weakness of this tool is that it takes time to complete. One must score all items to arrive at a score but this is not normally possible for all children, thus scores based on only some part of the GMFM-88 scale can lead to decreased reliability and validity.<sup>54</sup>

Needless to say, a “perfect” outcome measure for motor function is non-existent.

### 3.5.3 Caregiver strain index (CSI)

The CSI is a validated and reliable tool for measuring the burden of care giving.<sup>147</sup> The respondents are required to respond with Yes or a No. A yes is given a score of 1 and a no a score of zero.

Summation of yes responses gives the total score which ranges from 0 to 12. A score of 7 or more signifies a high level of stress.<sup>149</sup> The CSI was translated to Shona, and the translated tool was validated during the pilot study. (See appendices 2 and 3 for the English and Shona versions of the CSI)

### 3.5.4 Rationale for the use of the CSI

Caregiver burden is a complex, multi-dimensional concept which is not universally conceptualised. Inherently, various tools have been developed to assess it, the CSI was chosen for the following reasons:

- Its brevity reduces respondent burden
- Reliable and validated tool<sup>147</sup>
- Has been used elsewhere in studies assessing the burden of care in children with CP<sup>14 56</sup>

However, the CSI was originally designed for use in geriatric population<sup>149</sup>, and we did not find any studies reporting its validation in the paediatric population. Therefore, its construct validity in paediatric population maybe questionable. This is further compounded by the fact that it has not been validated and translated into Zimbabwean native languages.

### 3.5.5 The EQ-5D

The EQ-5D is a standardized and validated tool to assess Health Related Quality of Life (HrQOL) in adults and was developed by the EuroQol Group.<sup>154</sup> In the first section of the tool, respondents rate their own health in the following 5 domains:

- mobility
- self-care
- usual activities (work, study, housework, family/leisure)
- pain/discomfort
- anxiety and depression

The ratings are based on a three-point Likert scale i.e. no problem, a moderate problem or extreme problem and they are rated as 1, 2, and 3 respectively. Utility scores are then used to transform the 5-digit number obtained from scoring the five dimensions into a discrete figure.<sup>154</sup> Utility scores for the Zimbabwean population are available.<sup>87</sup>

The second section of the tool is the EQ-5D visual analogue scale; respondents rate their health by marking on a linear scale which ranges from 0 to 100. The tool has been translated into several languages including Shona, a Zimbabwean native language. The Shona version of the EQ-5D has been found to be a valid and reliable tool in measuring HrQOL in the Zimbabwean adult population.<sup>87</sup> Further, it has been proven to have high test-retest reliability in the Zimbabwean population.<sup>87</sup> Therefore, both tools were administered based on the caregivers' preference (See appendices 4 and 5 for the English and Shona versions of the EQ-5D respectively)

### 3.5.6 Rationale for the use of the EQ-5D

An idea tool should possess the following attributes other than sound psychometric properties: brief, easy to use, and preferably self-administered.<sup>152</sup> The EQ-5D was selected for the following reasons:

- it has a translated and validated Shona version whereas , the SF-36 has not been locally translated

- utility scores for Zimbabwe are available which makes it easier for statistical analysis and comparison. Normative values for SF-36 are not available for Zimbabwe thus making comparisons with other populations difficult.
- the EQ-5D is easy to complete as is the SF-36 , thus reducing respondent burden <sup>153</sup>
- has far fewer items than the SF-36 thus it takes less time to complete <sup>150</sup>
- The EQ-5D has been used extensively in HRQoL research <sup>150</sup>
- It has been proven to have a high test-retest reliability in the Zimbabwean population <sup>87</sup>

However it must be pointed out that every outcome measure has its own flaws. Some authors argue that due to its brevity, the EQ-5D does not capture all multidimensionality of QOL. Further, it has ceiling effects i.e. it does not fully discriminate between those with full health and those with some health problems.<sup>158</sup>

### **3.5.7 MedRisk Instrument for Measuring Patient Satisfaction with Physical Therapy Care (MRPS)**

The MRPS is 12-item questionnaires for measuring patient satisfaction with physical therapy services .The questions are rated on a 5 Likert scale; from strongly disagree to strongly agree. It discriminates between internal factors and external factors which affect patient satisfaction.<sup>89</sup> Internal factors relate to patient –therapist interaction and external factors relate to factors relate to issues such as booking process and comfort of the waiting area and internal factors relate to patient-therapist interaction.<sup>89 96</sup> The MRPS has been proven to be reliable and valid tool which is exceptionally easy to administer.<sup>96</sup> The tool was modified as some of the terms were not culturally appropriate for the Zimbabwean context. For instance, the word “office” was omitted from the first question. Further, based on the recommendations of the University of Cape Town Ethical Committee, questions 2, 4 and 8 were positively worded. The committee was concerned that the negative wording of the original tool might confuse respondents. The developers of the tool argue that negatively wording prevents respondents from giving stereotypical answers. The modified tool was tested for reliability and validity during the pilot study. (See appendices 6 to 8 for the original and modified versions of the MRPS)

### **3.5.8 Rationale for use of the MRPS**

The MRPS was chosen for the following reasons:

- it is a validated and reliable tool
- was specifically designed for physiotherapy
- easy to complete
- short thus it takes less time to complete

- It has been translated and used in different countries i.e. it has been used in different cultural settings for instance Australia <sup>89</sup>

It can be urged that the Medrisk was developed and validated with a group of patients with orthopaedic diagnosis, however research has demonstrated that satisfaction is independent of diagnosis.<sup>93</sup> Likewise, the MRPS was developed in the USA, and its applicability in the Zimbabwean setting may be questionable since satisfaction with services maybe be context and culturally specific. Over and above, in our search of published literature, we did not find a standardized questionnaire which measures satisfaction with physiotherapy in caregivers of children with CP.

### **3.5.9 Rationale for the selection of the attendance index for measuring compliance in this study**

Given the vast array of compliance indices, the percentage attendance ratio was used as an outcome measure for this study for the following reasons:

- is extremely easy to use
- it is an objective scale
- has been used in other studies,<sup>102 107</sup> thus it enables comparability of our findings with other studies

Some authors it can argue that this index does not fully capture the multi-dimensionality of compliance.<sup>5</sup> However, the index was deemed adequate for the scope of this study. Further, we acknowledge the need of using multiple measurement tools especially in exploring in detail the subject of compliance.

### **3.5.10 Self-designed data sheet**

This was designed by the researcher to record information for every CP client and their caregiver. It contained three sections i.e. child and caregiver demographic details, intervention details and attendance register. (Please refer to appendix 9 for the data sheet).

## **3.6 Procedure**

The following steps were taken in carrying out the study: ethical approval was sought first and then a pilot study preceded the main study.

### **3.6.1 Ethical approval**

Application of ethical approval for the study was sought from the University of Cape Town Ethical Review Board, ref 109/2012 (see appendix 10). Upon approval; the researcher applied for permission to carry out the study from the Clinical Directors of HCH and CCH and heads of rehabilitation departments of the respective hospitals (See appendices 11-15). Thereafter,

application for ethical clearance was sought from the Medical Research Council of Zimbabwe (See appendix 16). Finally, permission was sought from the caregivers and rehabilitation professionals administering the treatments to be involved in the study. Written consent was requested from the consenting individuals. Further, verbal assent was requested from children with CP who could articulate. (See appendices 17 to 22 for the information letters and consent forms)

### 3.6.2 Pilot study

The broad aims of the pilot study were to:

- assess the researcher's intra-rater reliability in GMFM-88 scoring
- assess the validity and reliability of the translated Shona versions of the CSI and MRPS

The pilot study was done at the CRU and the participants were children with CP treated at the CRU and their caregivers. As the gross motor function scores were one of the outcome measures for the study, it was essential to assess the researcher's intra-rater reliability in GMFM-88 scoring. The researcher and an experienced physiotherapist carried out GMFM-88 measurements on 10 children. Selected children were of different CP sub variants and the levels of severity ranged from I to V as assessed on the GMFCS.<sup>169</sup> The measurements were performed on the same individuals on two separate occasions (two week time lag) and a comparison was done on the scores obtained to assess the intra-rater and inter-rater reliability. All the measurements were video-taped and the researcher and the Physiotherapist discussed their scores. An independent Physiotherapist acted as an adjudicator on one occasion when there was a disagreement until a consensus was reached. Training was continued until a 90% agreement level was achieved.

Translation of the CSI and MRPS into the native Shona language using the forward and backwards translation method was also done before the pilot phase of the study. Use was made of the WHO guidelines in carrying out the translation.<sup>170</sup> Forward translation from English to Shona was done by the researcher, and two therapists (PT and OT) with special interests in paediatrics. Backward translation was then done by a linguist in the department of Languages at the University of Zimbabwe. A panel consisting of the principal researcher, OT, PT and linguist then discussed the translated documents to ensure accuracy of the translations. The translated tools were piloted on a group of caregivers to assess for clarity and reliability. Both English and Shona versions of the tools were concurrently administered to 10 caregivers. The respondents found the translated tools to be clear and valid thus no amendments were done after the piloting.

### 3.6.3 Procedure for the main study

Recruitment	■												
CSI scoring			■					■					
EQ-5D scoring				■					■				
GMFM-88 scoring					■	■	■	■	■	■	■	■	■
Log sheet data capturing					■	■	■	■	■	■	■	■	■
MRPS scoring													■

Figure 3-2: Time plan of the study

#### 3.6.3.1 Recruitment

The initial plan was to introduce the researcher and research topic to the prospective participants in the form of an oral presentation in the native Shona language. The researcher was to explain the title, aims, objectives, rationale and potential benefits and risks of the study. Prospective participants would then be given the opportunity to ask any questions pertaining to the study. Recruitment was to be done after the oral presentation, and it had to be on a voluntary basis. However this was not feasible as the caregivers arrived at the different centres at different times. A decision was then made that the research team would approach the caregivers as they walked in, whilst they were awaiting treatment or alternatively after the child had been treated. A standardized procedure of recruitment was followed. This was especially necessary for the CCH group whereas for the Mabvuku group, most of the caregivers arrived before the arrival of the outreach team. The research team utilised that time for data collection procedures and this also ensured that the caregivers would not be delayed for too long after the therapy sessions. Further, recruitment was done on the scheduled dates of outreach visits (Tuesdays) and CP clinics (Wednesdays) for the respective centres.

As anticipated, some of the caregivers who brought the children for treatment were not their parents or legal guardians. For those who consented to taking part (n=6), they were given information sheets and consent forms to give to the parents or guardians of the child. The caregivers were then recruited if the parents/guardian consented to the children to take part in the study. The caregivers were assigned a study identification number which was also the same for the child.

The recruitment period lasted for a month i.e. from the 14<sup>th</sup> of May 2012 to the 4<sup>th</sup> of June 2012 rather than the initially planned two consecutive weeks. This was because some of the Mabvuku group, some did not attend the first outreach meeting after the schools holiday break. As for the CCH group, the caregivers were given different review dates so a four week period had the potential to recruit more participants. The appointment schedules of the CCH caregivers were also captured

as they were not scheduled consistently. This was essential as questionnaires were to be distributed at set time intervals (same time lags). Consequently, the completion dates for the questionnaires were different because of differences in treatment schedules.

### 3.6.3.2 Pre-study measurements

After recruitment, the next step was the administration of the CSI and EQ-5D questionnaires. Administration of the questionnaires was done on separate days and this was done to decrease the respondent burden and ensure more accurate responses. Furthermore, administration of questionnaires on different days was also deemed as an appropriate strategy for avoidance of inconveniencing the caregivers so as to minimize drop outs from the study. Both Shona and English versions of the tools were distributed just before treatment sessions or at the end of treatment sessions.

The research team would briefly explain to the caregivers the rationale of the tools and instructions on how to complete the questionnaires and as well as clarification of independent scoring of the tools. The tools were self-administered, for caregivers who were not literate and for those who preferred assistance in completion, the tools were read out, and the research team would fill in the responses. Food and drinks were provided at the end of questionnaires completion sessions as compensation for inconvenience. Baseline CSI and EQ-5D questionnaires were completed as between the 4<sup>th</sup>- 28<sup>th</sup> of June 2012 and 2<sup>nd</sup> – 31<sup>st</sup> of July 2012 respectively.

The next stage was documentation of GMFM-88 scores of children with CP. The GMFM-88 scoring was initially meant to be done by the researcher and an experienced physiotherapist. However, the physiotherapist was not available for most of the sessions, so a decision was made that the principal researcher was to carry out all the GMFM-88 measurements. Subsequently, there was potential for systematic error in the measurements. However this was mostly unlikely for the following reasons: the researcher was experienced in GMFM-88 scoring from undergraduate training and clinical work and had reached very high intra-rater reliability during the pilot phase of the study. More so, in other studies, GMFM measurements were performed by one evaluator.<sup>58</sup> Under ideal circumstances, GMFM-88 scoring should have been done by a blinded assessor to reduce bias. However, blinding would have entailed bringing in the study participants to one centre. This was going to be costly as the participants are located in different geographical locations. Additionally, the study is a comparison between community-based and hospital based treatment models, thus it was deemed appropriate to do the GMFM-88 measurements in the participants usually treatment settings. Measurements were done before or after the usual treatment sessions i.e. on scheduled treatment days for both groups to avoid inconveniencing the caregivers. Participants were provided with some

food and drinks at the end of GMFM-88 measurements as compensation for the inconvenience. GMFM-88 measurements were done from the 6<sup>th</sup> to the 30<sup>th</sup> of August 2012.

### **3.6.3.3 Main study measurements**

The researcher team filled the self-designed data sheet throughout the duration of the study. This captured information compliance and type of interventions delivered i.e. therapy or health promotional talks. Data was captured for every treatment session. The researcher was on site for the duration of the data collection period. This was deemed an appropriate strategy to help to build a good rapport with the participants as well as to keep track on them.

### **3.6.3.4 Post-study measurements**

At the end of the data collection, the same procedure as at baseline was followed in scoring the CSI, EQ-5D, GMFM-88 scores and additionally the modified MRPS questionnaire. Also, the same sequence was followed as at baseline and scoring was done on separate days. CSI questionnaires were administered as from the 3<sup>rd</sup> – 27<sup>th</sup> of September 2012, EQ-5D from the 1<sup>st</sup> – 31<sup>st</sup> of October 2013. GMFM-88 scoring was done from the 5<sup>th</sup> - 29<sup>th</sup> of November and MRPS was done as from the 3<sup>rd</sup> to the 18<sup>th</sup> of December 2012. There was a time difference of 7 months from recruitment to administration of the MRPS

## **3.7 Data Management**

The raw data was de-identified by coding the data; the children and caregivers were assigned an arbitrary identification number for the preservation of privacy and confidentiality. Files containing the raw data were kept in a locked and secure drawer at University of Zimbabwe Department of Rehabilitation for safe keeping and preservation of confidentiality. Only the researcher had access to the raw data. The digital copy of the data was encrypted and stored onto a password-locked laptop and was backed up on drop box and sky drive cloud storage platforms which are very secure.

## **3.8 Statistical Analysis**

Statistical analysis was performed using STATISTICA version 10, SPSS version 21 and Fishers' Exact calculator.<sup>171</sup> Both descriptive and quantitative statistical analysis methodologies were applied. As most of the data were non-parametric, the Mann-Whitney U and Chi-squared tests were used to compare results between the two groups in terms of the difference in:

- demographics
- GMFM-88 scores
- types of interventions rendered to children with CP
- range of CSI scores as well as the most reported problems on the CSI

- health profiles of caregivers on the domains of the EQ-5D
- satisfaction rates on the modified MRPS

The Fishers exact test was utilized were the data violated the assumptions of the Chi-squared test. Further, the Yates correction of continuity was applied were the degree of freedom was one for Chi-squared tests.

The ANOVA was used to compare scores at baseline and after three months for the following variables: GMFM-88, EQ-5D utility and VAS scores, and CSI scores. The data were first checked for normality using the Shapiro-Wilson test of normality before the ANOVA was applied. The F-ratio was also computed and the ANOVA was used when the ratio of the variances was less than 2. Moreover, the ANOVA is reported to be a very robust test which can produce accurate results even in instances where some of its assumptions are violated.<sup>172</sup>

Additionally, multiple regression analysis was performed to determine the predictors to changes in motor function in children with CP. Dummy variables were created for the categorical variable of the group and the ordinal variable of GMFCS was dichotomised into level 3 and above and level 4 and below. Score of one child was removed after residual analysis indicated that he/she had improved more than two standard deviations from the mean residual.

The spearman correlation coefficient was also performed to ascertain the relationship between EQ-5D scores, severity of CP and CSI scores. Finally, thematic analysis was conducted for responses to the open ended questions of the MRPS questionnaire for measuring satisfaction.

### **3.9 Ethical considerations**

#### **3.9.1 Introduction**

Outlined below are the ethical considerations for the study, please do refer to appendices 17 to 22 for the information sheets and consent forms respectively. The consent form was adopted from the post-graduate logbook of the School of Health and Rehabilitation Sciences, UCT.

#### **3.9.2 Autonomy**

Caregivers were treated as autonomous agents and partook of the study on voluntary basis. The study involved children with CP who have diminished autonomy and are vulnerable. Their caregivers were required to give a written consent to participate in the study. Verbal consent was asked of children who could articulate (n=3). Informed consent was also sought from the rehabilitation professionals who were treating the children with CP. All prospective participants were provided

with information about the study so as to empower them to make informed choices about participation in the study.

### **3.9.3 Confidentiality**

Confidentiality was maintained for the data collected during the study. The data was coded to maintain confidentiality, the CRU and CCH registers were used to identify names of the participants and they were assigned a numeric code. Only the researcher had access to the collected raw data, and it was kept in a safe locker.

### **3.9.4 Beneficence**

This study can potentially benefit children with CP by identifying the best treatment protocol. Further, it can help inform policy in designing protocols which also cater for the bio-psychosocial health of caregivers.

The researcher's strategic risk minimization plan for the research was as follows:

- Trained rehabilitation staff administered the treatments to minimize the possibility of physical injury.
- Funds were set aside for clinical care of participants in the event of an injury during GMFM-88 measurements
- The information which was gathered from the research was kept confidential, to minimize the social, legal and economic risks.

At the end of the study, the researcher, who has expertise in the area of paediatrics, conducted a refresher course for rehabilitation personnel involved in treatment. He, however, did not give any additional input of management suggestions during the course of the study as this would have contaminated the results. Further, caregivers with scores greater or equal to 7 on the CSI were referred appropriately as they were at risk of clinical distress/depression.

### **3.9.5 Justice**

Both groups of participants were treated equally to achieve social justice. The same selection criterion was used and participants were compensated equally. Likewise, data collection was done on the usual treatment days to avoid inconveniencing the caregivers from their usual daily routines. It is hoped that findings from this study would help to stimulate research on the best treatment protocols and inform policy on the best model for treatment of chronic paediatrics. Therefore, justice would have been served as the study involved the plight of minorities who are often left out in clinical research. Furthermore, with the emphasis of research in low income countries is mainly on

epidemic diseases such as HIV-AIDS, TB among others, as evidenced by the paucity of research in CP. Therefore, this study serves justice in the population of children with CP.

## 4 RESULTS

### 4.1 Introduction

This chapter presents the study findings, an overview of the research process will be presented first, and demographic characteristics of the sample will precede the presentation of results of study variables. The two groups had a different number of caregivers and children, n=20 and n=26 for the Mabvuku and CCH groups respectively. Consequently for the sake of clarity the data were mostly reported as proportions (percentages), based on Leicester University recommendations on comparing two groups with different sample sizes.<sup>173</sup> Additionally, the exact p-values will be presented as recommended by several authors<sup>174 175</sup> and we used an alpha level of 0.05 for all statistical tests unless otherwise stated.

The broad aim of this study was to compare the efficiency and effectiveness of a hospital-based and a community-based service delivery models in CP rehabilitation in different dimensions.

Consequently, the analysis was dichotomised into the following categories:

- 1 Treatment related factors- changes in motor function in the children with CP
- 2 Caregiver related factors – caregivers' strain, HRQoL, satisfaction and compliance with services

#### 4.2 Overview flow chart for the study

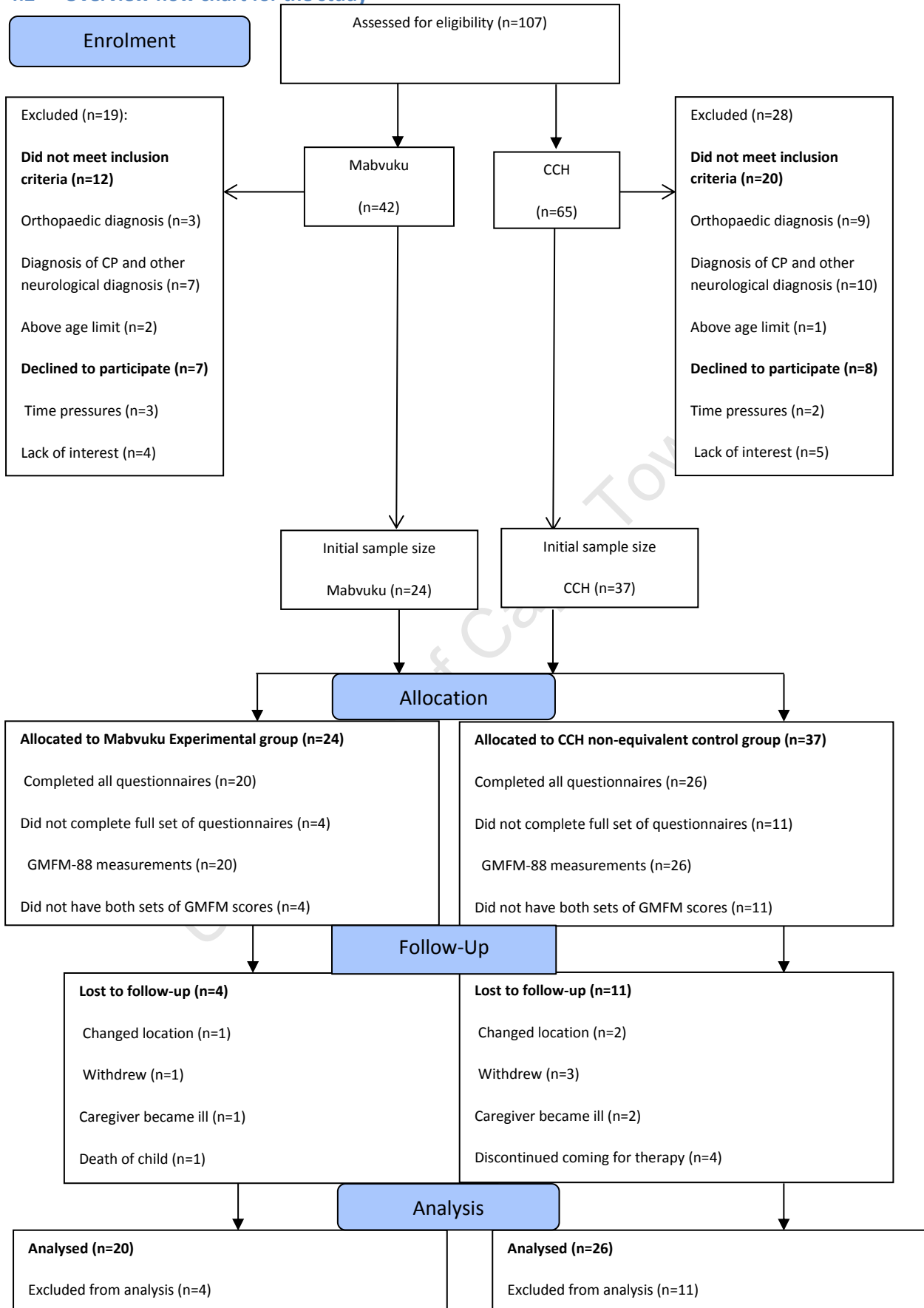


Figure 4-1: Overview chart for the study

Figure 4-1, page 66 gives a summary of the research process from enrolment to data analysis. A total of 107 potential participants were approached for recruitment into the study, of these, 42 were from Mabvuku and 65 from CCH. Forty-seven (47) did not meet the inclusion for the following reasons: orthopaedic diagnosis (n=12), diagnosis of CP with other co-morbid neurological diagnosis (n=17), above the upper age limit (n=3), time pressure (n=5), and consent was not obtained for 14 caregivers, and one was denied consent by the parents of the child. This resulted in an initial sample size of 61, of which 24 were allocated into the experimental group, (Mabvuku) and 37 were allocated into non-equivalent control group (CCH). Of the 61 allocated, 15 were lost to follow up, therefore, the total available data set for analysis was 46 (20 and 26 for the respective groups) (Figure 4-1).

