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The influence of the Malamulele onward intervention model on caregivers of children with cerebral palsy

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APPENDIX A

APPENDIX B

MAIN THEMES FROM FOCUS GROUP DISCUSSIONS

TABLE 1

THEME 1: VALIDATION

SUBTHEME	CATEGORIES	SUPPORTING DATA
Acceptance from others	Love and Respect from the therapists and hospital staff	*"You treated us very well. I was very happy when people come to see that we have disabled children". Participant 7.* *"I started him at physio when he was four months and I received love from the first time I started. Even now that we have guests from Gauteng, I receive love even more". Participant 4.* *"I could see that it is nice here at the Hospital. We are welcomed". Participant 5.*
	Acceptance from family members and community	*"We live happily with our neighbours. They love my child". Participant 4.* *"She is much adored by my sister's children. They take her and put her on a bicycle and take her to Church or to the Crèche. Sometimes they go to the shop nearby. Indeed they love her a lot". Participant 12.* *"I got very shocked when it was said I was going to come here, you know, I was going to come to this meeting today. They said no leave the child. I got surprised to know that he is not going, but will stay and eat the slaughtered sheep. So I am surprised that they (the family) regard him as a person amongst people". Participant 10.*
Acceptance from caregivers	Accepting the child and his/her disability	*"I thought he was a child who was troubled by the evil spirits. He was a child who could not do a thing. When I came to the Malamulele physios I saw a big change in my child. Now he can see me, laugh and do other things he could not". Participant 21.* *"He is clever, even more than those who have school bags on their backs on their way to school. The only problem I have is that I wish his hands could do something". Participant 16.* *"I accepted even though he is disabled. I was proud of him because he is my first grandson". Participant 19.*

TABLE 2

THEME 2: EMPOWERMENT

SUBTHEME	CATEGORIES	SUPPORTING DATA
Education	New knowledge and understanding	*"With … I learned to be contented with the circumstances because it was said that things will delay". Participant 19.* *"Me, the week we were here at the hospital with you and our children. I felt, I feel very happy, feel free. It was because most of the things I did not know how to do them. So now, by meeting with you I got more knowledge". Participant 4.* *"It is so nice for me to go to Tafalofefe. Now, they teach me things I am supposed to do with him". Participant 11.*
Self-efficacy	Practical skills and competence	*"When I put something in his mouth he pushes it to the jaws and chews it. May be meat or chicken – he chews it. Even if it has fallen down I can see it has been chewed not like before when he swallowed things without chewing". Participant 11.* *"I am teaching him what you taught us. I feel very happy within myself". Participant 7.* *"So I have learned many things, even the sleeping methods. I was told to put him on his side with his arm underneath his body. I must put a pillow for him to rest on and another pillow must be between his thighs". Participant 4.*
	Use of equipment	**"***He did not know how to drink. If I gave him some water I was forced to use a spoon. There at the Hospital they gave me a mug with a hole. I was to use it when I am giving him liquids. Now he can drink with the mug, even water or milk. I give him when I feel he is thirsty and he is drinking with a gulp (makes a swallowing sound) in a nice way". Participant 11.* *"Me, as I am sitting here I am a madam. Under the equipment I got for my child. To understand, I was on holiday and I packed all the stuff to show them that my child is taken care of. My child can stand and move his feet now. And when he stands he does not become rigid like he used to. I am a madam and I am so proud of it, I say look at these things my child got". Participant 10.*

TABLE 3

THEME 3: WELLBEING

SUBTHEME	CATEGORIES	SUPPORTING DATA
Reduced burden for the caregiver	Reduced physical strain when using the special equipment.	*"I used to carry him on my back and hands and he was heavy. Now there are these things to drive him around. I do not have a problem". Participant 17.* *"Before we had the chair he was always crying to be put on our backs, not wanting to be put down. Participant 2.* *"I feel well health-wise. Because I used to carry him on my back and hands and he was heavy. Now there are these things to drive him around". Participant 19.*
	Support from the family and community.	*"I can put him in the buggy and the other kids push him the whole day, playing with him". Participant 9.* *"If he is sick I phone him (the child's father) and he responds promptly. Sometimes, I would ask one of the two ladies who live in the neighbourhood and they normally come and help even if it is at night". Participant 4.* *"I get assistance from my brother. If I go to the river to fetch water he looks after him as if he was his own child". Participant 7.*
	More free time for other activities.	"*Since he received the equipment for sitting and walking I was able to perform my activities". Participant 17.* *"I used to carry her with my hands. Now I can put her there and make her stand on the standing frame and play and then I am able to do my activities around the home". Participant 18.* *Ï can place him in his chair while I'm working, doing everything I have to do". Participant 2.*
Relief for the child	Increased comfort and freedom for the child.	***"**He can now sit on the chair I received and he enjoys it. Even if he is crying I put him in the chair and drive him around the house and he falls asleep". Participant 11.* *"He used to be stiff. Now when I dress him up he is very happy because I tell him that here is your clothing item and he laughs". Participant 19.* *"He is very pleased with his stand box the one you have given him. Now he is very happy when I put him in the stand box for his feeds". Participant 7.*

