CARERS’ EXPERIENCES AND COPING STRATEGIES WITH
DOWN SYNDROME CHILDREN

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This project is submitted in partial fulfilment of
the requirement for the degree of
Bachelor of Nursing with Honours

Faculty of Medicine and Health Sciences

UNIVERSITI MALAYSIA SARAWAK

2010
ABSTRACT

This paper explores carers’ experiences and their coping strategies employed in raising Down syndrome children so as to provide insight into the wellness of carers and families with Down syndrome children. A qualitative approach using semi-structured interviews was adopted and ten carers participated in this study. The term ‘carer’ was used as there is one adopted parent whereas the others were the biological parents. Kübler-Ross’ (1969) five stages of grief was used to describe carers’ responses with Down syndrome children at the initial and later stages. Different experiences were encountered by carers in the process of raising Down syndrome children according to the child’s age. Thus coping strategies varied accordingly. Six themes were formulated on coping strategies: support, seeking alternative remedies and alternative resources, teamwork in the family, closer monitoring, providing a stable, normal environment and increase demand on time, and self reliance. The findings provide implications to carers, health care professionals, and community.

Keywords: Down syndrome children, carers, experiences, coping strategies
ACKNOWLEDGEMENT

First and foremost I would like to thank Allah s.w.t for giving me such a wonderful family, supervisor, and friends. Without their support, I might not be able to go through this challenging process and to complete this final year project.

I would like to thank my dear family members who supported me all the way through these four years. Special thanks to my aunt, Chen Anderson and my mother, Nadiah Lee Abdullah for their continuous support, guidance and understanding throughout this final year project. I also wish to thank my uncle, Jason Lee, my two lovely sisters, Aisya and Yasmin for being there.

Much appreciation and thank you to my course coordinator, who is also my supervisor, Dr. Zabidah Putit, for her constant advice, guidance and support which led to the successful completion of this final year project.
A special acknowledgement to the Dean of the Faculty of Medicine and Health Sciences, Universiti Malaysia Sarawak, Tan Sri Datu Professor Dr. Mohamad Taha Arif, for approving the ethical clearance in conducting this research.

Sincere thanks to Kiwanis Down Syndrome Foundation Johor Bahru Centre, Pertubuhan Bagi Ibubapa Kanak-Kanak Cacat Sarawak (Pibakat) and Sekolah Kanak-Kanak Istimewa Johor Bahru for allowing me to conduct my research there.

Not forgetting the carers who willingly participated in this study and for their time and energy.

I would also like to take this opportunity to thank all who have contributed in making this study a success; all the lecturers and clinical teachers. To my friends, Tan Wen Han and Cicely Khoo Yen Wee, who have been my loyal companions while going through all the ups and downs in my life as a student at UNIMAS. Thank you.
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INTRODUCTION

This study describes carers' experiences in raising Down syndrome children. Coping strategies carers employed with Down syndrome children in this study were explored and identified. This study also identified nurses' roles and responsibilities in caring for carers with Down syndrome children.

The Momentum to this Study

After reading a few theses, I acknowledged Zabidah's (2001) style of writing in how she came out with her research and adapting it into my research writing. The momentum to this study derived from a friend of mine who has a Down syndrome child. Mandy always shared with me how stressed she was in dealing with this special child. She cried every time she shares with me her experiences in raising this child. This was her second child and she first knew of the diagnosis only after the birth of the child. She faces many ongoing challenges with regards to raising this child. The child not only has physical defects, but also developmental disabilities. Therefore, much time, energy and money was spent on this child. Since this child was born she seldom leaves her home as she claims to be stressed and her marriage has broken down since this child was born. She complains that she does not get
proper support from her family and health care providers. Consequently, these contributed to her negative response in caring for her special child.

The Drive to Research

Many issues were raised in my mind during this period and I struggled within myself every time my friend shared with me her personal experiences in raising Down syndrome child. Was her motive in sharing with me the issues because “she wants me to be just a good listener or beyond that?” Or is it because “she thinks I am a student nurse and thus expect me to give some professional guidance?”