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### 4.3 Demographic characteristics of the sample

Table 4-1 below shows the general demographic characteristics of the sample. A detailed outline of the various demographic characteristics ensues.

Table 4-1: Study population demographic characteristics, N=46

		Mabvuku n (%)	CCH n (%)	Total n (%)	Statistic	p- value
<b>Sex of children with CP</b>	Males	11(55)	14 (54)	25 (54)	$\chi^2=0.049$ $\alpha$ Df=1	0.825
	Females	9 (45)	12 (46)	21 (46)		
<b>Mean age of children in months (SD)*</b>		44 (49)	12 (7)	26 (36) *	U=170.0 Z=-1.928	<b>0.047</b>
<b>GMFCS Level</b>	1	5 (25)	8 (30.8)	13(28.3)	Fishers' Exact	0.953
	2	3 (15)	4 (15.4)	7 (15.2)		
	3	2 (10)	4 (15)	6 (13)		
	4	2 (10)	2 (7.7)	4 (8.7)		
	5	8 (40)	8 (30.8)	16 (34.8)		
<b>CP type</b>	Spastic	16 (80)	21 (80.8)	37(80.4)	Fishers' Exact	0.625
	Athetoid/dyskinetic	3 (15)	2 (7.7)	5 (10.9)		
	Ataxic	1 (5)	1 (3.8)	2 (4.3)		
	Mixed	0	2 (7.7)	2 (4.3)		
<b>Mean caregiver age (SD)* in years</b>		33 (12)	28 (5)	30.4 (9.2)	U=192 Z=1.496	0.134
<b>Relationship to child</b>	Mother	16 (80)	22 (84.6)	38(82.6)	Fishers' Exact	0.727
	Grandmother	2 (10)	3 (11.5)	5 (10.9)		
	Sibling	2 (10)	1 (3.9)	3 (6.5)		
<b>Caregiver educational level</b>	Primary	2 (10)	2 (7.7)	4(8.7)	Fishers' Exact	0.976
	Secondary	13 (65)	17 (65.4)	30 (65.2)		
	Tertiary	4 (20)	5 (19.2))	9 (19.6)		
	None	1 (5)	2 (7.7)	3 (6.5)		
<b>Caregiver employment Status</b>	Unemployed	12 (60)	16 (61.5)	28 (60.9)	Fishers' Exact	0.626
	Informally employed	7 (35)	7 (26.9)	14 (30.4)		
	Formally employed	1 (5)	3 (11.5)	4 (8.7)		

\*Not normally distributed, non-parametric tests used,  $\alpha$  - with Yates correction of continuity

#### 4.3.1 Gender of the children

Males constituted a greater proportion of the sample i.e. 54.3% (n=25), yielding a 1.19 male to female ratio and a Chi-squared test revealed a non-significant difference in the proportions of males and females across the two groups,  $\chi^2=0.049$ ,  $df=1$ ,  $p=0.825$ .

#### 4.3.2 Age of the children

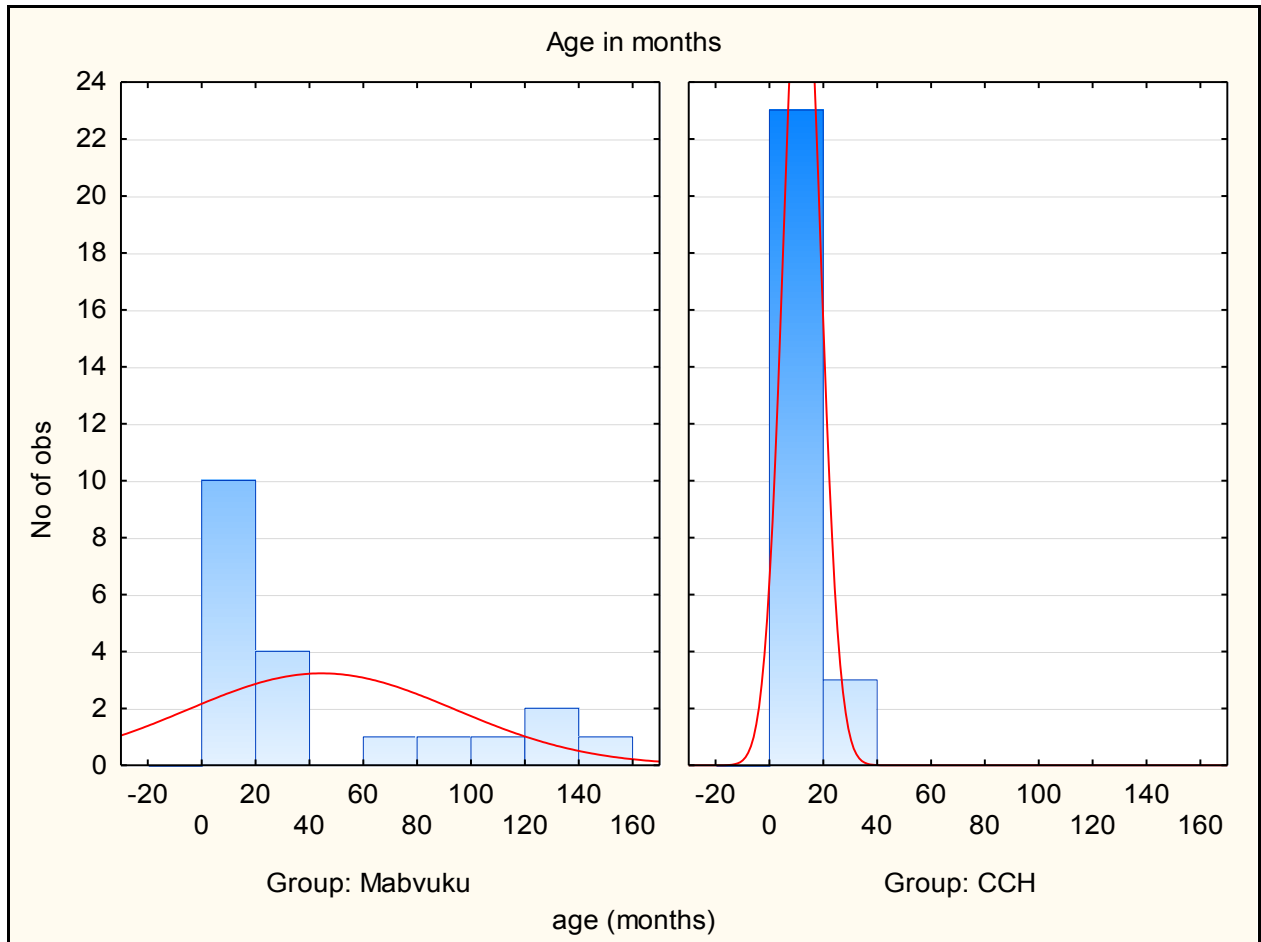


Figure 4-2: Age distribution of children with CP, n=46

The sample finally consisted of 46 children, with a mean age of 26 (SD 36, range of 2 -141) months (Figure 4-2) The mean age of children receiving community based treatment was 44 (SD=49, range 3-141) months and that of children receiving hospital based services was 12 (SD=7, range 2-32) months. As can be seen in Figure 4-2 above, the age distribution was not normally distributed (Shapiro-Wilk,  $W=.590$ ,  $p<.001$ ), with a skewness co-efficient of 2.29 (SE 0.51) and Kurtosis of 4.09 (SE 0.69). Consequently the non-parametric Mann Whitney U test was used to compare the ranking order of the age and it revealed that the children receiving community based treatment were significantly older,  $U=170$ ,  $Z=1.98$  &  $p=.047$ .

### 4.3.3 CP type

Spastic CP constituted the majority of the cases, 80.4 % ( n=37) with ataxic and mixed CP constituting the least proportion of cases, 4.3% (n=2) apiece. They were no statistically significant differences across the two groups, (Fishers' exact p =0.625).

### 4.3.4 GMFCS levels for children with CP

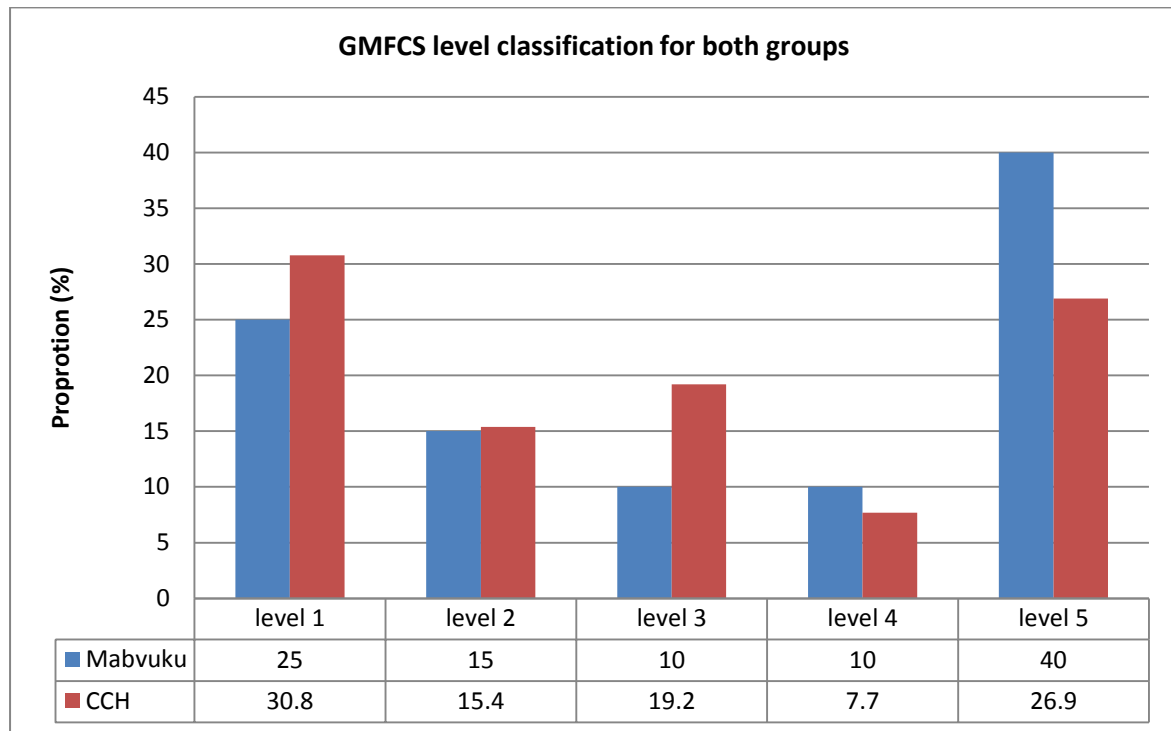


Figure 4-3: GMFCS level classification for the groups, n=46

In terms of the severity of functional impairment as measured by the GMFCS, for both groups, level V constituted the greatest proportion 32.6% (n=15) with level IV constituting the least proportion, 8.7 % (n=4) (Figure 4-3). However, more of the children in the community based treatment group were in Levels IV and V, (61.5% compared to 38.5%) the association was not statistically significant, P (Fishers' exact) = 0.953.

### 4.3.5 Caregiver s' age

The mean caregiver age for the community based treatment group was 33 (SD=12: range=22-65 & median=30) and that of caregivers in the hospital based group were 28 (SD=5: range=19-39 & median=29). Mann Whitney U test was used to compare the ranking order of caregivers' age, and it revealed that the two groups were comparable, U=192, Z=1.50, p=0.134.

#### **4.3.6 Caregiver relationship status with child**

Most of the caregivers were mothers, 82.6 % (n=38) and there was a non-significant statistical difference between the two groups in terms of relationship status, p (Fishers' Exact) =0.727.

#### **4.3.7 Caregivers' educational status**

Most of the caregivers, 93.5 % (n=43), had attained some form of education, with most caregivers having attained secondary education, 65.2% (n=30) .The two groups were comparable in terms of educational status, p (Fishers' Exact) =0.976

#### **4.3.8 Caregivers' employment status**

Most of the caregivers were unemployed, 61% (n=28), with 30.4% (n=14) informally employed and 8.7 % (n=4) formally employed. The two groups were comparable in terms of employment status, p (Fishers' Exact) =0.626

#### **4.3.9 Summary of demographic characteristics of the sample**

Although the children in the community based treatment were significantly older than children in the hospital-based group, the two groups were comparable in terms of: proportions of children within the GMFCS levels, caregiver's: age, educational status, employment status and relationship with child.

#### 4.4 Gross motor function scores of children with CP

##### 4.4.1 Changes in GMFM-88 scores over three months, within groups

As can be seen in Table 4-2 below, the mean scores of both groups improved over the three months. The difference between the scores was significant for both groups. However neither group gained more.

Table 4-2: GMFM-88 scores over three months, n=46

	At baseline		At three months		Difference		Statistic		p-value	
	Mabvuku	CCH	Mabvuku	CCH	Mabvuku	CCH	Mabvuku	CCH	Mabvuku	CCH
<b>Mean</b>	45.2	44.8	50.2	47.3	5.0	2.5	T=24	T=60	<.001	0.01
<b>SD</b>	23.5	17.1	26.0	18.4	6.9	4.3	Z=2.86	Z=2.57		
<b>Median</b>	47.5	43.5	50.5	47.5	2.5	2.0				
<b>Range</b>	7-92	12-78	6-90	16-79	2 - 24	5 - 14				

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#### 4.4.2 Changes in GMFM-88 scores across groups

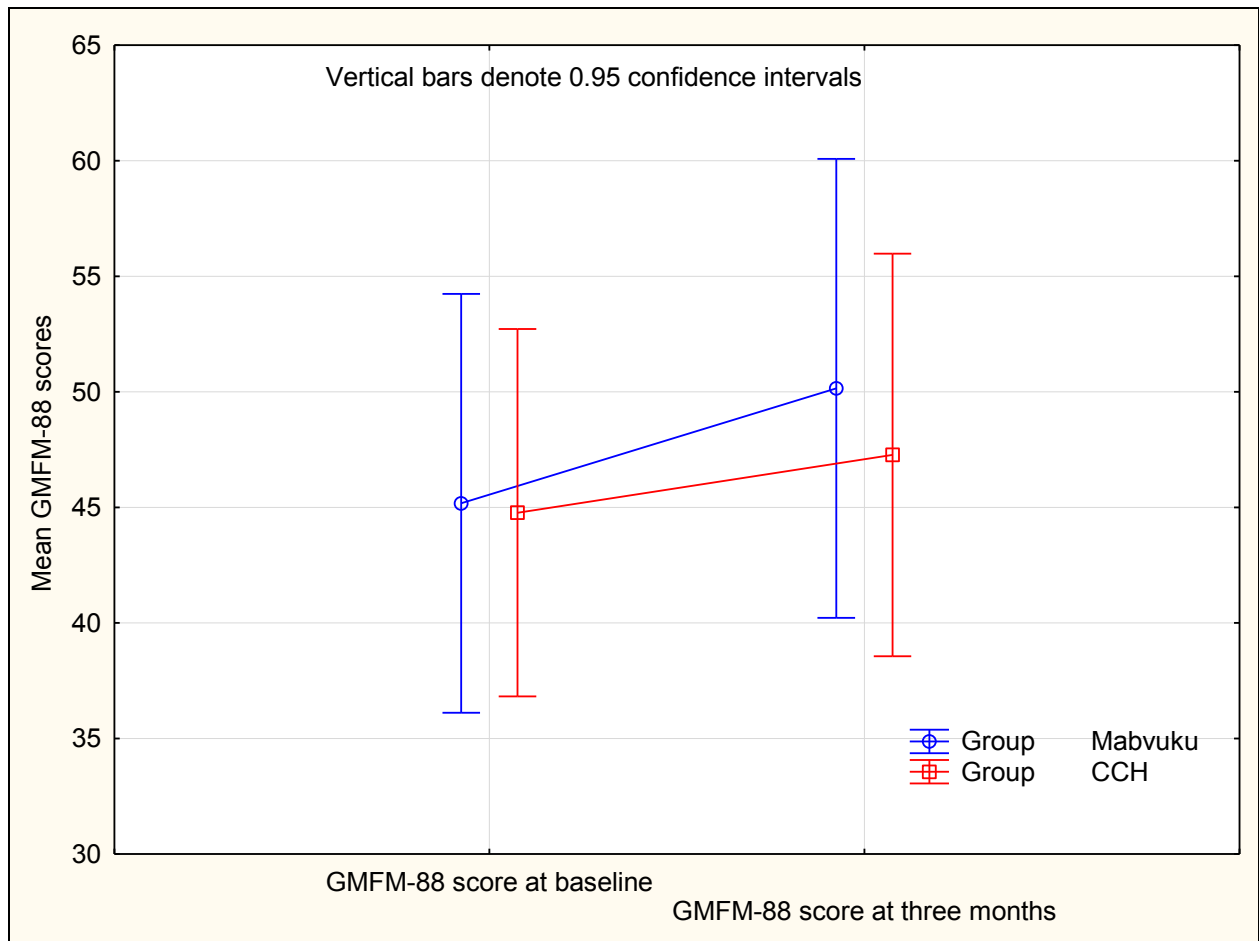


Figure 4-4: GMFM-88 scores over three months, n=46

Figure 4-4 above shows a comparison of GMFM-88 scores at baseline and at three months. To test for changes in the changes in mean GMFM-88 scores, a one-way ANOVA was performed and it yielded no significant differences between the two group,  $F(1, 44) = 2.22, p = .143$ .

#### 4.4.3 Factors affecting GMFM-88 scores

Table 4-3 below shows the results of a multiple regression analysis of predictors to changes in functional scores in children with CP.

Table 4-3: Predictors of changes in functional scores

	Amount of change - b	Standard error of b	t(41)	p-value
Intercept	4.55	0.967	4.70	<.001
Mabvuku Group	3.53	1.441	2.45	0.019
Severe category	-4.68	1.285	-3.64	0.001
Age (months)	-0.04	0.019	-1.89	0.066

The correlation between age and change in score was tested and found to be non-significant ( $r = -.103$ ,  $p = .497$ ). Spearman's rho indicated that as the level of severity increased in terms of GMFCS level, so the amount of improvement decreased ( $\rho = -.568$ ,  $p < .000$ ). However, as age was significantly different between the two groups and there were more severely affected children in the community based treatment group, regression analysis was done to establish which factors predicted the amount of change in the GMFM Score. Dummy variables were created for the categorical variable of the group and the ordinal variable of GMFCS was dichotomised into level 3 and above and level 4 and below. The resulting model accounted for 25% of the variance (adjusted  $R^2 = .25$ ) after the score of one child was removed after residual analysis indicated that he/she had improved more than two standard deviations from the mean residual. The results are in and indicate that, once age and category were controlled for, children in the community based treatment group improved 3.5 points more than children receiving hospital based services. Children who were more severely disabled showed 4.7 points less improvement and for each month of age, children showed .04 less improvement, although this was not significant. Additionally, changes in GMFM-88 scores were negatively and significantly co-related to level of severity,  $r = -0.57$ ,  $p < 0.05$ .

#### 4.4.4 Summary of GMFM-88 scores

Both groups showed significant improvement over the three months of the study, although there was no difference between the GMFM-88 scores between the groups post-study. However multiple regression analysis indicated that membership of the community based treatment group predicted greater improvement once severity and age were accounted for.

#### 4.5 Comparison of the treatment (therapy) sessions

Table 4-4 below outlines the type of treatment rendered to the children with CP and the child to therapist ratio for the duration of the study period.

Table 4-4: Treatment sessions details for the study duration

		Mabvuku	CCH	Statistic	p-value
<b>Type of treatment given</b>	Therapy sessions	7	21	$\chi^2=1.62\alpha$ df=1	0.203
	Health promotional talks	7	7		
<b>Therapist hours ratio</b>	Mean (SD)	0.29 (.07)	0.21 (.10)	t(43)=3.19	0.003

$\alpha$  - With Yates correction of continuity

Therapist hour's ratio was calculated by dividing the product of number of therapists and total number hours of therapy provided by total number of children treated over the study period. As can be seen in Table 4-4 above, there were no statistically significant differences in terms of the organization of treatment sessions,  $\chi^2=0.711$ , df=1, p=0.399 and children in the community based group received a significantly higher amount of therapy time, t(43)=3.19, p=0.003.

