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FINDING PEACE IN LIFE'S UNEXPECTED JOURNEY: THE PROCESS OF GRIEVING AND IDENTITY TRANSFORMATION FOR MOTHERS OF CHILDREN WITH DOWN SYNDROME

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FINDING PEACE IN LIFE'S UNEXPECTED JOURNEY: THE PROCESS OF GRIEVING AND IDENTITY TRANSFORMATION FOR MOTHERS OF CHILDREN WITH DOWN SYNDROME

A DISSERTATION APPROVED FOR THE
DEPARTMENT OF COMMUNICATION

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Dedication

To Jiarui Daniel Yin, my beloved younger son, my life transformer, my treasure I have found in my journey of searching the deep meaning and understanding of the motherhood.

To Jiaxiang Samuel Yin, Daniel's big and dearly loved brother, my oldest son, my first born, and my first admirer who renders his total trust in making me his mother and accepts me as who I am regardless of what I have done.

I feel honored and proud to be the mother of my two precious sons. They have taught me valuable lessons of life; provoked me to be truthful to myself; and inspired me of never giving up and giving in under any life circumstances. Their unconditional love nourishes my body and strengthens my soul to live a meaningful life every day.

I love you all forever!

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As a mother of a child with Down syndrome, I have experienced the devastation and traumatic loss of my dreamed baby. Along with the identity loss of being a typical mother, I have also lost all my dreams, hopes, and become disconnected with my life. As a matter of fact, while I was expecting my new born, I was simultaneously expecting me receiving my intellectual baby, the dissertation to complete my doctoral degree and reach the highest achievement in my academic endeavor. Nevertheless to say, metaphorically both my expected babies died right after I was informed of my child's diagnosis of Down syndrome and the series of medical complications. This sudden, harsh reality together with the fluctuations of emotions almost suffocated me to permanently bury my dream of completing my dissertation.

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continuous support, their intellectual inspirations, their heart-felt encouragement and trust in me over my life course of coping and managing all challenges encountered. Without all their support, I will not be here sharing my research and life story in my dissertation.

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Abstract

This qualitative study concerns the process of grieving and identity transformation for mothers of children with Down syndrome. The study aimed to understand the identity loss of mothers of child with disability through their grieving process, and explored how mothers of children with Down syndrome reconstruct their identity during the experience of raising a child with Down syndrome. In addition, the study identified the key events that contributed to the identity reconstruction. In this study, data were collected from 20 mothers of children with Down syndrome in the west of Michigan area. Semi-structured individual in-depth interviews were conducted, recorded, transcribed, coded and analyzed for the report. The grounded theory was adopted to explore and analyze the notions of self, identity, and the experiences of raising a child with Down syndrome through narratives offered by the mothers in the study. The findings of the study lent support to what has been discovered in the previous research regarding the stress, the struggle, and the frustration experienced by parents of children with disabilities. However, the stories of the mothers revealed that during the grieving process, they were not only grieving over the psychological loss of their expected children, but also grieving over a collection of secondary psychological loss, which fundamentally defines who they are as a mother, a wife, a caregiver, a daughter, a sister, a friend, and a coworker. Furthermore, the narratives pertain to the transitional identities the mothers identified undoubtedly inform the nature of the self. The set of transitional identities of a personal health care provider, a resilient fighter, and a knowledgeable educator are derived from the deep sense-making of their engaged daily activities and interactions of taking care of their children's needs. Finally, the narratives of finding peace in their lives and reconstruct the new identity of the mothers they wanted to be

emphasize on their own interpretation and understanding of what the motherhood really constitutes.

Key words: Down syndrome, psychological loss, identity loss, and motherhood

Chapter 1: **Finding a Self in a Life's Unexpected Journey**

A. Introduction

On January 10th, 2011, my second son, Daniel, was born and on that day the person who I was, died. When the team of doctors and nurses walked in and out of my hospital room checking on Daniel on that day, a sudden chill and fear ran all over me. First, we were given the devastating news that he had Atrioventricular Septal Defect (AVSD), a heart defect that requires an open heart surgery. I didn't even have enough time to breathe over the diagnosis, and then the doctors delivered a crushing blow of another diagnosis, Down syndrome. My world and my life completely collapsed right there at that moment. My second son, for whom we just celebrated his birth, was labeled "a severely sick" and "a disabled child born with Down syndrome"! As a mother, there were no words to describe my feelings.

The rest of the conversation in my room was a blur; I only remember bits and pieces. I didn't like the parts I heard. I remembered clearly asking everyone to leave my room and leave me alone. They left with our newborn son for further blood work and tests. I sat in my bed motionlessly as if I was dead. Not a single tear shed, not a cry heard, and not a word said. I was in a complete state of shock. My husband tried to comfort me by saying that the doctors must have made a mistake. MISTAKES? I was just told that the baby who was going to make me laugh, who would love his big brother, who would give us so much joy, and who would just complete the family never existed. I still loved my baby boy. But what about all those dreams and hopes I had allowed myself to dream for him and his big brother were now gone. My baby boy, Daniel, might not be able to go to school with his big brother, he might not be able to

learn to drive, he might not be able to play tennis as his brother does, he might not be able to hold a job, and he might not be able to get married or go to college. All those dreams died instantly with me. What about our family? What about me, a mother who just wanted to be a typical and normal mother like all other mothers in the world? Daniel was not the child I had expected. I felt like I had received a gift that I didn't ask for. This gift rocked my world upside down. I also realized that our baby boy faced the instant stigmatization as a Down syndrome child; in addition, we, along with Sammy, our older son, were instantly turned into a "special needs family." How we were going to deal and live with that?

Daniel stayed in neonatal intensive-care unit (NICU) for almost two months before we could take him home. I have never cried so much in my entire life as I did during those two months. Of course I was devastated, feeling going insane from grief and helplessness when I started processing the unrelenting and continuing diagnoses that marked Daniel's life trajectory. During all those days, I lived in worry, fear, guilt, and shame. But the worst part came after Daniel was discharged from the hospital. Now I was on my own to take care of him. The mixed feelings of happiness and nervousness was exhausting and overwhelming. Would I be competent to monitor his heart to make sure he was breathing fine? Can I be trusted to insert feeding tubes to ensure he gets the nutrition he needed to grow? Suddenly the confident, competent, and experienced mother in me disappeared. I became this helpless, pitiful, and incompetent woman. A woman I did not recognize nor do I know was in me all along.

