# CHAPTER FIVE

# RESULTS: PHASE ONE
# ESTABLISHING THE RELIABILITY AND VALIDITY OF MODIFIED SCALES

As described in the previous chapter, this study consisted of two phases – Phase 1 which used quantitative methods, and Phase 2 which was qualitative. To facilitate comprehension and interpretation of all the data, the results and discussion for each phase are presented separately. Chapters 5 and 6 contain the results and discussion for Phase 1 and Chapters 7 and 8 contain the results and discussion of Phase 2. Both phases of the study are brought together in Chapter 9 where the main messages and findings arising from the study are discussed.

## 5.1 INTRODUCTION

The results from Phase 1, which are mainly quantitative data, are divided into three sections:

1. Demographic data are presented in Section 1.
2. Analysis of the psychometric properties of each scale is presented in Section 2.
3. Relationships and correlations between scale scores and other variables such as place of residence and severity of the child's disability are presented in Section 3.

A short reflection summarising the main findings is given at the end of each section or sub-section.

## 5.2 SECTION 1: DEMOGRAPHIC CHARACTERISTICS AND DESCRIPTIVE DATA

Descriptive characteristics of the study sample are presented in this first section of the results. They are divided into six main categories:

1. A description of the number of interviews conducted, who was interviewed and how many hospitals were visited.
2. Demographic characteristics of the children included in the study, namely their ages; their CP and their gross motor functional classification.
3. Information relating to their therapy attendance, namely the length of time they had been attending therapy; how long it took them to travel to the hospital and the mode of transport used.
4. Demographic characteristics of the caregivers including their age, educational, marital and employment status as well as the amount of time spent looking after their child and a description of their interaction with the child.
5. Demographic characteristics of the fathers including their age, education and employment status.
6. Socio-economic status of the study population

### 5.2.1 Interviews conducted

Thirty-one hospitals (13 in Gauteng Province and 18 in Limpopo Province) met the inclusion criteria for the study. Caregivers at all 13 hospitals in Gauteng were included as well as those from 14 of the 18 hospitals in Limpopo. The reason for not including the remaining four hospitals in Limpopo was that the target sample size of 240 caregivers (120 in Gauteng Province and 120 in Limpopo Province) was exceeded after visiting 14 hospitals in Limpopo.

Data collection began in Gauteng. Halfway through this phase of the data collection, direct observation of the interviews together with random tape recordings revealed

that the interviewing technique of one of the three interviewers was unsatisfactory and that this was influencing the participants' responses. Thus all interviews conducted by this interviewer were discarded and not included in the analysis and she no longer participated in the study.

A total of 263 caregivers were interviewed: 127 (48.3%) were from Gauteng and 136 (51.7%) were from Limpopo. Two hundred and twenty-nine (87.1%) of the caregivers were mothers; 23 (8.7%) were grandmothers; five (1.9%) were paid caregivers; two (0.8%) were fathers and the remainder (4 [1.8%]) were siblings or close relatives. Main reasons why the mother was not the main caregiver were that she was either ill or had died (12 [4.5%]); she was working (10 [3.8%]); she was at school (5 [1.9%]); she was nursing a small baby at home (5 [1.9%]); or she had absconded or separated from the child and family (2 [0.8%]).

Four caregivers had to be excluded because they had other hospital appointments or a bus or taxi to catch which meant there was insufficient time for them to complete the interview. None of the caregivers who were invited to join the study refused to be interviewed.

### 5.2.2 Demographic characteristics of children

#### 5.2.2.1 Ages of children

The ages of the children are depicted in Table 5.1.

**Table 5.1 Ages of children (n = 263)**

| Age | Frequency | Percent | Cumulative Percent |
|---|---|---|---|
| 0 - 3 yrs | 170 | 64.6 | 64.6 |
| 4 - 7 yrs | 72 | 27.4 | 92.0 |
| 8 - 11 yrs | 17 | 6.5 | 98.5 |
| 12 - 15 yrs | 3 | 1.1 | 99.6 |
| 15 - 18 yrs | 1 | 0.4 | 100.0 |
| **Total** | **263** | **100.0** | |

Over half of the children (148) were male whilst 115 (43.7%) were female. The mean age was 3.34 years (sd = ± 2.6) whilst the median and mode were both two years.

Just over a third of the children (99 [37.6%]) were on anti-convulsant therapy and a further ten children (3.8%) had previously taken medication for fits. The caregivers of nearly two-thirds of the children (169 [64.3%]) were receiving a Care Dependency Grant whilst a further 46 (17.5%) had applied and were still waiting for the grant.

#### 5.2.2.2 Classification

The classification of motor impairment as well as the children's functional classification is shown in Table 5.2.

**Table 5.2 Classification of motor impairment and GMFCS Classification**

| | | n | % |
|---|---|---|---|
| **Classification:** | Spastic | 146 | 55.5 |
| | Dyskinetic | 78 | 29.7 |
| | Hypotonic | 21 | 8.0 |
| | Ataxic | 3 | 1.1 |
| | Mixed | 15 | 5.7 |
| | **TOTAL** | **263** | **100.0** |
| **GMFCS level:** | Level 1 | 21 | 8.0 |
| | Level II | 21 | 8.0 |
| | Level III | 48 | 18.3 |
| | Level IV | 73 | 27.7 |
| | Level V | 100 | 38.0 |
| | **TOTAL** | **263** | **100.0** |

Over half of the children (146 [55.5%]) had spastic cerebral palsy and nearly a third (78 [29.7%]) had dyskinetic cerebral palsy. The majority of children (173 [65.7%]) were functioning in either Level IV or V on the GMFCS, indicative of minimal independent motor function.

Figure 5.1 shows the functional classification by GMFCS with respect to the predominant type of motor impairment.

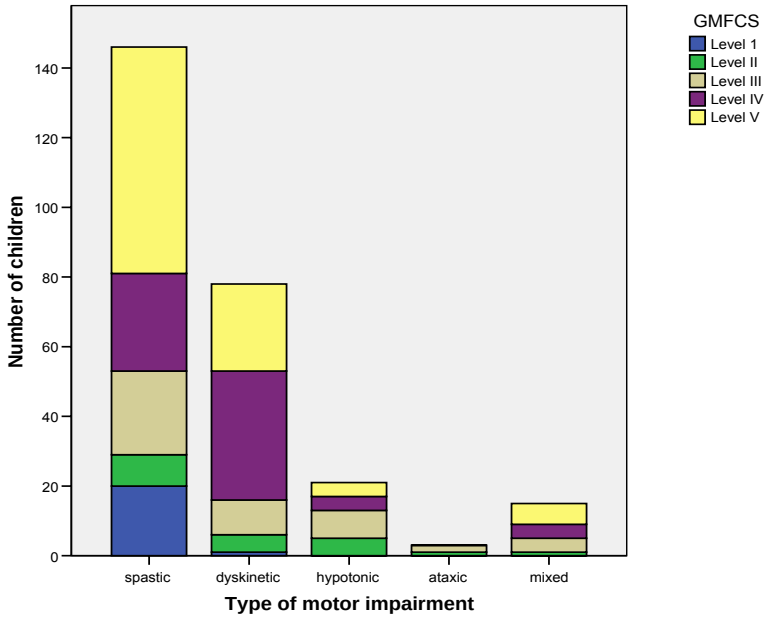


**Figure 5.1 Distribution of type of motor impairment by GMFCS**

The main form of communication for most children (164 [61.9%]) was crying or making sounds and noises and only 15% (n=40) communicated verbally. Over half of the caregivers (149 [56.2%]) said that their children's communication signals could not be understood by other people whilst only 12.1% (n=32) of the children could be clearly understood. These figures indicate that very few children had any functional communication.

### 5.2.3 Therapy attendance

Most children (217 [82.5%]) attended therapy once a month whilst eight (3%) received weekly therapy. Just under half (123 [46.8%]) of the caregivers said that they had attended therapy six times during the previous six months and a further 85 (32.3%) had attended four to five times during the same time period. This means that over 90% of caregivers interviewed had attended therapy regularly during the past six months. Nearly two-thirds of the children had been attending therapy for a

year or longer and just over 10% (33 [12.5%]) of children had been receiving therapy for five years or longer.

Just over a third (94 [35.7%]) of the caregivers spent 30 minutes or less getting to the hospital, just less than a third (83 [31.6%]) spent between 30 and 60 minutes travelling whilst the remaining third spent over an hour each way to get to the hospital. Most (229 [87.1%]) caregivers travelled by taxi whilst five (1.9%) came by private car.