##### 4.5.1 Summary of treatment sessions details for the duration of the study

The types of interventions offered were almost similar for both groups and children in the community based group received a significantly higher amount of therapy time

## 4.6 CSI scores

### 4.6.1 Comparison of caregiver's CSI scores at baseline and at three months

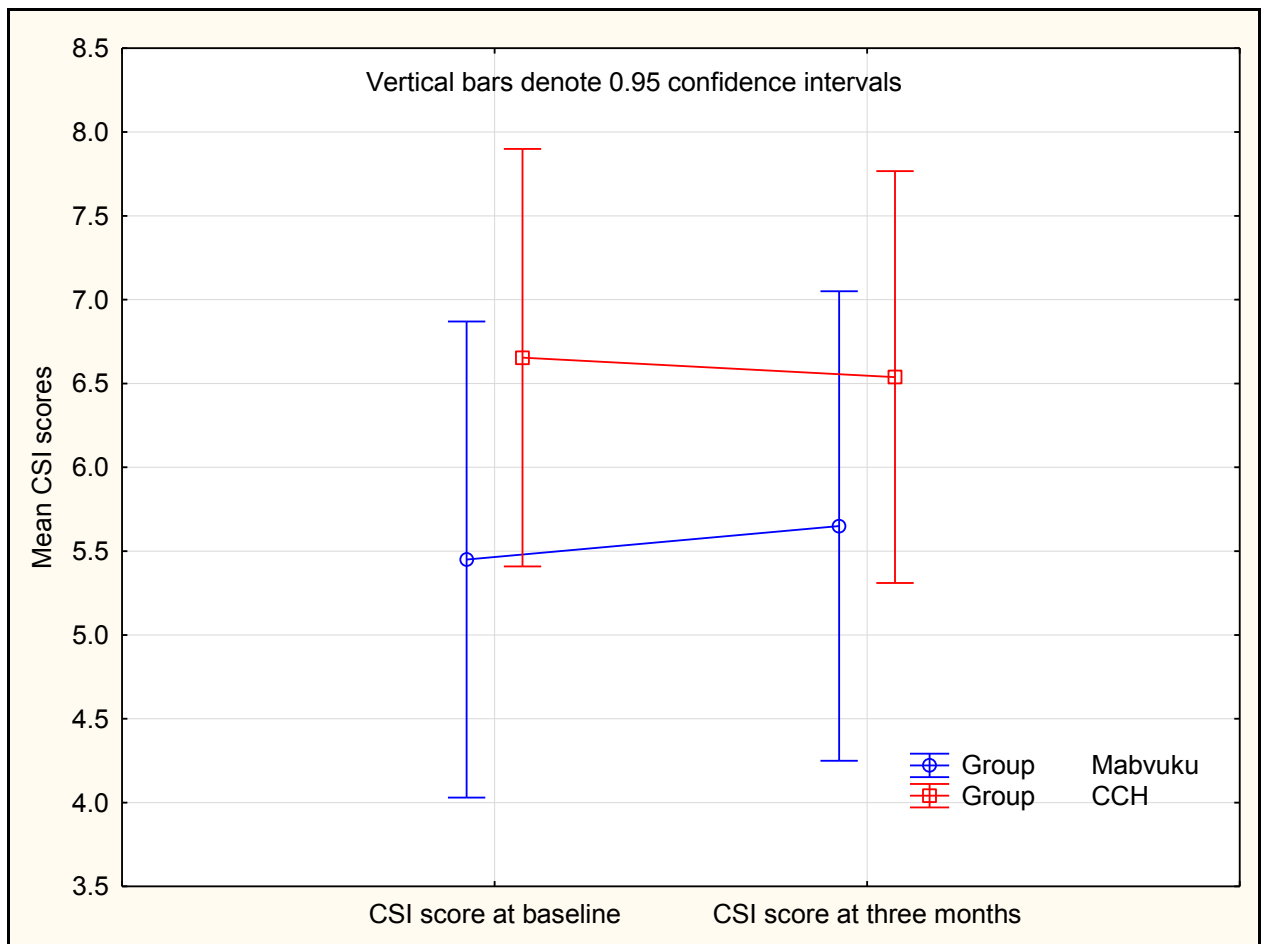


Figure 4-5: CSI scores comparison at baseline and at three months, n=46

To test for changes in the mean CSI scores at baseline and at three months, a one-way ANOVA of CSI scores was performed, and it yielded no significant differences between the two groups,  $F(1, 44) = .19961$ ,  $p = .65723$ . The mean and standard deviations are shown in Table 4-5 below.

Table 4-5: CSI scores comparison at baseline and at three months, N=46.

	At baseline		At three months	
	Mabvuku	CCH	Mabvuku	CCH
<b>Mean</b>	5.45	6.65	5.65	6.54
<b>SD</b>	3.73	2.62	3.54	2.73
<b>Median</b>	5.5	7	6	7

#### 4.6.2 Comparison of caregiver's CSI scores ranges at baseline and at three months

CSI scores range from zero to 12 with a score of seven or more indicating signs of stress. As seen from Table 4-6 below, just above half of the caregivers experienced exhibited signs of stress and there were no significant differences between the proportions of caregivers experiencing stress both at baseline and at three months between the two groups.

Table 4-6: Range of CSI scores at baseline and at three months, N=46.

Score range	At baseline (%)			statistic	p-value	At three months (%)			Statistic	p-value
	Mabvuku n(%)	CCH n(%)	Total n(%)			Mabvuku n(%)	CCH n(%)	Total n(%)		
0-6	12 (60)	11 (42.3)	23 (50)	$\chi^2 = 0.796\alpha$	0.372	11 (55)	11 (42.3)	22 (47.8)	$\chi^2 = 0.31\alpha$	0.578
7-12	8 (40)	15 (57.7)	23 (50)	df=1		9 (45)	15 (57.7)	24 (52.2)	df=1	

$\alpha$ - with Yates correction of continuity

### 4.6.3 Comparison of frequencies of reported CSI problems

The frequencies of reported problems on the CSI is outlined Table 4-7 below.

Table 4-7: Frequency of reported problems on the CSI for both groups, N=46.

CSI domains responses		Baseline					At three months				
		Mabvu	CCH	Total	Statistic	p-value	Mabvu	CCH	Total	Statistic	p-value
		ku n(%)	n(%)	n(%)			ku n(%)	n(%)	n(%)		
<b>Sleep</b>	Yes	3 (15)	9 (34.6)	12 (26.1)	$\chi^2$ =1.35 $\alpha$	0.245	2 (10)	9 (36.2)	11(23.9)	Fishers	<b>0.082</b>
	No	17(85)	17(65.4)	34(73.9)	df=1		18 (90)	17 (63.4)	35(76.1)	exact	
<b>Inconvenient</b>	Yes	8 (40)	16 (61.5)	24 (52.2)	$\chi^2$ =1.33 $\alpha$	0.249	10 (50)	15 (57.7)	25 (54.3)	$\chi^2$ =0.049 $\alpha$	0.825
	No	12(60)	10(38.5)	22(47.8)	df=1		10 (50)	11(42.3)	21(45.7)	df=1	
<b>Physical strain</b>	Yes	10 (50)	19 (73.1)	29 (63)	$\chi^2$ =1.69 $\alpha$	0.194	10 (50)	18 (69.2)	28 (60.9)	$\chi^2$ =1.04 $\alpha$	0.308
	No	10(50)	7(26.9)	17(37)	df=1		10(50)	8(30.8)	18(39.1)	df=1	
<b>Confining</b>	Yes	12 (60)	13 (50)	25 (54.3)	$\chi^2$ =0.142 $\alpha$	0.707	9 (45)	13 (50)	22 (47.8)	$\chi^2$ =0.002 $\alpha$	0.964
	No	8(40)	13(50)	21(45.7)	df=1		11(55)	13(50)	24(52.2)	df=1	
<b>Family adjustments</b>	Yes	10 (50)	16 (61.5)	26 (56.5)	$\chi^2$ =0.233 $\alpha$	0.629	7 (35)	14 (53.8)	21 (45.7)	$\chi^2$ =0.948 $\alpha$	0.330
	No	10(50)	10(38.5)	20(43.5)	df=1		13(65)	12(46.2)	25(54.3)	df=1	
<b>Personal plans</b>	Yes	11 (55)	19 (73.1)	30 (65.2)	$\chi^2$ =0.929 $\alpha$	0.335	11 (55)	21(80.8)	32 (69.5)	$\chi^2$ =2.43 $\alpha$	0.119
	No	9(45)	7(26.9)	16(34.8)	df=1		9(45)	5(19.2)	14(30.4)	df=1	
<b>Emotional adjustments</b>	Yes	7 (35)	16 (61.5)	23 (50)	$\chi^2$ =2.21 $\alpha$	<b>0.074</b>	7 (35)	16 (61.5)	23 (50)	$\chi^2$ =2.21 $\alpha$	<b>0.074</b>
	No	13(65)	10(38.5)	23(50)	df=1		13(65)	10(38.5)	23(50)	df=1	
<b>Upsetting behaviour</b>	Yes	8 (40)	7 (26.9)	15 (32.6)	$\chi^2$ =0.385 $\alpha$	0.535	6 (30)	5 (19.2)	11 (23.9)	Fishers	0.494
	no	12(60)	19(73.1)	31(67.4)	df=1		14(70)	21(80.8)	35(76.1)	exact	

<b>Has changed</b>	Yes	6 (30)	6 (23.1)		$\chi^2$	0.847	7 (35)	5 (19.2)		$\chi^2$	
					=0.037 $\alpha$					=0.755 $\alpha$	
	no	14(70)	20(76.9)	34(73.9)	df=1		13(65)	21(80.8)	34(73.9)	df=1	
<b>Work adjustments</b>	Yes	11 (55)	15 (57.7)	26 (56.5)	$\chi^2$	0.906	11 (55)	13 (50)	24 (52.2)	$\chi^2$	0.964
					=0.014 $\alpha$					=0.00 2 $\alpha$	
	no	9(45)	11(42.3)	20(43.5)	df=1		9(45)	13 (50)	22(47.8)	df=1	
<b>Financial strain</b>	Yes	14 (70)	15 (57.7)	29 (63)	$\chi^2$	0.583	17 (85)	17 (65.4)	34 (73.9)	$\chi^2$	0.245
					=0.302 $\alpha$					=1.35 $\alpha$	
	no	6(30)	11(42.3)	17(37)	df=1		3(15)	9(34.6)	12(26.1)	df=1	
<b>Overwhelmed</b>	Yes	14 (70)	22 (84.6)	36 (78.3)	Fishers	0.292	16 (80)	24 (92.3)	40 (87)	Fishers	0.380
					exact					exact	
	no	6(30)	4(15.6)	10(21.7)			4(20)	2(7.7)	6(13)		

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As seen from Table 4-7, there were no significant differences in the proportions of reported problems by caregivers across the groups, both at baseline and at three months. There were fluctuations in the proportions of reported problems, with increase in four domains from baseline values and two domains remaining constant. The least reported problem was sleep disturbances. Financial problems and being overwhelmed by caregiving constituting the bulk of the reported burden. In summary, a majority of caregivers reported strain due to caregiving as signified by the fact that more than 50% of the caregivers reported strain in nine out of the 12 CSI domains, and this is presented graphically in Figure 4-6 below:

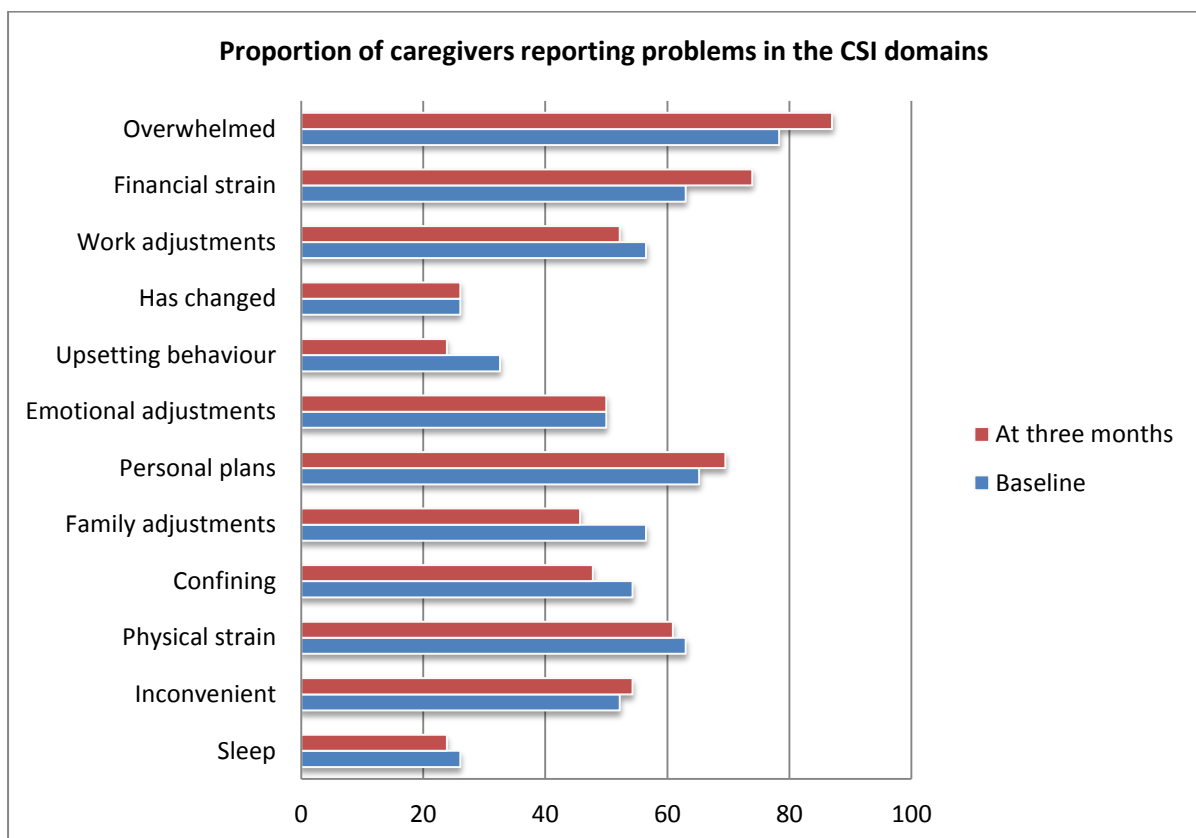


Figure 4-6: Summary of proportion of caregivers reporting problems, N=46

#### 4.6.4 Summary of CSI scores

Most of the caregivers experienced the burden of care and this increased with the chronicity of care. The burden of care was universal across the groups as they were no statistically significant differences between the two groups. Furthermore, the most strain was experienced in finances with the greater portion of caregivers expressing that they were overwhelmed by caregiving. Therefore there is no difference in levels of strain in recipients of community based treatment and hospital based treatment.

## 4.7 EQ-5D scores for both groups

### 4.7.1 Health profiles of caregivers at baseline and at three months

Table 4-8 below shows the proportions of reported problems in the EQ-5D domains across the groups.

Table 4-8: Health states of caregivers, N=46

Baseline					At 3 months					
EQ-5D domain	Mabvuk u n(%)	CCH n (%)	Total n (%)	Statistic	p- value	Mabvuk u n (%)	CCH n (%)	Total n (%)	Statistic	p- value
<b>Mobility</b>										
No problems	14 (70)	16 (61.5)	30 (65.2)	$\chi^2$ = 0.081 $\alpha$ df=1	0.776	13 (65)	18 (69.2)	31 (67.4)	$\chi^2$ =0.00 $\alpha$ df=1	0.989
Problems	6 (30)	10 (38,5)	16 (34.8)			7 (35)	8 (30.8)	15 (32.6)		
<b>Self-care</b>										
No problems	17 (85)	23 (88.5)	40 (86.9)	Fishers exact	1.00	16 (80)	20 (76.9)	36 (78.3)	Fishers exact	1.00
Problems	3 (15)	3 (11.5)	6 (13)			4 (20)	6 (23.1)	10 (21.7)		
<b>Usual activities</b>										
No problems	14 (70)	17 (65.4)	31 (67.4)	$\chi^2$ =0.00 $\alpha$ df=1	0.989	15 (75)	15 (57.7)	30 (65.2)	$\chi^2$ =0.827 $\alpha$ df=1	0.363
Problems	6 (30)	9 (34.6)	15 (32.6)			5 (25)	11 (42.3)	16 (34.8)		
<b>Pain/ discomfort</b>										
No problems	7 (35)	8 (30.8)	15 (32.6)	$\chi^2$ =0.00 $\alpha$ df=1	0.989	3 (15)	9 (34.6)	12 (26.1)	$\chi^2$ =1.35 $\alpha$ df=1	0.245
Problems	13 (65)	18 (69.2)	31 (67.4)			17 (85)	17 (65.4)	34 (73.9)		
<b>Anxiety/ depression</b>										
No problems	5 (25)	5 (19.2)	10 (21.7)	Fishers exact	0.726	5 (25)	3 (11.5)	8 (17.4)	Fishers exact	0.267
Problems	15 (75)	21 (80.8)	36 (78.3)			15 (75)	23 (88.5)	38 (82.6)		

$\alpha$  - with Yates correction of continuity

As can be seen in Table 4-8, a greater proportion of caregivers did not have problems with mobility, self-care, and usual activities at baseline and at three months. On the contrary, a greater proportion of the caregivers experienced some form of pain/discomfort and anxiety/depression, with the passage of time. They were no statistically significant differences in the reported problems between the two groups at baseline and at three months. Figure overleaf graphically outlines the summary of caregiver’s health status.

#### 4.7.2 Summary of proportions of caregivers with problems in the EQ-5D dimensions

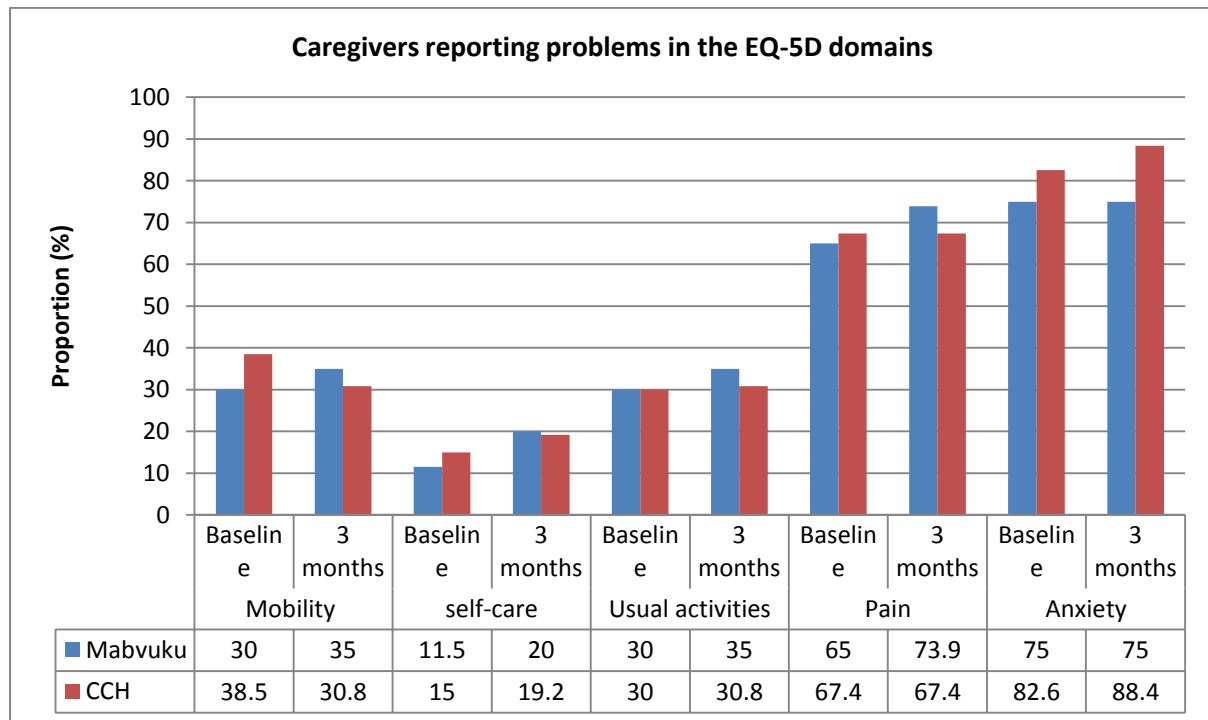


Figure 4-7: Summary of proportions of caregivers with problems in the EQ-5D dimensions, N=46

#### 4.7.3 Comparison of utility scores at baseline and at three months for both groups

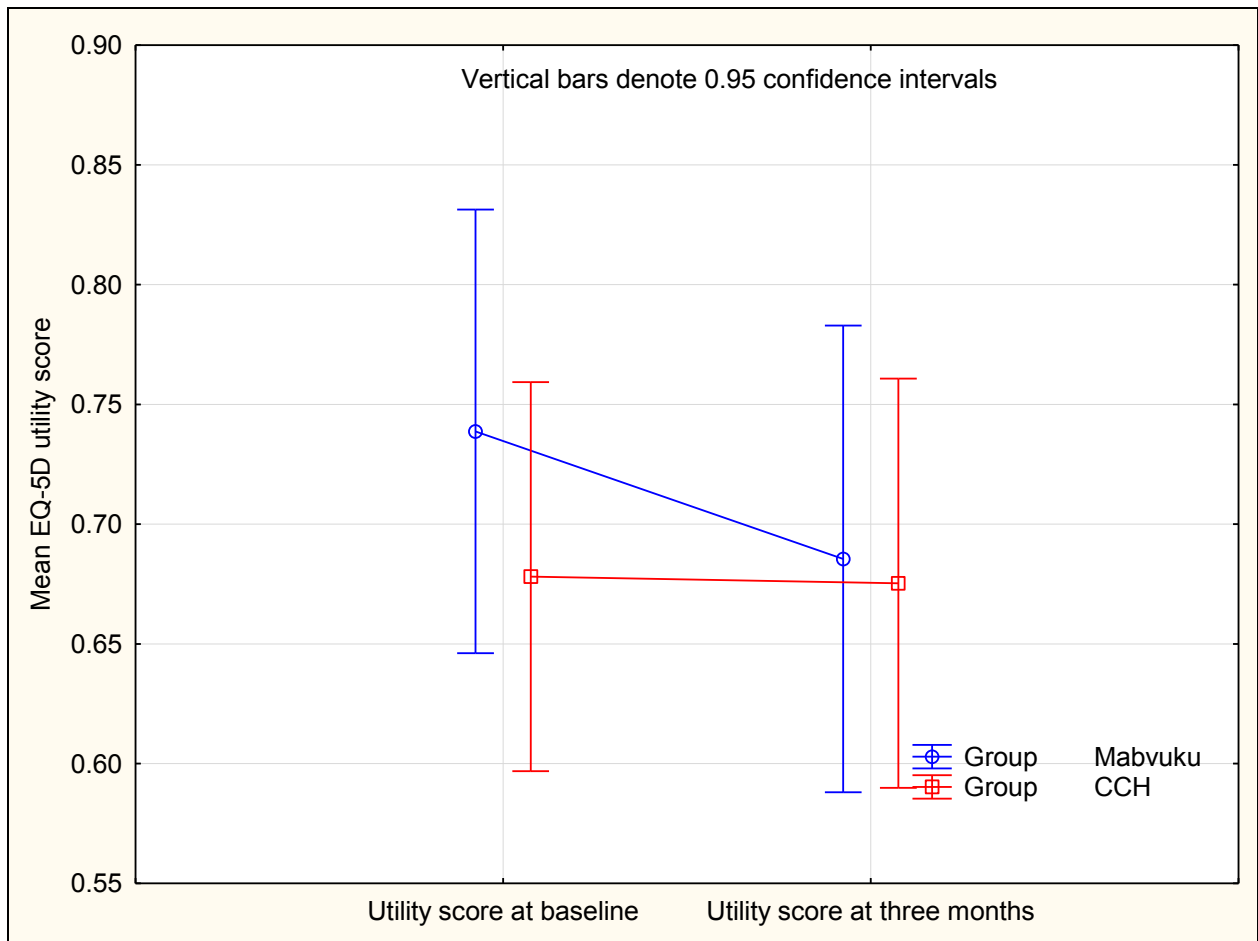


Figure 4-8 Comparison of utility scores at baseline and at three months for both groups

Figure 4-6 above shows a comparison of EQ-5D utility scores at baseline and at three months. To test for changes in the changes in mean utility scores, a one-way ANOVA was performed, and it yielded no significant differences between the two group,  $F(1, 44) = 1.63$ ,  $p = .208$ . The means and standard deviations are shown in Table 4-9 below.

