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THE INFLUENCE OF

THE MALAMULELE ONWARD INTERVENTION MODEL

ON CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY

by

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A Research Report submitted to

the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg,

in partial fulfilment of the requirements for the Degree of

Master of Science in Medicine (Child Health Neurodevelopment).

Johannesburg, 2016

DECLARATION

I, Marilyn Jean Adan, declare that this research report is my own work.

It is being submitted in partial fulfilment of the requirements for the degree of Master of Science in Medicine (Child Health Neurodevelopment) at the University of the Witwatersrand, Johannesburg.

It has not been submitted before for any degree or examination at this or any other University.

Signature

Signed this day in Johannesburg

day of , 2016

In gratitude for

the loving support and understanding I received

from my husband, Jock, my children, Jacqui and Jonathan,

and my grandchildren, Ryan, Danica, Jonny and Carly,

whilst completing this degree

and

in loving memory of my parents,

George and Joan Paxton

PRESENTATION ARISING FROM THIS RESEARCH REPORT

Mrs M. Adan, Dr G. Saloojee and Prof P. McInerney (2012). *The Influence of the Malamulele Onward Intervention Model on Caregivers of Children with Cerebral Palsy*. Poster presentation at the International Congress of Psychology in Cape Town, South Africa from 22 to 27 July 2012.

ABSTRACT

Aim

This study utilised data collected during focus group discussions with caregivers of children with cerebral palsy in the Mnquma sub-district of the Eastern Cape that were conducted as part of a much larger, longitudinal study into the use of the Malamulele Onward Intervention Approach. This Approach provides intensive therapeutic intervention for children with cerebral palsy who live in poor rural areas in South Africa as well as education and home programme training for their caregivers.

Method

This study explored the influence of the Approach on the caregivers' lives whose children attended the cerebral palsy clinics at the Butterworth and Tafalofefe Hospitals. The focus group discussions took place after the initial assessment of the children in 2007 and during follow-up visits in 2008, 2009 and 2010.

The participants included IsiXhosa-speaking primary caregivers (N = 21, 16 mothers and 5 grandmothers). The discussions were audiotaped, transcribed and translated from IsiXhosa to English by professional translators and the content was analysed using thematic coding techniques.

Findings

Five main themes emerged related to the open ended questions posed to participants, namely 'validation', 'empowerment', 'wellbeing', 'faith and hope' and 'stress and strain'. They revealed positive feedback on the Malamulele Onward programme and indicated that participation was worthwhile. Information on cerebral

palsy proved useful and techniques learned and special equipment provided resulted in improvement in their children.

Conclusions

In general, the caregivers of children with cerebral palsy in this study reported a reduction in burden of care, improvement in psychological status and social support with enhanced quality of life overall.

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