### 5.2.4 Caregivers' demographic characteristics

Demographic characteristics of the caregivers are shown in Table 5.3.

**Table 5.3 Demographic characteristics of caregivers (n = 263)**

| Demographic characteristics | | n | Percentage |
|---|---|---|---|
| **Age-groups:** | 18-24 yrs | 65 | 24.7 |
| | 25-34 yrs | 114 | 43.3 |
| | 35-44 yrs | 49 | 18.6 |
| | 45-54 yrs | 21 | 8.0 |
| | >54 yrs | 7 | 2.7 |
| | Unknown | 7 | 2.7 |
| **Educational status:** | No schooling | 20 | 7.6 |
| | Some primary schooling | 42 | 15.9 |
| | Some high school | 91 | 34.6 |
| | Completed high school | 92 | 35.0 |
| | Some tertiary education | 17 | 6.5 |
| | Unknown | 1 | 0.4 |
| **Marital status:** | Married | 91 | 34.6 |
| | Living together | 42 | 15.9 |
| | Divorced | 7 | 2.7 |
| | Separated | 10 | 3.8 |
| | Widowed | 6 | 2.3 |
| | Never married | 106 | 40.3 |
| | Not applicable | 1 | 0.4 |
| **Employment status:** | Works full time | 22 | 8.4 |
| | Works part time | 11 | 4.2 |
| | Piece jobs | 15 | 5.7 |
| | Unemployed | 206 | 78.3 |
| | Not applicable | 9 | 3.4 |

The majority of caregivers (179 [69.9%]) were under the age of 35 years. Nearly 90% (235 [89.4%]) had been to school whilst six (2.3%) were still at school. Over

three-quarters (206 [78.3%]) of the caregivers were unemployed. Only 22 (8.4%) had full-time employment, 11 (4.2%) worked part-time and 15 (5.7%) had “piece jobs” or temporary work. The kind of employment was mostly as domestic workers, shop assistants and cashiers, or doing informal trading (e.g., selling fruits, vegetables and sweets). Half the caregivers were either married or living together with a partner (133 [50.5%]) whilst 106 (40.3%) were single and the remaining 24 (9.1%) were divorced, separated or widowed.

#### 5.2.4.1 Caregivers’ interaction and relationship with child

Most caregivers (217 [81.9%]) spent between ten and twelve hours looking after the child each day. Very few children (20 [7.5%]) were at a crèche or day care centre. Just over 10% of the caregivers (n=33) said there was no one with whom they could leave their child for a few hours. For the remainder, it was the caregiver’s mother (i.e., the child’s grandmother), a neighbour or a close family relative with whom the mother was able to leave her child.

Nearly a third of caregivers (82 [30.9%]) said their children were “difficult”, mainly because the children “cried a lot” or were “always sick.” However, almost all caregivers (240 [91.3%]) described their children as “happy” whilst 8.7% (n=23) said their children were “unhappy.”

### 5.2.5 Fathers’ demographic characteristics

Fathers’ demographic characteristics are shown in Table 5.4.

**Table 5.4 Demographic characteristics of fathers (n=263)**

| Demographic characteristics | | n | Percentage |
|---|---|---|---|
| Age-groups: | 18 - 24 yrs | 16 | 6.1 |
| | 25 -34 yrs | 82 | 31.2 |
| | 35 - 44 yrs | 60 | 22.8 |
| | 45 - 54 yrs | 26 | 9.9 |
| | 55 – 75 yrs | 5 | 1.9 |
| | Unknown/ Not applicable | 74 | 28.1 |
| Education status: | No schooling | 21 | 8.0 |
| | Some primary schooling | 15 | 5.7 |
| | Some high schooling | 63 | 23.9 |
| | Completed high school | 93 | 35.4 |
| | Has some tertiary education | 19 | 7.2 |
| | Unknown / Not applicable | 52 | 19.8 |
| Employment status: | Works full time | 102 | 38.8 |
| | Works part-time | 8 | 3.0 |
| | Piece jobs | 43 | 16.3 |
| | Unemployed | 77 | 29.3 |
| | Not applicable | 33 | 12.6 |

Thirty-three (12.5%) fathers had either died or their whereabouts were unknown and they no longer had contact with their children or the child's caregiver. Just under a third of the fathers (83 [31.6%]) were married to the child's mother. Forty percent (n=106) of fathers lived in the same household as the child and the child's mother; 20.9% (n=55) lived in another household nearby and 19.8% (n=52) were either migrant workers or lived far away, coming home only at monthly or three monthly intervals. Mean age of the fathers was 35.6 years, the youngest being 20 years and the oldest 70 years.

Over a third of fathers (102 [38.8%]) had full-time employment, mainly in low-income jobs such as security guards, labourers, petrol attendants, wood packers, drivers and messengers. Twenty fathers (7.6%) had professional occupations such as teacher, policeman, minister, shopkeeper or banker.

Most caregivers (171 [65.0%]) said that the child's father provided emotional support, 142 (54%) provided financial support and 137 (52.1%) provided material support in the form of clothes and food. Over a quarter of caregivers (75 [28.5%]) said that the child's father did not provide any kind of support at all for the child.

The average amount of time spent by fathers (or the mother's new partner) with their children daily is shown in Table 5.5.

**Table 5.5 Amount of time father spent with child (n=257)**

| Number of hours per day spent with child | During weekdays | Percent | During the weekends | Percent |
|---|---|---|---|---|
| spends no time | 101 | 38.4 | 88 | 33.5 |
| 1-3 hrs | 128 | 48.6 | 97 | 36.9 |
| 4 - 6 hrs | 20 | 7.6 | 49 | 18.6 |
| 7 - 9 hrs | 6 | 2.3 | 9 | 3.4 |
| 10 - 12 hrs | 2 | 0.8 | 14 | 5.3 |
| Unknown / not applicable | 6 | 2.3 | 6 | 2.3 |
| **Total** | **263** | **100.0** | **263** | **100.0** |

### 5.2.6 Socio-economic status

The majority of families lived in formal housing whilst just over a quarter lived in informal shacks or mud huts as shown in Table 5.6.

**Table 5.6 Housing quality**

| Housing quality | | n | Percentage |
|---|---|---|---|
| **Construction** | Formal (bricks/cement blocks ) | 189 | 71.9 |
| | Informal (shack, mud) | 74 | 28.1 |
| **Water supply** | Piped indoors | 50 | 19.0 |
| | Piped to yard | 111 | 42.2 |
| | Piped to street | 72 | 27.4 |
| | River, dam | 12 | 4.6 |
| | Other | 18 | 6.8 |

About two-thirds of households had a fridge, a television or a cell phone whilst just over ten percent had a microwave, a fixed line telephone or a car as shown in Table 5.7.

**Table 5.7 Commodity ownership**

| Commodity ownership | | n | Percentage |
|---|---|---|---|
| **Main method of cooking** | Electric stove | 99 | 37.6 |
| | Fire made with wood | 90 | 34.2 |
| | Paraffin stove | 46 | 17.5 |
| | Coal | 21 | 8.0 |
| | Gas | 7 | 2.7 |
| **Fridge** | Yes | 177 | 67.3 |
| | No | 86 | 32.7 |
| **Microwave** | Yes | 35 | 13.3 |
| | No | 228 | 86.7 |
| **Television** | Yes | 173 | 65.8 |
| | No | 90 | 34.2 |
| **Radio** | Yes | 150 | 57.0 |
| | No | 113 | 43.0 |
| **Telephone (fixed line)** | Yes | 30 | 11.4 |
| | No | 233 | 88.6 |
| **Cell phone** | Yes | 167 | 63.5 |
| | No | 96 | 36.5 |
| **Car** | Yes | 39 | 14.8 |
| | No | 224 | 85.2 |

The SES index was calculated using the formula described in point 4.5.4 in Chapter 4. It followed a normal distribution curve as shown in Figure 5.2.