The nurse’s main role is well known since Nightingale’s era and that is to care for the needy. However, my responses seemed inadequate in helping her out. Therefore, several questions developed in my mind on how other carers with Down syndrome children cope with the ongoing tough challenges? Moreover, “how can nurses help in helping carers with the process of raising Down syndrome children?” Hence, the idea of embarking into this qualitative study of carers’ coping strategies of children with Down syndrome was established in the hope that the findings will help these carers. Furthermore, the findings can be published and disseminated through seminars or campaigns to help more carers with Down syndrome children and inform health professionals.
**Background of the Study**

Down syndrome is common in Malaysia. According to the statistics on the website for Kiwanis Down Syndrome Foundation in Malaysia (2005) the incidence of Down syndrome in this country is one in 660 live births. As modernisation approaches more women are deciding to have children at a later age (Sunil, 2009). Many studies report that the chances of birthing Down syndrome children increase with the maternal age of 35 years and above (Jersey, 2009; emedicinehealth, 2009; Newton, 2004). However, 80% of Down syndrome pregnancies in this country are born to younger mothers whose age is less than 35 years (Zulkiple, 2008; Kiwanis Down Syndrome Foundation, 2005). Younger mothers are viewed as inexperienced comparatively to older mothers. They often do not know the proper way to raise a child let alone a child with special needs. Thus, studies on Down syndrome children should be widely publicised.

**Problem Statements**

Indeed, there were quite few studies conducted on parents’ and families’ experiences carried out particularly in developed countries such as Australia, United Kingdom and Denmark (Van Riper, 2007; Graungaard & Skov, 2006; Sullivan, 2001). However, few studies have been conducted on coping strategies with Down syndrome children. A wide literature search was conducted and confirmed that there were few researches focusing on carers’ coping strategies, conducted especially in
Malaysia. Perhaps such studies have been done but not published in Malaysia yet. Nevertheless, research regarding coping strategies with Down syndrome children in Malaysia should be highlighted. Coping strategies are crucial in order to enable carers and families with Down syndrome children gain a quality of life in the process of raising this kind of child. In addition, even though Down syndrome is common there are still many negative outcomes. Thus, several questions have been formulated in this study based on this topic as Malaysia is a developing, multiracial and multi-religion country. What contributes to the different responses and coping strategies, carers of children with Down syndrome in Malaysia experience and employ? Besides, most of the services in Malaysia mainly focus on the child; conversely, they have neglected the carers’ needs (Pibakat¹, 2009). Thus, in relation to the above problem statements I would like to embark into this research with the title of “Carers’ coping strategies with Down syndrome children.”

¹Personal communication with personnel in Pibakat, on 18/8/2009 at Pertubuhan Bagi Ibubapa Kanak-Kanak Cacat Sarawak
Research Question

1. What are the experiences faced by carers in raising Down syndrome children?

2. How do carers cope while raising Down syndrome children?

3. What are the types of coping strategies carers use in raising Down syndrome children?

Research Objectives

1. Explore carers’ experiences with Down syndrome children.

2. Explore how carers’ cope with Down syndrome children.

3. Identify the types of coping strategies carers used.

Purpose of the Study

This research is conducted in order to gain in-depth insight of the experiences and coping strategies carers employ with Down syndrome children. The purpose is to provide information to the health care providers and to highlight the importance of caring for carers.
Significance of the Study

This study identify nurse’s role in caring for carers with Down syndrome children. It will aid professionals to gain a better understanding of the responses and emotions at what can be a very stressful time.

This study also can increase awareness amongst carers with Down syndrome children in facing possible challenges by promoting better understanding and some coping strategies which can help improve the quality of life in families with Down syndrome children.

This study also helps to increase community awareness and provides a better understanding in response with Down syndrome children.

In summary, this study can help families with Down syndrome children cope more effectively by having a better understanding and employ better coping strategies.

Operational Definitions

Down syndrome

Down syndrome is also known as trisomy 21 and is due to extra genetic materials that causes development disability both mentally and physically (Newton, 2004). Besides having unique facial presentations, Down syndrome individuals may or may not have
health problems. Also, they have weaker immune systems that make them susceptible to multiple health problems.

**Carer**

Carer is the caregiver who looks after the Down syndrome child at home, provides major support and cares for the child. Besides spending much time with the child, the carer is a person who knows the child’s daily conditions, is closest to the child and is the main advocator. The carer is not necessarily the biological parent.

**Coping strategies**

Coping strategies are specific efforts and actions, both behavioural and psychological, that carer employs to deal with stressful events in raising Down syndrome children (Lazarus & Folkman, 1984).