The life of coming back home with Daniel was very chaotic. I was a huge mess. I knew: From that point on, I would no longer be able to sleep in, have time for myself,

or to take my older son out for any activities. Before Daniel turned to one year old, I made numerous visits to hospitals and heard doctors telling me things that I didn't want to hear. I cried on my way there and on my way home. I cried before I go there and after I get home. I muttered every single curse I know. As a mother, I was supposed to protect this child and fix all his problems. Instead, I felt broken and completely powerless.

It was a nightmare. I did not know how I went through those events through day after day, handling all the demands to care for Daniel. Some days, I face my day with a kind of numbness, trying to absorb it all. Other times, I felt a great deal of anger and sadness. There were also times I wish I could have vanished from the world and just to steal some time to breathe. I was a depressed mess, seeing nothing meaningful and life valueless. I was miserable, living in a deep, dark, and ugly hole to let myself slowly die inside. Over years, I devoted all my heart and soul to care for Daniel. I neglected my profession, my husband, and my older son Sammy, who all needed me just as much.

Since then, four years have passed. My journey with my son Daniel is still on-going. I have to admit that it hasn't been easy for us. At different stages, I ran into different challenges. Reflecting upon my mothering experience, I am proud to say that Daniel has taught me countless truths about myself and about life. Many of the truths about myself I would have preferred not to know. I have come to realize how utterly selfish and naive I was. Daniel's disability has shown me that the small irritations of life are nothing to worry about anymore. Life is much bigger than I had thought before. Daniel has taught me the things I had strived for in life and considered important are not what I thought to be. Not that my values and appreciation of life are unimportant, but

rather, my life's journey has been rattled, shifted, and modified permanently. I also realize that while my dreams become less lofty; my life goals are simpler and more grounded. Daniel has taught me how to love him and learn to love anyone in my life in any condition. But all these truths, all these understandings and knowledge have not come without an abundance of tears or endless struggles and frustrations.

The person who I was died on the day Daniel was born.

I didn't become a mother on that day to Daniel, but I really became a mother when I managed to survive in caring and raising a son with Down syndrome. Drawing from my personal experiences and accounts, I am motivated to understand how the mothers of children with Down syndrome transformed their life walking the journey with their children and reconstruct their identities.

As Giddens (1991, p. 53) puts it: "Self-identity is not a distinctive trait, or even a collection of traits, possessed by the individual. It is the self as reflexively understood by the person in terms of his or her biography". Following the traditions of symbolic interactions, Charmaz (1987) and Yoshida (1993) defined the self and identity in a similar manner: a reflexive, emergent structure which is shaped by social and personal identities. In the past four years, I have been searching the answers to my question of who I am? Coping with my son's physical health and his disability has not been an easy journey for me. During the process, I have been constantly experiencing the struggles of how I should present myself or construct my self-images under different circumstances and respond to the changes at different stages of my son's and my life. There have also been so many times that I have to share my experience of having a child with Down syndrome and its impact on my life and my whole family. I remembered every stories I

shared about my son, how his disability and our life have changed dramatically from the day he was born. However, regardless of the versions of stories I shared with my extended family relatives, colleagues, friends, my students or strangers, the plot line always stays the same: Who am I? Or how I would like them to view me?

Enlightened by the readings by Charmaz (1995) and many other scholars (A. Frank, 2000; Goffman, 1959; Hsieh, 2004; Wiener & Dodd, 1993), I have gradually reconciled myself with who I am through the lens of interactive and social interactions. And I think what Taylor (1989, p. 35) has shared helps me to understand self in a more organized way:

And this question finds its original sense in the interchanging of speakers. I define who I am by defining where I speak from, in the family tree, in social space, in the geography of social status and functions, in my intimate relations to the ones I love, and also crucially in the space of moral and spiritual orientation within which my most important defining relations are lived out.

B. Objectives of the study

The objectives of this study are to: (1) understand the identity loss of mother of child with disability through their grieving process, (2) explore how mothers of child with Down syndrome reconstruct their identity during the experience of raising a child with Down syndrome informed by the interactionist approach that links narratives and identity construction. I adopted grounded theory to explore the notions of self, identity, and the experiences of raising a child with Down syndrome. The focus was on their narratives and social interactions (solicited through individual in-depth interviews with

mothers of child with Down syndrome), exploring how they construct their identities as mothers of child with Down syndrome.

Scheper-Hughes (1992, p. 28) once passionately stated:

> We cannot rid ourselves of the cultural self we bring with us into the field any more than we can disown the eyes, ears, and skin through which we take in our intuitive perceptions about the new and strange world we have entered. ...we struggle to do the best we can with the limited resources we have at hand – our ability to listen and observe carefully, empathetically, and compassionately.

The validity of my findings hinges on my ability to understand and relate. I do not aim to be a "neutral, objective" investigator, providing insights into detached scholarly interests. As a fellow mother of a child with Down syndrome, I share the same journey with my participants and relate to all their tears, struggles, curses, and happiness. Our common experiences are fundamental to the credibility and reliability of the study.

My aims are both theoretical, applied, *and* personal. I want to not only identify the common themes and processes, but also help others who share the same life's unexpected journey to face the rocky but also rewarding road ahead. I view this as my life's mission.

Chapter 2: **Literature Review**

A. Families of Children with Developmental Disabilities

Having a child with a disability or disabilities has personal, family, and social implications (Emerson, 2003a; Floyd & Gallagher, 1997; Heiman, 2002). Scholars across various disciplines have recognized the potential impact of childhood disability on family life and have contributed a considerable amount of research on families of children with different developmental disabilities. This line of research examines how parents, siblings, other family members and the families as a whole manage their day-to-day life in responding and coping with their children' disability.