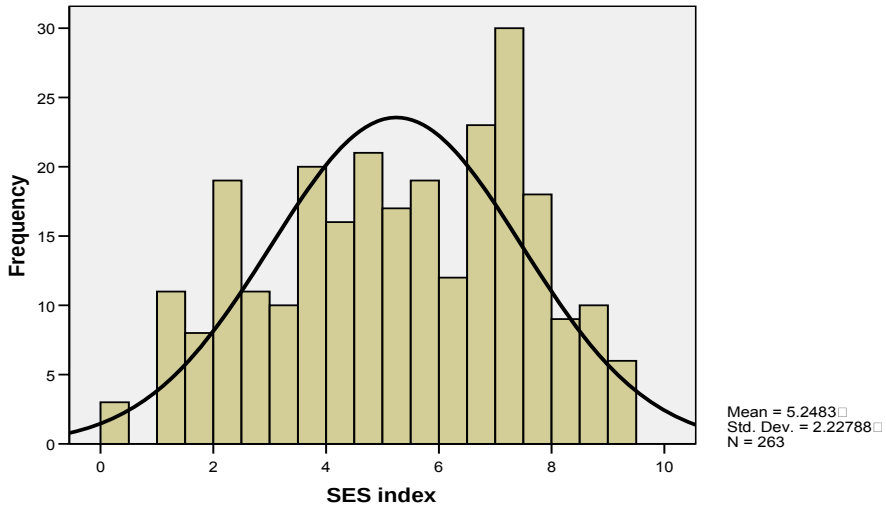


**Figure 5.2 Socio-economic status index**

The mean SES index was 5.25 and the median 5.44. The minimum score was 0.00 and the maximum 9.48. A quarter of the families (25.5% [n=67]) fell into the “low SES” category whilst another quarter (24.7% [n=66]) fell into the “high SES” category.

Total household income is shown in Table 5.8.

**Table 5.8 Total household income (n = 263)**

| Income | Frequency | Percent | Cumulative Percent |
|---|---|---|---|
| Less than R100 | 2 | 0.8 | 0.8 |
| R100 - R500 | 26 | 9.9 | 10.6 |
| > R500 – R1000 | 85 | 32.3 | 43.0 |
| < R1000 - R3000 | 113 | 42.9 | 85.9 |
| < R3000 - R5000 | 24 | 9.1 | 95.1 |
| More than R5000 | 11 | 4.2 | 99.2 |
| Unknown | 2 | 0.8 | 100.0 |
| **Total** | **263** | **100.0** | |

A third of households (133 [32.3%]) had an income of R1000 or less. The Care Dependency Grant was the only source of income for a fifth of households (57 [21.7%]). Just under half of households (128 [48.7%]) had a regular income and this was from one or more members of the household having employment. Other sources of income came from occasional employment, old age or disability pensions, rent, and in one case, a maintenance grant.

### 5.2.7 Summary of demographic and descriptive data

The descriptive and demographic information provides a profile of the caregivers and children who comprised the study population. Almost all caregivers (96%) interviewed were either the child’s mother or grandmother. Most (58%) had completed primary school education and the majority (78%) were unemployed. Those who were employed had low-income jobs. Only 40% of fathers lived in the same household as the child and the child’s mother and a quarter of fathers provided no support to the mother or the child. One third of fathers were employed.

Caregivers depended on the public transport system (mostly minibus taxis) to get to the hospital for their monthly therapy appointments.

The children included in the sample population of this study were very young, the average age being three years with over 90% being under the age of seven years. Two-thirds of children were in GMFCS Levels IV and V and few had any functional communication. They were mostly children with spastic quadriplegia (56%) but there were also a large number of children (30%) with dyskinetic cerebral palsy.

The Care Dependency Grant was the only source of income for a fifth of the families and a third of families in this study had a monthly income of R1000 or less. Just less than half of households (49%) had a regular monthly income from at least one member of the household having a job.

## 5.3 SECTION 2: ANALYSIS OF SCALES

This section addresses the first research question posed in Chapter 1, namely, “Can tools that have been developed and used in developed countries be used to assess the impact of rehabilitation interventions on caregivers and families of children with CP in poorly resourced areas in South Africa?” Specifically, this question meets the first objective of the study which was to ascertain whether tools and scales developed in contexts different from the context of this study are appropriate for use in this community.

Results of the analysis of the psychometric properties are presented separately for each scale. Comments made by caregivers as they completed the questionnaire are included with each scale as this is helpful in understanding and expanding upon caregivers’ perceptions and attitudes towards the dimensions covered in each scale.

On eight of the questionnaires, some of the scales were incomplete, i.e., the caregiver had missed some of the items. It was noted by the interviewers that despite detailed explanations, three caregivers did not understand the Personal Quality of Life and Mental Health Scales and thus their responses for these scales were not considered to be reliable. These together with any scale which was incompletely filled in were excluded from the analysis. This means that the total number of completed questionnaires available for analysis (n) was different for each scale, and these numbers are reported throughout.

For the test-retest reliability of each scale, the mean time interval between the first and second administration was 19 days.

### 5.3.1 Caregiver-Child Scale

This scale was an adapted version of the Judson Maternal Self-rating Scale (Judson and Burden, 1980). Each item is measured on a 5-point scale with higher scores reflecting more positive attributes. Means for each of the items were between 3.25 and 4.60 as shown in Table 5.9.

**Table 5.9 Descriptive statistics for Caregiver-Child Scale**

| Scale item | Mean | SD | n |
|---|---|---|---|
| My child and I have lots of fun together | 4.42 | ±0.71 | 260 |
| Lots of people are interested in my child | 3.53 | ±1.03 | 260 |
| I am enjoying my child | 4.54 | ±0.70 | 260 |
| I find it easy to show affection to my child | 4.52 | ±0.75 | 260 |
| I am proud of my child | 4.60 | ±0.67 | 260 |
| I find it difficult to play with my child | 4.22 | ±1.23 | 260 |
| I feel that I have a relationship (a bond) with my child | 4.45 | ±0.68 | 260 |
| I know that my child may not be able to do things like other children of the same age | 3.68 | ±1.10 | 260 |
| I am able to share worries about my child | 3.42 | ±1.24 | 260 |
| I am finding it difficult to look after my child | 4.15 | ±1.41 | 260 |
| I understand my child | 4.54 | ±0.73 | 260 |
| I feel I can cope when strangers ask questions or say negative things about my child | 3.25 | ±1.39 | 260 |

The lowest mean, 3.25, was for the item “I feel I can cope when strangers ask questions or say negative things about my child", although this item also had the highest standard deviation of 1.39 indicating the greatest variation in caregivers’ responses to this question. The highest mean, 4.60 was for the item “I am proud of my child.”

#### 5.3.1.1 Reliability

Cronbach’s alpha for the twelve item scale was 0.61, regarded as “undesirable” according to Arias and de Vos (1996). For the test-retest reliability, the Intraclass Correlation Coefficient (ICC) was also low at 0.42 (95% CI: 0.07 - 0.68; p=0.01).

#### 5.3.1.2 Validity

The first two criteria for item convergent validity, namely equivalent variance of all items in the hypothesized scale and corrected item-total correlation coefficients of r ≥ 0.40, (the correlation of the item with the overall scale controlling for all the other variables), were not met. Only one item had a corrected item-total correlation coefficient ≥ 0.40 as shown in Table 5.10.

**Table 5.10 Corrected item-total correlation coefficients (r) for Caregiver-Child Scale**

| Scale Item | r | Cronbach's Alpha if Item Deleted |
|---|---|---|
| My child and I have lots of fun together | **0.29** | 0.59 |
| Lots of people are interested in my child | **0.27** | 0.59 |
| I am enjoying my child | **0.32** | 0.58 |
| I find it easy to show affection to my child | **0.33** | 0.58 |
| I am proud of my child | **0.47** | 0.56 |
| I find it difficult to play with my child | **0.09** | 0.63 |
| I feel that I have a relationship (a bond) with my child | **0.36** | 0.58 |
| I know that my child may not be able to do things like other children of the same age | **0.19** | 0.60 |
| I am able to share worries about my child | **0.34** | 0.57 |
| I am finding it difficult to look after my child | **0.29** | 0.58 |
| I understand my child | **0.30** | 0.58 |
| I feel I can cope when strangers ask questions or say negative things about my child | **0.20** | 0.61 |

Items with lowest r-values (i.e. less than 0.3) were then removed and multi-trait scaling repeated until the first two criteria for item convergent validity were met. Following this process, just four items remained as shown in Table 5.11.