**Down syndrome children**

Down syndrome children are children from the age of five to eleven who suffer unique facial presentations, health problems and development disabilities. These presentations, health problems and development disabilities were similar to those Newton (2004) described. Also referred to as “special child/ren” in this study.
LITERATURE REVIEW

Introduction

Down syndrome children commonly suffer from unique facial presentations, developmental disabilities and multiple health problems (Zulkiple, 2008; Newton, 2004). Historically, many studies were conducted on parents’ responses and experience in raising Down syndrome children. Many negative outcomes were documented. Parents of Down syndrome children were found to have a higher level of stress compared to those of typically developing children (Shelley, Veek, Kraaij & Garnefski, 2009; Van Riper, 2007; Graungaard & Skov, 2006; Riordon, 2005; Jones & Passey, 2004; Lam & Mackenzie, 2002). They express difficulty in raising Down syndrome children compared to their other typically developing children (Hemmati, Amiri, Dadkhah, 2008; Wong, Wong, Martinson, Chen, He, 2004; Lam & Mackenzie, 2002). Therefore, coping strategies are crucial for carers to cope with the daily challenges faced in the process of raising Down syndrome children. Positive and effective coping strategies are the essence in order to gain a quality of life in the process of raising this special child. From this literature review, two qualitative studies specifically by Lam & Mackenzie (2002) and Graungaard & Skov (2006)
were used whereas the majority of the studies used the quantitative approach and some were published books and published articles from the website.

The literature review will be described in two parts: carers’ experiences and carers’ coping strategies

**Carers’ Experiences**

Most parents experience overwhelming shock, doubt and denial when they first know that their child has Down syndrome (Jilg, 2008; Graungaard & Skov, 2006; Maxwell & Barr, 2005; Newton, 2004; Lam & Mackenzie, 2002). Due to somewhat entrenched social stigma parents with Down syndrome often feel shame in breaking the news to their family members, friends and neighbours (Jones & Passey, 2004). Likewise, carers with Down syndrome children tend to keep their feelings to themselves due to stereotype and social stigma from those around them. This finding is similar to Shelley et al. (2009), Wong et al. (2004), Lam & Mackenzie (2002) and Sullivan (2002). Parents experience stress, lack of understanding by others, and negative social attitudes (Jones & Passey, 2004). Besides that, parents claim that the manner in which professionals break the news of their newborn is unpleasant and traumatic (Hemmati et al., 2008; Newton, 2004; Jones & Passey, 2004). Due to multiple health problems and developmental disabilities, most parents feel stressed and helpless as they were not given proper guidance and support from the health care
professionals and their significant other/s (Newton, 2004; Jones & Passey, 2004). In summary carers’ experiences from previous studies include signs of denial, stress and feeling ignored.

Signs of denial were shown by carers from previous studies such as self-blame for having this special child or blaming others, retaining hope and creating future images (Shelley et al., 2009; Graungaard & Skov, 2006; Lam & Mackenzie, 2002) whereas some blame others for having this child (Shelley et al., 2009). In Lam’s and Mackenzie’s study the parents believed that the birth of a disabled child was a sign of heaven’s punishment due to their ancestor’s wrongdoings and therefore they have to bear the consequences of such misconduct (2002). The hidden reason for them to respond in such a way is because of the unexpected, shock and knowledge deficit (Hemmati et al., 2008; Graungaard & Skov, 2006; Jones & Paasey, 2004; Newton, 2004; Wong et al., 2004; Lam & Mackenzie, 2002;). Furthermore, some carers feel shame for having this kind of child and they view it as a great challenge when dealing with family, friends, neighbours, and public (Jones & Passey, 2004; Wong et al., 2004; Lam & Mackenzie, 2002).

Stress was the commonest emotion found in carers with Down syndrome children. Causative factors include increased workload, time usage within and outside of home,
increased financial strain, arguments between husband and wife, and between parents and children, having to deal with friends and neighbours and health care professionals were significant findings in most of the studies (Shelley et al, 2009; Van Riper, 2007; Cunningham, 2006; Riordan, 2005; Jones & Passey, 2004; Newton, 2004; Lam & Mackenzie, 2002).

Feeling ignored was to be most significant in carers from previous studies. Most carers complain that they were not being listened to and not being understood by the health care professionals (Graungaard & Skov., 2006; Wong et al., 2004; Jones & Passey, 2004; Newton, 2004; Lam & Mackenzie, 2002; Scorgie, Wilgosh, Sobsey & McDonald, 2001).

**Carers’ Coping Strategies**

In view of the above issues, coping strategies are crucial for carers to confront the daily challenges in raising Down syndrome children. Coping strategies are specific efforts, actions, both behavioural and psychological, that people employ to deal with stressful events. Lazarus and Folkman (1984) categorised coping strategies into two major groups: emotion-focused and problem-focused. Emotion-focused are responses such as crying, ignoring and avoidance; whereas problem-focused response is the acceptance approaches such as searching information and learning new skills.
Previous studies mention that psychological support from the spouse, family members and friends are crucial elements in dealing with stress related to raising Down syndrome children (Van Riper, 2007; Scorgie et al., 2001). Similarly, spiritual support such as inner faith and religious belief is also an important fundamental coping strategy (Van Riper, 2007; Scorgie et al., 2001). Furthermore, self reliance, utilizing resources such as collaborating with professionals, balancing roles between husband and wife are also important coping strategies mentioned (Lam & Mackenzie, 2002; Scorgie et al, 2001). Carers’ coping strategies employed from previous studies were carer’s own health, emotional and practical support, seeking social support, faith, collaboration with health care professionals, carers’ attitude, teamwork between husband and wife, self reliance and seeking alternative resources and remedies.