Table 4-9: Comparison of EQ-5D utility scores at baseline and at three months, N=46

EQ-5D Utility scores	At baseline		At three months	
	Mabvuku	CCH	Mabvuku	CCH
Mean	0.74	0.68	0.69	0.68
SD	0.15	0.24	0.21	0.22
Median	0.78	0.78	0.79	0.74

#### 4.7.4 Comparison of EQ-5D VAS scores at baseline and at three months for both groups

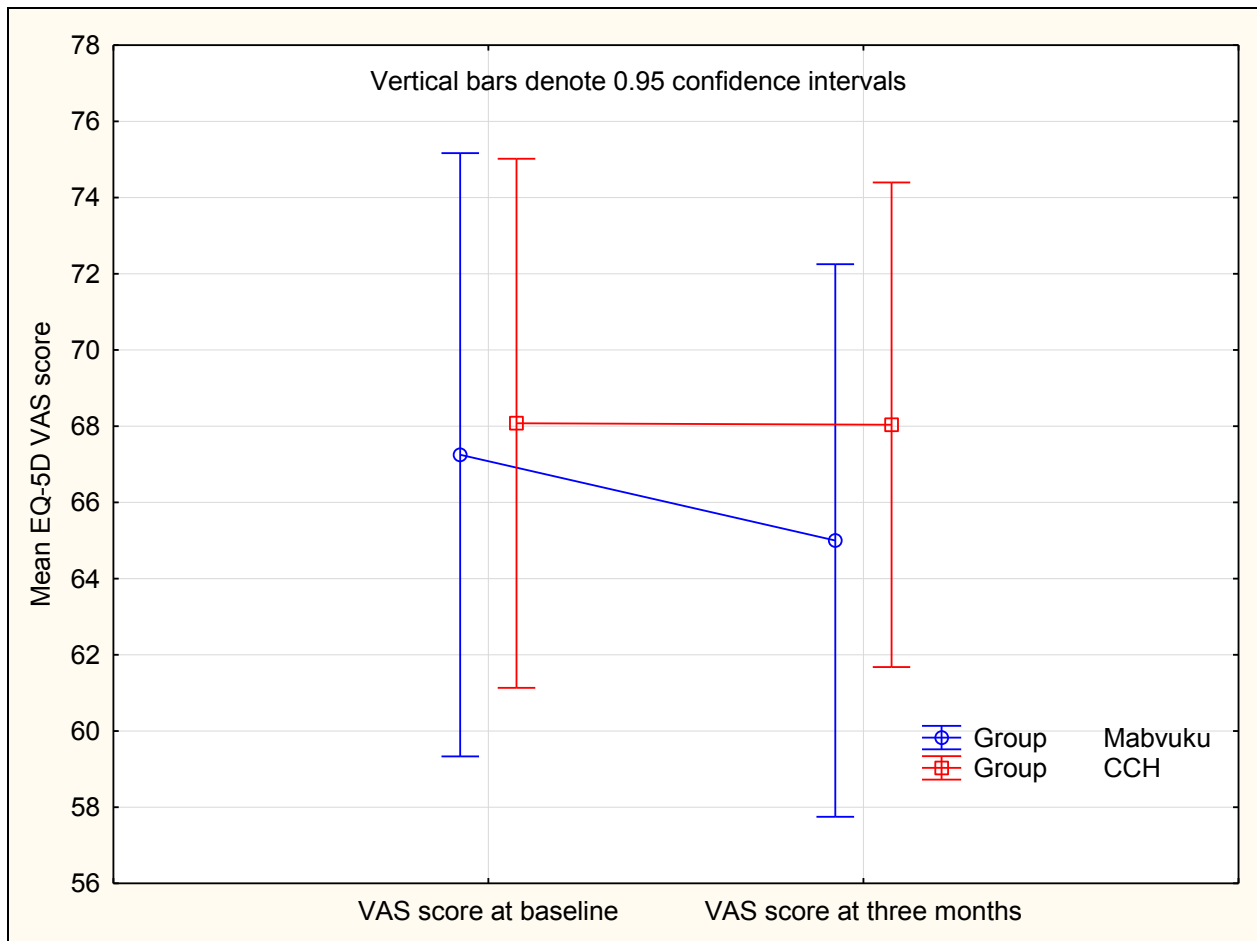


Figure 4-9 EQ-5D VAS scores over three months, N=46

Figure 4-7 above shows a comparison of EQ-5D VAS scores at baseline and at three months. To test for changes in mean EQ-5D VAS scores, a one-way ANOVA was performed at, and it yielded no significant differences between the two groups,  $F(1, 44)=.398$ ,  $p=.531$ . The mean and standard deviations are shown in Table 4-10 below.

Table 4-10: EQ-5D VAS scores over three months, N=46

EQ-5D VAS scores	At baseline		At three months	
	Mabvuku	CCH	Mabvuku	CCH
<b>Mean</b>	67	68	65	68
<b>SD</b>	18	17	17	16
<b>Median</b>	70	70	60	60

#### 4.7.5 Correlations between EQ-5D scores and other variables

Table 4-11 below shows how EQ-5D scores were related to other variables and the marked correlations are significant at  $p < 0.05$ .

Table 4-11: Correlations between EQ-5D scores and other variables

	GMFCS level	VAS score at baseline	Utility score at baseline	CSI score at baseline
<b>GMFCS level</b>	1.0	-0.095	-0.131	-0.146
<b>VAS score baseline</b>	-0.095	1.0	0.757*	-0.326*
<b>Utility score baseline</b>	-0.131	0.757*	1.0	-0.256
<b>CSI score baseline</b>	-0.146	-0.326*	-0.256	1.0

\* Marked correlations are significant at  $p < .05$

There was significant positive correlation between EQ-5D utility scores EQ-5D VAS scores at baseline and at three months. Additionally, there was also a significant negative correlation between baseline EQ-5D utility and CSI scores at three months and between baseline EQ-5D VAS scores and CSI scores at baseline and at three months.

#### 4.7.6 Summary of EQ-5D results

The two groups were comparable in their HrQOL as they were no statistically significant differences in all EQ-5D domains and summative scores. However, most of the caregivers reported that they suffered from pain/discomfort and anxiety/depression, which increased with the passage of time. Furthermore, caregivers who reported a greater burden of care subsequently reported poorer HrQOL. Likewise, although not statistically significant, caring for a severely impaired child was associated with declined HRQoL.

## 4.8 Satisfaction with services

### 4.8.1 Overview of satisfaction domains for both groups

Table 4-12 below shows a summary of the comparison of satisfaction with rehabilitation services across the two groups. A detailed outline of the various satisfaction domains then ensures.

**Table 4-12: Satisfaction with rehabilitation services, N=46.**

Satisfaction domain	Group	Strongly disagree n (%)	Disagree n (%)	Neutral n (%)	Agree n (%)	Strongly agree n (%)	Statistic	p-value
<b>Registration process</b>	Mabvuku	0	0	1 (5)	7 (35)	12 (60)	Fishers'	0.354 Exact
	CCH	0	0	2 (7.7)	14 (53.8)	10 (38.5)	Exact	
	Total	0	0	6 (13.0)	21 (45.7)	22 (47.8)		
<b>Comfort of waiting area</b>	Mabvuku	1 (5)	0	5 (25)	8 (40)	6 (30)	Fishers'	0.421 Exact
	CCH	0	1 (3.8)	10 (38.5)	11 (42.3)	4 (15.4)	Exact	
	Total	1 (2.2)	1 (2.2)	15 (32.6)	19 (41.3)	10 (21.7)		
<b>Time therapist spends with child</b>	Mabvuku	1 (5)	1 (5)	2 (10)	4 (20)	12 (60)	Fishers'	<.001 Exact
	CCH	0	4 (15.4)	10 (38.5)	10 (38.5)	2 (7.7)	Exact	
	Total	1 (2.2)	5 (10.9)	12 (26.1)	14 (30.4)	14 (30.4)		
<b>Amount of explanations given by therapist</b>	Mabvuku	0	0	1 (5)	4 (20)	15 (75)	Fishers'	0.028 Exact
	CCH	0	5 (19.2)	4 (15.4)	8 (30.8)	9 (43.6)	Exact	
	Total	0	5 (10.9)	5 (10.9)	12 (26.1)	24 (52.2)		
<b>Being treated with respect</b>	Mabvuku	0	1 (5)	1 (5)	5 (25)	13 (65)	Fishers'	0.610 Exact
	CCH	0	1 (3.8)	2 (7.7)	11 (42.3)	12 (46.2)	Exact	
	Total	0	2 (4.3)	3 (6.5)	16 (34.8)	25 (54.3)		
<b>Having concerns listened to</b>	Mabvuku	0	0	0	4 (20)	16 (80)	Fishers'	<.001 Exact
	CCH	0	1 (3.8)	10 (38.5)	7 (26.9)	8 (30.8)	Exact	
	Total	0	1 (2.2)	10 (21.7)	11 (23.9)	24 (52.2)		
<b>Having all questions answered</b>	Mabvuku	0	0	2 (10)	3 (15)	15 (75)	Fishers'	0.023 Exact
	CCH	0	2 (7.7)	7 (26.9)	9 (34.6)	8 (30.8)	Exact	
	Total	0	2 (4.3)	9 (19.6)	12 (26.1)	23 (50)		
<b>Being given future advice</b>	Mabvuku	0	0	0	5 (25)	15 (75)	Fishers'	0.001 Exact
	CCH	1 (3.8)	5 (19.2)	5 (19.2)	9 (34.6)	6 (23.1)	Exact	
	Total	1 (2.2)	5 (10.9)	5 (10.9)	14 (30.4)	21 (45.7)		
<b>Receiving instructions on home exercise program</b>	Mabvuku	0	1 (5)	2 (10)	2 (10)	15 (75)	Fishers'	0.259 Exact
	CCH	2 (7.7)	3 (11.5)	4 (15.4)	6 (23.1)	11 (42.3)	Exact	
	Total	2 (4.3)	4 (8.7)	6 (13.0)	8 (17.4)	26 (56.5)		

<b>Overall satisfaction</b>	Mabvuku	0	1 (5)	1 (5)	5 (25)	13 (65)	Fishers'	<b>0.038</b>
	CCH	4 (15.4)	3 (11.5)	6 (23.1)	6(23.1)	7 (26.9)	Exact	
	Total	4 (8.7)	4 (8.7)	7 (15.2)	11 (23.9)	20 (43.5)		
<b>If they will return for future services</b>	Mabvuku	0	0	2 (10)	4 (20)	14 (70)	Fishers'	<b>0.124</b>
	CCH	0	1 (3.8)	8 (30.8)	7 (26.9)	10 (38.5)	Exact	
	Total	0	1 (2.2)	10 (21.7)	11 (23.9)	24 (52.2)		

#### 4.8.2 Differences in satisfaction between the two groups

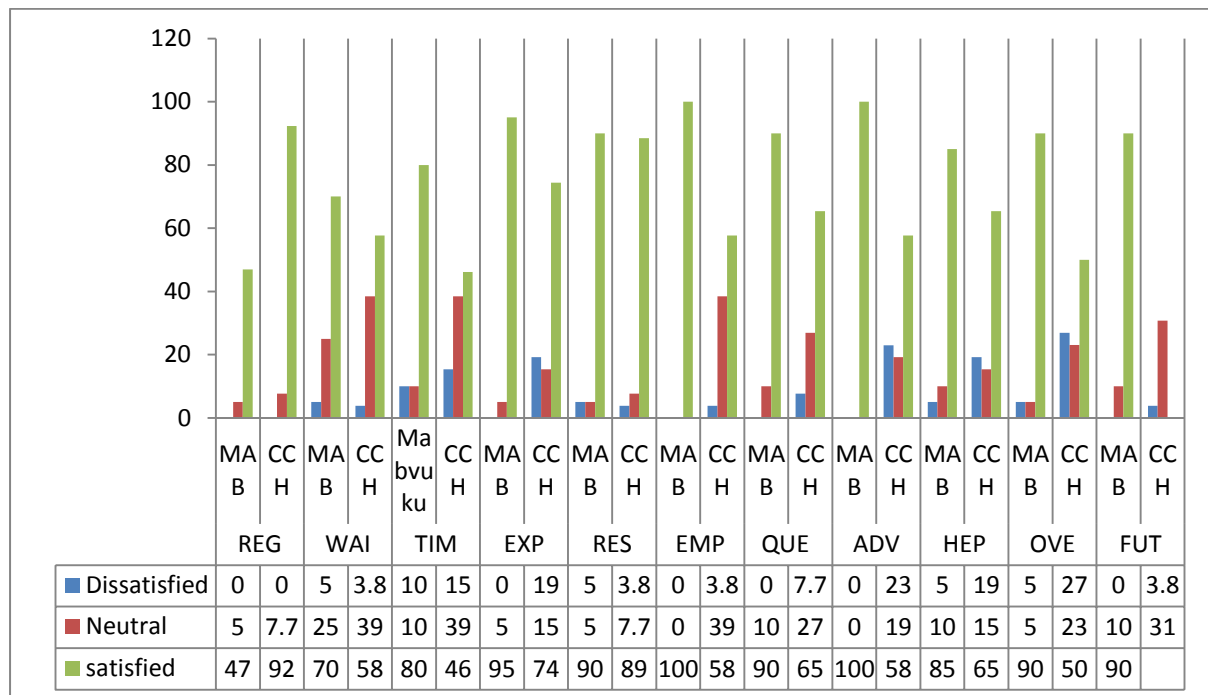


Figure 4-10: Differences in satisfaction, N=46

**\*Key – MAB-mabvuku, REG- registration, WAI-waiting area, TIM-time, EXP-explanations, RES-respect, EMP-empathy, QUE- questions, ADV- advice, HEP- home exercise program, OVE- overall satisfaction, FUT- future utilization of services.**

Figure 4-10 above is a graphical depiction of the difference between satisfaction with services across the two groups. For the sake clarity, ratings of “strongly disagreed” and “disagreed” were classified as dissatisfied. Likewise, “agreed” and “strongly agreed” ratings were classified as satisfied.

As can be seen in Figure 4-10 above, most of the caregivers were satisfied with services with the exception of the following domains:

- Time therapist spends with child
- Amount of explanations given by therapists
- The empathy given by therapists
- Level of answering of questions by therapists
- Overall satisfaction

In the fore-mentioned categories, caregivers in the community based treatment group were significantly more satisfied as compared to caregivers in the hospital based group.

### 4.8.3 Factors influencing satisfaction – results from the open ended questions

Twenty participants responded to the open-ended questions. Thematic content analysis approach was utilized to analyse the open-ended responses. It involved identifying, and analysing recurrent themes and the emergent themes were dichotomised into internal and external factors. Internal factors relate to patient/therapist interaction and treatment process. External factors relate to logistical and environmental factors such as the processes of making bookings and the comfort of the waiting area.<sup>95</sup>

#### 4.8.3.1 Internal factors

Table 4-13 below shows a summary of comments made by caregivers with regards to internal variables to satisfaction.

Table 4-13: Comments on internal variables of satisfaction, n=29

Variable	Mabvuku	CCH	Combined
Time	4	11	15
HP talks	0	2	2
Friendliness of staff	7	5	12

- Some of the caregivers, (n=15), felt that therapists did not spend adequate time with their children. This was vividly expressed in the following statement by one of the caregivers, " I feel that therapists rush through sessions and as a result, it makes it harder for me to totally grasp the exercises they prescribe that I should do at home"
- Some caregivers, (n=2), from CCH expressed satisfaction with the HP talks which were being offered as expressed in the following statement : " I find the monthly talk very helpful as I never got any information with regards to my child from the doctors when my child was diagnosed of cerebral palsy"
- Twelve caregivers from both groups complimented the friendliness of rehabilitation staff. One caregiver from CCH had this to say, " I feel more accepted by rehabilitation staff than how I am treated at the outpatient department by medical and nursing staff. They should keep up the good work as they really understand what we go through as parents of children with disabilities"

#### 4.8.3.2 External factors

Table 4-14 below shows a summary of comments made by caregivers with regards to external variables to satisfaction.

Table 4-14: Comments on external variables to satisfaction, n=20

Variable	Mabvuku	CCH	Combined
Booking schedules	0	9	9
Waiting area	6	5	11

- Some of the caregivers in the CCH group, n=9, reiterated the need for consistent booking schedule as the booking were made so random. This is summarised in the following statement by one of the caregivers: “I would prefer to be given a more consistent booking schedule so that I can plan in advance as I have to keep my family afloat as well”.
- Caregivers in both groups (n=11), suggested that services providers needed to improve the waiting area. They complained about the shortage of chairs to seat as most of them had to stand whilst waiting for their child to be treated. In the community based treatment group, caregivers suggested the expansion of the treatment area as they felt it was getting inadequate with the increasing number of children being referred to the community centre for therapy.

#### 4.8.4 Summary of satisfaction results

Caregivers receiving community based services seemed to be more satisfied with services as compared to those receiving hospital based services. Statistically significant differences were in the following domains: time therapist spends with child, amount of explanations, empathy given by therapists, level of answering of questions by therapists and overall satisfaction. Further, caregivers were appreciative of the HP talks and the professionalism of rehabilitation practitioners. However, caregivers expressed the need for improvement in the waiting area and booking schedules.

## 4.9 Compliance results

### 4.9.1 Compliance rates for the two groups

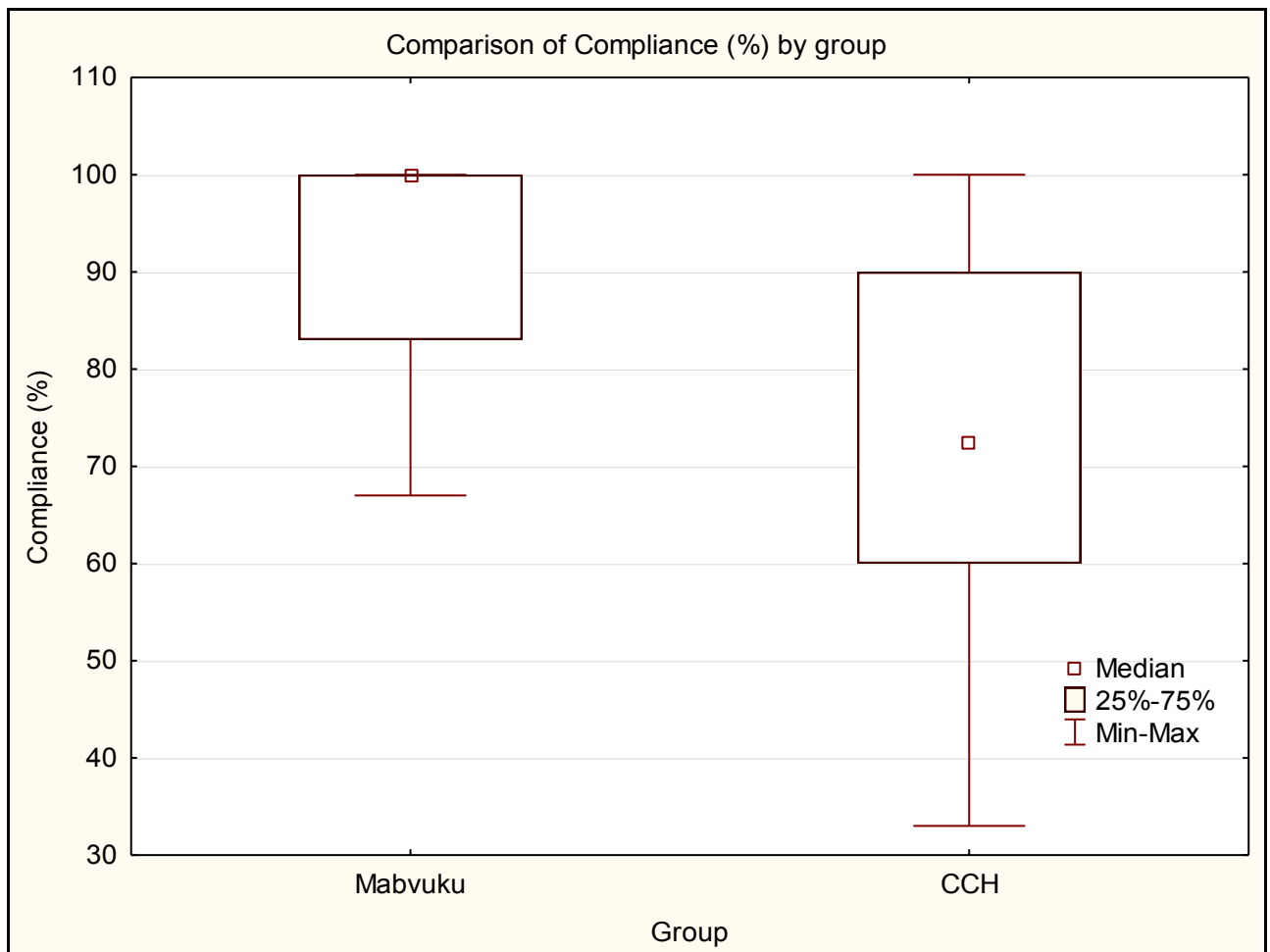


Figure 4-11 : Comparison of compliance rates across groups, n=46

The percentage compliance was calculated by dividing the number of attendances by the maximum number of attendances possible. Caregivers in the community based treatment group were expected to attend every two weeks and the baseline for this group was therefore 14. For the hospital based group, caregivers were given a variable number of appointments; the number of appointments was taken as the denominator and the number of kept appointments as the numerator. The mean percentage compliance was 93.3 (SD 11.3, median=100 & range: 67-100) for community based treatment group and 72.8 (SD 20.3, median=72.5 & range: 33-100) for the hospital based group. The data were not normally distributed (Shapiro-Wilk  $W=.850$ ,  $p<.001$ ), and consequently the Mann Whitney U test established that there was a significant difference in the rank ordering of compliance for the two groups ( $Z=-3.56$ ,  $p<.001$ ).

#### 4.9.1.1 Summary of compliance rates

Caregivers in the community based treatment group were more compliant as compared to caregivers receiving hospital-based services.

#### 4.10 Summary of results

- Although children receiving community based treatment children were significantly older than children in the hospital based services arm, the two groups were comparable in terms of demographics of both children and caregivers.
- There was a non-significant difference in the GMFM-88 scores for both groups and both groups showed some significant improvements in their GMFM-88 scores over the three months period.
- The types of interventions offered were similar for both groups, and the hospital based services group had a higher child to therapist ratio.
- The two groups of caregivers were comparable in their HrQOL as there were no statistically significant differences in EQ-5D scores, either before or after the study period. Further, most of the caregivers reported that they suffered from pain/discomfort and anxiety/depression, which increased with chronicity of care.
- Most of the caregivers experienced a high burden of care and this increased with the chronicity of care. The burden of care was universal across the groups as there were no statistically significant differences between the two groups. Furthermore, the most strain was experienced in the area of finances with the greater portion of caregivers expressing that they were overwhelmed by caregiving.
- Caregivers in the community based treatment group seemed to be more satisfied with services as compared to recipients of hospital based services. Statistically significant differences were in the following domains: time therapist spends with child, amount of explanations, empathy given by therapists, level of answering of questions by therapists and overall satisfaction. Further, caregivers were appreciative of the HP talks and the professionalism of rehabilitation practitioners. However, caregivers expressed the need for improvement in the waiting area and booking schedules.
- Caregivers in the community based treatment caregivers were more compliant as compared to caregivers receiving hospital-based services.

## 5 DISCUSSION

### 5.1 Introduction

The results will be discussed in the order they were presented. Demographics will be discussed first and discussion of treatment-related factors will precede the discussion of caregivers-related variables.

#### 5.1.1 Comparability of the two groups

The two groups were equivalent in all facets of demographics with the exception of age of children. Equivalency is essential for results to be comparable across the two groups. However, the high loss to follow up in the hospital based group is potentially worrying. Needless to say, the aim of the study was to compare the two models as is. Therefore, it was not part of our objectives to minimize loss to follow up as this would have contaminated our results. Notwithstanding this, there is a need for further exploration as a loss to follow up may be reflective of poorer continuity of care.

Further, the two groups were comparable in terms of the children GMFCS levels, and this is crucial as the literature suggests a correlation between GMFCS level and level of caregiver burden.<sup>66</sup> Our sample included children of all severity. This is essential as some studies only recruited either children with minor impairments or children who are severely affected and this limits the generalizability of such findings.

### 5.2 Demographic characteristics of the sample

As outline below, the discussion of demographic characteristics of children with CP will precede that of the caregivers.