**Table 5.11 Item convergent validity for revised Caregiver-Child Scale**

| Scale item | SD | Variance | r | Cronbach's Alpha if Item Deleted |
|---|---|---|---|---|
| I am enjoying my child | ±0.70 | 0.49 | 0.46 | 0.63 |
| I find it easy to show affection to my child | ±0.75 | 0.56 | 0.41 | 0.66 |
| I am proud of my child | ±0.67 | 0.45 | 0.54 | 0.58 |
| I feel that I have a relationship (a bond) with my child | ±0.68 | 0.46 | 0.47 | 0.62 |

Cronbach's alpha for this scale was 0.68, regarded as "minimally acceptable" (Arias and de Vos, 1996). The ICC for test-retest reliability of this four item scale remained low at 0.34 (95% CI = -0.25 – 0.623; p = 0.03).

#### 5.3.1.3 Comments from caregivers

As described in the methodology chapter (section 4.4.5) comments and reasons for assigning a particular score to each item were recorded for 96 caregivers (Appendix Q). With two exceptions, scores were appropriate for the reasons provided. One caregiver clearly expressed her confusion at having to grade each item when she remarked *"My answer is yes. I'm not sure if it is 5 or 4 or 3, the answer is yes." (Study no. 513*). Some items were open to misinterpretation, e.g., in response to the statement "I am able to share my worries" one caregiver responded *"I am worried because my child does not have any equipment." (Study no. 243)* and in response to the statement "I am proud of my child (I am happy to take the child anywhere)", another caregiver commented *"Only a little of the time because the child is heavy and I have no buggy." (Study no. 167)*

A common expression used by caregivers regarding their relationship with their child *was "I don't have a problem with this child. This child is a gift from God and I love my*

*child."* Very few caregivers expressed negative feelings towards their child. These comments are supported by the high mean scores for the items "I am proud of my child", "I am enjoying my child" and "I find it easy to show affection to my child."

The most common reason given for finding it difficult to play with the child was that the child cried. A quarter (72 [27.7%]) of caregivers admitted that most or all of the time they did not cope well when strangers asked questions or said negative things about their child. This is supported by the fact that this item had the lowest mean score on the scale.

#### 5.3.1.4 Summary

The Caregiver-Child Scale as modified and adapted for use in a South African setting does not work for this population of caregivers. Possible reasons for this problem will be explored in the next chapter. A four-item version, with just one factor, may have possibilities for use with South African caregivers; however its psychometric properties are weak and only minimally acceptable.

### 5.3.2 Family Support Scale

This 31-item scale, an expanded version of Dunst's 18 item Family Support Scale (Dunst et al., 1994), was completed by 261 caregivers. Each item is measured on a 5-point scale. Descriptive statistics of this scale are shown in Table 5.12.

**Table 5.12 Descriptive statistics and corrected item-total correlation coefficients for Family Support Scale**

| Item | Mean | SD | r | n |
|---|---|---|---|---|
| parents | 3.22 | ±1.86 | 0.17 | 261 |
| partner | 3.11 | ±1.83 | 0.10 | 261 |
| in-laws | 1.73 | ±1.50 | 0.24 | 261 |
| close family | 3.09 | ±1.61 | 0.17 | 261 |
| extended family | 2.00 | ±1.40 | 0.26 | 261 |
| partner's family | 1.93 | ±1.44 | 0.16 | 261 |
| friends | 2.11 | ±1.38 | 0.33 | 261 |
| partner's friends | 1.31 | ±1.05 | 0.36 | 261 |
| other children | 2.44 | ±2.15 | 0.13 | 261 |
| neighbours | 2.44 | ±1.35 | 0.29 | 261 |
| other parents | 2.67 | ±1.26 | 0.31 | 261 |
| people I work with | 0.54 | ±1.14 | 0.25 | 261 |
| parent support groups | 0.81 | ±1.51 | 0.43 | 261 |
| social groups | 1.29 | ±1.54 | 0.39 | 261 |
| church | 3.12 | ±1.51 | 0.43 | 261 |
| traditional healer | 0.92 | ±1.39 | 0.23 | 261 |
| prophet | 1.34 | ±1.68 | 0.27 | 261 |
| private doctors | 1.94 | ±1.81 | 0.43 | 261 |
| school / day-care | 0.63 | ±1.41 | 0.14 | 261 |
| therapists | 4.23 | ±0.92 | 0.01 | 261 |
| comm rehab worker | 0.59 | ±1.16 | 0.40 | 261 |
| social worker | 2.29 | ±1.90 | 0.20 | 261 |
| hospital doctors | 3.92 | ±1.04 | 0.30 | 261 |
| nurses | 3.38 | ±1.07 | 0.30 | 261 |
| comm health worker | 1.27 | ±1.72 | 0.47 | 261 |
| education dept | 0.35 | ±1.00 | 0.33 | 261 |
| social develop dept | 0.91 | ±1.37 | 0.44 | 261 |
| home affairs | 2.42 | ±1.70 | 0.21 | 261 |
| local councillor | 1.42 | ±1.19 | 0.41 | 261 |
| street committees | 1.05 | ±1.17 | 0.40 | 261 |
| tribal leaders | 1.15 | ±1.45 | 0.41 | 261 |

The mean scores for each item ranged from 0.35 for “education department” to 4.23 for “therapists”. The score for therapists also had the lowest standard deviation.

#### 5.3.2.1 Reliability

Cronbach’s alpha for the 31-item scale was 0.78, indicating “very good” reliability (Nunnally, 1978). The ICC for the test-retest reliability was acceptable at 0.53 (95% CI: 0.04 - 0.81; p=0.02).

#### 5.3.2.2 Validity

The first two criteria for item convergent validity, namely equivalent variance of all items in the hypothesized scale and corrected item-total correlation coefficients, or r ≥ 0.40, were not met as demonstrated in Table 5.12 above. Only nine of the 31 items had a corrected item-total correlation coefficient ≥ 0.40.

#### 5.3.2.3 Further analysis

In view of the above poor results for the adapted and extended version of the Family Support Scale, the 18 items of the original Family Support Scale were analysed for reliability and validity. Cronbach's alpha for this 18-item scale was 0.65, which is "minimally acceptable." (Arias and de Vos,1996). The first two criteria for item convergent validity were not met either.

#### 5.3.2.4 Summary of psychometric properties

Although the 31 item scale was shown to be reliable in terms of the internal consistency and test-retest reliability, it is not valid. Thus further statistical procedures such as factor analysis were not appropriate.

#### 5.3.2.5 Comments from caregivers

Comments and reasons for assigning a particular score to each item were recorded for 111 caregivers (Appendix P). From these comments it is apparent that caregivers understood the scale as the scores allocated were appropriate for the reasons given. The only inconsistency or point of confusion was what score to allocate when a particular source was not available, e.g., "*I don't have friends. My family are my friends" or "My friend is my husband"*. Six caregivers supplied examples of these types of comments. In these situations, some caregivers allocated a score of 0 whilst others a score of 1. Caregivers whose families (including parents, other children, close and extended family) lived far away were also unsure whether to allocate a score of 0 or 1, or higher in cases where, when they did see each other, the support was very positive.

### 5.3.2.6 Family Support Scale Scores

As described in Chapter 3, the score for each item was transformed into a binary digit (each item on the scale was marked as either present or absent) and the scores were summed for each participant. Table 5.13 shows the scores obtained for each of the five subscales of the Family Support Scale; the total scores for the 31 item scale; the total scores obtained for the original 18 item scale (this was done so that comparisons could be made with other studies); and the simple count of number of supports available to each participant.

**Table 5.13 Descriptive statistics of subscale and total scores for Family Support Scale**

| Score | n | Mean | Median | SD | Minimum | Maximum |
|---|---|---|---|---|---|---|
| Formal kinship subscale | 261 | 8.31 | 9 | ±3.56 | 0 | 15 |
| Partner support subscale | 261 | 6.78 | 7 | ±3.72 | 0 | 15 |
| Informal kinship subscale | 261 | 10.97 | 11 | ±4.21 | 2 | 23 |
| Social organization subscale | 261 | 8.02 | 7 | ±4.75 | 0 | 23 |
| Professionals subscale | 261 | 25.54 | 25 | ±9.06 | 7 | 54 |
| Total Score (31 item FSS) | 261 | 59.62 | 58 | ±16.38 | 27 | 122 |
| Total Score (18 item FSS) | 261 | 37.07 | 37 | ±9.55 | 17 | 71 |
| Simple count (number of sources of support available) | 261 | 15.32 | 15 | ±4.59 | 6 | 30 |

The average number of supports available to caregivers was 15, with a minimum of 6 and a maximum of 30.