Carers’ own health is vital in raising Down syndrome children. Due to child’s multiple care demands such as health problems and developmental disabilities, the parent’s physical and mental health are important aspects to be considered in order to cope with Down syndrome children effectively (Jilg, 2008; Van Riper, 2007; Cunningham, 2006; Lam & Mackenzie, 2002; Scorgie et al., 2001).

Emotional and practical support is vital in assisting carers cope with Down syndrome children (Van Riper, 2007; Graungaard & Skov, 2006; Greer, Grey & McClean,
2006; Newton, 2004; Jones & Passey, 2004; Lam & Mackenzie, 2002; Sullivan, 2002; Scorgie et al., 2001). Support ranges from emotional support to practical support from the family, the partner, themselves, their parents and other carers with the same kind of children and close friends were reported as an important coping strategy. Sharing with close friends, talking to other parents who have children with similar conditions, families and neighbours participation in taking care of Down syndrome children were some of the examples of emotional and practical support. Additionally, financial affordability is crucial in order to cope with Down syndrome children effectively (Van Riper, 2007; Cunningham, 2006).

Seeking social support is found to be an effective coping strategy (Shelley et al., 2009; Graunagard & Skov, 2006; Greer et al., 2006; Jones & Passey, 2004; Jilg, 2008; Newton, 2004; Lam & Mackenzie, 2002; Sullivan, 2002; Scorgie et al, 2001). Examples are learning about special education services and the rights in this area by enrolling the child to participate in early intervention programs and being involved actively with the child's activities and learning new skills acquired to raise this special child. Additionally, being involved in social networks like parent support groups and going on outings were helpful coping strategies.
Faith such as inner faith and religious belief plays a crucial role in affecting carers’ coping with Down syndrome children (Van Riper, 2007; Lam & Mackenzie, 2002; Sullivan, 2002; Scorgie et al., 2001). Having faith in God, turning to religion, religious conviction, and appealing to supernatural power are examples of religion belief (Van Riper, 2007; Lam et al., 2002; Sullivan, 2002; Scorgie et al., 2001). Furthermore, belief in one’s own inner strength and having faith in the child’s strength is an exemplar of inner faith in spiritual support (Van Riper, 2007; Scorgie et al., 2001). Collaborating with health care professionals are also important in order to gain better understanding and coping (Graungaard & Skov, 2006; Jones & Passey, 2004; Lam & Mackenzie, 2002; Scorgie et al., 2001). Furthermore, finding a good health care professional is an effective coping strategy in order to provide optimal care to the child (Jilg, 2008; Graungaard & Skov, 2006; Newton, 2004; Lam & Mackenzie, 2002; Scorgie et al., 2001).

Attitudes such as patience, initiative, determination, optimism, valuing the child’s contributions are important requirements of carers in raising this kind of child (Jilg, 2008; Van Riper, 2007; Cunningham, 2006; Newton, 2004; Wong et al., 2004; Scorgie et al., 2001). Besides that, being assertive and advocating self confidently on
behalf of their children were useful coping strategies (Van Riper, 2007; Cunningham, 2006; Scorgie et al., 2001).

Teamwork between husband and wife was another coping strategy (Van Riper, 2007; Jones et al., 2004; Newton, 2004; Cunningham, 2006; Lam & Mackenzie, 2002; Scorgie et al., 2001). Marital relationship plays a very important role in influencing the coping abilities required in raising Down syndrome children (Lam & Mackenzie, 2002; Scorgie et al., 2001). Carers reported spending time together, learning to communicate openly, and creating mutual ownership of family problems and solutions as keys to safeguarding their marriage (Cunningham, 2006; Scorgie et al., 2001). Dividing roles and responsibilities also gives each child quality time, and telling other siblings regarding their Down syndrome sibling was the key to family cohesion and harmony (Van Riper, 2007; Jones & Passey, 2004; Newton, 2004; Scorgie et al., 2001).

Self reliance was mentioned as an effective coping strategy when the spouse or family member is not supportive (Lam & Mackenzie, 2002) and there is improper guidance from health care professionals (Graungaard & Skov, 2006; Jones & Passey, 2004). A study even discovered a mother who had to withhold information from her