#### 5.2.1 Sociodemographics of children with CP

The male to female ratio was 1.19 as opposed to 1.00 figure from the 2002 national population census,<sup>176</sup> and this can be a threat to the representativeness of the sample. However, the ratio is comparable to other studies as more boys get CP than girls.<sup>13 58 71</sup>

The fact that community based treatment children were significantly older poses a threat on the comparability of the two groups as ideally the two groups should have been matched in terms of age. This is because literature postulates that the burden of care may increase with increase in age of children. For instance, children become heavier to lift in transfers as they grow older.<sup>73</sup> However, other authors postulate that the burden of care is more in younger in younger children as they require more assistance in ADLs others.<sup>61</sup> Additionally, matching was not feasible as this would have resulted in a very small sample size with very low power.

The discrepancy in age of children between the two groups poses questions as to the extent of follow up of clients between the two groups. The older age of the community children may indicate that this form of service delivery is preferable as not only younger children are brought in for intervention. As outreach is done within community, follow up is easier. As children with CP grow older, they become heavier to transport and taking into account, the low SES of the study participants, it can be difficult for those utilizing hospital-based services because of the associated long term financial burden.

## **5.2.2 Caregiver demographic characteristics**

### **5.2.2.1 Caregiver relationship status**

The finding that all of the caregivers were women, the bulk of the caregivers being mothers consisting is consistent with other studies.<sup>61 63</sup> More so, this is also a reflection of the African culture where the responsibility is almost always left entirely to the mothers<sup>177</sup> or grandmothers.

### **5.2.2.2 Caregivers' educational and employment status**

This literacy rate of caregivers in our sample was comparable to the 2010 figures released by the United Nations Development Programme (UNDP) which states that the literacy rates for females in the adult (15+ years) and youth (15-24 years) groups were 90% and 100% respectively.<sup>178</sup> Our results also corroborate with findings from the validation of the Shona EQ-5D questionnaire by Jelsma et al.<sup>87</sup> Their study revealed that 2.4% of the respondents had not attained some form of education. However, the higher figure in this study (6%) can be accounted for by the economic meltdown in our country which has resulted in literacy rates declining in the last decade.<sup>25 179</sup> All in all, educational attainment of caregivers is reflective of the population of Zimbabwe.

Furthermore, literature suggests a link between lower educational attainment and unemployment in CP caregivers.<sup>46</sup> However, the high literacy rate in Zimbabwe and the high unemployment rate negate this hypothesis. According to the UNDP, the overall rate of unstructured unemployment for Zimbabwe in 2003 was 63% and that of women was 70%.<sup>180</sup> Further, according to the ILO, the rate of informal employment rose to 80% in the year 2004.<sup>181</sup>

## **5.3 Discussion of changes in functional (GMFM-88) scores of children with CP**

Children and caregivers had had interventions for varying lengths of time and changes in the outcome measures might have taken place prior to the study. We had initially set to evaluate the amount of prior interventions the children had undergone. However, this was not feasible due to poor record keeping and as this approach was very prone to recall bias in caregivers.

Literatures stipulate that age of children can determine the extent of functional/motor changes in children with CP, with greater changes in younger children.<sup>18</sup> However, our results indicate that age is not predictive of functional changes. This may be explained by ceiling effects of the GMFM-88,<sup>142</sup> given that one of the groups (community based treatment) had significantly older children. Further, regression analysis showed that children in the community based treatment group showed greater improvement and several factors can account for this difference. Firstly, some of the rehabilitation workers in the community based treatment group are based in a specialist unit and have developed skills in child treatment whereas there is no “specialization” in hospital based rehabilitation professionals as they are occasionally rotated.

Secondly, the lower child to therapist ratio in the community based treatment group ensures ample time for treatment and demonstration of techniques to caregivers and this may lead to better functional outcomes. Further, literature states that a good therapist-child relationship may influence changes in functional outcomes as it increases in treatment adherence and this can enhance treatment efficacy.<sup>45</sup> Additionally, the continuity of care in the community based treatment may serve as an enhancer to enhance treatment efficacy. Likewise, our findings are in concordance with literature which states that the severity of CP is negatively correlated to changes in functional outcomes.<sup>52</sup>

## **5.4 Discussion of the burden of caregiving a child with CP on caregivers**

### **5.4.1 Overview**

Caregivers in both groups reported considerable strain due to care-giving and this is similar to findings from other studies which report that caregiving a child with CP can be stressful.<sup>1 59 60 61 62</sup> Furthermore, as noted previously,<sup>1 61 64</sup> the burden is multifactorial as caregivers experience strain in most of the CSI domains and the strain increased with the chronicity of care. Discussion of the CSI findings is discussed under the following categories: economic, physical and psycho-social burden.

### **5.4.2 Economic burden**

Our results are consistent with literature which suggests that caregiving can result in an increased financial burden.<sup>28 49 59 61 63 66 67 70 71</sup> This was evident across both groups. Although no comparison was made with the financial situation of parents of typically developing children (which was a weakness of the study), three quarters of respondents reported an increased financial burden. Caregiving leads to compromised working opportunities due to the conflicting demands of caregiving and employment thus ultimately resulting in limited opportunities to enter gainful employment.<sup>28 59 66 67</sup> Likewise, in a cross sectional study on 91 Bangladeshi caregivers, a country with similar developmental challenges, mothers of children with CP of the age range 1.5-5 years concluded that

caregiving results in an added economic burden. The authors recommended that economic empowerment of caregivers in the form of micro-credit programs may lead to reduced financial burden. Furthermore, they postulated that provision of low cost aids would also help to alleviate physical and financial burden in caregivers.<sup>46</sup> This could also be useful in the Zimbabwean context.

Furthermore, CP is more prevalent in people of lower SES,<sup>114</sup> and as poverty is part of a vicious cycle, caregivers of lower SES are likely to have lower educational attainment, have diminished opportunities of finding employment and subsequently are at high risk of financial strain.<sup>182</sup> This is true across different contexts. A Canadian study comparing health outcomes of 468 caregivers of children with CP with the general population revealed that caregivers had lower academic attainment, had limited work opportunities and were more likely to be unemployed and subsequently had lower income levels.<sup>66</sup> The mean age of their participants was 40.3 (SD 6.7) years and age range was 23-63 years which was comparable to our sample.

The increase in financial burden with the passage of time can be accounted for by the recurrent usage of medical services<sup>183</sup> which adds to the costs of raising a child with a disability. As CP is associated with diverse impairments,<sup>17 44</sup> children with CP often require routine medical attention<sup>183</sup> and this may overburden limited financial budgets, particularly in those who are drawn from lower SES groups. Additionally, the greater financial burden in community based caregivers may be partially due to the fact that the group constituted significantly older children. Financial needs are likely to increase with the ageing of children. For instance, expenses such as special education are incurred at a later stage of life.

#### **5.4.3 Physical burden**

Our results are consistent with literature which states that caregiving can lead to physical strain.<sup>66 67</sup> This can be explained by the fact that most children would require assistance in ADLS due to activity limitations they face<sup>61</sup> and this would be universal regardless of service delivery model .

As children receiving community based services were significantly older and more were at GMFCS level 5, it would seem reasonable to expect the caregivers to complain of more physical strain as the children would be heavier to carry and need more care. However, although not statistically significant, a greater proportion of caregivers in the hospital based services group suffered physical strain. It is possible that as the caregivers in the community based treatment group had to walk relatively smaller distances to access rehabilitation services, they might have had less physical strain. Additionally, as they would have undergone workshops where they would have been taught on lifting techniques, they might have been more likely to engage in proper ergonomics resulting in the lower

physical strain reported. However, there have not been evaluation reports on the efficacy of the workshops in reducing physical burden in caregivers.

#### 5.4.4 Psycho-social burden

Long term caregiving has been shown to predispose caregivers to strain, stress, depression and distress which is of chronic duration relative to the rest of the population.<sup>62 66 67 74</sup> The psychosocial burden is multifactorial and most caregivers complained of psychosocial problems as measured by the CSI.

Further, findings from this study concur with literature which states that caregivers occasionally experience sleep problems<sup>61 75</sup>, and this was irrespective of the mode of service delivery although it approached significance. Children with CP suffer from a wide range of impairments and these may account for abnormal sleep patterns. For instance, pain is prevalent in children with CP and this can lead to the child displaying altered sleep patterns,<sup>61 184</sup> which would affect the care-giver, particularly in the small homes in which the majority of residents of the two suburbs live. Furthermore, most of the children suffer from communication problems; therefore “excessive crying” may be the only viable way of communication and may result in altered sleep for caregivers.<sup>184</sup> Furthermore, some of the altered sleep problems can be an expression of behavioral problems in the children with CP.<sup>76</sup> As children in the community based treatment group were significantly older, it may be that the caregivers would have developed ways of dealing with sleep problems with the passage of time. Alternatively it could be a reflection in the differences in the management of underlying conditions which result in sleep problems. By and large, disrupted sleep is likely to result in stress in caregivers and physical fatigue and this perpetuates a vicious cycle. This underscores the need to screen and treat pain in children with CP.<sup>184</sup>

Caregiving can also result in changes in personal plans and this could impact on the social life of caregivers and social connections.<sup>62 77 80</sup> As many of the participants reported changes in personal plans, that caregiving is confining and is inconvenient, it's reasonable to infer that caregiving a child with CP alters social life and connections as most of the time is spend caregiving.

##### 5.4.4.1 Emotional changes

Our findings concur with literature which stipulates that caregiving can be emotionally draining for caregivers.<sup>61 71 78 79</sup> A Canadian study comparing health outcomes of 468 caregivers of children with CP with the general population revealed that although caregivers experienced the same levels of social support and family functioning, they had decreased opportunities and subsequently, suffered from distress which was of chronic duration.<sup>66</sup> Furthermore, they were more likely to suffer from

emotional and cognitive problems, as well as chronic illnesses.<sup>66</sup> In our context, emotional problems can stem from the stigmatization and discrimination against disability.<sup>33</sup> Cultural beliefs as to the cause of the disability may contribute towards this stigmatization and consequently social isolation and emotional problems in caregivers.<sup>27 33</sup> Cerebral palsy can be viewed as a curse from ancestral spirits for wrongdoings such as promiscuity during pregnancy.<sup>27</sup> Further, stigmatization in its worst form, may led to the locking up of children with CP in homes thus denying them access to medical treatment.<sup>27 33</sup>

Additionally, as much time is spent in caregiving, this may lead to social isolation, and this may contribute to emotional problems as social interaction has been demonstrated to act as a buffer for the burden of care.<sup>1 61 65</sup> Furthermore, in extreme cases, the bearing of a child with a disability can lead to marriage breakdown and subsequent emotional problems in mothers as they have to bear the burden of caregiving on their own. However, a UK study reported that caregiving a child had no effect on the caregivers' marital status.<sup>71</sup> The contrast in findings may be attributed to the differences in socio-economic and cultural contexts. For instance, as the UK is a high resource setting, it most likely that caregivers would have better access to support services which can aid in acceptance of the child's disability. Whereas lack of knowledge and cultural beliefs may led to marriage breakdown in our cultural setting.

In addition, the decline in the proportion of caregivers who complained of family adjustments from index to three months may be attributed to the acceptance of the child's condition. Additionally, professional advice and counseling from treating therapists could also have contributed to this acceptance.<sup>59</sup>

#### **5.4.4.2 Upsetting behaviour**

Behavioral problems are the strongest predictor of maternal stress.<sup>46 76 77 78</sup> Additionally, behavioral problems can also manifest as other psycho-social problems such as emotional problems and depression.<sup>76</sup> The decrease in the proportion of caregivers complaining of children behavioral problems can be attributed to several factors. Firstly, through the health promotional efforts by the therapists, caregivers may have gained insight into how to deal with behavioral problems through workshops, health promotional lectures or as part of treatment programs. Additionally, caregivers could possibly have developed strategies to deal with behavioral problems of their children as their parenting skills could have improved with the passage of time.

#### 5.4.4.3 Being overwhelmed by caregiving

As reported in literature, caregiving a child with CP can be overwhelming as it can negatively affect caregivers physically, emotionally and psychosocially.<sup>1 61 64 65</sup> The increase in the proportion of caregivers who felt overwhelmed can be accounted for by the fact that caregiving demands increase with time. Furthermore, the burden is cumulative and chronicity of care has been shown to lead to further deterioration of caregivers HRQoL. A similar study which was conducted in the UK on 70 caregivers of children with CP, revealed that compared with caregivers of children without long term health conditions, caregivers of children with CP reported lower satisfaction with life, were more depressed and more anxious.<sup>71 111</sup>

Likewise, a Canadian cross sectional study,<sup>74</sup> revealed that compared to the general population, caregivers of children with health problems (468 in number) were more likely to :

- suffer from at least one chronic illness
- have activity limitations
- exhibit lower general health status
- be depressed and subsequently more likely to smoke more

This was regardless of the fact that the two groups were equivalent in terms of social support, family functioning, marital satisfaction, number of children in the household and SES. Literature also states that caregivers of younger children suffer more burden as they require more assistance.<sup>61</sup> Further, they may be going through the grieving process thus delaying acquisition of formal support services.<sup>71</sup> This can in part account for a greater proportion of caregivers who were overwhelmed with caregiving in the hospital based group.

#### 5.4.5 Summary of CSI discussion

Findings from the current study concur with literature which postulates that the burden of care is multifactorial and that there is interplay of these factors<sup>59 60 61 62 64</sup> For instance, literature postulates that caregiving leads to conflict between caregiving and occupational roles.<sup>28 59 63 66 67 71</sup> Our findings are in accordance with this as most of the caregivers reported that caregiving was inconvenient, had led to change in personal and family plans. Likewise, our results are consistent with literature which stipulates that the level of burden increases with chronicity of care. Additionally, our results seem to suggest that there other factors which contribute towards caregiver burden other than the model of service delivery as there were no statistically significant differences between the two groups. However, caregivers in the community based treatment group did report fewer problems in most

areas, and there was a trend in favour of the community based group with regard to sleep, emotional adjustment and personal plans which might indicate a greater level of support through interaction with the group.

As opposed to some other studies,<sup>61 74</sup> findings from the current study reveal that the level of severity is not associated with the level severity of impairment of children with CP. This discrepancy could be because the small sample size led to a small effect size. However, findings from a Nigerian study which compared the health status of caregivers of children with CP against caregivers of typically developing children, concurs with our findings.<sup>27</sup> Additionally, proxy studies were conducted on a different population than ours i.e. the Kenyan study was conducted on caregivers of children with intellectual disability and it revealed that severity of disability, low self-esteem and poor social support were predictive of caregiver burden.<sup>72</sup> In summary, caregiving a child with CP is burdensome and this is regardless of the service delivery under scrutiny.

## 5.5 Discussion of HRQoL of caregivers

### 5.5.1 Overall comparison

To the best of our knowledge, this is the first study comparing the outcomes of two service delivery models in CP rehabilitation from the perspective of caregivers. Proxy studies have compared the HRQoL of caregivers of children with CP either against: the general population<sup>66</sup>, caregivers of healthy children<sup>81 63 74 84</sup>, and against caregivers of children with minor health problems.<sup>58</sup> Further, other studies have evaluated the HRQoL of caregivers of children with CP using caregivers of children with CP as their own controls.<sup>29 82</sup>

Our results are similar to those of the validation of the EQ-5D Shona questionnaire by Jelsma and colleagues.<sup>87</sup> They distributed the questionnaire to 42 respondents from a high density suburb in Harare, similar to those in this study. The mean age of the respondents was 34.3 (SD 11, 3) years, which was comparable to our sample whose mean was 30.4 (SD 9.2) years. Further, the mean VAS score for their sample was 77.5 (SD 17, 4): range 40-100, which was also comparable to our sample. Likewise, their results revealed that most of the respondents had problems with mobility, self-care and usual activities. Further, most of the caregivers experienced pain and reported anxiety/depression and this was also similar to our study. Elsewhere, a study on the validation of the Xhosa version of the EQ-5D in South Africa concurred that the most reported problems in the general population in order of magnitude were: pain, mobility and depression.<sup>88</sup> However, the increased proportion of respondents reporting mobility problems was due to recruitment of patients with mobility problems as respondents in their study.

Proxy studies corroborate that long term caregiving can have a negative effect of caregivers' HRQoL.<sup>29 63 58</sup> A study on Brazilian 65 caregivers of children with CP revealed their caregivers experienced lower HRQoL on all domains of the SF-36 and this was in comparison to 58 caregivers of non-disabled individuals. Unlike other studies,<sup>58</sup> they incorporated all levels of severity as measured by the GMFCS. This selection criterion was similar to our study.

Our results suggest that the HrQoL of the caregivers in the two intervention groups was comparable. This was not expected as it was hypothesised that regular group meetings within a community context would result in greater support and an increased perceived HRQoL. However, as HRQoL is variable, subjective and multifactorial,<sup>7 28</sup> mode of service delivery may be therefore be a poor predictor of HRQoL in caregivers. Furthermore, as there was no randomization, confounders to HRQoL were not accounted for which might have resulted in the two groups yielding the same results. Confounders such as providing care for the elderly, chronically ill or disabled relative, presence of a chronic illness, caring for another child below the age of two, having a child at home with special health needs,<sup>58</sup> additional number of other children/adults under the care of the caregivers, available amount of assistance, additional tasks, and the amount of caregiving given among others were not factored in, which might have accounted for the similarity of caregivers' HRQoL. Methodologically, the use of a unidimensional index might not have been sufficient to capture the multidimensionality of HRQoL hence the similarity in outcomes between the two groups. Furthermore, events in between administration of the instruments could have led to changes in EQ-5D scores,<sup>88</sup> for instance loss of loved one can lead to increased rating of depression scores.

### **5.5.2 Mobility, usual activities and self-care**

As our sample consisted of relatively younger caregivers, the prevalence of mobility problems and problems with usual activities was low. This concurs with findings by Jelsma et al.<sup>87</sup> in their validation of the Shona version of the EQ-5D study. Their sample consisted of 42 residents of a high density suburb in Harare with a mean age 34.3 (SD 11.3) years. The study setting was the same with our study and the two groups were comparable in terms of age, educational attainment and employment status.<sup>87</sup> Although though not statistically significant, there was a slight increase in reported self-care problems from baseline figures. This may be attributed to increase in pain with the passage of time which might therefore lead to activity limitations in caregivers.

### **5.5.3 Pain**

Pain was the major complaint by caregivers as compared to the other domains on the EQ-5D. This findings is consistent with outcomes from other studies.<sup>58 87</sup> Further, pain has been always been

cited as a problem in HRQoL surveys e.g. 40% of respondents in the validation of Shona EQ-5D complained of pain.<sup>87</sup>

Further, lifting and carrying children would probably result in pain and our findings support the fact that the intensity of pain also increases with the passage of time.<sup>28</sup> This could be more likely as there is no adapted transport for the CWDs. Further, wheelchairs are scarcely available for older children thereby resulting in the caregivers carrying the children which may increase the pain levels. Additionally, the method of carrying would also have accounted for the slight increase, for instance the kangaroo method would have been more ergonomically safer as opposed to the traditional method of carrying on the back utilized by the caregivers.

#### **5.5.4 Anxiety/depression**

Our results corroborate that caregiving a child with CP may lead to anxiety/depression in caregivers.<sup>28 62 67 71</sup> Further, our results are comparable to the general population as most of respondents, 50 % (n=21) in the validation study of Shona version of the EQ-5D also reported anxiety/depression.<sup>87</sup> The increased proportion of caregivers reporting anxiety/depression can be presumed to be secondary to the burden of caregiving.

An Irish study on 161 caregivers of children with CP revealed that, female caregivers exhibited lower HRQoL scores as measured by the SF-36 and more so in the mental health component.<sup>78</sup> In our study, the mode of service delivery did not seem to relate to the magnitude of the anxiety/depression. However, the magnitude of anxiety/depression resultant of caregiving a child with CP is difficult to quantify because of methodological flaws in designs of the studies which have explored the matter. For instance, Cheshire et al.<sup>71</sup> compared the HRQoL of caregivers of children with CP and other co-morbid conditions (46% of the sample) and came to the conclusion that caregiving a child with CP leads to anxiety/depression, yet the comorbid conditions can be confounding to caregivers HRQoL.

#### **5.5.5 Effect of severity of CP on caregivers' burden and HRQoL**

In contrast to our findings, a Canadian cross sectional study,<sup>74</sup> demonstrated that the level of severity was significantly, positively correlated with the burden of care. This discrepancy with our findings can be attributed to the difference in the age of participants. The caregivers were older, i.e. mean age of 39.4 (SD 11.4) years and the age range for the participants was wider range (2-21 years) in contrast to our sample. Likewise, the discrepancy in findings could be because of our small sample size with an inherent small effect size and the inclusion of older people with CP in the Canadian

sample. Further, differences in socio-economic and cultural context can serve to explain the differences as burden of care is context specific.

A Turkish study which was done at a public hospital comparing the HRQoL of mothers of 40 mothers of children with CP and 44 mothers of children with minor impairments revealed that the severity of CP was also associated with lower scores in all domains of the SF-36 except for the physical domain.<sup>58</sup> However, the study only recruited more severely affected children i.e. GMFCS levels IV and V which may have resulted in the association between level of severity and poorer HRQoL. A similar study in Ireland, on 161 caregivers of children with CP also corroborates that caring for a more dependent child is associated with greater perceived bodily pain due to the extra demands it poses.<sup>75</sup> More so, although not statistically significant, caregivers of children in the GMFCS levels IV and V scored lower on all domains of the SF-36 than those of levels 1 to 3 and chronicity of care was associated with a decline in QOL.<sup>21</sup> However, the sample had a lower proportion of children in the GMFCS level V and was recruited from one centre thus limiting the generalizability of the findings. Elsewhere, a cross sectional study on 23 caregivers in rural India revealed that severity was negatively correlated to caregivers' QOL, mental health and needs 29 Discrepancy with our findings can be attributed to the following:

- most of the children were of moderate to severe disability, 87% (n=20)
- their sample constituted older children , mean age was 12.9 years (SD 8.25; range 3 -30)
- unlike other studies, they utilized the WHO-QOL BREF to measure HRQoL and the GHQ-28 to measure health status

All in all, the inherent challenge in most of the studies done so far is the limitation of the generalizability of findings due to small sample sizes<sup>58</sup> which was also an inherent challenge for our study . This small effect size could have led to discrepancies in findings, nevertheless there seems to be agreement that caregiving a child with CP is strenuous and leads to subsequent decline in HRQoL of caregivers.

#### **5.5.6 Conclusion of EQ-5D discussion**

The limited number of studies on HRQoL research in low-income countries<sup>82</sup> makes comparisons of our findings difficult. However, our findings support the literature in that, HRQoL is multifactorial and that caregiving a child with CP can lead to deterioration of HRQoL. Furthermore, our results seem to suggest that mode of service delivery may not predictive of caregivers HRQoL. The lack in difference between the two groups could have been due to our small sample size thus a small effect size.

Another contributor to the lack of difference between the two groups was that there were more

children with GMFCS level V and the children were older in the community based treatment group. It might be that the support given by the community group could have contributed to equalizing the HRQoL as in the light of the literature, it was expected that the caregivers in the community based treatment group would report worse HRQoL. However, due to the quasi-experimental nature of our study, causality could not be inferred and confounders were not accounted for, and this is speculation.