### 5.3.2.7 Least and most valued sources of support

The ten highest scoring categories of sources of support, in order, were: therapists, hospital doctors, nurses, parents, partner, church, close family, other parents, my other children, and neighbours.

The ten lowest scoring categories of sources of support also serve to illustrate their availability (or the lack thereof). They were, in order from lowest to highest: Department of Education, people I work with, community rehabilitation workers,

parent support groups, school/day care centres, Department of Social Development, traditional healers, street committees, tribal leaders and community health workers.

#### 5.3.2.8 Summary

Neither the original nor the extended version of the Family Support Scale is suitable for use in a disadvantaged South African population. However, it can be used to determine the number of supports available and could be useful in identifying gaps in support systems.

### 5.3.3 Personal Quality of Life (PQOL) Scale

As explained in Chapter 3, the PQOL scale as used by Westaway et al. (1999a) in a poorly-resourced South African setting was not adapted or modified for this study. It is scored on a 0 to 10 point scale with higher scores reflecting greater satisfaction with PQOL. Descriptive statistics are shown in Table 5.14.

**Table 5.14 Descriptive statistics for PQOL scale**

| Item | Mean | SD | n |
|---|---|---|---|
| Yourself | 9.37 | ±1.27 | 257 |
| Partner | 6.30 | ±4.20 | 257 |
| Family life | 8.16 | ±2.15 | 257 |
| Friends | 5.27 | ±3.35 | 257 |
| Time to do things | 5.24 | ±3.15 | 257 |
| Neighbours | 5.58 | ±2.30 | 257 |
| Income | 5.20 | ±2.96 | 257 |
| Social life | 5.50 | ±3.75 | 257 |
| Health | 8.89 | ±1.65 | 257 |
| Happiness | 8.74 | ±1.90 | 257 |
| Life in general | 8.68 | ±1.98 | 257 |

The means for each of the ten items ranged from 5.20 (How satisfied are you with your income?) to 9.37 (How satisfied are you with yourself?). The four highest scoring items, namely those addressing satisfaction with self, personal health, happiness and family life were all above 8.0. No item, even “Income”, scored below a value of 5. Several items had a wide standard deviation, notably those addressing partner and social life. These broad standard deviations possibly reflect the fact that

participants were either highly satisfied, e.g., they said their partner gave them good support, or they were highly dissatisfied because their partner had abandoned them. Further examples of spontaneous comments made by caregivers can be found in Appendix S.

#### 5.3.3.1 Reliability

Cronbach's alpha for the ten item scale was 0.61, regarded as "undesirable" (Arias and de Vos, 1996). For test-retest reliability, the ICC was high at 0.85 (95% CI: 0.67 - 0.93; p=0.00).

#### 5.3.3.2 Validity

The first two criteria for item convergent validity were not met. Only two items had a corrected item-total correlation coefficient of r ≥ 0.40 as shown in Table 5.15.

**Table 5.15 Corrected item-total correlation coefficients**

| Item | r | Cronbach's Alpha if Item Deleted |
|---|---|---|
| Yourself | **0.30** | 0.56 |
| Partner | **0.08** | 0.61 |
| Family life | **0.31** | 0.53 |
| Friends | **0.22** | 0.55 |
| Time to do things | **0.44** | 0.48 |
| Neighbours | **0.20** | 0.55 |
| Income | **0.31** | 0.52 |
| Social life | **0.40** | 0.49 |
| Health | **0.11** | 0.57 |
| Happiness | **0.33** | 0.53 |

Numerous iterations of the scale were done, each time omitting those items with the lowest corrected item-total correlation coefficients and then repeating multi-trait scaling. However, this failed to produce a result that fulfilled the criteria for item convergent validity. As the internal consistency as measured by Cronbach's alpha was < 0.70, and only two of the items had a corrected item-total correlation

coefficient value r > 0.40, it was inappropriate to conduct further analysis such as factor analysis.

#### 5.3.3.3 Comments made by caregivers whilst completing the PQOL scale

Spontaneous comments from 153 caregivers were recorded as they completed the PQOL Scale (Appendix S). Visual inspection of these comments suggests that the scoring was appropriate, e.g., a score was 0 was given to a partner who *"ran away because of the disabled child"* whilst a score of 10 was given to a partner who *"gives me good support."*

The comments were also helpful in providing a glimpse into caregivers' perceptions of their lives and how they viewed their present circumstances. A noticeable trend was that although several items, e.g., "partner", "income", "social life", "neighbours", "my time to do things" were given very low scores (<5), caregivers would rate their overall happiness and satisfaction with life as a 10, with comments such as *"I am living a good life because my family gives me a lot of support"* or *"I am living a good life with my family. My husband gives this child good support and he (my child) is a gift from God."*

#### 5.3.3.4 Summary

Although the test-retest reliability of the PQOL was very good (ICC = 0.85), the internal consistency was poor and the scale failed to meet the first two criteria needed for content validity. This means that the PQOL scale in its present form cannot be used to measure Personal Quality of Life in South African caregivers of children with CP.

### 5.3.4 Mental Health Subscale

Similar to the PQOL scale, the Mental Health Subscale was not adapted or modified for this study, for reasons given in Chapter 3. This five item scale, scored from one to six, with higher scores meaning better mental health, was taken from the Medical

Outcomes Study (MOS) Short-Form-20 Health Survey designed by Stewart et al. (1988). Descriptive statistics of the scale are presented in Table 5.16.

**Table 5.16 Descriptive statistics for Mental Health Subscale**

| Item | Mean | SD | n |
|---|---|---|---|
| How much of the time have you been a nervous person? | 4.67 | ±1.41 | 257 |
| Have much of the time have you felt calm and peaceful? | 4.24 | ±1.53 | 257 |
| How much of the time have you felt downhearted and blue? | 4.56 | ±1.40 | 257 |
| How much of the time have you been a happy person? | 4.67 | ±1.36 | 257 |
| How much of the time have you felt so down in the dumps that nothing could cheer you up? | 4.91 | ±1.37 | 257 |

### 5.3.4.1 Reliability

Cronbach's alpha for the five item scale was 0.85, indicating "very good" reliability (Arias and de Vos, 1996; Nunnally, 1978). The ICC for test-retest reliability was good at 0.63 (95% CI: 0.21 - 0.83; p=0.006).

### 5.3.4.2 Validity

The first two criteria for item convergent validity were fulfilled as demonstrated in Table 5.17.

**Table 5.17 Item convergent validity for Mental Health Subscale**

| Item | Scale Variance if Item Deleted | r | Cronbach's Alpha if Item Deleted | Z |
|---|---|---|---|---|
| How much of the time have you been a nervous person? | 20.92 | 0.63 | 0.82 | 6.78 |
| Have much of the time have you felt calm and peaceful? | 20.43 | 0.60 | 0.83 | 6.22 |
| How much of the time have you felt downhearted and blue? | 20.38 | 0.69 | 0.81 | 8.00 |
| How much of the time have you been a happy person? | 20.61 | 0.69 | 0.81 | 8.00 |
| How much of the time have you felt so down in the dumps that nothing could cheer you up? | 20.84 | 0.67 | 0.81 | 7.50 |

### Item discriminant validity

All items correlated significantly higher with their own subscale than with the scale for PQOL, exceeding the discriminant validity criterion (Z>1.96) as shown in Table 5.17 above.

**Factor structure**

A direct solution (principal components analysis) was used to analyse this five-item scale. Communality estimates for these five items ranged from 0.55 to 0.67. The Kaiser-Meyer-Olkin measure of item sampling adequacy was 0.83, in the "meritorious" range according to Kaiser (1974). In addition, this value fulfilled Sitzia's requirement of 0.80 for content validity (Sitzia, 1999). Bartlett's test of sphericity confirmed that the population matrix was not an identity (Chi-square = 513.95, df=28, $p<0.001$), meaning that the data were suitable for factor analysis.

Based on the eigenvalues, the percentage of the total variance accounted for by different numbers of factors and the scree plot, one factor, accounting for 62% of the variance, was extracted. All the items loaded onto this factor with the following values: nervous (0.77); calm and peaceful (0.75); downhearted and blue (0.82); happy (0.81); down in the dumps (0.80).

