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Never~ending caring:

The experiences of caring for a child with cerebral palsy

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Abstract

Cerebral palsy is one of the chronic conditions which have become a serious health burden worldwide. Consequently, this health burden involves healthcare as a whole, regardless of whether the focus is on the macro or micro system. Glaserian grounded theory was employed to explore and explain the experiences of families who have a child with cerebral palsy, particularly in the Thai cultural context. Unstructured interviews and participant observations were used along the process of data collection from 15 families who have a child with cerebral palsy. Data encompassed a variety of qualitative data sources: interviews, observational field notes, personal documents, pictures, drawings, and information from a literature review. The process of data analysis was guided by Glaserian grounded theory throughout the processes of constant comparative analysis to generate a substantive theory. The substantive theory comprised three core categories: **Enduring despair, culture of obligation and responsibility and living with**, which were integrated into the basic social psychological process of *never-ending caring*. The metaphor of a waterwheel was used to depict the basic process. The substantive theory of *never-ending caring* for a child with cerebral palsy provided an explicit understanding of the experiences of these families in day-to-day living with, and care of, a child with cerebral palsy. It is hoped that this understanding will be a constituent of health care – particularly of people with chronic conditions, whereby the practice of healthcare professionals will improve, thus enhancing the efforts of their work to achieve the ultimate goal of improving the quality of life of children with cerebral palsy and their families.

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Table of Contents

Abstract	i
Acknowledgements	iii
Table of Contents	v
List of Figures	xi
List of Tables	xiii
Preface	xv
Chapter 1: Significance and background of the study	
Introduction	1
Significance and background of the study	2
The study	4
The thesis outline	5
Conclusion	8
Chapter 2: Literature review	9
Introduction	9
The development of international policies for persons with disabilities	10
The development of national plans and policies for persons with disabilities in Thailand	12
Cerebral palsy	15
Etiology	16
Causes of cerebral palsy	17
Incidence and prevalence	18
Diagnosis	18
Classification of cerebral palsy	19
Treatment	20
Experience of families toward chronic conditions	21
Parents and caregivers	21

Siblings	23
Conclusion	25
Chapter 3: Design and methods	27
Introduction	27
Symbolic interactionism	27
Grounded theory methodology	29
Methodological development	30
Glaserian Grounded theory	32
Grounded theory and Nursing	34
The study design	35
The sampling strategy	35
Participants characteristics	39
Ethical considerations	41
Methodological rigour	44
Data collection	45
Participant observation	46
Unstructured interviews	46
Data analysis	48
Substantive coding	48
Selective and theoretical coding	53
Conclusion	55
Chapter 4: Enduring despair	57
Introduction	57
An overview of the experience of never-ending caring for a child with cerebral palsy	58
Enduring despair	60
Suffering and blaming:	
Finding reasons and blaming	62
Expression of suffering	67
The burden of care	73

Conclusion	77
Chapter 5: Culture of obligation and responsibility	79
Introduction	79
Culture of obligation and responsibility	80
Having faith:	
Being Buddhist	80
Personal beliefs	89
Obligation and responsibility	94
Conclusion	100
Chapter 6: Living with: Learning to live the situation	101
Introduction	101
Living with: Learning to live with the situation	102
Dealing with the situation	102
Strategies to bring up	115
Physical health treatment	124
Having positive feelings	133
Conclusion	140
Chapter 7: Living with: Preparing for an uncertain future	143
Introduction	143
Living with: Preparing for an uncertain future	146
Vulnerability of a child with cerebral palsy	144
Planning for the future	146
Living with hope	156
Conclusion	162
Chapter 8: Never-Ending Caring	165
Introduction	165
A grounded theory of never-ending caring for a child with CP	165
Never-ending caring for a child with cerebral palsy	170

Facing the situation	172
Learning to deal with the situation by themselves	174
Learning to live with and care for a child with CP	175
Conclusion	176
Chapter 9: Discussion, limitations and implications	177
Introduction	177
Discussion	177
Limitations	182
Implications	183
Nursing practice for:	
Long term care for a child with cerebral palsy	183
Enhancing sharing experience	186
Sharing experience as a psychological support	186
Sharing experience as knowledge	187
Nursing education	189
Further research	190
Conclusion	190
References	193
Appendices	211
Appendix I – The Participant Information Sheet	213
Appendix II – Informed consent	217
Appendix III – Ethics approval by the Khon Kaen University Ethics Committee for Human Research	221
Appendix IV – Ethics approval by Massey University Human Ethics Committee	225
Appendix V – The permission form of the Special Education Center in Region 9, Khon Kaen, Thailand	229
Appendix VI – The permission form of the Khon Kaen Special Educational School	233

Appendix VII – The permission form of the Mary Immaculate School for disabled children	237
Appendix VIII – Glossary	241