## 5.6 Discussion of satisfaction with services

### 5.6.1 Overview

Satisfaction variables can be broadly classified into internal and external factors. External factors relate to technical issues such as booking process and comfort of waiting area and internal factors relate to patient-therapist interaction.<sup>89 90 91</sup> Our survey yielded high satisfaction rates with services and is comparable to other satisfaction surveys which tend to produce high satisfaction rates.<sup>90 91 95</sup>

96 97 99 185

### 5.6.2 Effect of external factors to satisfaction

Most caregivers were satisfied with the booking process and caregivers in the community based treatment group were more strongly satisfied. This can possibly be explained by the fact that therapy sessions were held consistently every tonight, whereas with the hospital based group, the bookings were more random. Some authors postulate that bookings should be made in line with the schedules of clients to maximise satisfaction and compliance.<sup>90 91</sup> Therefore, the consistency in bookings might be seen as an enhancer to the satisfaction for caregivers in the community based treatment group as it also gave them more control over planning their routines. This is very noteworthy considering that most of the caregivers were unemployed and reported financial strain. Furthermore, for those who were employed, most of them were informally employed. Therefore, a consistent booking schedule grants caregivers the autonomy to plan their schedules in advance which may be critical in juggling between sourcing for survival and attending therapy sessions. Findings from the open ended questions also support this proposition as one of the caregivers in the hospital based treatment group stipulated the following, "I would prefer to be given a more consistent booking schedule so that I can plan in advance as I have to keep my family afloat as well".

The lifetime commitment to therapy for children with CP can be burdensome to caregivers and some authors have postulated that intermittent treatment frequency is more tolerable for caregivers.<sup>12</sup> This could also explain why the fortnight gap is more acceptable to caregivers in the community based treatment group as depicted by higher compliance and satisfaction rates.

Most caregivers were also satisfied with the comfort of waiting area, however the correlation between comfort of waiting area and overall satisfaction was of intermediate strength yet the comfort of seating area can have a bearing on overall satisfaction.<sup>89</sup> Therefore, in the context of the local setting, it is the author's opinion that availability of seats would greatly affect satisfaction as most caregivers have to stand while awaiting services.

### 5.6.3 Effect of internal factors to satisfaction

Several factors may explain why caregivers in the community based treatment group were more satisfied with services as compared to caregivers in the hospital based group. Firstly, a lower child to therapist can be seen as an enhancer to satisfaction. A lower child to therapist ratio would translate to more time per child. Evidence supports that the greater the amount spent with the therapist, the greater the satisfaction.<sup>93</sup> Further, Tordis et al.<sup>45</sup> postulated that caregivers perfect their handling skills by observing and having more contact with therapists. Secondly, a lower ratio would also imply less time pressure on the part of therapists. This could have accounted for the dissatisfaction with the amount of explanations and the advice given by therapists in recipients of hospital based services.

Additionally, for the community based group, high satisfaction rates can be attributed to the fact that most of the caregivers would have attended workshops on CP prior to joining the outreach groups. This is essential as the amount of knowledge of the impairment(s)/health condition and of the treatment process is associated with greater satisfaction.<sup>8 90 99</sup> More so, these workshops give caregivers ample time to ask questions as opposed to the usual treatment scenario where the pressure is to serve as many clients in a short space of time. Furthermore, workshops are also an excellent platform for practical demonstrations of various treatment regimes. Therefore, it seems reasonable to expect caregivers who would have gone through workshops to be more satisfied with prescribed home exercise programs as they will have background knowledge of therapy.

In addition, under the current system, most caregivers would come with a lot of unanswered questions as to their children's condition as the diagnosis of CP can be catastrophic to the parents.<sup>76</sup> It is likely that due to time pressure and shortage of professional counsellors, caregivers in the hospital based group were more likely to leave with unanswered questions which cannot be addressed in normal treatment sessions as opposed to workshops scenario.

Organizational issues have a bearing on the inter-personal relationship between therapists and caregivers thus ultimately affecting satisfaction.<sup>90 91 95 97</sup> The discrepancy in satisfaction can be accounted for by organizational differences between the two modes of care, for instance,

differences in continuity of care. Continuity of treatment, whereby the therapists are allocated a specific workload i.e. the same therapist treats the same child/patient(s) over a period of time has been shown to increase client satisfaction.<sup>90</sup> Moreover, continuity of care has the potential to provide a platform for more dialogue and understanding between caregiver and therapist as opposed to being treated by a different therapist all the time. Therefore, it can influence the degree to which caregivers are satisfied with the empathy accorded to them by therapists. As for the hospital based group, continuity of care is difficult to achieve as the therapists are occasionally rotated through hospital placements. Additionally, for the hospital based group, caregivers are served as they come into the department whereas for the community based treatment group, caregivers would have arrived before the outreach team so it's much easier to allocate them to their specific therapists.

More so, the time pressure CCH therapists face can lead them to appear to be "less empathetic" as their mission will be to get through the clinic and continue with other duties. This also echoed in a study by Devreux et al.<sup>99</sup> who compared patient satisfaction with physiotherapy services at a private, public and teaching hospital? Their findings revealed that recipients of private hospital services were less satisfied with care as the therapists focus more in "physical treatment" results and seeing more clients within a short space of time. This was because of time limitations, and as a result, therapists did not have much time to listen to all the client needs.<sup>99</sup>

Above all, the high satisfaction rate with the respect accorded caregivers by therapists is a reflection of the high level of professionalism of rehabilitation professionals. In other studies, being respected by the therapist was found to positively correlate with satisfaction.<sup>89 91</sup> In addition, it's also a sign of a good rapport between therapists and caregivers, which is essential in attaining satisfaction.<sup>90</sup> The high level of satisfaction with the explanations and advice given by therapists and prescribed exercise programs for both groups is comparable to findings from other studies.<sup>89 90 91 93</sup> This is also a reflection of professionalism among the therapists as health education and promotion is an obligation for therapists.

#### **5.6.4 Global measures of satisfaction**

Global measures of satisfaction refer to the overall satisfaction with all facets of service delivery and also reflect the willingness of the client to utilize the services in the nearest future.<sup>89 93</sup> The overall satisfaction rate for community based treatment was comparable to findings of other physiotherapy satisfaction surveys, which like most consumer tend to yield high rates of satisfaction.<sup>89 93</sup> This greater satisfaction can be explained by the fact that attending the outreach meetings was not a financial burden as it is done within caregivers' community in contrast to some

of the caregivers in the hospital based group who may have required money to get to the hospital. This is even more difficult for those with older children as they may need to carry them on their backs. Likewise, the unavailability of adapted public transport makes the situation even more difficult.

Likewise, the fact that services are available within their own community, consistent booking schedule, lower child to therapist ratio which would mean more personal care and this could have contributed to this greater satisfaction. Additionally, the caregivers are given an energy drink after therapy sessions and this also offers them a platform for social interaction. Social interaction has been postulated as one of the major buffers to the strain associated in caregiving a child with CP,<sup>59</sup> of which outreach meetings enhance social connectivity of the caregivers. Having therapy in a group setting also allows for greater interaction, knowledge exchange and relationship formation between the caregivers and this might also impact on satisfaction with services received. The opportunity for caregivers in the hospital based group is limited in that most caregivers depart as soon as their child has received attention.

Further, the contrasting lower overall rating for hospital based services can be attributed to a greater proportion of caregivers who were neutral in their ratings. These clients could have been reluctant to critique service, and this can be interpreted as social desirability bias. They might have been reluctant to express dissatisfaction for fear of discontinuation of services as many of them would not afford the alternative option of expensive private physiotherapy services. Alternatively, neutrality in ratings maybe a reflection of sub-optimal service provision,<sup>100</sup> which may warrant further investigation.

### 5.7 Compliance discussion

The compliance rates for both groups are comparably higher than the rates reported in literature.<sup>4</sup>

<sup>109</sup> <sup>4</sup> It must be mentioned that most of the literature is based on compliance of patients with musculoskeletal conditions such as LBP, neck pain, knee and hip pain/problems. Compliance for CP rehabilitation is dependent on the caregiver and child factors thus it can be hypothesized that compliance determinant factors in musculoskeletal patients could be different from the ones of CP. To the author's knowledge there is dearth in compliance rates specific to CP thus the observed discrepancy in compliance rates.

However, the observed discrepancy in compliance rates can be attributed to the different service delivery models as the two groups were comparable at baseline. For instance, logistical issues such as transportation problems have been shown to lead to non-compliance. This are very important to note especially in the context of low income nations where there is no adapted public transportation

for people with disabilities.<sup>102</sup> Likewise, a study in Nigeria revealed that lower compliance with attendance of appointments was attributed to financial burden.<sup>114</sup> Lack of money can explain the lower compliance rate in caregivers in the hospital based group as some of the caregivers would require money for transportation to the hospital whereas for the community based group, services are provided within the caregivers' community which negates the need for money for transportation.

Availability of social support<sup>104 107 110</sup> may also explain the higher compliance rate in the community based treatment group. Since outreach is done within the service recipient's community, it is much easier for family members to accompany caregivers to treatment sessions as this did not pose any financial burden. This is in contrast to the hospital based group as this would have increased the already existent financial burden.

Lack of clinical knowledge on impairment can lead to non-compliance.<sup>112</sup> As the community based treatment caregivers would have attended CP workshops prior to joining the outreach group, it is expected that they will be more knowledgeable about CP and would have possibly enhanced compliance. It is of the author's view that the monthly health promotional (HP) talks done for caregivers in the hospital based group might not be adequate to satisfy and adequately answer all caregivers' need for information. The reasons for this proposition are, firstly, deficit in the human resources e.g. professional counsellors mean that after diagnosis, the child are referred for therapy without the caregivers going through counselling sessions. Therefore, caregivers are bound to present their children for therapy with a lot of unanswered questions. Secondly, the monthly HP talks are not condition specific; there are more of generic talks which might not really satisfy the need for information which would possibly enhance the compliance.

Additionally, perceived difficulty with exercises are associated with high rates of non-compliance.<sup>110</sup> The hospital based group is faced with a greater challenge of time pressure during treatment sessions due to a higher patient to therapist ratio. Therefore, therapists might not have enough time to adequately demonstrate exercises to caregivers and this may decrease the caregiver's self-efficacy and lower in-treatment adherence. A platform where there is more time for demonstrations can avert this, for instance during workshops there will be adequate time to explain and demonstrate various treatment routines.

The nature of the patient/practitioner relationship also affects the extent of compliance.<sup>112</sup> Due to the high children to therapist ratio and the inherent time pressure, it is most likely that there will be less time to build a good relationship and understanding between therapists and caregivers in the

hospital based services group. This is further complicated with the absence of continuity of care in the hospital based group, therefore it can be expected that compliance will be subsequently lower as the therapist-caregiver relationship might not be that strong.

Prolonged treatment is associated with poor compliance with treatment.<sup>102</sup> Assuming that therapy commenced after the diagnosis of CP, it seems reasonable to expect caregivers in the community based treatment group to be less compliant as they had significantly older children and could be coming for longer for therapy. Further, the increased weight of the older children in the community based treatment group would act as a barrier to compliance as most of the caregivers carry the children on their backs when coming for therapy. However, results from this study negated this hypothesis implying predictors in compliance to CP might be explained by other factors and this calls for further research to explore determinants of compliance in the Zimbabwean context.

Logistical issues such as booking schedules have been demonstrated to affect the levels of compliance and satisfaction with services.<sup>53 90 91</sup> Further, research on the effect of treatment frequency has yielded inconclusive results/evidence.<sup>18 45 53</sup> However, a study by Christiansen & Lange,<sup>53</sup> suggests that intermittent frequency is equally efficacious when compared to continuous dosage. The median compliance rate in their study was 93% for the children receiving intermittent therapy<sup>53</sup> and this was comparable for children receiving community based treatment in our study (median of 100%). Therefore, evidence from our findings suggests that a two week gap may be tolerable for caregivers and may result in equal gains in functional outcomes.

Organizational differences may also serve to explain the differences in compliance between the two groups. As we did not ascertain the permanent residency of the caregivers, it could be that some of the caregivers from the hospital based services group could have relocated to their permanent homes after having had sought treatment at the central (referral) hospital. This is in contrast to the community based treatment group who were more likely to be residing permanently in Mabvuku community where services were being offered. This could have led to the discrepancy in compliance rates.

#### **5.7.1 Conclusion of compliance discussion**

Although there is a dearth in compliance research in low-income countries<sup>105</sup> thus making comparability of findings difficult, results from the present study suggests that the mode of service delivery is predictive of compliance rates. Providing rehabilitation services within a community setting results is associated with improved attendance, even by the caregivers of older and somewhat more disabled children.

## 5.8 Limitations

The small sample size of our study limits the generalizability of our findings. There were other limitations which indicate that the findings from the present study need to be interpreted with caution for the following reasons:

We conducted a simplistic evaluation e.g. we only considered human resources allocation and other overheads such as the cost of fuel, depreciation of the vehicle used for the outreach program was not accounted for, therefore a further economic appraisal is needed to ascertain the real financial efficacy of the optimal program.

A (primary) caregiver is defined as the person responsible for most of the day-to-day decision-making and cares for the child,<sup>17 62</sup> and are mothers in most cases.<sup>61</sup> However, respondents to questionnaires might not have been the primary caregiver, and in cases of shared responsibility it becomes difficult to ascertain extent of burden. In addition, the precise time for caregiving was not documented.<sup>62</sup> Unlike other studies, positive psychological aspects of caregiving<sup>71</sup> were not explored.

There may have been errors in the measuring instruments for the following reasons. Social desirability bias might have been present as questionnaires were filled in the department or in the outreach centre. In other studies questionnaires were administered in a quiet room.<sup>30</sup> This would have increased accuracies of responses and would have prevented caregivers from copying others. However, this was not feasible as they were no facilities to do this. There may also have been systematic error risk as the principal researcher carried out all measurements. Further, unlike other studies,<sup>30</sup> blinding of GMFCS measurements was not done

Confounding variables were not accounted for since there was no randomization. Matching could have reduced confounders; however, matching was not practical as it would have led to a very small sample size. Potential confounders included and are not limited to the following:

1. number of hours spend caregiving per day<sup>75</sup>, caregiver income levels<sup>74</sup>, amount of social support available<sup>66</sup>
2. caring for another child who needs assistance in ADLs<sup>30</sup>
3. presence of chronic /severe medical condition such as stroke, diabetes mellitus<sup>30</sup>. Comorbid conditions in caregivers could have accounted for decline in HRQoL<sup>61</sup>
4. previous back surgery<sup>30</sup>
5. *absence of a history of severe or chronic psychological disorder with an onset before the diagnosis of CP in the child*<sup>30</sup>

Furthermore, differences in the service delivery models may act as a confounder to the observations from the study. Firstly, the differences in the skill levels of the therapists may have had any influence on outcomes. In essence, the community-based staff can be regarded as more “specialized” as most of them were housed within a specialized centre. In addition, therapists in the community are provided with extra incentives which could have resulted in the differences in delivery of services. Secondly, as caregivers receiving community-based services would go through workshops and counselling sessions, this inherently leads to a discrepancy in contact time with therapists which could have accounted for the differences in outcomes. Thirdly, the booking of appointments was secondary to the discretion of the treating therapists for the hospital-based group and there was no standardized scheduling of appointments. As for the community-based group, outreach meetings were held consistently every fortnight, hence the discrepancy in the number of treatment sessions over the data collection period. Consequently, the two groups were compared on the denominator of different number of appointments which could have skewed the results.

More so, in order to achieve matching of the sample, our participants were drawn from high density areas with the assumption that they would be of the same SES status. However, residing in high density areas is not necessarily synonymous with low SES or parity in SES.

## 6 CONCLUSION AND RECOMMENDATIONS

The study met the stated objectives. It was determined that the community based treatment children were older, with six children being over the age of five in this group and all children being younger than five in the hospital based group. In all other aspects the two groups were equivalent, although more of the children in the community group were in GMFCS IV and V (50% as opposed to 38.5%).

The children in both groups improved significantly on the GMFM-88 and when regression analysis was used to control for severity and age, it emerged that membership of the community based group predicted a significantly greater improvement, as did less severe GMFCS and a younger age.

However the impact on the care-givers HRQoL was less marked and the results of the CSI and EQ-5D indicated an increased strain and a decreased HRQoL. No differences were detected either between groups or over time, within groups, with the caregivers' reported strain and HRQoL although there was a tendency for the number reporting problems to increase over time. The majority of both groups reporting an impact on inconvenience, physical strain, confining, family adjustments; personal plans and work adjustments. The greatest number reported problems with financial strain and feeling overwhelmed. The EQ-5D items that were most affected were pain/discomfort (at least 65% in both groups) and anxiety/depression (at least 75% in both groups). Further studies in form of RCTs are necessary to ascertain the extent to which models of care buffer caregiver burden.

As the children in the community based group were older and higher proportions were in Levels IV and V, their care-givers might be expected to report greater strain and decreased HRQoL. This was not the case, which might indicate that the community, group based intervention mitigated the impact of severity and chronicity of care to a certain extent. This hypothesis however, needs to be empirically tested. It is clear that the care-givers are in need of additional support, particularly financial and emotional.

Caregivers in the community based treatment group were significantly more satisfied overall and with certain aspects of service provision. These aspects specifically related to the time spent with the child and the amount of information given regarding the condition and home exercise programme. Although the compliance with treatment was high, it was significantly better in the community based treatment group.

Our findings seem to suggest that the provision of care within a community setting is preferable in that it was associated with a greater improvement in functioning, greater satisfaction with services

and better compliance. In addition, care-givers continued to bring in older children for therapy, which was encouraging. It is therefore suggested that this is the preferred method of service delivery. Further research is needed however to cost the methods of service delivery. The OP may be more expensive as transport costs to the site are transferred from the caregivers to the service providers. In addition, the time spent may be less for the caregivers and more for the rehabilitation providers, again transferring the increased time to the care-providers. Another factor is that those involved with the community based treatment group had developed specialised skills in the treatment of children as they were based in a specialist children's unit. This may have resulted in the greater improvement seen in the functioning of this group.

The recommendations that emerge from this study therefor include:

- The OP should be implemented whenever possible. However costing of the different models needs to take place in order to determine the feasibility cost of transferring the management of children with CP from institutions to the community.
- Treatment should be continued, even for older children as improvement was noted in both groups, including the community based treatment group in which the children were older.
- Consistent booking schedules should be implemented.
- More education and training of the care-givers needs to take place in the institutional setting. This might require that certain therapists are identified who specialise in paediatrics within the hospital setting. It appears that the rehabilitation offered by the specialised staff of the CRU resulted in overall better outcomes and this might be a function of their skill as much as of the setting.
- National policies and schemes to assist caregivers and individuals with CP should be put in place. Caregivers should be encouraged to form or join support groups. Both rehabilitation personnel and care-givers should be encouraged to advocate strongly for some form of financial support, such as a disability allowance which has been instituted in South Africa.
- The issue of the optimal treatment is controversial; however, a fortnight treatment frequency seems to be tolerable for caregivers in our setting.
- There is a need to assess the health of caregivers as it's negatively by the effects of caregiving and design interventions to alleviate the burden.
- Caregivers/clients should routinely be given the opportunity to assess satisfaction as quality assurance measures.

In conclusion, caring for children with CP may be a blessing and/or a burden. CP requires intervention at impairment, activity, participation and environmental levels. OP seems to address

most of these needs, and provided it is affordable, should be the service delivery method of choice. Further, there is a need to support the determined women who keep bringing in their disabled children month after month; year after year so that they do not need to bear the burden of care alone and, that they can share the blessings of having a child with others who are experiencing the same problems. Additionally, community based treatment seems to offer a more holistic approach to CP management as it also relieves the burden of care on the caregivers as well as meeting the functional needs of children with CP.

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Check (✓) the appropriate score: if an item is not tested (NT), circle the item number in the right column

Item	A: LYING & ROLLING	SCORE				NT
1.	SUP, HEAD IN MIDLINE: TURNS HEAD WITH EXTREMITIES SYMMETRICAL.....	0	1	2	3	1.
* 2.	SUP: BRINGS HANDS TO MIDLINE, FINGERS ONE WITH THE OTHER.....	0	1	2	3	2.
3.	SUP: LIFTS HEAD 45°.....	0	1	2	3	3.
4.	SUP: FLEXES R HIP AND KNEE THROUGH FULL RANGE.....	0	1	2	3	4.
5.	SUP: FLEXES L HIP AND KNEE THROUGH FULL RANGE.....	0	1	2	3	5.
* 6.	SUP: REACHES OUT WITH R ARM, HAND CROSSES MIDLINE TOWARD TOY.....	0	1	2	3	6.
* 7.	SUP: REACHES OUT WITH L ARM, HAND CROSSES MIDLINE TOWARD TOY.....	0	1	2	3	7.
8.	SUP: ROLLS TO PR OVER R SIDE.....	0	1	2	3	8.
9.	SUP: ROLLS TO PR OVER L SIDE.....	0	1	2	3	9.
* 10.	PR: LIFTS HEAD UPRIGHT.....	0	1	2	3	10.
11.	PR ON FOREARMS: LIFTS HEAD UPRIGHT, ELBOWS EXT., CHEST RAISED.....	0	1	2	3	11.
12.	PR ON FOREARMS: WEIGHT ON R FOREARM, FULLY EXTENDS OPPOSITE ARM FORWARD.....	0	1	2	3	12.
13.	PR ON FOREARMS: WEIGHT ON L FOREARM, FULLY EXTENDS OPPOSITE ARM FORWARD.....	0	1	2	3	13.
14.	PR: ROLLS TO SUP OVER R SIDE.....	0	1	2	3	14.
15.	PR: ROLLS TO SUP OVER L SIDE.....	0	1	2	3	15.
16.	PR: PIVOTS TO R 90° USING EXTREMITIES.....	0	1	2	3	16.
17.	PR: PIVOTS TO L 90° USING EXTREMITIES.....	0	1	2	3	17.
<b>TOTAL DIMENSION A</b>						

Item	B: SITTING	SCORE				NT
* 18.	SUP, HANDS GRASPED BY EXAMINER: PULLS SELF TO SITTING WITH HEAD CONTROL.....	0	1	2	3	18.
19.	SUP: ROLLS TO R SIDE, ATTAINS SITTING.....	0	1	2	3	19.
20.	SUP: ROLLS TO L SIDE, ATTAINS SITTING.....	0	1	2	3	20.
* 21.	SIT ON MAT, SUPPORTED AT THORAX BY THERAPIST: LIFTS HEAD UPRIGHT, MAINTAINS 3 SECONDS.....	0	1	2	3	21.
* 22.	SIT ON MAT, SUPPORTED AT THORAX BY THERAPIST: LIFTS HEAD MIDLINE, MAINTAINS 10 SECONDS.....	0	1	2	3	22.
* 23.	SIT ON MAT, ARM(S) PROPPING: MAINTAINS, 5 SECONDS.....	0	1	2	3	23.
* 24.	SIT ON MAT: MAINTAINS, ARMS FREE, 3 SECONDS.....	0	1	2	3	24.
* 25.	SIT ON MAT WITH SMALL TOY IN FRONT: LEANS FORWARD, TOUCHES TOY, RE-ERECTS WITHOUT ARM PROPPING.....	0	1	2	3	25.
* 26.	SIT ON MAT: TOUCHES TOY PLACED 45° BEHIND CHILD'S R SIDE, RETURNS TO START.....	0	1	2	3	26.
* 27.	SIT ON MAT: TOUCHES TOY PLACED 45° BEHIND CHILD'S L SIDE, RETURNS TO START.....	0	1	2	3	27.
28.	R SIDE SIT: MAINTAINS, ARMS FREE, 5 SECONDS.....	0	1	2	3	28.
29.	L SIDE SIT: MAINTAINS, ARMS FREE, 5 SECONDS.....	0	1	2	3	29.
* 30.	SIT ON MAT: LOWERS TO PR WITH CONTROL.....	0	1	2	3	30.
* 31.	SIT ON MAT WITH FEET IN FRONT: ATTAINS 4 POINT OVER R SIDE.....	0	1	2	3	31.
* 32.	SIT ON MAT WITH FEET IN FRONT: ATTAINS 4 POINT OVER L SIDE.....	0	1	2	3	32.
33.	SIT ON MAT: PIVOTS 90°, WITHOUT ARMS ASSISTING.....	0	1	2	3	33.
* 34.	SIT ON BENCH: MAINTAINS, ARMS AND FEET FREE, 10 SECONDS.....	0	1	2	3	34.
* 35.	STD: ATTAINS SIT ON SMALL BENCH.....	0	1	2	3	35.
* 36.	ON THE FLOOR: ATTAINS SIT ON SMALL BENCH.....	0	1	2	3	36.
* 37.	ON THE FLOOR: ATTAINS SIT ON LARGE BENCH.....	0	1	2	3	37.
<b>TOTAL DIMENSION B</b>						

Item	C: CRAWLING & KNEELING	SCORE				NT
38.	PR: CREEPS FORWARD 1.8m (6')	0	1	2	3	38.
* 39.	4 POINT: MAINTAINS, WEIGHT ON HANDS AND KNEES, 10 SECONDS	0	1	2	3	39.
* 40.	4 POINT: ATTAINS SIT ARMS FREE	0	1	2	3	40.
* 41.	PR: ATTAINS 4 POINT, WEIGHT ON HANDS AND KNEES	0	1	2	3	41.
* 42.	4 POINT: REACHES FORWARD WITH R ARM, HAND ABOVE SHOULDER LEVEL	0	1	2	3	42.
* 43.	4 POINT: REACHES FORWARD WITH L ARM, HAND ABOVE SHOULDER LEVEL	0	1	2	3	43.
* 44.	4 POINT: CRAWLS OR HITCHES FORWARD 1.8m (6')	0	1	2	3	44.
* 45.	4 POINT: CRAWLS RECIPROCALLY FORWARD 1.8m (6')	0	1	2	3	45.
* 46.	4 POINT: CRAWLS UP 4 STEPS ON HANDS AND KNEES/FEET	0	1	2	3	46.
47.	4 POINT: CRAWLS BACKWARDS DOWN 4 STEPS ON HANDS AND KNEES/FEET	0	1	2	3	47.
* 48.	SIT ON MAT: ATTAINS HIGH KN USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS	0	1	2	3	48.
49.	HIGH KN: ATTAINS HALF KN ON R KNEE USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS	0	1	2	3	49.
50.	HIGH KN: ATTAINS HALF KN ON L KNEE USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS	0	1	2	3	50.
* 51.	HIGH KN: KN WALKS FORWARD 10 STEPS, ARMS FREE	0	1	2	3	51.