	Improvement in their children's condition	*"There is improvement in him now. And he also uses his brain. If I say 'No' he hears me. There is something I am happy for". Participant 11.* *"When I first came to the physios he could do nothing. He was just a limpy person. But when I came to the physio he became better than what he was before" Participant 4.* *"When she was asleep she could not roll to the other side. But now she rolls and looks to the other side or sleep with her tummy or with her back". Participant 12.*
Positive psychological state	Reduced psychological distress	*"Ever since we came back with him from the Hospital in October there are so many things I am happy about". Participant 5.* *"I get some happiness in my house very much together with him. I go and call the children from the neighbourhood far away in order for him to be happy. I did not know he knows how to laugh, but because there were so many children visiting him I saw his teeth – no he can laugh". Participant 5.* *"We are very happy about you all of us as parents, truly inside our souls". Participant 11.*
	Gratitude	*"During the therapy session there was a difference after you touched our children with your hands. I saw him crawling which never happened before. This is the best thing ever. I am grateful about this thing". Participant 8.* *"What I am saying is that I am very thankful to the ladies that are visiting the Hospital and me. The Clinic seems to be far, but I do not even get tired. I go because this is my grandchild". Participant 4.* *"These things he got from the Hospital make me very happy because then he was a child who used to sleep and get bed sores on his head. Now, there is no problem because he sits on his bums. Now he tries to stand, there is no problem". Participant 12.*
	Moral support from other caregivers of children with CP who are part of the programme	*"I noticed a change when I met other parents who have children with disabilities because I was able to talk about my child". Participant 15.* *"I met other parents with disabled children. I noticed that I am not the only one who has a disabled child". Participant 13.*

		“In my village I was the only one coming here. But when I started coming here I saw many people and I was relieved”. Participant 15.

TABLE 4

THEME 4: FAITH AND HOPE

SUBTHEME	CATEGORIES	SUPPORTING DATA
Uplifting coping strategies	Wishing for further improvement	*"So I wish to see him walking one day, going to school like other children and I hope one day he will walk, this is not the end of his life". Participant 12.* *"I just wish that she can stand up and walk. I can say I have hope now that she is crawling she is going to walk. I have that hope from the bottom of my heart". Participant 8.* *"There is a big difference. Therefore, I have a hope. I have not told myself that she will never walk. I anticipate that she will walk and when at the school age she will go to school like other children. Even if she will never be exactly at the same level with other children, I have a hope". Participant 14.*
	Spiritual faith.	*"Some days I feel very emotional and could cry when I see his peers. Then it appears to me that the Lord does not allow one to be tempted more than one can handle. In time I began to gradually be accepting of his condition". Participant 6.* *"I wish him and myself to be in good health so that I am able to hold my grandchild. So that I am able to take care of him because he is a gift. It's God's creation. I have no complaints". Participant 17.* **"***Now I have hope that he will be like other children. God will make him sit like other children". Participant 5.*

TABLE 5

THEME 5: STRESS AND STRAIN

SUBTHEME	CATEGORIES	SUPPORTING DATA
Persistent hardships	Forced resignations	*"I got him when I was working in Johannesburg. I came to leave him with my mother at home. But when he became sick I was forced to stop working, to come back and to stay at home. Now, I do not think I will be able to go to work in faraway places. I wish I can get work at a place nearby so that my baby stays with her (the grandmother) so that I can wake up and come back late. So the things I wished for did not go according to my plans. They were so much interrupted". Participant 14.* *"My wish as someone who was already working was that, perhaps, I will be given study leave and go to school in places like Johannesburg. But ever since I got this baby, I cannot go far away and leave him at home. Therefore, the other things that make me not to go to faraway places is this baby". Participant 15.*
	Dashed hopes and wishes	**"***I wished for a child that I could take care of while he was growing up, take him to school and ask him to do something for me. And then I got the baby and he was disabled. Therefore, I did not wish for a disabled child, but I got a disabled child. My wishes did not go as I wanted". Participant 4.* *"I got very frustrated when I delivered him because I found out that he was disabled. I did not expect that I will give birth to all of them disabled". Participant 9 who has two children with CP.*
	Impediments	"*So if he gets sick, which is a big worry for me as this happens a lot and scares me". Participant 4.* *"I say I have been preaching this issue that I have a sick child at home. I cannot attend your celebrations properly. I am just saying that I am not a people's person to my neighbours because they gossip about me, saying I'm selfish and I keep myself indoors". Participant 11.* **"***My problem is that we stay in the rural areas, far from the transport services. I have to get people to help me carry him with my arms". Participant 5.* *"The taxi drivers do not want the wheelchairs. They say they don't fold. The roads are in bad condition and we are unable to use them (the wheelchairs) when we take our children to the bus stop. We get pain in our shoulders from carrying a heavy load. This is what I feel plays a role in deteriorating our health as parents of disabled children". Participant 20.*

	Lack of alternative placement facilities	*"I wish that he can be educated so that he is bright in his head. I wish for there to be a school where he can learn". Participant 16.* *"I wish we can get a place to take care of our children because some of us are working". Participant 15.* *"Me too, I wish we have a place for our children to stay and come home on weekends". Participant 4.*