During the mid-20th century, the bulk of literature regarding families of children with developmental disabilities pointed to predominantly negative outcomes. Disruptions to the "normal family life-cycle" have been the first noted impact of raising a child with a developmental disability could have on a family (Farber, 1960). Following these findings, various studies have documented that families of children with developmental disabilities often experience more interpersonal stress, social isolation, marital conflicts, tension among siblings, caring burden (Hayes & Watson, 2013; Sarafino, 2011; Woodman, 2014). Both parents and children from families with children with developmental disability are also at risk for poorer physical and mental health (Emerson, 2003a, 2003b; R. P. Hastings, 2003; Raina et al., 2005). In addition, the experience of chronic sorrow (Damrosch & Perry, 1989; Mallow & Bechtel, 1999; K. Whittingham, Wee, Sanders, & Boyd, 2013) decreased self-esteem (Ali, Hassiotis, Strydom, & King, 2012; Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986) and increased level of psychological distress (Bristol, Gallagher, & Schopler, 1988; Estes et

al., 2013). Parents of children with developmental disabilities are often conceptualized as being in a persistent state of "mourning" (Lalvani, 2008; McGuire, 2010). Parents are generally depicted as less optimistic and self-efficacious (Cheng & Tang, 1995) and more negative and self-blaming (Damrosch & Perry, 1989). As a result, professionals have long assumed that families of children with disabilities are engaged in never-ending struggles to alleviate the problems associated with having a child with a disability (Wickham-Searl, 1992).

The literature advanced our understanding on some aspects of rearing a child with a developmental disability. However, prior to 2000s, an underlying presumption in this line of research was that "a family with a child who has a disability is a family with a disability" (Glidden, 1993, p. 438). These studies aimed to demonstrate that families of children with disabilities engage in negative behaviors and experience a quality of life that is less than satisfying. Do most families with children who have developmental disabilities face the inevitability of a "lesser" future than families without children with disabilities? The answer is a complicated one. While the experiences of dysfunction and maladjustment among families of children with developmental disabilities are prevalent, these studies failed to recognize the resilience and optimism that are inherent in human nature. Roll-Pettersson (2001, p. 1) find that for the majority of parents, there was "…insufficient evidence to support professionals continuing to adhere to the adaptation-mourning model [of adjustment], together with its associated pathological-dysfunctional paradigm."

The emerging view based on the recent literature suggests that parenting a child with disability do not necessarily lead to negative consequences for the families

(Richard P. Hastings & Taunt, 2002; Kearney & Griffin, 2001; Myers, Mackintosh, & Goin-Kochel, 2009; Trute, Hiebert-Murphy, & Levine, 2007). Emerson (2003a, 2003b)cautioned against associating raising a child with developmental disability with negative outlook, such as increased parental stress, marital conflicts, or negative family outcome. For example, research findings suggested that couples who had children with developmental disabilities more often than not had strong, mutually rewarding marriages, developed innovative ways to cope with higher caregiving demands, rated as cohesive and harmonious families with higher morale (Abery, 2006). When comparing families with children with Down syndrome with families of non-disabled children, Van Riper, Ryff, and Pridham (1992) found no differences in individual, marital, or family functioning between these groups of parents. In many studies, families of children with Down syndrome were characterized by resilience and adaptive functioning (King, Scollon, Ramsey, & Williams, 2000; Poehlmann, Clements, Abbeduto, & Farsad, 2005; Van Riper, 2007; Van Riper et al., 1992).

Moreover, there has been an increasing recognition in recent years that parents of children with disabilities report positive perceptions regarding their parenting experience in addition to negative ones (Kearney & Griffin, 2001; Myers et al., 2009; Trute et al., 2007). This should not be taken to mean that negative perceptions are not a part of these families' experiences. Studies have indicated that parents of children with developmental disabilities may report higher levels of stress when compared with parents of more typically developing children (Blacher & Baker, 2007; Hendriks, De Moor, Oud, & Savelberg, 2000; Little & Clark, 2006). However, a range of studies seem to indicate that although parents of children with developmental disabilities report

increased demands, higher levels of emotional stress, or negative feelings, they simultaneously report positive experiences, spiritual and personal growth, increased familial bonds, and enrichment in their lives as a result of their experiences (J. Gill & Liamputtong, 2009, 2011; Richard P. Hastings & Taunt, 2002; G. Landsman, 2005; Stainton & Besser, 1998).

In addition, as researchers adopt participant-centered qualitative approaches, there is an increasing emphasis on allowing the parents to voice their own interpretations and understanding of their situations (Lam & Mackenzie, 2002; Scorgie, Wilgosh, & Sobsey, 2004). As a result, researchers' understanding and investigation of the families of children with developmental disabilities have become more nuanced, recognizing the complexity of parents' both positive and negative perceptions. The recent literature suggests that after an initial period of shock and uncertainty, most families of children with developmental disabilities learn to effectively manage the demands, disruptions, and stress. They often regain healthy families functioning or even thrive over time (Chen, Jo, & Donnell, 2004; Ferguson, Gartner, & Lipsky, 2000; Lalvani, 2008; Trute, Benzies, & Worthington, 2012; Van Riper, 2007).

Goddard, Lehr, and Lapadat (2007) indicated that the narratives of parents of children with disabilities represent a critical perspective that acknowledges both the difficulties as well as the rewards of this experience, noting that parents of children with disabilities "did not present themselves as suffering from chronic sorrow or inordinate amount of stress" (Goddard et al., 2007, p. 285). Instead, these parents acknowledge that the experience of sadness and stress was a reality in their lives, their narratives focused on the ways in which they made sense of their child's disability and on their

resistance to assumptions about their lives. Despite the considerable and on-going stresses involved in parenting a child with a disability, many parents reported such an experience is positive and transformative (B. Gill, 1997; S. E. Green, 2002, 2007; Scorgie & Sobsey, 2000; Steele, 2000). For example, Green (2002) examined how parenting a daughter with cerebral palsy led to profound personal and life perspective changes for a mother. The mother describes the changes as her daughter "opened up some areas of [her] soul that would otherwise lie dormant" (p. 24). Steele (2000) presented a father of a daughter with progressive physical disability described his personal transformation with a heightened sense of compassion. Similarly, Lalvani (2008) indicates that mothers of children with Down syndrome describe their own lives as encompassing the full range of parenting experiences from feelings of stress, uncertainty, or sadness to feelings of contentment and joy.