#### 5.3.4.3 Comments made by caregivers whilst completing the Mental Health Subscale

The comments of 36 caregivers were recorded as they completed the Mental Health Subscale (Appendix R). Thirteen said that they were happy because they "*had no problems"* (n=6), they or their child were in good health (n=5), they received support from their husband (n=1) or because they had seen an improvement in the child during the past month (n=1).

Reasons for and comments about being unhappy, nervous and downhearted during the past month were recorded for 22 caregivers. The main reason for feeling unhappy or downhearted was the child's ill health (n=10). Other reasons given included domestic strife (n=3); unemployment of either the caregiver or her partner (n=4); or a lack of support from the child's father (n=3).

#### 5.3.4.4 Mental Health Scores

The mean score for the Mental Health Subscale was 72.2 (sd = ±22.3). This compares with a mean score of 78.0 for the general population in America (Stewart et al., 1989) and is similar to a mean score of 70.9 for urban Black South African adults with diabetes (Westaway et al., 1999c). These were the only two published studies found using this particular subscale which is a forerunner of the Medical Outcomes Study (MOS): Short Form 36 Health Survey (SF36). Both scales are scored in a similar fashion.

Raina et al. (2005) used the SF36 to assess the Mental Health of 468 caregivers of children with CP in Canada. A mean score of 69.34 (sd = ±42.60) was obtained in their study. However, as different versions of the Mental Health scale were used in each study, direct comparisons cannot be made.

Nearly a third of caregivers [81 (31.4%)] had a score of 67 or lower, indicative of "poor mental health" (Stewart et al., 1988). This figure is similar to the 31.0% found in American adults with chronic health conditions (Stewart et al., 1988) but lower than the figure of 38.0% found for South African urban Black South Africans with diabetes (Westaway et al., 1999c).

#### 5.3.4.5 Summary

These results demonstrate that the Mental Health Subscale is psychometrically sound, and has excellent reliability as measured by the internal consistency and test-retest reliability. Visual inspection of the comments made by caregivers indicates that the scores allocated were consistent with the reasons provided.

### 5.3.5 Measure of Processes of Care (MPOC) Scale

The 22-item MPOC Scale was an adapted and modified version of the MPOC-20 developed in Canada by King et al. (2004a). The scale comprises five subscales, each of which was separately analysed. Each item is scored on a seven point scale

with higher scores being reflective of more positive attributes. The mean scores and internal consistencies for each of the subscales are shown in Table 5.18.

**Table 5.18 Mean scale scores and internal consistency of MPOC-22(SA)**

| | Enabling and partnership | Providing general information | Providing specific information | Co-ordinated and comprehensive care | Respectful and supportive care |
|---|---|---|---|---|---|
| n | 260 | 260 | 260 | 260 | 260 |
| Number of items | 4 | 5 | 4 | 4 | 5 |
| Mean | 4.36 | 4.05 | 5.52 | 5.11 | 5.79 |
| Median | 4.25 | 4.20 | 5.62 | 5.25 | 6.00 |
| Mode | 3.25 | 4.20 | 5.00(a) | 5.25 | 6.00 |
| Std. Deviation | ±1.22 | ±1.39 | ±0.91 | ±1.05 | ±0.79 |
| Variance | 1.49 | 1.94 | 0.82 | 1.09 | 0.63 |
| Range | 6.25 | 6.20 | 4.75 | 6.50 | 4.20 |
| Minimum | .75 | .80 | 2.25 | .50 | 2.80 |
| Maximum | 7.00 | 7.00 | 7.00 | 7.00 | 7.00 |
| Cronbach's alpha | 0.30 | 0.66 | 0.24 | 0.42 | 0.60 |

(a) Multiple modes exist. The smallest value is shown

### 5.3.5.1 Reliability

Cronbach's alpha for each of the subscales varied between 0.30 and 0.66 whilst for the overall scale, Cronbach's alpha was 0.78. For test-retest reliability, the ICCs were between 0.51 and 0.61 as shown in Table 5.19.

**Table 5.19 Test-retest reliability of MPOC-22 (SA) (n=27)**

| SCALE | TIME 1 | | TIME 2 | | INTRACLASS CORRELATION COEFFICIENT |
|---|---|---|---|---|---|
| | M | SD | M | SD | |
| Enabling and partnership | 4.15 | ±1.21 | 4.52 | ±1.08 | 0.51 (95% CI: 0.16 – 0.74; df=26; p=0.003) |
| Providing general information | 4.35 | ±1.18 | 4.25 | ±1.33 | 0.51 (95% CI: 0.17 – 0.74; df=27; p=0.002) |
| Providing specific information | 5.00 | ±1.02 | 5.08 | ±1.04 | 0.52 (95% CI: 0.17 – 0.74; df=28; p=002) |
| Co-ordinated and comprehensive care | 5.17 | ±1.02 | 5.37 | ±0.85 | 0.61 (95% CI: 0.32 – 0.80; df=28; p=000) |
| Respectful and supportive care | 5.45 | ±0.85 | 5.76 | ±0.58 | 0.53 (95% CI: 0.21 - 0.75; df=28; p=0.001) |

### 5.3.5.2 Validity

The first two criteria for item convergent validity were not fulfilled as demonstrated in Table 5.20.

**Table 5.20 Item convergent validity for MPOC-22(SA)**

| | r | Cronbach's Alpha if Item Deleted |
|---|---|---|
| good job as parent | **0.473** | .080 |
| talk to you | **0.354** | 0.80 |
| caring atmosphere | **0.337** | 0.80 |
| needs of whole child | **0.390** | 0.80 |
| team member consistent | **0.243** | 0.80 |
| explain treatment choices | **0.224** | 0.81 |
| opportunity to make decisions | **0.425** | 0.80 |
| enough time to talk | **0.511** | 0.79 |
| treat you as an equal | **0.519** | 0.79 |
| consistent info about child | **0.333** | 0.80 |
| treat you as an individual | **0.442** | 0.80 |
| explain during therapy | **0.432** | 0.80 |
| explain between visits | **0.111** | 0.81 |
| explain assessment results | **0.287** | 0.81 |
| info types of services | **0.376** | 0.80 |
| info child disability | **0.525** | 0.79 |
| whole family obtain info | **0.343** | 0.80 |
| info in various forms | **0.400** | 0.80 |
| advice how to get info | **0.413** | 0.80 |
| explain main concerns/worries | **0.394** | 0.80 |
| follow-up | **0.385** | 0.80 |
| handling suggestions/ideas | **0.390** | 0.80 |

Only nine of the 22 items had corrected item-total correlation coefficients $r > 0.40$, thus one of the criteria for item convergent validity was not met. All items with corrected item-total correlation coefficients $< 0.40$ were then removed and multi-trait scaling repeated until the corrected item-total correlation coefficients were $\geq 0.40$. Eight items remained as shown in Table 5.21.

**Table 5.21 Item-convergent validity for revised MPOC-8 (SA)**

| Item | SD | r |
|---|---|---|
| Provide enough time so you don't feel rushed | ±1.33 | 0.40 |
| Treat you as an equal rather than just as the parent of a patient | ±1.48 | 0.40 |
| Treat you as an individual rather than as a "typical" parents of a child with disability | ±1.42 | 0.42 |
| Have information available about your child's disability | ±2.04 | 0.47 |
| Have information available to you in various forms, such as pictures, booklets, videos, etc | ±2.04 | 0.43 |
| Provide advice on how to get information | ±2.35 | 0.40 |
| Ensure that you have had a chance to explain the concerns and the things which worry you most about your child | ±1.75 | 0.44 |
| Give you suggestions and ideas of things to do which make it easier to handle and look after your child | ±1.51 | 0.42 |

Cronbach's alpha for this scale was 0.73. This is regarded as "respectable" (Arias and de Vos, 1996). Descriptive statistics for the 8 item scale are shown in Table 5.22.

