Never-ending caring:
The experiences of caring for
a child with cerebral palsy

A thesis presented in fulfillment of the requirements for the degree of
Doctor of Philosophy
in
Nursing
at Massey University, Palmerston North, New Zealand.

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2008
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.
Along the journey of this research inquiry, I have learned in each step of the undertaking to explore the direct experiences of families who have a child with cerebral palsy. Without their participation this research could not have been accomplished. First of all, I have to acknowledge all participants, who were willing to participate in this research such as parents, grandparents, siblings, neighbours, the teachers and physiotherapists, who work at special institutes for disabled children, and the children with cerebral palsy. I appreciate that they gave me a wonderful opportunity to listen and learn about their experiences. I always told them that they all were my teachers, who shared actual knowledge which I could never have found from textbooks. I hope that the outcomes of my study will return them more benefits.

I express my gratitude to my supervisors, Professor Julie Boddy and Professor Denise Dignam, for their wisdom and support along the journey of my study. I have learned a great deal from their guidance, which they have dedicated to my thesis. My sincere appreciation goes to my good friend, Lesley Batten, for her expert advice at the time I developed the methodology for my research proposal. She has always been supportive when I faced difficult situations. I appreciate Dr. Charmaine Hamilton for her guidance when I first developed my research question. Very special thanks go to for Dr. Regina Pernice for her suggestions and support. I have gained more determination from my friends, Dr. Martin Woods, Dr. Suzanne Phibbs, Dr. Gretchen A. Good, and I thank them for their encouragement and support.

I have a deep gratitude for my mother, Khun Mae Chak, who has been alongside me on my journey through this study. She has always been supportive and encouraging even though I have been away for a long time. I am very grateful to my father, Khun Poa Klan, who had no chance to see the success of his daughter. I hope that he is watching me with a big smile in heaven. I also have gained
plenty of encouragement from my family. A special and sincere thank you must go to all my respected sisters and brothers, my brother and sister in law, and all my lovely nieces, nephews and their sons.

This thesis could not have been accomplished without this group of wonderful people, who helped me to retain the participants’ words and their perspectives. A special thank you for transcribers: the blind students at the blind school and the students at Khon Kaen University, Thailand. I also appreciate all who helped me with translation groups: Vilai Payne, Norman Mangnall, Karinrat Jury, Permsin, and P’ Lex. The last ones, important persons, a special and sincere thanks must go to John Wyatt and Karen Stanley for their guidance in improving the English grammar and expressions in this dissertation - Thank you very much to you all.

I have also developed deep gratitude for all of my colleagues at the Faculty of Nursing, Mahasarakham University, Mahasarakham, Thailand, for their encouragement and providing me a wonderful opportunity to study for this degree. Many thanks must go to Ladda Sanseha, Narisa Wongpanarak, Urai Jumpavadee, Prompjit Horbbonheurm and all of staff at the Department of Family Nursing for their support and encouragement. Special and sincere thanks to Jirapa Siriwatanametanon, for her encouraging and sharing knowledge of grounded theory during our study. A special thank you to Piyaporn Boonphadh for helping to develop some computer graphics and many thanks go to Somsawanuch Chamusri, Supatra Buatee, Quantar Balthip, Weerawate Utto, Thamarat Phanamornkith, Nong Ple and other Thai students for encouraging and giving me support. My deepest gratitude is extended to mom Gay Eustance, for her love and support – a warm welcome for the first night in New Zealand. Many thanks for my good friends Ubon Cha-On and Kasinee Boonyawatanangkul, who have always been encouraging me throughout this journey.

Finally, I need to acknowledge the Royal Thai Government for the Royal Thai Scholarship, which assisted in the completion of this thesis. Thank you.
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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 prematurity (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.