Another area of research in this area is the experiences of siblings of children with developmental disabilities. While they may experience some initial adjustment difficulties (Simmerman, 2001), they have formed favorable self-concepts (Skotko & Levine, 2006). They also reported developing additional strengths (Graff et al., 2012; Skotko & Levine, 2006; Van Riper, 2000). Also, the literature suggests that compared to families with all children developing typically, siblings of a child with Down syndrome do not experience major differences in adjustment (Cuskelly & Gunn, 2006; Stores, Stores, Fellows, & Buckley, 1998) and their family relationships are as good as or better (Cuskelly & Gunn, 2003; Hannah & Midlarsky, 2005).

In short, the literature has provided strong evidence that parents do not experience the birth of a child with a developmental disability in a homogeneous

manner (Risdal & Singer, 2004; Weiss, 2002). There is considerable variability in individual responses and coping strategies to the presence of a child with disability as well as a wide range of outcomes for families of children with disabilities.

Despite the shifts in analytical focuses and positive findings regarding families with children with disabilities (Helff & Glidden, 1998), it is important to acknowledge that the birth of a child with a developmental disability, the devastation, the loss, the trajectory demands, and the stress continue to be a part of reality for these families. Previous research has provided us with a good understanding about (1) the substantial (negative and positive) impact a child of developmental disability has on the families and (2) how parents and families describe and understand their experience of raising a child with developmental disability. However, there is limited research examining how parents make sense of their child's disability upon hearing their child's diagnosis, go through the grieving process, and reconstruct their own identities.

This dissertation is inspired by my personal experience of raising a child with Down syndrome with severe health problems. Rather than glossing over the process as a transformative experiences, my goal is to examine this process as a gendered experience as it challenges the core meanings and functions of motherhood (McKeever & Miller, 2004; Pelchat, Lefebvre, & Levert, 2007). By investigating how mothers with Down syndrome children relocate and restructure their identities as women, mothers, and wives within the familial and sociocultural contexts, I hope to identify meaningful and adaptive strategies that can assist others who may share the same journey.

B. Identity Loss during the Grieving Process

The birth of a child with any kinds of developmental disabilities can alter the family structures and family lives in a profound way. Previously taken-for-granted lives are immediately challenged and various serious strains are inevitably placed on the families. Parents always find themselves have to deal with a multitude of emotional upheavals and uncertainties simultaneously. Feelings of despair and helplessness tend to make every day a battle to survive for most families upon hearing the diagnosis of their child. Parents of newborn children with developmental disabilities typically express their first response to the diagnosis as "devastation" and "lost" (Huang, St John, Tsai, & Chen, 2011; Klein & Schive, 2001). For many of these parents, a complicated process similar to bereavement - grieving begins (Emde & Brown, 1978). It is often recognized that families need to grieve for the child they had thought they would have. Trainer (1995) discusses that families of children with Down syndrome may grieve the child that they thought they would have as well as the loss of the family's "normalcy."

In addition, from the perspective of a mother, such a loss may have fundamental impact on her identity as a mother, wife, and caregiver of the family (Gray, 2003; Marvin & Pianta, 1996). Fathers and mothers of children of developmental disability have significantly different caregiving and grieving responses (Bruce, Schultz, & Smyrnios, 1996; Gray, 2003; Pelchat et al., 2007). Between the two parents, mothers are more likely to assume the majority and primary care responsibilities while other family members might become gradually distant from the task (Falloon, Boyd, & McGill, 1984; Roach, Orsmond, & Barratt, 1999). These mothers often experience higher level of emotional distress and higher needs of emotional support even years after the child's diagnosis (Bruce et al., 1996; Pelchat et al., 2007). It is not uncommon

for these mothers to feel a sense of duty that drives them to endure a considerable level of distress, discomfort, frustrations, struggles, or even embarrassment or criticism without much complaint (Bruce et al., 1996; Gray, 2003; Pelchat et al., 2007). Nevertheless, soliciting emotional support can be difficult even among family members. For example, if a person wishes to reduce anxiety through sharing traumatic experiences, telling stories to supportive others who exhibit avoidant behaviors can be stressful (Dyregrov, 2003). The dilemma of managing their own and others' anxiety may make individuals actively discourage others from talking about the traumatic experiences and inhibiting their own conversations, even though they report a continuing desire to discuss their own experiences (Pennebaker & Harber, 1993; Stone & Pennebaker, 2002). Despite the significance of such a powerful event, there has been limited examination from these mothers' experiences of loss and corresponding changes in identities. Psychologist Rando (1984, p. 119) argues, "in the thanatological literature there has been relatively less writing devoted to the topic of parental loss of a child as compared to other losses." I propose that exploring how these mothers process grief is essential to our understanding how a family with children with developmental disabilities can survive and thrive after the shattered dreams of a taken-for-granted future (Gyulay, 1989).

There are two categories of loss (Rando, 1993): Physical and psychological loss. Physical loss is the loss of something tangible, such as a job or a house. It is fairly easy for people to acknowledge this loss and validate that certain feelings and emotions aroused by this loss need to be dealt with. Psychosocial loss or symbolic loss is the loss of something intangible. These losses could include such things as loss of relationship, a

taken-for-granted identity, or a familiar environment, and so on. Unlike physical loss, it can be difficult for others to recognize or relate to psychological loss, even among family members (Bruce et al., 1996; Seligman & Darling, 2009; Widdison & Salisbury, 1989). Parents of children with developmental disabilities experience a psychological loss of their dreamed baby (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Klein & Schive, 2001). Physically, their baby is not lost; he or she is right there with them. Psychologically, the child they were expecting never arrived (Klein & Schive, 2001; Moses, 1988). The diagnosis of their child not only makes the baby look different in their eyes, but also makes the parents feel different about being parents to a child with disabilities (Ali et al., 2012; J. Gill & Liamputtong, 2011; S. E. Green, Davis, Karshmer, Marsh, & Straight, 2005).