**Table 5.22 Descriptive statistics for MPOC-8 (SA)**

| Item | n | Mean | Median | Mode | SD | Mini-mum | Maxi-mum |
|---|---|---|---|---|---|---|---|
| Provide enough time so you don't feel rushed | 260 | 5.70 | 6.00 | 6 | ±1.333 | 0 | 7 |
| Treat you as an equal rather than just as the parent of a patient | 260 | 5.49 | 6.00 | 6 | ±1.477 | 0 | 7 |
| Treat you as an individual rather than as a "typical" parents of a child with disability | 260 | 5.52 | 6.00 | 6 | ±1.424 | 1 | 7 |
| Have information available about your child's disability | 260 | 4.67 | 5.00 | 6 | ±2.042 | 1 | 7 |
| Have information available to you in various forms, such as pictures, booklets, videos, etc | 260 | 4.49 | 5.00 | 6 | ±2.041 | 0 | 7 |
| Provide advice on how to get information | 260 | 3.62 | 4.00 | 1 | ±2.353 | 0 | 7 |
| Ensure that you have had a chance to explain the concerns and the things which worry you most about your child | 260 | 5.32 | 6.00 | 6 | ±1.749 | 0 | 7 |
| Give you suggestions and ideas of things to do which make it easier to handle and look after your child | 260 | 5.69 | 6.00 | 6 | ±1.506 | 0 | 7 |

### 5.3.5.3 Factor structure

A direct solution (principal components analysis) was used to analyse this eight item scale. Communality estimates for these eight items were all above the criterion of 0.30 (Child, 1970) ranging from 0.41 to 0.70. The Kaiser-Meyer-Olkin measure of item sampling adequacy was 0.80, the "meritorious range", according to Kaiser

(1974). In addition, this value fulfilled Sitzia's requirement of 0.80 for content validity (Sitzia, 1999). Bartlett's test of sphericity showed that the population matrix was not an identity (Chi-square = 296.936, df=28, p<0.001).

The scree plot revealed that the best solution was a two factor (VARIMAX) rotational solution as shown in Table 5.23.

**Table 5.23 Orthogonal (VARIMAX) rotational solution for the MPOC-8(SA)**

| | Component | |
|---|---|---|
| | **1** | **2** |
| enough time to talk | **0.83** | -0.04 |
| treat you as an equal | **0.64** | 0.16 |
| treat you as an individual | **0.57** | 0.27 |
| info child disability | 0.41 | **0.50** |
| info in various forms | 0.24 | **0.59** |
| explain main concerns/worries | **0.57** | 0.29 |
| handling suggestions/ideas | 0.13 | **0.70** |
| advice how to get info | 0.04 | **0.76** |

Extraction Method: Principal Component Analysis.

The variance explained by Factor I was 35% and 13% for Factor II. Each factor contained four significant loadings. Factor loadings are described in terms of the most frequent positive or negative responses to the statements.

The loadings on Factor I were related to an interpersonal factor, namely that of respectful and supportive care and comprised the following items:

- enough time to talk
- treat you as an equal, rather than just as a parent
- treat you as an individual, rather than as a "typical" parent
- ensure that you had the chance to explain the things that worry you most

Factor II related to an informational factor, namely that of providing information and advice and comprises the following four items:

- have information available about your child's disability

- have information available to you in various forms, such as pictures, booklets, video, etc
- provide advice on how to get information
- give you suggestions and ideas of things to do which make it easier to handle and look after your child

#### 5.3.5.4. Comments from caregivers

Whilst completing the scale, caregivers spontaneously gave reasons for giving an item a particular score (see Appendix S). Generally, the scores allocated by the caregivers were in line with the reasons given. Comments were generally non-specific, e.g., “The therapists and doctors help me” or “The service here is good.” As fewer concrete examples were given to illustrate why a particular score was given, caregivers seemed to find this scale more difficult to complete. One caregiver who said she wanted to complete the scale herself filled in all the blocks and when asked why, responded “I saw the big spaces and so I thought I had to fill them all.”

#### 5.3.5.5 Correlation of MPOC-8(SA) with two satisfaction variables

A small but positive correlation existed between the eight item MPOC-SA and two satisfaction variables thus supporting the construct validity of the revised scale as shown in Table 5.24.

**Table 5.24 Pearson correlation coefficients for association between satisfaction and MPOC-8(SA) scores**

| | N | Gain something from each session | Satisfaction with service |
|---|---|---|---|
| Factor 1(respectful and supportive care) | 252 | 0.32 | 0.38 |
| Factor 2 (providing information and advice) | 248 | 0.16 | 0.28 |

All correlations significant at the 0.01 level

#### 5.3.5.6 Summary of analysis of MPOC-20

The MPOC-20, as developed in Canada, and then modified and adapted for use in a South African population, does not work in this new setting in this version. However,

an eight item version of the MPOC, with just two factors, does appear to have possibilities for use in a South African population.

Many caregivers found the MPOC difficult to complete as they had little or no exposure to or experience of some items on the scale or to the concept of making the type of discriminative distinctions expected in MPOC.

#### 5.3.5.7 Best and least liked aspects of service

After completing the MPOC scale, caregivers were asked to name the three aspects they liked best and the three aspects they liked the least about the service. A total of 224 caregivers provided responses to the first question, and 168 to the second. The responses are shown in Table 5.25 and Table 5.26. They were separated into those from Gauteng and those from Limpopo Province to highlight differences in the service between urban and rural hospitals.

**Table 5.25 What caregivers liked best about the service**

| Response | Gauteng | Limpopo |
|---|---|---|
| Good therapy service (ie the exercises or "training" the children receive) | 67 (24.4%) | 92 (34.4%) |
| Therapists' caring attitude to child and caregiver and good communication with caregivers | 88 (32.0%) | 80 (30.0%) |
| Doctors role ( examining the children; good communication with mothers and caring attitude) | 32 (11.6%) | 29 (10.9%) |
| Caregiver taught specific skills handling and interacting with the child | 32 (11.6%) | 15 (5.6%) |
| Caregiver affirmed and made to feel good about herself; felt respected | 16 (5.8%) | 19 (7.1%) |
| Assistance with grants, schools, transport costs, food and food supplements, nappies, toys, equipment | 4 (1.6%) | 21 (7.9%) |
| Therapists' punctuality; short waiting time for treatment) | 10 (3.6%) | 1 (0.4%) |
| Hospital environment (neat, clerks good) | 9 (3.3%) | 1 (0.4%) |
| Children receive good medication | 11 (4.0%) | 2 (0.7%) |
| Centralised service for children ("all in one place'), services free | 4 (1.4%) | 2 (0.7%) |
| Friendly nurses: assistance with interpretation | 2 (0.7%) | 5 (1.9%) |
| **TOTAL NUMBER OF"BEST LIKED ASPECTS" GIVEN BY CAREGIVERS** | **275 (100.0%)** | **267 (100.0%)** |

**Table 5.26 What caregivers liked least about the service**

| Response | Gauteng | Limpopo |
|---|---|---|
| Dispensary: long queues to get medicine | 51 (31.7%) | 10 (7.1%) |
| Clerks and OPD: waiting times for files; rude clerks; inefficient service | 29 (18.1%) | 33 (23.2%) |
| Nurses' attitudes: rude, harsh, uncaring | 18 (11.2%) | 10 (7.1%) |
| Doctors: uncaring; impatient; see children infrequently; poor explanation of results and medications | 17 (10.6%) | 11 (7.7%) |
| Therapists: uncaring; in a hurry; lazy; poor explanations; arrive late; don't speak the language; lazy; poor treatment; no follow-up appointment; poor communication with parents | 13 (8.1%) | 27 (19.0%) |
| Waiting time for therapy | 7 (4.3%) | 11 (7.7% |
| Being treated disrespectfully by cleaners, clerks in therapy department; general unhelpfulness | 7 (4.3%) | 9 (6.4%) |
| OPD – long queue to see doctor, even when child sick | 7 (4.3%) | 1 (0.7%) |
| Distance and transport to the hospital | 6 (3.7%) | 3 (2.1%) |
| No home visits; therapy too infrequent | 5 (3.1%) | 3 (2.1%) |
| Bureaucracy – being shunted from pillar to post | 1 (0.6%) | 2 (1.4%) |
| Lack of therapy equipment and wheelchairs | 0 | 17 (12.0%) |
| Not enough doctors and therapists | 0 | 5 (3.5%) |
| **TOTAL NUMBER OF "LEAST LIKED ASPECTS" GIVEN BY CAREGIVERS** | **161 (100.0%)** | **142 (100.0%)** |

In both Gauteng and Limpopo the therapists' caring attitudes towards the child and the caregiver together with the exercises or "training" the child received were the most common positive attributes of the service. Long queues at the dispensary waiting for medicine were more of a problem in Gauteng whilst a lack of therapy equipment and wheelchairs was more of a problem in Limpopo. Uncaring and lazy therapists were more of a concern in Limpopo than Gauteng. In both provinces caregivers complained about the poor service at the Out Patients Department where they had to collect their files.