List of Figures

Figures

Figure 3.1	Theoretical field note and theoretical sampling	39
Figure 3.2	Questions used for the process of constant comparative analysis	50
Figure 3.3	Putting some theoretical codes on the door	51
Figure 3.4	Using “the mind map” as a “theoretical memo”	52
Figure 3.5	Taking theoretical memos	53
Figure 4.1	<i>Never-ending caring</i> for a child with cerebral palsy	59
Figure 5.1	Theoretical field note of making merit with ID3’s family	88
Figure 5.2	The incense burner in front of ID1’s house	91
Figure 6.1	An explanation of the process of <i>never-ending caring</i> for a child with cerebral palsy	102
Figure 6.2	The drawing of friends by ID14	119
Figure 6.3	Theoretical field note of the advantage of having friends	119
Figure 6.4	The record of a child with cerebral palsy	127
Figure 6.5	The equipment for training to walk from ID5’s family	129
Figure 6.6	Tools designed for training ID14 to walk	130
Figure 6.7	Tools designed for training ID14 to walk	131
Figure 6.8	The bamboo railings for walking training	132
Figure 6.9	The handwriting of ID14	135
Figure 6.10	The drawing of ID8	136
Figure 7.1	The front page of the guideline document for taking care of ID6, written by the mother	150
Figure 7.2	A part of the document about “Brushing teeth” in the guidelines for taking care of ID6, written by the mother	151
Figure 7.3	A part of the document about “Things ID6 likes” from the guidelines for taking care of ID6, written by the mother	152
Figure 8.1	Using the Six C’s coding family of Glaser (1978)	

	to explain the basic social psychological process of <i>never-ending caring</i> for a child with cerebral palsy	166
Figure 8.2	The metaphor of a waterwheel	172

List of Tables

Tables

Table 2.1	Causes of Cerebral Palsy	17
Table 2.2	Classification of Cerebral Palsy	19
Table 2.3	Treatments for Cerebral Palsy	20
Table 3.1	Excerpt from Data	48
Table 3.2	Generating Codes	49
Table 3.3	The experience of <i>never-ending caring</i> for a child with CP	53
Table 4.1	Enduring Despair , the First Core Category of <i>Never-Ending Caring</i> for a Child with CP	61
Table 5.1	Culture of Obligation and Responsibility , the Second Core Category of <i>Never-Ending Caring</i> of a Child with CP	80
Table 6.1	Living with the Second Core Category of <i>Never-Ending Caring</i> for a Child with Cerebral Palsy (Part 1: Learning to Live with the Situation)	103
Table 7.1	Living with the Second Core Category of <i>Never-Ending Caring</i> for a Child with Cerebral Palsy (Part 2: Preparing for an Uncertain Future)	144

Preface

The research topic for this thesis was born from my experience as a Neonatal Intensive Care Unit nurse. As a NICU nurse, I played an important role in taking care of newborn babies who needed special care of respiratory, fluid and electrolyte management, glucose management, infection control and temperature control. Besides the clinical care of babies, I also supported their families, including parents and grandparents, both at an emotional level and in the provision of information. I explained to the family the baby's clinical condition and what treatment he/she was receiving as they, on behalf of the baby, had the right to know the information. Eventually, the happy time would come when babies were discharged to go home with their parents. All health professionals were proud of their contribution to caring for the babies. It is a wonderful moment in time to see babies go home with their families after they had spent lengthy periods in hospital since they were born. I hold vivid memories about these special moments, when parents and grandparents had big smiles on their faces.

I tried to meet the goals of neonatal intensive care – firstly to try to save all babies' lives as well as to prevent as far as possible, any complications which might occur to them during their treatment. The lives of some babies, who had severe health conditions such as hypoxia, respiratory distress syndrome, prematurity, very low birth weight, hypoglycaemia, and congenital abnormalities such as hydrocephalus, meningitis, spina bifida, were able to be saved. However, they sometimes had unavoidable complications such as Retinopathy of prematurity¹ (ROP). I have a clear memory regarding one case of hydrocephalus;

¹ Retinopathy of prematurity (ROP) is oxygen toxicity in the premature baby who has body weight <1 kg and gestational age < 28 wks; this is the most common morbidity in the premature baby (Enzman Hagedorn, Gardner, Dickey, & Abman, 2006).

we were very concerned about the future of the baby. I discussed with my colleagues the quality of life of the baby and his parents. How could he survive without his parents? The discharge time of this case was totally different from the first ones whereby we were concerned about how the family would take care of the baby. I felt quite ambivalent about the outcome of our work as nurses and feelings of sadness remain with me today.

That experience inspired me to research what is going on in the families who have a child with a chronic health condition after the hospital discharge. Prematurity and very low birth weight infants have a high risk for neonatal and infantile mortality and morbidity (Gardner, Johnson, & Lubchenco, 2006), in which cerebral palsy is one of these consequences. This serious complication requires long-term care from many persons who are relevant to the child such as health professionals, non-health professionals and their families. Thus this study focuses on the experience of families with a child with cerebral palsy, in the Thai context.