In addition, there are also secondary losses that accompany any types of loss discussed above. These secondary losses include such things as feeling, behaviors, and interactional patterns that occurred between the mourners and the loved ones. Having and welcoming a healthy newborn in a family are typically described as an expected, exciting and joyful event. For mothers of children with Down syndrome, the initial feeling they tend to experience after hearing their child's diagnosis could be overwhelmingly sad, shocked, confused and disappointed (Huang et al., 2011; Klein & Schive, 2001). The natural behaviors and interactional patterns (of holding, kissing, celebrating, talking about and nursing their child) are consequently disrupted or modified to accommodate these mixed emotions (e.g., confusion, anger, frustration, and joy) and medical interventions (that address certain medical complications such as heart defect, seizures, or breathing problems).

The loss of hopes, dreams, assumptions, expectations and beliefs that all required the loved one's presence is another type of secondary loss. With no exception, all parents have fantasies and dreams about their child and their child's future. These hopes and dreams begin to mature and intensify throughout their pregnancy. Parents naturally indulge themselves in imagining the kind of person their child will become, the pride and joy they will experience as a parent, and the relationships they will have with him or her. These self-indulgent daydreams are a normal part of parent-child attachment process. However, as parents, we fail to or unwillingly recognize that these hopes and expectations may entail hidden costs: The crushing blow to one's taken-for-granted future when a child is born with a medical condition or disability (Johnson, 2000). Parents of children with Down syndrome have similar dreams and hopes for their newborn as other parents of children with no disability. But they are forced to face a reality in which their original dreams and hopes for their child may be irrelevant and nonexistent. Instead, they have to adjust their expectations and hopes in the face of substantial uncertainties inherent to the diagnosis of Down syndrome.

The third type of secondary loss refers to the loss of a person to fulfill certain roles in the mourner's life. The mourner may lose a husband or a wife in their prior companionship. This usually happens when the husband or wife cannot bear the below of the diagnosis and enormous responsibility of caring for their child. In the same way, the mourners may lose contact with friends or other family members. In addition, mourners often need to take on new responsibilities as well. For example, mothers of children with Down syndrome need to devote the majority of their time and efforts to take care of their child. With the demands of caring for their child, mothers usually

withdraw from their previous career or social activities to attend to their child's needs (Dumas, Wolf, Fisman, & Culligan, 1991; Roach et al., 1999). All of these secondary losses can occur with such speed that the mourner may not realize how completely their life has just changed and with little time to develop effective coping skills (Doka & Aber, 1989). Ultimately, all these secondary losses will need to be mourned just as the initial loss is.

The loss of taken-for-granted identities is fundamental to parents' experiences upon hearing their child's diagnosis of disability (Beresford, Rabiee, & Sloper, 2007). It is important to recognize that identity is not fixed. Rather, identities are multi-dimensional, multi-level social constructs to be negotiated within the parents' social network (Antaki & Widdicombe, 1998b; Hsieh, 2004; Tracy, 2013). For example, many parents of children with disabilities reported that their work, interests, and personal relationships play a key role in their sense of identity and which they wanted to have time or support to allow them to pursue (Beresford et al., 2007). In this sense, it is natural to argue that during the grieving process, one of the complications has been identifying for whom and what the parents are grieving.

I argue that mothers of children with Down syndrome not only grieve the psychological loss of their dreamed child, but also the collection of secondary losses. For example, to mothers, realizing their child with Down syndrome might not be able to obtain higher education, hold a job, drive on their own, and get married someday is considered to be a huge loss and grief. Simultaneously, mothers of children with Down syndrome are more likely to terminate their career prematurely, forgo personal interests and ambitions, and lose certain relationships (e.g., divorced, friends leaving) in order to

meet the complex, multi-dimensional needs of their child. Everything mentioned here constitutes the totality of an individual, a mother in this case. In other words, during the grieving process, mothers are actually grieving the loss of their identity, which defines who they are in society, in their family and to the child with Down syndrome.

While there has been significant research on parental experience of raising a child with a disability that ranges from parental well-being, social support (both perceived and received), marital relationships, impact on siblings, and narratives of their experience, there have been limited studies exploring parents' grieving experience with different types of loss as they reconstruct the meanings of their child's disabilities and their identities.

A number of grief theorists (Bristor, 1984; Kübler-Ross, Kessler, & Shriver, 2005; Prigerson & Maciejewski, 2008; Sagula & Rice, 2004), have organized the process of grief into stages: denial, anger, bargaining, depression, and acceptance. It needs to be noted that mourners do not usually go through those stages in a particular order as a linear movement, but rather a cyclical movement (Blaska, 1998; Gillies & Neimeyer, 2006; Ruscher, 2012). Going through the grieving process is a uniquely different experience that transforms mothers' lives. It is this grieving process that finally brings mothers to come to terms with their child's diagnosis and their life change (the acceptance stage). It is this grieving process that eventually helps mothers to recover from their loss. This recovery is the process of updating, rebuilding, and replacing the hopes and expectations they had for their "anticipated child," and the process of understanding parenthood, reclaim their life normalcy, and redefine who they are in society, in their family, to their child with Down syndrome, and to themselves.

C. Conceptualizing Identities: Differences in theoretical approaches

Joas (2000, p. 2) noted that the self is "one of the greatest discoveries in the history of the social sciences." The concept of "self" has long been a contested and a prolific field of research in multiple disciplines, including psychology and sociology. Over years, scholars have offered a variety of definitions of "self". Some suggests that self is an unformed and unfixed concept (Giddens, 1991); some claims that self is a relatively stable concept (Terracciano, Costa, & McCrae, 2006; Terracciano, McCrae, & Costa Jr, 2010); and others argue that self is more fluid and made of multiple identities (Goffman, 1959; G.H. Mead & Morris, 2009; Stets & Burke, 2005). According to Gecas and Burke (1995), identity refers to the various meanings attached to oneself by self and others, and locates one in social space through the relationship implied by the identity. Currently, two prevalent theories in the literature have offered a theoretical framework or foundation to understand the concept of identity: identity theory (Sheldon Stryker, 1980, 1987) and social identity theory (Tajfel, 2010). Both theories have captured the fundamental interplay between the individual and the social world.