#### 5.3.5.8 Summary

Caregivers generally expressed satisfaction with current services. They valued the physical treatment the child received as well as the caring attitude of the staff towards their children. The provision of equipment, food supplements and nappies together with assistance with equipment, grants, and finding a school, were also important. Waiting times at the dispensary, the out-patient department and for therapy, as well being treated disrespectfully were the main criticisms.

## 5.4 SECTION 3: COMPARISONS, RELATIONSHIPS AND CORRELATIONS

In this section, objectives 2 – 4 of this study are addressed in turn. All these objectives concerned "caregiver outcomes" and were dependent on the assumption that these outcomes could be measured. The outcomes of interest were caregivers' personal quality of life, mental health, adaptation and interaction with their child and involvement with family support networks. The assumption was made that high scores on each of these scales would indicate a positive caregiver outcome.

However, as the Caregiver-Child Scale, the Family Support Scale and the Personal Quality of Life Scale have been shown to be invalid for this population, it is not possible to obtain a total score for any of these scales which means that an overall score for caregiver outcome cannot be calculated. This makes it impossible to meet these three study objectives.

Nonetheless, although the scales as a whole are not valid, individual scale items are apparently useful, e.g., from the PQOL scale the items "how do you rate your happiness" and "how satisfied are you with your life in general" can be used as a proxy for quality of life; the actual number of supports available to a caregiver can be used instead of a score from the FSS; and the scores from the MPOC-8(SA) can be used.

### 5.4.1 Predictive factors of good mental health and family support networks

Objective 2 was to ascertain whether there were factors which could predict a positive caregiver outcome in terms of their quality of life, mental health, interaction with their child and their involvement with family support networks.

Multiple regression was used to determine the most important predictors of caregiver's mental health. The following variables were entered into a regression analysis: place of residence (i.e. whether urban or rural); whether the child received a Care Dependency Grant; the severity of the child's disability; caregiver's marital

status; caregiver's employment status; father's employment status; total household income; the child's age and the caregiver's happiness (the score obtained from the question "How do you rate your happiness?" on the PQOL scale.

Variables which had no correlation with caregiver's mental health were then excluded. They included caregiver's age; caregiver's educational level; MPOC-8 (SA); socio-economic status, number of supports available to the caregiver. Of these variables, only two, happiness and the child's age were found to be predictors of caregiver's mental health as shown in Table 5.27. The child's age had a negative correlation implying that the younger the child, the higher the caregiver's mental health score.

**Table 5.27 Predictors of caregiver's mental health**

| Variable | Beta | t | p |
|---|---|---|---|
| Urban/rural | 0.09 | 1.33 | 0.18 |
| Receive CDG | -0.02 | -0.30 | 0.76 |
| GMFCS | 0.06 | 0.99 | 0.32 |
| Marital status | -0.04 | -0.61 | 0.54 |
| Employment status | -0.01 | -0.20 | 0.84 |
| Father employment status | 0.04 | 0.67 | 0.51 |
| Total household income | -0.07 | -1.03 | 0.31 |
| **Happiness** | **0.27** | **4.24** | **0.00** |
| **Child age** | **-0.14** | **-2.12** | **0.04** |

The model summary obtained from the regression analysis is shown in Table 5.28.

**Table 5.28 Model summary of the predictors of caregivers' mental health**

| | | | | | Change Statistics | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Model | R | R Square | Adjusted R Square | Std. Error of the Estimate | R Square Change | F Change | df1 | df2 | Sig. F Change |
| 1 | .191(a) | .036 | .008 | 21.90493 | .036 | 1.277 | 7 | 236 | .262 |
| 2 | .323(b) | .104 | .074 | 21.16381 | .068 | 17.818 | 1 | 235 | .000 |
| 3 | .348(c) | .121 | .087 | 21.00920 | .017 | 4.472 | 1 | 234 | .036 |

a Predictors: (Constant), Total household income, Employment status, GMFCS, Father employment status, Urban/rural, Receive CDG, Marital status

b Predictors: (Constant), Total household income, Employment status, GMFCS, Father employment status, Urban/rural, Receive CDG, Marital status, Happiness

c Predictors: (Constant), Total household income, Employment status, GMFCS, Father employment status, Urban/rural, Receive CDG, Marital status, Happiness, Child age

Model 3 shows that total household income, employment status, GMFCS, father employment status, urban/rural, receive CDG, marital status all together explain only 1% of the variance. Happiness explains a further 6.6% and the child's age explains a further 3.3%

### 5.4.2 Comparison between urban and rural caregivers

Objective 3 was to ascertain whether place of residence (that is, urban or rural) makes a difference to the outcomes of interest, namely caregivers' quality of life, mental health, attitude towards their child and involvement with a family support network. The comparison between urban and rural caregivers is shown in Table 5.29.

**Table 5.29 Comparison between urban and rural caregivers and their children**

| | | Urban | Rural | Test statistic |
|---|---|---|---|---|
| Age of child | N | 127 | 136 | p=0.01 |
| | Mean | 2.94 | 3.71 | |
| | SD | ±2.46 | ±2.67 | |
| Mother's number of years of completed schooling | N | 127 | 136 | p<0.01 |
| | Mean | 11.27 | 8.24 | |
| | SD | ±7.31 | ±4.07 | |
| Socio-economic status | N | 127 | 136 | p<0.01 |
| | Mean | 6.47 | 4.11 | |
| | SD | ±1.75 | ±2.02 | |
| Caregiver employment status (comparison across 5 categories) | N | 127 | 136 | P<0.01 |
| Father employment status (comparison across 6 categories) | N | 127 | 136 | p=0.02 |
| Severity of disability (comparison across 5 categories) | N | 127 | 136 | p=0.02 |
| Mental health | N | 125 | 133 | p<0.01 |
| | Mean | 68.29 | 75.76 | |
| | SD | ±23.78 | ±20.92 | |
| No. of family supports available to caregiver | N | 124 | 135 | p<0.01 |
| | Mean | 14.19 | 16.41 | |
| | SD | ±3.77 | ±5.01 | |
| Happiness | N | 125 | 135 | p<0.01 |
| | Mean | 8.39 | 9.07 | |
| | SD | ±2.17 | ±1.59 | |
| Life in general | N | 125 | 135 | p=0.02 |
| | Mean | 8.39 | 8.95 | |
| | SD | ±2.17 | ±1.83 | |
| MPOC (SA-8) | N | 124 | 134 | P<0.01 |
| | Mean | 39.00 | 41.82 | |
| | SD | ±8.71 | ±7.42 | |

In Limpopo Province, the more rural area, children were slightly older and more severely disabled, caregivers less well educated and with higher unemployment rates for both caregivers and fathers, and households poorer. In terms of caregiver outcomes, caregivers in Limpopo had more sources of family support, were happier and more satisfied with life in general, had better mental health and considered the rehabilitation therapy services to be more family centred. All these differences were statistically significant.

There were no significant differences in terms of actual household income although household size in Limpopo was larger ($p<0.01$). There were also no significant difference in terms of caregivers' age, the number of children receiving care dependency grants, whether the caregiver had someone with whom she could leave her child, or how she rated her partner.

### 5.4.3 Severity of child's disability in relation to caregiver outcomes

Objective 4 was to ascertain whether the severity of a child's disability has an impact on the caregiver outcomes described above.

No significant differences across the five GMFCS groups with regard to life in general ($p=0.16$), caregiver happiness ($p=0.34$), mental health scores ($p=0.30$), number of family supports ($p=0.55$), or the MPOC-8(SA) were found ($p=0.27$).

The five GMFCS groups were then collapsed into two groups (GMFCS Levels I – III and GMFCS Levels IV and V). The only significant result was for the Mental Health scores where caregivers of the more severely disabled children had slightly better mental health ($n = 170$; mean = 74.26) than caregivers of less severely disabled children ($n = 88$; mean = 68.05) ($p=0.048$). However, as the p-value here is very close to 0.05, the significance of this result is marginal and might represent a Type I error.

### 5.4.4 Summary

There were no factors which were predictive of caregivers' outcomes in terms of their mental health. Despite being poorer and having more children who were more severely disabled, caregivers in rural areas were happier, enjoyed better mental health, were more satisfied with their lives and had more sources of family support. The severity of the child's disability was not related to any of the following factors: caregiver's life in general; caregiver's happiness; caregiver's mental health or the number of family supports.

The results from these three sections are discussed in the following chapter.