TOTAL DIMENSION C

Item	D: STANDING	SCORE				NT
* 52.	ON THE FLOOR: PULLS TO STD AT LARGE BENCH	0	1	2	3	52.
* 53.	STD: MAINTAINS, ARMS FREE, 3 SECONDS	0	1	2	3	53.
* 54.	STD: HOLDING ON TO LARGE BENCH WITH ONE HAND, LIFTS R FOOT, 3 SECONDS	0	1	2	3	54.
* 55.	STD: HOLDING ON TO LARGE BENCH WITH ONE HAND, LIFTS L FOOT, 3 SECONDS	0	1	2	3	55.
* 56.	STD: MAINTAINS, ARMS FREE, 20 SECONDS	0	1	2	3	56.
* 57.	STD: LIFTS L FOOT, ARMS FREE, 10 SECONDS	0	1	2	3	57.
* 58.	STD: LIFTS R FOOT, ARMS FREE, 10 SECONDS	0	1	2	3	58.
* 59.	SIT ON SMALL BENCH: ATTAINS STD WITHOUT USING ARMS	0	1	2	3	59.
* 60.	HIGH KN: ATTAINS STD THROUGH HALF KN ON R KNEE, WITHOUT USING ARMS	0	1	2	3	60.
* 61.	HIGH KN: ATTAINS STD THROUGH HALF KN ON L KNEE, WITHOUT USING ARMS	0	1	2	3	61.
* 62.	STD: LOWERS TO SIT ON FLOOR WITH CONTROL, ARMS FREE	0	1	2	3	62.
* 63.	STD: ATTAINS SQUAT, ARMS FREE	0	1	2	3	63.
* 64.	STD: PICKS UP OBJECT FROM FLOOR, ARMS FREE, RETURNS TO STAND	0	1	2	3	64.

TOTAL DIMENSION D

Item	E: WALKING, RUNNING & JUMPING	SCORE				NT
* 65.	STD, 2 HANDS ON LARGE BENCH: CRUISES 5 STEPS TO R.....	0	1	2	3	65.
* 66.	STD, 2 HANDS ON LARGE BENCH: CRUISES 5 STEPS TO L.....	0	1	2	3	66.
* 67.	STD, 2 HANDS HELD: WALKS FORWARD 10 STEPS.....	0	1	2	3	67.
* 68.	STD, 1 HAND HELD: WALKS FORWARD 10 STEPS.....	0	1	2	3	68.
* 69.	STD: WALKS FORWARD 10 STEPS.....	0	1	2	3	69.
* 70.	STD: WALKS FORWARD 10 STEPS, STOPS, TURNS 180°, RETURNS.....	0	1	2	3	70.
* 71.	STD: WALKS BACKWARD 10 STEPS.....	0	1	2	3	71.
* 72.	STD: WALKS FORWARD 10 STEPS, CARRYING A LARGE OBJECT WITH 2 HANDS.....	0	1	2	3	72.
* 73.	STD: WALKS FORWARD 10 CONSECUTIVE STEPS BETWEEN PARALLEL LINES 20cm (8") APART.....	0	1	2	3	73.
* 74.	STD: WALKS FORWARD 10 CONSECUTIVE STEPS ON A STRAIGHT LINE 2cm (3/4") WIDE.....	0	1	2	3	74.
* 75.	STD: STEPS OVER STICK AT KNEE LEVEL, R FOOT LEADING.....	0	1	2	3	75.
* 76.	STD: STEPS OVER STICK AT KNEE LEVEL, L FOOT LEADING.....	0	1	2	3	76.
* 77.	STD: RUNS 4.5m (15'), STOPS & RETURNS.....	0	1	2	3	77.
* 78.	STD: KICKS BALL WITH R FOOT.....	0	1	2	3	78.
* 79.	STD: KICKS BALL WITH L FOOT.....	0	1	2	3	79.
* 80.	STD: JUMPS 30cm (12") HIGH, BOTH FEET SIMULTANEOUSLY.....	0	1	2	3	80.
* 81.	STD: JUMPS FORWARD 30 cm (12"), BOTH FEET SIMULTANEOUSLY.....	0	1	2	3	81.
* 82.	STD ON R FOOT: HOPS ON R FOOT 10 TIMES WITHIN A 60cm (24") CIRCLE.....	0	1	2	3	82.
* 83.	STD ON L FOOT: HOPS ON L FOOT 10 TIMES WITHIN A 60cm (24") CIRCLE.....	0	1	2	3	83.
* 84.	STD, HOLDING 1 RAIL: WALKS UP 4 STEPS, HOLDING 1 RAIL, ALTERNATING FEET.....	0	1	2	3	84.
* 85.	STD, HOLDING 1 RAIL: WALKS DOWN 4 STEPS, HOLDING 1 RAIL, ALTERNATING FEET.....	0	1	2	3	85.
* 86.	STD: WALKS UP 4 STEPS, ALTERNATING FEET.....	0	1	2	3	86.
* 87.	STD: WALKS DOWN 4 STEPS, ALTERNATING FEET.....	0	1	2	3	87.
* 88.	STD ON 15cm (6") STEP: JUMPS OFF, BOTH FEET SIMULTANEOUSLY.....	0	1	2	3	88.

TOTAL DIMENSION E

Was this assessment indicative of this child's "regular" performance? YES  NO

COMMENTS:

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### GMFM RAW SUMMARY SCORE

DIMENSION	CALCULATION OF DIMENSION % SCORES			GOAL AREA <small>(indicated with ✓ check)</small>	
A. Lying & Rolling	Total Dimension A 51	=	51	× 100 = _____ %	A. <input type="checkbox"/>
B. Sitting	Total Dimension B 60	=	60	× 100 = _____ %	B. <input type="checkbox"/>
C. Crawling & Kneeling	Total Dimension C 42	=	42	× 100 = _____ %	C. <input type="checkbox"/>
D. Standing	Total Dimension D 39	=	39	× 100 = _____ %	D. <input type="checkbox"/>
E. Walking, Running & Jumping	Total Dimension E 72	=	72	× 100 = _____ %	E. <input type="checkbox"/>
<b>TOTAL SCORE =</b> $\frac{\%A + \%B + \%C + \%D + \%E}{\text{Total \# of Dimensions}}$ $= \frac{\quad + \quad + \quad + \quad + \quad}{5} = \frac{\quad}{5} = \quad \%$					
<b>GOAL TOTAL SCORE =</b> $\frac{\text{Sum of \% scores for each dimension identified as a goal area}}{\text{\# of Goal areas}}$ $= \frac{\quad}{\quad} = \quad \%$					

**GMFM-66 Gross Motor Ability Estimator Score <sup>1</sup>**

GMFM-66 Score = \_\_\_\_\_ to \_\_\_\_\_

95% Confidence intervals

previous GMFM-66 Score = \_\_\_\_\_ to \_\_\_\_\_

95% Confidence Intervals

change in GMFM-66 = \_\_\_\_\_

<sup>1</sup> from the Gross Motor Ability Estimator (GMAE) Software

**TESTING WITH AIDS/ORTHOSES**

Indicate below with a check (✓) which aid/orthosis was used and what dimension it was first applied. (There may be more than one)

AID	DIMENSION	ORTHOSIS	DIMENSION
Rollator/Pusher.....	<input type="checkbox"/> _____	Hip Control.....	<input type="checkbox"/> _____
Walker.....	<input type="checkbox"/> _____	Knee Control.....	<input type="checkbox"/> _____
H Frame Crutches.....	<input type="checkbox"/> _____	Ankle-Foot Control.....	<input type="checkbox"/> _____
Crutches.....	<input type="checkbox"/> _____	Foot Control.....	<input type="checkbox"/> _____
Quad Cane.....	<input type="checkbox"/> _____	Shoes.....	<input type="checkbox"/> _____
Cane.....	<input type="checkbox"/> _____	None.....	<input type="checkbox"/> _____
None.....	<input type="checkbox"/> _____	Other.....	<input type="checkbox"/> _____
Other.....	<input type="checkbox"/> _____		

(please specify) (please specify)

**RAW SUMMARY SCORE USING AIDS/ORTHOSES**

DIMENSION	CALCULATION OF DIMENSION % SCORES			GOAL AREA
				(indicated with ✓ check)
F. Lying & Rolling	Total Dimension A	=	× 100 =	A. <input type="checkbox"/>
	51	=	51	
G. Sitting	Total Dimension B	=	× 100 =	B. <input type="checkbox"/>
	60	=	60	
H. Crawling & Kneeling	Total Dimension C	=	× 100 =	C. <input type="checkbox"/>
	42	=	42	
I. Standing	Total Dimension D	=	× 100 =	D. <input type="checkbox"/>
	39	=	39	
J. Walking, Running & Jumping	Total Dimension E	=	× 100 =	E. <input type="checkbox"/>
	72	=	72	
<b>TOTAL SCORE =</b>	$\frac{\%A + \%B + \%C + \%D + \%E}{\text{Total \# of Dimensions}}$			
	=	+ + + +	=	%
		5	5	
<b>GOAL TOTAL SCORE =</b>	$\frac{\text{Sum of \% scores for each dimension identified as a goal area}}{\text{\# of Goal areas}}$			
	=		=	%

<b>GMFM-66 Gross Motor Ability Estimator Score <sup>1</sup></b>	
GMFM-66 Score = _____	_____ to _____
	95% Confidence Intervals
previous GMFM-66 Score = _____	_____ to _____
	95% Confidence Intervals
change in GMFM-66 = _____	
<small><sup>1</sup> from the Gross Motor Ability Estimator (GMAE) Software</small>	

## Appendix 2: Caregiver Strain Index - English version

I am going to read a list of things that other people have found to be difficult. Would you tell me whether any of these apply to you?

	Yes = 1	No = 0
<b>Sleep is disturbed</b> (e.g., because . . . is in and out of bed or wanders around at night)		
<b>It is inconvenient</b> (e.g., because helping takes so much time)		
<b>It is a physical strain</b> (e.g., because of lifting in and out of a chair; effort or concentration is required)		
<b>It is confining</b> (e.g., helping restricts free time or cannot go visiting)		
<b>There have been family adjustments</b> (e.g., because helping has disrupted routine; there has been no privacy)		
<b>There have been changes in personal plans</b> (e.g., had to turn down a job; could not go on vacation)		
<b>There have been emotional adjustments</b> (e.g., because of severe arguments)		
<b>Some behavior is upsetting</b> (e.g., because of incontinence; . . . has trouble remembering things; or . . . accuses people of taking things)		
<b>It is upsetting to find . . . has changed so much from his/her former self</b> (e.g., he/she is a different person than he/she used to be)		
<b>There have been work adjustments</b> (e.g., because of having to take time off)		
<b>It is a financial strain</b>		
<b>Feeling completely overwhelmed</b> (e.g., because of worry about . . . ; concerns about how you will manage)		
<b>Total Score</b>		

### Appendix 3: Caregiver Strain Index - Shona version

Ndichaverenga zvimwe zvezvinhu zvakaonekwa zvakaoma nevamwe vanhu. Mungadzidzewo here imi, kuti zvinokubatai Seiko.

	HONGU	KWETE
<b>Kuvhiringidzwa kurara</b> (semuenzaniso, <b>nekuda kwekuti...</b> anoti imwe nguva ari pamubheda kana anongo tenderera uri husiku).		
<b>Zvinonetsa</b> (semuenzaniso,sezvo uchisimudza murwere,panotoda samba rakawanda nekuzvipira zvakanyanya).		
<b>Patova nekupesana kwemhuri</b> (semuenzaniso unenge watosiya basa repamurungu,kutadza kana kenda kuzororo)		
<b>Pave nekutsamwisana</b> (semuenzaniso <b>zvakuonzera kupokana nekukakavadzana kusingapere</b> )		
<b>Humwe hunhu hwake hunogumbura</b> (semuenzaniso,anozviitira mubhurugwa)		
<b>Zvinogumbura kuziva kuti...ashanduka zvikuru kubva zvaangaari</b> ,(sekuti,anenge ava munhu mutsva kubva zvaava ari)		
<b>Zvinovhiringidza basa</b> (sekuti unoramba ongotora mazuva ekusave pabasa akawanda)		
<b>Ndinonzwa Kuremerwa kukuru</b> (semuenzaniso,ndinonyanya kushushikana zvakanyanya uye ndinobatwa nekufunga neramangwana)		
<b>Zvinokweva mari</b>		
<b>Ndinonzwa Kuremerwa kukuru</b>		
<b>TOTAL SCORE</b>		

#### Appendix 4: South African English version of the EQ-5D

By placing a tick in one box in each group below, please indicate which statements best describe your own state of health TODAY.

##### **Mobility**

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

##### **Self-Care**

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

##### **Usual Activities** (e.g. work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

##### **Pain/Discomfort**

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

##### **Anxiety/Depression**

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

---

Compared with my general level of health over the past 12 months, my state of health today is:

- Better  PLEASE TICK
- Much the same  ONE

Worse



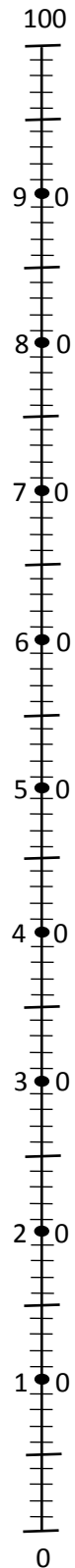
Best

To help people say how good or bad their state of health is, we have drawn a scale on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale, in your opinion, how good or bad your own health is today. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your state of health is today.

**Your own  
state of health**

imaginable



Worst

imaginable

## Appendix 5: EQ-5D – Shona version

Muchikwata chimwe nechimwe chemhinduro dzinotevera, isa mucherechedzo

mukabhokisi kari kumucheto seizvi  pamhinduro imwe chete yaunofunga kuti ndiyo inonyatsotsanangura utano hwako PARINHASI.

### Kugona kufamba

Handinetseki kufamba

Kufamba kunondinetsa

Handigone kana nekufamba kose

### Kuzvishambidza

Ndinogona zvangu kuzvishambidza

Handinyatsogona kuzvigezesa kana kuzvipfekedza

Handigone kuzvigezesa kana kuzvipfedza

### Mabasa enguva dzose

Handinetseki nokuita mabasa angu andinowanzoita nguva dzose

Ndinonetseka kuita mabasa angu andinowanzoita mazuva ose

Handichagoni kuita mabasa angu andaiwanzoita mazuva ose

### Kurwadziwa/ Kusagadzikana

Handisi kurwadziwa

Ndinorwadziwa zwangu zvishoma

Ndinorwadziwa zvakananyanya.

### Kunetsekana mupfungwa / Kuremerwa

Hapana zvinondinetsa mupfungwa

Ndine zvinodinetsa zwakati kuti

Ndirikushushikana zvakananyanya

---

Kana ndichienzanisa utano hwangu pamwedzi gumi nemiviri yapfuura neparinhasi,

ndingati zvangu nhasi:

Zvava nani

SARUDZA

Zvakangofanana

BHOKISI

Zvatonyanya

RIMWE CHETE

University of Cape Town

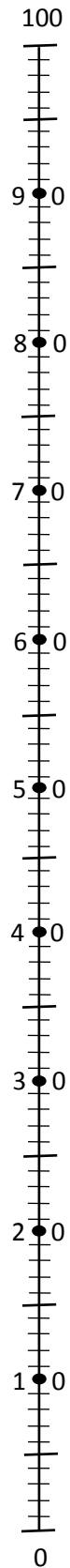
Kuti tibatsire vanhu kuti vaone kunaka kana kushata kwakaita utano hwavo parinhasi, takupa chikero ichi chekupimisa nacho utano hwako. Chine nhamba dzinobvira pasi pana 0 kusvika kumusoro kuna 100. 0 anoratidza utano hwakadzikira hwemunhu anorwara zvakasvoipisa. 100 anoratidza utano hwakaisvonakisa hwemunhu asingarware.

Tinokumbira kuti unongedze nhamba pachikero apa yaunofunga kuti ndiyo inoratidza ipo chaipo pane utano hwako nhasi uno. Ita izvi nokunyora mutsetse unotangira kubva pachibhokisi chiri pazasi icho wakananga nechekurudyi uko kunechikero uchinoguma ipo chiapo pane nhamba yawasarudza yaunofungira kuti ndiyo chaiyo inoratidza pava neutano hwako nhasi.

**Utano  
hwako nhasi**



Utano  
hwakaisvonakisa



Utano  
hwakaisvoipisa

**Appendix 6: The original MRPS**

1. Age: \_\_\_\_\_ (years)      2.  Male  Female
3. General area of treatment (check all that apply):  Neck  Back  Arm  Leg  Foot/Ankle  Hand/Wrist  
 Other (specify): \_\_\_\_\_

**Please answer the questions below by circling the response which best describes your opinions about your treatment.**

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1 The office receptionist is courteous.	1	2	3	4	5
2 The registration process is not appropriate.	1	2	3	4	5
3 The waiting area is comfortable (in terms of lighting, temperature, de'cor and furnishings).	1	2	3	4	5
4 My therapist did not spend enough time with me.	1	2	3	4	5
5 My therapist thoroughly explains the treatment(s) I receive.	1	2	3	4	5
6 My therapist treats me respectfully.	1	2	3	4	5
7 My therapist listens to my concerns.	1	2	3	4	5
8 My therapist did not answer all my questions.	1	2	3	4	5
9 My therapist advises me on ways to avoid future problems.	1	2	3	4	5
10 My therapist gives me detailed instructions regarding my home program.	1	2	3	4	5
11 Overall, I am completely satisfied with the services I receive from my therapist.	1	2	3	4	5
12 I would return to this office for future services or care.	1	2	3	4	5

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Appendix 7: Modified MRPS – English version

Caregiver code



Please answer the questions below by **CIRCLING THE RESPONSE** which best describes your opinions about the treatment of your child

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
The registration process is appropriate	1	2	3	4	5
The waiting area is comfortable	1	2	3	4	5
The therapist spend enough time with my child	1	2	3	4	5
The therapist thoroughly explained the treatments my child receives	1	2	3	4	5
My therapist treats me respectfully	1	2	3	4	5
The therapist listens to my concerns	1	2	3	4	5
The therapist did answer all of my questions	1	2	3	4	5
The therapist advises me on ways to avoid future problems	1	2	3	4	5
The therapist gives me detailed instructions regarding the home exercise program	1	2	3	4	5
Overall, I am completely satisfied with the services I receive from the therapists	1	2	3	4	5
I would return for future services/care	1	2	3	4	5

What do you like most about the services that your child is receiving.....

.....

What do you think need to be improved for the delivery of better services?

.....

.....

**THANK YOU FOR COMPLETING THIS QUESTIONNAIRE!!!!**



Caregiver code

Ndapota pindurai mibvunzo iri pazasi muchiisa denderedzwa pane mhinduro  
inonyatsotsanangura marapirwe arikuitwa mwana wenyu

	Ndinopokana nyakanyanya	Ndinopokana	Nidri pakati nepakati	Ndinobvuma	Ndinobvuma zvakananyanya
Kunyoreswa kwatakaita kunogutsa	1	2	3	4	5
Nzvimbo yekumirira inogutsa	1	2	3	4	5
Chiremba wangu ane nguva zhinji nemwana wangu	1	2	3	4	5
Chiremba wangu akatsanangura zvizere maererano nemarapirwo anoita mwana wangu	1	2	3	4	5
Chiremba wangu anorapa mwana wangu zvane chiremerera	1	2	3	4	5
Chiremba wangu anoteerera nhunha dzangu	1	2	3	4	5
Chiremba wangu anopindura mibvunzo yangu yese	1	2	3	4	5
Chiremba wangu anondiyambira nzira dzekudzivirira dambudziko muneramangwana	1	2	3	4	5
Chiremba wangu anondizivisa zvizere maererano nehurongwa hwekubatsira mwan kumba nemaexercise	1	2	3	4	5
Kuzadzikisa, ndagutsikana zvizere nerubatsiro rwandinowana kubva kuna chiremba wangu	1	2	3	4	5
Ndinotarisa kudzoka zvakare kana ndoda rubatsiro mune ramangwana	1	2	3	4	5

Mungandiudzavo here zvamunonyanya kufarira nemarapirwo arikuitwa vana venyu?

.....  
.....  
.....

Mungandiudzavo here zvamunofunga zvingaitwe pakusimudzira marapirwe anoita vana venyu?

.....  
.....  
.....