The development of social identity theory is responding to the argument from social psychologists for the collective aspects of self. It has been considered the funding theoretical framework to understand identity. Social identity theory focuses on the extent to which individuals identify themselves in terms of group memberships (Tajfel & Turner, 2004). In other words, an individual will define the self in terms of social category/groups into which one falls, and to which one feels to belong. What groups we

belong to are closely connected to our pride and self-esteem. Thus, when a specific social identity becomes the salient, we have the tendency to create the categories of "us" versus "them". Our self-image will be enhanced or diminished by the status of the group to which we belong. This is also known as in-group versus out-group. Social identity theory states that the out-group will be discriminated against by the individuals belong to that in-group category.

Children who are born with Down syndrome automatically fall into the socially recognized group of "the disabled". Saxton (2000) stated that individuals with disabilities are viewed as a minority group in the society that has been denied full access to mainstream of life. In this sense, the identity of children with Down syndrome will be diminished by the status of the group which is defined as the disabled and the minority. Families of children with Down syndrome are in no exception, captured in the disabled family group created by society. Mothers of these children are simultaneous deemed to be mothers of disabled children. This is the instant fear faced by families in receiving their child's diagnosis of disability from health professionals. Most researchers have argued that the families of disabled individuals experience courtesy stigma (Ali et al., 2012; Gray, 1993, 2002; S. E. Green, 2003). Goffman first argued that the parents in such families experience stigmatization due to their affiliation with the stigmatized individuals rather than through any characteristics of their own (Goffman, 1963). However, Goffman also argued that parents of a disabled child is a type of "wise" person whose "relationship through the social structure to a stigmatized individual…leads the wider society to treat individuals in some respects as one" (Goffman, 1963, p. 43). Upon receiving the diagnosis of Down syndrome of their child,

parents of a normal family suddenly turn into parents of dysfunctional family. For instance, mothers of child with Down syndrome remove them from the same identity as other "typical, normal" mothers ascribed by the society. The identity concern of parents of child with disability becomes a salient, master identity that cannot be disguised once known by others (Charmaz, 1994; Deaux, 1991).

Different from social identity theory, Stryker's identity theory (Sheldon & Burke, 2000; Sheldon & Serpe, 1994; Sheldon Stryker, 1987) explains that individuals have distinct components of self, called role identities, for each of the role positions in society that we occupy. Therefore, individual's social behavior intertwines with the reciprocal relations between self and society. Role identities are self-conceptions or self-definitions that individuals apply to themselves in viewing themselves occupying different social roles. For example, a person's role identities may include the fact that she is a mother, a wife, a caregiver, and a college professor. The social roles are flexibly and strategically adopted and claimed by an individual in response to situational and contextual demands (Tracy, 2013). Identity salience is conceptualized as the likelihood that the identity will be invoked in diverse situation. People with the same social roles may behave differently in a given situation due to their different understanding and interpretation of the context demands (Hsieh, 2004; Thoits, 1991; Tracy, 2013). For example, despite the shared identity as a parent, one may choose to work during the weekend to ensure a better financial future for his/her children while another may choose to spend time with his/her children to maintain parent-child bonding. Identity theory proposes that the salience of a particular identity will be determined by the person's commitment to that role and their interpretation of the contextual demands.

Commitment, defined as the "degree to which the individual's relationships to particular others are dependent on being a given kind of person" (S. Stryker & Statham, 1985, p. 345).

According to identity theory, parents of children with Down syndrome are more likely to subject to their role dilemma while trying to balancing the family life and providing care for their child with extra demands. As the theory states, mothers of children with Down syndrome have a compilation of discrete identities that are tied to their social roles such as mothers, wives, daughters, sisters, and professionals (with particular careers). It is well recognized in literature that mothers tend to have overwhelming responsibility for the caregiving role for the family and their children (S. Ryan & Runswick-Cole, 2008). For mothers of disabled children, this role is often expanded and challenged due to the extra caring demands posed by their child's diagnosis. One consequence for these mothers is that they are often limited in pursuing other roles separate from that of caring for their child. For instance, some mothers might choose to end a career and devoted herself to the mother role; or some mothers might be detach themselves from a wife role diverging all here engirt to care of their disabled child (Dyson, 1997; Floyd & Gallagher, 1997; Wickham-Searl, 1992). This echoes the concepts of identity salience and commitment described in identity theory.

Social identity theory defines *personal identity* as a set of idiosyncratic traits and personality characteristics (Hogg & Abrams, 1988; Turner, Hogg, Oakes, Reicher, & Wetherell, 1987); in contrast, *social identity* is defined through memberships in social categories. Tajfel in his social identity theory also proposed that social and personal identities exist at the opposite end of continuum (Tajfel, 2010; Tajfel & Turner, 2004).

Deaux (1996) argued that this isolation of the personal identity from the social identity ignores the fact that it is impossible to understand personal traits without considering social identities. One of the critiques of social identity theory claims that social identities are categorizations of the self into more inclusive social units and depersonalizes the self-concept (Brewer, 1991). People often create multiple and potentially overlapping social categories as they define and manage various identities to meet the situational and contextual demands (Hsieh, 2004, 2006; Verkuyten, 1997). Rather than adopting a fixed identity within a social category or treating personal/social identities as oppositions, individuals often exhibit fluid, holistic, and strategic performance and understanding (Howard, 2000; Tracy, 2013). Various scholars have argued that a distinction between personal and social identity cannot be made as such identity boundaries are fluid, blurred, and potentially overlapping (Breakwell, 1992; Brewer, 1991; Markus & Wurf, 1987). In other words, meanings of personal identities are constructed in and dependent on the social context. Thus one's personal identity cannot be separated from the context in which it develops (Duveen & Lloyd, 1986). Reid and Deaux (1996) concluded that an integration of personal with social identities a better conceptual model than a segregated model. Researchers also argue that multiplicity of identities is not only conceptually reasonable but also psychological desirable. James (1950) argues for multiplicity in discussing material, social and spiritual selves.

Symbolic inter-actionists argue that identities locate a person in social space where individuals attach symbolic meanings to themselves and other people. Identities are constructed and negotiated through social interactions (Hewitt, 1976; Hsieh, 2004;

Sheldon Stryker, 1980; Tracy, 2013). Both Mead (1925) and Cooley (1998) acknowledged self as a product of social interaction, through their interactions with others; people come to know who they are. A core mechanism in the identity construction process is that of "taking the role of the other," a dialogic view of identity construction as one places oneself in others' shoes as they reflect and conceptualize their own identities. People may have as many distinct selves because there are distinct groups they tend to identify with.

Researchers in the fields of language and social interaction have demonstrated that individuals' identities change over the course of interactions (Antaki & Widdicombe, 1998a, 1998b; Hsieh, 2004). Contextual variations can result in shifts in identity claims. They sternly encourage working from participants' own orientation to identity, rather than deriving analytical identity claims from their designated social categories/groups. Moreover, both identity and social identity theories have underemphasized how identities shift over time. The interactional approach acknowledges and addresses the development and transition of identities through interactions over time (Galvin, 2005; Hsieh, 2004; Sheldon & Burke, 2000).

How mothers of children with developmental disabilities respond to and make sense of their child's diagnosis, how they adapt their life to caring for their child, and how they adjust or reconstruct their identity may be best understood in the context of the ways in which their interaction experience with others either from their immediate family or their social networks; and through the meanings that they attach to this life event of having a child with developmental disabilities. Mothers of a child with Down syndrome do not experience their life events and construct their identities in isolation.

For example, Lalvani (2008) indicated that the social implications of a child's diagnosis of Down syndrome, including issues of acceptance and rejection, are among the predominant concerns raised by mothers. The meanings of their experience and identities are contextually situated and culturally constructed. For example, among Asian families, some view disability as a sign of good fortune, while others view it as punishment or as an act of God that cannot be changed (Fadiman, 1997; Miles, 1997). Similarly, among Jamaican and Korean cultures, disability is often viewed as caused by supernatural forces or as wrongdoings of ancestors (Kim-Rupnow, 2005; D. Miller, 2005). In some East Asian cultures, people may also attribute a child's disability to the mothers' failure to follow appropriate dietary practices or violate certain social taboos during their pregnancy (A. Ryan & Smith, 1989). Therefore, mothers of a child with disability might be viewed as a failure, or an incompetent figure.

In this this study, I adopt a symbolic interaction approach and the concept of identity multiplicity of identity concept, integrating identity and social identity theories to understand how mothers of child with Down syndrome negotiate and reconstruct their identities while going through different stages of grieving process, recognizing their identity loss, and finally finding themselves in accepting their child and their diagnosis.

D. Examining Disability Identity through the lens of Chronic Illness and Identity

Identity and notions of the self in disabled individuals have generated a great deal of interest among diverse fields, including social psychology, medical sociology, cultural studies, and political studies to name a few. Because disability is often treated as a stigmatized condition, individuals with disabilities as well as their family members

can experience negative perceptions from the general public (Ali et al., 2012; J. Gill & Liamputtong, 2011; Goffman, 1963; Gray, 2002). Within the literature, there have been different approaches to study disability. One approach views disability as the outcome of biological impairment, a biomedical model in conceptualizing disability. By focusing on physical difference, disabled individuals are defined as a group of people whose bodies do not work as or look different from "normal" others. The difference leads to view disabled people as deviants as they cannot work as productively as others (Byrom, 2004; Shakespeare, 1996). In other words, disability reflects a form of biological determinism, which limits an individual from functioning normally. In this view, increased levels of disability are associated with decreased levels of quality of life experienced (Saxton, 2000). The biomedical approach, thus, views negative self-identity as an outcome of physical impairment, and focuses on the need for eliminating the disability, adjustment, mourning, and coming to terms with loss. By treating disability as a loss and a negative biological characteristic, the biomedical approach to disability fails to address individuals' desire to maintain their "disabled" status (Savulescu, 2002; Tucker, 1998) or finding joy or positive experiences as a result of their own or their children's disability (Blacher & Baker, 2007; Myers et al., 2009; Stainton & Besser, 1998).

In contrast to the biomedical approach, a sociological approach views negative self-identity of disabled individuals as a result of the experience of oppressive social relations (Fine & Asch, 1988; Hahn, 1988). As a result, such an approach focuses attention on the possibilities for changing society, empowering disabled individuals, and promoting a different self-understanding (Shakespeare, 1996). For example, Saxton

(2000) found individuals with disability are considered to be a minority group; and individuals with disabilities have been subjected to the same forms of discrimination and segregation as members of other oppressed groups. This line of research has produced rich and complex understanding about how individuals with disabilities manage their social worlds and social identities, highlighting interactionist and social constructionist emphases on conceptualizing the meanings and functions of disabilities (Charmaz, 1995, 1999a; Goffman, 1959, 1961, 1963). These studies have brought issues of impairment and identity into the mainstream of sociological literature, exploring the effect of identity and self of impairment and the corresponding impacts to adjustment to loss, coping and mourning (Shakespeare, 1996). Individuals with impairment or chronic conditions often suffer loss of self (Charmaz, 1994, 1995), requiring them to process and negotiate new meanings and functions of their identities so that they can maintain a sense of control in their desired life-world (Charmaz, 1991, 2002a; Shakespeare, 1996).