**TINOTENDA ZVIKURU NEKUPINDURA MIBVUNZO!!!!**

University of Cape Town

Appendix 9: Self-designed data sheet

Section A: Caregiver demographic details

Code		<input type="checkbox"/>
Age (in years):		<input type="checkbox"/>
Sex:	Female	<input type="checkbox"/>
	Male	<input type="checkbox"/>
Relationship to child:	Parent	<input type="checkbox"/>
	Grandparent	<input type="checkbox"/>
	Sibling	<input type="checkbox"/>
	Employed caregiver	<input type="checkbox"/>
	Other, please specify.....	
Educational level:	Primary	<input type="checkbox"/>
	Secondary	<input type="checkbox"/>
	Tertiary	<input type="checkbox"/>
	Other, please specify.....	
Employment status:	unemployed	<input type="checkbox"/>
	Formal	<input type="checkbox"/>
	Informal	<input type="checkbox"/>
	House keeper	<input type="checkbox"/>
	Other, please specify.....	

**Section B: Intervention details**

Week	Type of intervention				Number of professionals				Total number of cases treated	Duration of treatment session
	Therapy	Health promotional talk	Counseling	other	PTs	OTs	RTs	Cs		
1										
2										
12										

**Section C: Attendance registers**

week	Caregiver code	Attendance	
		Yes	No
1			
2			
12			

## Appendix 10: HREC approval letter

UNIVERSITY OF CAPE TOWN



Health Sciences Faculty  
Human Research Ethics Committee  
Room E52-24 Groote Schuur Hospital Old Main Building  
Observatory 7925  
Telephone [021] 406 6338 • Facsimile [021] 406 6411  
e-mail: shuretta.thomas@uct.ac.za

10 April 2012

**HREC REF: 109/2012**

**Mr J Dambi**  
c/o Prof J Jelsma  
Health & Rehab  
F-Floor  
OMB

Dear Mr Dambi

**PROJECT TITLE: A COMPARISON OF HOSPITAL-BASED AND COMMUNITY-BASED TREATMENT MODELS IN CEREBRAL PALSY REHABILITATION.**

Thank you for responding to the issues raised by the Faculty of Health Sciences Human Research Ethics Committee in your letter dated 5<sup>th</sup> April 2012.

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

**Approval is granted for one year till the 30<sup>th</sup> April 2013.**

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010) if the study is completed within the approval period.

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

**Please quote the HREC. REF in all your correspondence.**

Yours sincerely

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, HSF HUMAN ETHICS**

Federal Wide Assurance Number: FWA00001637.  
Institutional Review Board (IRB) number: IRB00001938

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

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

s.thomas

Appendix 11: Harare Central Hospital clinical director approval letter

Telephone: 621100-19  
Fax: 621157



Reference:

**HARARE CENTRAL HOSPITAL**  
P. O. Box ST 14

SOUTHERTON

Harare

---

24 April 2012

Dambi Jermaine M.  
University of Zimbabwe  
College of Health Sciences  
Department of Rehabilitation  
P O Box A178  
**HARARE**

Dear Dambi,

**REF: "COMPARISON OF HOSPITAL –BASED AND COMMUNITY-BASED MODELS OF CEREBRAL PALSY REHABILITATION" AT HARARE CENTRAL HOSPITAL:**

I am glad to advise you that your application to conduct a study entitled: **"A Comparison of Hospital –Based and Community-Based Models of Cerebral Palsy Rehabilitation"** in Harare Central Hospital, has been approved by the Harare Hospital Ethics committee.

You are advised to avail the results of your study whether positive or negative to the hospital through the committee for our information.

Yours sincerely,

A rectangular stamp with a pink border. At the top, it reads 'HARARE CENTRAL HOSPITAL' and 'DEPARTMENT OF MEDICINE'. In the center, there is a handwritten signature in blue ink. Below the signature, the date '24 APRIL 2012' is stamped. At the bottom, it reads 'DR. C. PASI'.

**Chairman Harare Central Hospital Ethics Committee**

Appendix 12: Harare Central Hospital head of rehabilitation department approval letter

Telephone: 621100/19  
Fax: 621157/666449



HARARE CENTRAL HOSPITAL  
P O Box ST 14  
SOUTHERTON  
Harare  
Zimbabwe

J M Dambi  
University of Zimbabwe  
Department of Rehabilitation  
PO Box AV178  
Avondale  
Harare

5 May 2012

Dear Sir

**RE: CONFIRMATION OF APPROVAL TO CARRY OUT STUDY**

This letter serves to confirm that permission has granted for you to carry out your research project within our Children Rehabilitation Unit. It is our hope that you will uphold ethical principles throughout your research.

We wish you the best of luck in your academic endeavors.

Yours truly

A handwritten signature in blue ink that reads 'P Mutsau'.

P Mutsau (Head of Rehabilitation Department)

Appendix 13: Harare Central head of CRU approval letter



**CHILDREN'S REHABILITATION UNIT**

A joint project of Dept. Of Paediatrics U.Z.,  
And  
Dept. Of Rehabilitation, Min Of Health

**POSTAL ADDRESS:**  
Harare Central Hospital  
P.O. Box ST 961  
Southerton  
Harare

Tel/Fax: 620175  
Tel: 621100 Ext:4070  
email: [cru@mweb.co.zw](mailto:cru@mweb.co.zw)

4 May 2012

University of Zimbabwe  
College of health sciences  
Department of Rehabilitation  
P.O. Box AV 178  
Avondale  
Harare

Dear Mr. J M Dambi

**RE: APPROVAL TO CARRY OUT RESEARCH AT THE CHILDREN REHABILITATION UNIT**

I'm pleased to inform you that you have been granted permission to carry out your research entitled "A comparison of Hospital-based and community-based models of cerebral palsy rehabilitation" at our institution.

We wish you well and it is our hope that you will maintain ethical standards throughout your research.

Yours Faithfully

I Mhlanga  
(Program Manager)



---

PHYSICAL ADDRESS: 2nd Floor, Old Eye Unit, Harare Central Hospital

---

Appendix 14: Chitungwiza Central Hospital clinical director approval letter

Telephone: (070) 31850  
31038  
30828  
31138  
31489  
31861



HOSPITAL MANAGEMENT BOARD  
CHITUNGWIZA CENTRAL HOSPITAL  
P.O. BOX CZA 245  
ZENGEZA  
CHITUNGWIZA ZIMBABWE



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All correspondences to be addressed to the Executive Chairman & Chief Executive Office

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19 April 2012

The Chairperson  
Department of Rehabilitation  
University of Cape Town

Dear Professor M Blockman

**RE: PERMISSION FOR MR DAMBI TO CARRY OUT A RESEARCH STUDY  
AT CHITUNGWIZA CENTRAL HOSPITAL: REHABILITATION  
DEPARTMENT**

---

This letter serves to inform you that permission has been granted for Mr Dambi to carry out the research study on a comparison of hospital based and community based treatment models in cerebral palsy rehabilitation at Chitungwiza Central Hospital

Thank you.

Yours faithfully

PP

CHITUNGWIZA CENTRAL HOSPITAL  
Dr E Tadros  
Clinical Director  
**For: Chief Executive Officer**  
20 APR 2012  
PO BOX CZA 245 CHITUNGWIZA  
ZIMBABWE

---

Board Members: Dr. O. Moyo Chairman & Chief Executive Officer  
Mr D. Shonhiwa, Mr C.C. Chigumba, Mrs E.Y. Mangwende, Dr. W.B. Mujaji, Mr. J.K. Madzinga, Mrs A. Kurangwa

Appendix 15: Chitungwiza Central Hospital head of rehabilitation department approval letter

Telephone: (070) 31850  
31038  
30828  
31138  
31489  
31861



HOSPITAL MANAGEMENT BOARD  
CHITUNGWIZA CENTRAL HOSPITAL  
P.O. BOX CZA 245  
ZENGEZA  
CHITUNGWIZA ZIMBABWE



---

All correspondences to be addressed to the Executive Chairman & Chief Executive Office

---

19 April 2012

The Chairperson  
Department of Rehabilitation  
University of Cape Town

Dear Professor M Blockman

**RE: PERMISSION FOR MR DAMBI TO CARRY OUT A RESEARCH STUDY  
AT CHITUNGWIZA CENTRAL HOSPITAL: REHABILITATION  
DEPARTMENT**

---

This letter serves to inform you that permission has been granted for Mr Dambi to carry out the research study on a comparison of hospital based and community based treatment models in cerebral palsy rehabilitation at Chitungwiza Central Hospital

Thank you.

Yours faithfully

O Mrewa  
Head of Rehabilitation  
**For: Chief Executive Officer**



---

Board Members: Dr. O. Moyo Chairman & Chief Executive Officer  
Mr D. Shonhiwa, Mr C.C. Chigumba, Mrs E.Y. Mangwende, Dr. W.B. Mujaji, Mr. J.K. Madzinga, Mrs A. Kurangwa

## Appendix 16: Medical Research Council of Zimbabwe approval letter

Telephone: 791792/791193/792747  
Telefax: (263) - 4 - 790715  
E-mail: [mrcz@mrczimshared.co.zw](mailto:mrcz@mrczimshared.co.zw)  
Website: - [www.mrcz.org.zw](http://www.mrcz.org.zw)



Medical Research Council of Zimbabwe  
Josiah Tongogara / Mazoe Street  
P. O. Box CY 573  
Causeway  
Harare

### MRCZ APPROVAL LETTER

Ref: MRCZ/B/333

08 May, 2012

**Dambi Jermaine M**  
19 Beechy Road  
Southerton  
Harare

#### RE:-A comparison of Hospital based and Community based models of Cerebral Palsy Rehabilitation.

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has reviewed and approved your application to conduct the above titled study. This is based on the following :-

- a) Study Protocol.
- b) Caregivers and Rehabilitation Professionals Informed Consent Form (English and Shona).
- c) Data collection tools.

- **APPROVAL NUMBER** :MRCZ/B/333  
The above details should be used on all correspondences, consent forms and documents as appropriate.
- **APPROVAL DATE** : 08 May, 2012
- **EXPIRATION DATE** : 07 May, 2013
- **TYPE OF MEETING** : Expedited review

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted one month before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices.
- **MODIFICATIONS:** Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices.
- **QUESTIONS:** Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on [mrcz@mrczimshared.co.zw](mailto:mrcz@mrczimshared.co.zw).

#### Other:

- Please be reminded to send in copies of your final research results for our records as well as for the Health Research Database
- You are also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

MRCZ SECRETARIAT  
FOR CHAIRPERSON  
MEDICAL RESEARCH COUNCIL OF ZIMBABWE



PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH  
Registered with the USA Office for Human Research Protections (OHRP) as an International IRB  
(IRB Number IRB00002409 IORG0001913)

## Appendix 17: Caregivers information letter – English version

University of Zimbabwe

Faculty of Medicine

Department of Rehabilitation

Box A178

Avondale

Harare, Zimbabwe

Date.....

### **RE: REQUEST TO PARTICIPATE IN THE STUDY ENTITLED: A COMPARISON OF HOSPITAL-BASED AND COMMUNITY- BASED MODELS OF CEREBRAL PALSY REHABILITATION**

Dear prospective participant

My name is Jermaine M Dambi and I'm a Masters in Physiotherapy student at the University of Cape Town (UCT) in South Africa. I'm conducting a study to compare differences in outcomes of hospital-based and community-based approaches to Cerebral Palsy treatment/rehabilitation. This study is a requirement for my post graduate studies and I'm doing it under the guidance and supervision of Professor J Jelsma of UCT.

Provision of rehabilitation services in Zimbabwe is mainly through the hospital-based approach and some hospitals also offer community –based treatment. However, nothing is known about the best method of delivering rehabilitation services. This study hopes to come up with recommendations of the most effective model for the treatment of children with cerebral palsy (CP) and the best methods of providing psycho-social care and support to caregivers as long term caregiving has been shown to have a negative effect on the health and well-being of the caregiver. Thus findings of this research will be used to come with a model which provides holistic treatment.

Cerebral palsy is the most common cause of childhood disability and a lifetime condition and there is a very strong need to come up with a very effective model of providing rehabilitation treatment. It's against this background that you are being invited to participate in this study. If you decide to participate, your child will go through a process of standardized tests of physical function and they are similar to the procedures that they go through during their treatment sessions. The tests can take 10 to 45 minutes depending on the age and form of CP the child has. The measurements will be

done twice i.e. at the beginning and end of the study period. Please also take note that it will be the researcher's responsibility to organize clinical care in the event that your child is injured during the tests. However, the researcher will exercise extreme caution to avoid such unfortunate occurrences.

You will be requested to complete five brief questionnaires i.e. two at the beginning and three at the end of the study period. Please take note that your children will continue to receive their normal treatment for the duration of the study. However the measurements of function will be done before treatment session and you will be asked to fill in the questionnaires after treatment sessions. The study is expected to run for 3 months.

There are no associated benefits in participating in this study. However, you (and the children) will be provided with food and drinks on the days of testing physical function of the children and during questionnaires completion days.

Please do take note that you are not obliged to participate in the study. Participation is on voluntary basis and if you decide not to participate, it won't have any bad consequences in your access to rehabilitation services. You will be also free to withdraw from the study at any stage without any penalty or need to explain your withdrawal. However, in the event that you choose to withdraw, please do try by all means necessary to notify the researcher about your decision.

Information gathered about you and your child will be kept confidential. You will be assigned a code for identification purposes and no names will be used for reference in the study and publications. Only the researcher and possibly the Ethical committee will have access to the information. The information will be kept in a safe and locked drawer at The University of Zimbabwe.

Please do not hesitate to contact me or my supervisor if you have any queries.

Yours faithfully

Dambi Jermaine M

N.B contact details

0773 444 911/0733 193 114/ (04) 791 631 Ext 2293

[jermaine.dambi@uct.ac.za/jermainedambi@gmail.com](mailto:jermaine.dambi@uct.ac.za/jermainedambi@gmail.com)

(Professor Jelsma- Jennifer.Jelsma@uct.ac.za)

## Appendix 18: Caregivers information letter– Shona version

University of Zimbabwe

Faculty of Medicine

Department of Rehabilitation

Box A178

Avondale

Harare, Zimbabwe

Date.....

**RE: CHIKUMBIRO CHEKUITA TSVAGIRIDZO INONZI KUENZANISA MUCHENGETERWO EMURWERE  
AKAFA MUTEZO INONZI CELEBRAL PALSY REHABILITATION PANZVIMBO YEARI NEPAANO  
CHENGETWA KUMBA.**

Mudikani anokwikwidza

Zita rangu ndinonzi Jermaine M. Dambi.Ndiri mudzidzisi wedzidzo yepamusoro inoongorora nezve mitezo ndichifunda ne University ye Cape Town mu South Africa(UCT).Ndiri kuda kuita tsvakiridzo yekucherechedza nzira dzingashandiswa kurapwa kwevana vezera rechidiki,tsvakiridzo iyi inodiwa kushanda muzvidzidzo zvangu zvepamusoro uye ndichiita ndiripasi pekutungamirirwa nekutarisirwa zvidzidzo zvangu naProfessor J.Jelsma weku UCT.

Bvumo yekuona nezvekuumbiridza mutezo mu Zimbabwe yakanyanya kurerekerera kuitirwa pamwe nekuchengeterwa murwere wacho muchipatara uye zvimwe zvipatara zvinoda hurongwa hwekurapira murwere kumba.Nekudaro hapana chinozivikanwa maererano nemhando tsvene yekupa pakuumbiridza mutezo.Chidzidzo ichi chinetarisiko yekuburitsa zvakakodzera mukurapwa kwevana vane Cerebral Palsy( CP) pamwe nenzira dzekupa mubatsiri wemurwere kuti arerukirwe pakuchengeta.

Cerebral Palsy chirwere chinoshandikwa nacho zvakananyanya chichikonzera kusaita mushe kwemitezo yevana muzera rechidiki zvinova zvinozoenderera mberi muhupenyu hwake uye panotodiwa kutarisirwa zvakasimba kuti pave nenzira yakakodzera yekurapa nekudzorera mutezo pakare.Munokokwa kuti mukwikwidzewo mutsvakiridzowo iyi.Kana wafunga kukwikwidza,mwana wako anoenda muongororo yakarongeka yekushanda kwemitezo uye yakafanana nekuongororwa kwaanosimboitwa pakurapwa kwake.Kuongororwa kwacho kunotoro nguva yakareba zve maminiti

gumi uye nemhando ye CP ine mwana wacho.Mupimo unoitwa kaviri sepakutanga nekupedzisa tsvakiridzo.

Ndapota cherechedzai kuti ibasa remuongorori kuti aronge hurongwa hwekuchipatara mushure mekunge mwana wako awira mutsaona ari muhurongwa hwekuongororwa.nekudaro mungorori achararisa zvakananyanya kudzivirira kuitika kwetsaona kuti dzisaitike.Uchakumbirwa kuti upindure hwaro yemapepa matatu sekuti hwaro yemapepa maviri pakutanga kwetsvakiridzo,nehwaro imwe chete pekupedzisira kwetsvakiiridzo.Ndapota cherechedzai kuti vana venyu vacharamba vachiwana kurapwa kwavo kwenguva dzose panguva yatarwa tsvakiridzo.Nekudaro kupimwa kwemashandiro emutezo kuchaitwa mushure menguva yekurapwa uye uchadiwa kuti upindure mibvunzo kana nguva yekurapwa yapera,tsvakiridzo inotarisirwa kutora mwedzi mitatu.

Ndini wenyu akavimbika

Dambi Jermaine M

**N.B** Kana muine mibvunzo munogona kundichaira runhare kana kubata mufudzi wangu panhamba dzinoti

0773 444 911/0733 193 114/ (04) 791 631 ext 2293

[jermaine.dambi@uct.ac.za/jermainedambi@gmail.com](mailto:jermaine.dambi@uct.ac.za/jermainedambi@gmail.com)

Professor Jelsma: Jennifer.Jelsma@uct.ac.za

**Appendix 19: Caregivers consent form – English version**

I .....have read (or had read to me by .....) the information letter .  
I understand what is required of me and my child/ legal ward and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I know that I can withdraw at any time if I so wish and that it will have no bad consequences for me.

Signed:

.....

.....

Participant

Date and place

.....

.....

Researcher

Date and place

.....

.....

Witness

Date and place

University of Cape Town

**Appendix 20: Caregivers consent form – Shona version**

Ini.....(ndaverenga kana kuti ndaverengerwa)  
na.....hwaro hwetsamba. Ndanzwisisa kuti chii chinodikanwa kwandiri nemwana wangu uye ndaona ndichipindurwa mibvunzo yangu zvizere. Handina kunzwa kunge ndamanikidzwa kuti ndikwikwidze mutsvakiridzo uye ndaita nekuda kwangu. Ndinoziva kuti ndinokwanisa kubuda mazviri chero nguva yandada ndisinga sangani nedambumdziko.

Signed

.....

ANOKWIKWIDZA

.....

MUONGORORI

.....

HWITINESI

.....

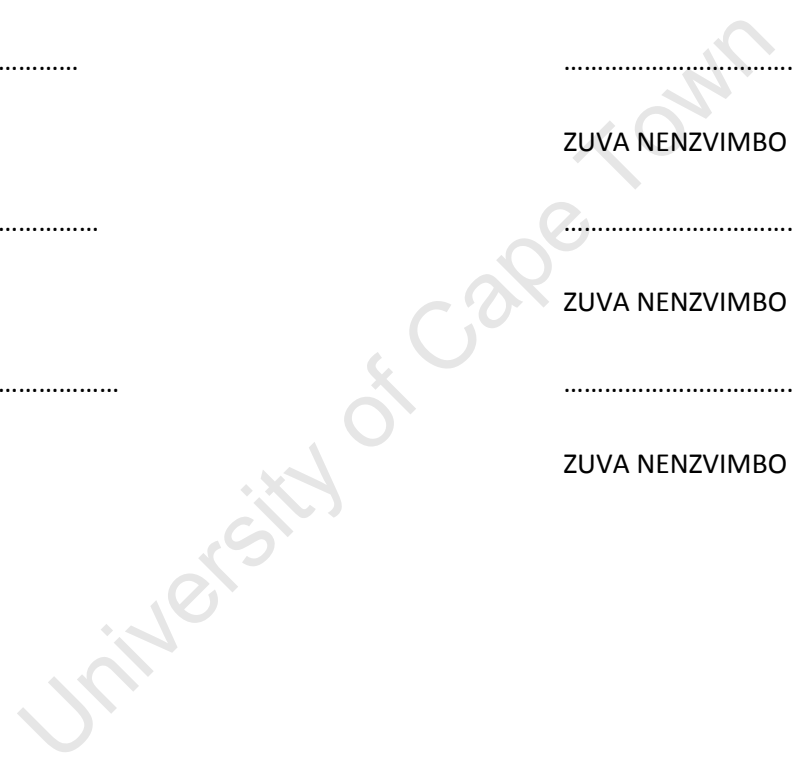
ZUVA NENZVIMBO

.....

ZUVA NENZVIMBO

.....

ZUVA NENZVIMBO



## Appendix 21: Rehabilitation professionals' information letter

University of Zimbabwe

Faculty of Medicine

Department of Rehabilitation

Box A178

Avondale

Harare, Zimbabwe

Date

### **RE: REQUEST TO PARTICIPATE IN THE STUDY ENTITLED, "A COMPARISON OF HOSPITAL-BASED AND COMMUNITY- BASED MODELS OF CEREBRAL PALSY REHABILITATION".**

Dear prospective participant

My name is Jermaine M Dambi and I'm a Masters in Physiotherapy student at the University of Cape Town (UCT) in South Africa. I'm conducting a study to compare differences in outcomes of hospital-based and community-based approaches to Cerebral Palsy treatment/rehabilitation. This study is a requirement for my post graduate studies and I'm doing it under the guidance and supervision of Professor J Jelsma of UCT.

Provision of rehabilitation services in Zimbabwe is mainly through the hospital-based approach and some hospitals additionally offer community –based treatment services for children with cerebral palsy (disabilities). However, nothing is known about the best method of delivering rehabilitation services. This study hopes to come up with recommendations of the most effective model for the treatment of children with cerebral palsy (CP) and providing psychosocial care and support to caregivers as long term caregiving has been shown to have a negative effect on the health and well-being of the caregiver. Thus findings of this research will be used to come with recommendations for a model which provides holistic treatment.

If you decide to participate, you will be requested to assist in delivering treatments as you normally do. I kindly request permission to observe the interventions you will be carrying out on children with CP. The research is by no means an evaluation of your clinical skills nor will the findings be used for any form of appraisal. Also you will not benefit directly from participation, but it's the hope of the researcher that the outcomes of this study will assist in coming up with evidence based

recommendations of a model which will ultimately assist in planning of rehabilitation services and improving treatment efficacy.

Please do take note that you are not obliged to participate in the study i.e. participation is on voluntary basis. You will be free to withdraw from the study at any stage without any penalty or need to explain your withdrawal.

Information gathered during the study will be kept confidential; no names will be used during data collection and subsequent data analysis. Only the researcher and possibly the Ethical committee will have access to the information. The information will be kept in a safe and locked drawer at The University of Zimbabwe.

Yours faithfully

Dambi Jermaine M

**N.B** For any queries please do contact me or my supervisor on the following contact details

0773 444 911/0733 193 114/ (04) 791 631 ext 2293

[jermaine.dambi@uct.ac.za/jermainedambi@gmail.com](mailto:jermaine.dambi@uct.ac.za/jermainedambi@gmail.com)

Professor Jelsma: Jennifer.Jelsma@uct.ac.za

**Appendix 22: Rehabilitation professionals' consent form**

I .....have read the information letter. I understand what is required of me and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I know that I can withdraw at any time if I so wish and that it will have no bad consequences for me.

Signed:

.....

.....

Participant

Date and place

.....

.....

Researcher

Date and place

.....

.....

Witness

Date and place

University of Cape Town