The notion of loss, disruptions and adjustment, the personal and social meaning of disability, the concern of life control and others' reactions, are all significant issues to consider while trying understanding the challenges of living with a disability. Drawing from the literature on the disruptions and losses associated within chronic illness and the process of reconstructing one's self and identity, I argue that mothers of children with disability are no different from individuals with impairment or chronic illness in terms of the sense-making process of their losses and reconstructing their identity. Furthermore, mothers of children with disability have occupied a complex and marginal position within disability studies (S. Ryan & Runswick-Cole, 2008). The literature

marginalizes these mothers' roles and experiences because their lack of disability status is categorized and conceptualized as non-disabled others in the lives of individuals with disability (S. Ryan & Runswick-Cole, 2008). Rather than being entitled to have their independent, legitimate experiences and voices in the journey of their children's disability, these mothers' voices were treated to peripheral to and be dependent on the experiences and voices of disabled individuals.

Goffman (1963) noted that the wise is a group of people who share a normal status but accepted by the stigmatized individuals as understanding and accepting of their conditions (e.g., mothers of children with disability). Nevertheless, the wise also experience the similar loss and courtesy stigma as the disabled individuals and those with chronic illness (Ali et al., 2012). Bosticco and Thompson (2005) argued that parents' bereavement is a type of deep illness and noted, "Their bodies, minds, and emotions exhibit signs of the 'illness' of bereavement, crying out for the opportunity to give voice to their experience" (p. 391). Recognizing mothers of child with disability also share similar experiences as bereaved parents, placing them in the center stage of our investigation is essential to theory development and practice implication for families with children with disabilities. These mothers undoubtedly and absolutely experience the type of deep illness as those bereaved parents. The only difference that distinguishes these two groups of parents is mothers of child with Down syndrome do not experience the physical, but psychological loss of their child while bereaved parents actually experience the physical loss of their child. Nevertheless, while the bereaved parents' experiences can be final, these mothers' experiences of loss and grief can be

on-going and unrelenting as their children reach every developmental stage (e.g., crawling, walking, speaking, eating on one's own, and going to school).

The personal and social meanings of disability or chronic illness have a tremendous impact on how an individual view himself or being viewed by others (Charmaz, 1987). Chronic illness separates the person of the present from the person of the past, and influences images of self-envisioned for the future (Charmaz, 2002a; Corbin & Strauss, 1987). There is no question that the diagnosis of Down syndrome can be terrifying and identity-changing experiences for women who were simply looking forward to be mothers (Barnett et al., 2003; Georgsson Öhman, Saltvedt, Waldenström, Grunewald, & Olin-Lauritzen, 2006; Klein & Schive, 2001). Kelly (2005) argue that many parents of impaired children face a set of challenges in understanding the relatively taken-for-granted sense of what means to be a "parent" now become the subject of conscious making, unmaking, and remaking sense of their identity. In addition, Goffman's influential work charts the relationship between an individual's 'virtual social identity', that is, the expectations one might have of an individual, and their "actual social identity". Where there is a disparity between the two, the individual's identity may be 'spoiled' and the individual is "reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 12).

Previous research on the families of the disabled has also argued that the families of disabled individuals experience what Goffman referred to as a "courtesy stigma" (S. E. Green, 2003; S. E. Green et al., 2005; Scambler & Hopkins, 1986). In other words, members of such families experience stigmatization because of their affiliation with the stigmatized individual rather than through any characteristic of their

own (Ali et al., 2012). They are regarded as normal yet different (Birenbaum, 1970). However, when an illness is categorized as potential genetic flaws (Burnes, Antle, Williams, & Cook, 2008) or is avoidable through preventive care/screening, mothers of children carrying such an illness may experience various forms of stigma, including social blames for their lack of personal personalities, potential discriminatory attitude toward their genetic flaws, and courtesy stigma for being associated with a disabled person (C. A. James, Hadley, Holtzman, & Winkelstein, 2006; Markel, 1992; Voysey, 1972).

Gregory (1991, p. 124) point out, the popular literature on baby care often suggest that "disability is unlikely, undesirable and to be avoided at all cost." From this perspective, mothers are not encouraged to assume the role of the "the wise," who are understanding and accepting of stigmatized individuals' condition (Goffman, 1963). They are encouraged to enforce the social stigma against disabilities. Therefore, many mothers of child with disability are occupied with the sense of fear about how other people view them, particularly as there is a deep parental, cultural conceptualization of perfect children and good parents (Kearney & Griffin, 2001; G. H. Landsman, 1998; S. Ryan & Runswick-Cole, 2008). "To be the mother of a disabled child is to be different - a mother because she undoubtedly has a child, yet somehow not a mother in terms of the conventional notions of motherhood that pervade our society" (Gregory, 1991, p. 121). In short, mothering a disabled child is fundamentally a different experience to mothering a non-disabled child (Beckman, 1991; Greenspan, 1998; A. C. Miller, Gordon, Daniele, & Diller, 1992; Singer, 2006).

The definition of disability and the resulting implications for identity are influenced by one's own interpretations and by the evaluations of others. Family, friends, health professionals, and colleagues all play a role in defining the individual's identity. Families with children with disabilities often adopt different strategies to cope with the effects of stigma about their child's disability try to normalize their encounters with the outside world (Canary, 2008; Gray, 1993). Many mothers of children with disability have reported that they had changed considerably in their behaviors and performances in public involving their children (Piskur et al., 2012; Russell & Norwich, 2012; Sandler & Mistretta, 1998; Wickham-Searl, 1992). Theses mothers manage the delicate balance and elevated stress of the challenges to present a publically acceptable image (e.g., an unruly, manageable child) while maintaining the appearance of competent parenting (Estes et al., 2013; Garaham, 1982; Woodman, Mawdsley, & Hauser-Cram, 2015). For mothers of children with disability, their parenting competence is often under public scrutiny and can be easily questioned as the child's disability may not be readily transparent to the public (S. Ryan & Runswick-Cole, 2008; Koa Whittingham, Wee, Sanders, & Boyd, 2011). Todd and Jones (2003) highlighted the surveillance mothers of disabled children face while interacting with health professionals, experiencing a 'disciplinary gaze' as their behaviors and the child's health and success are subject to the professionals' evaluations. The increased parenting stress has been known to result in increased risks of parental maltreatment of children with disabilities (Weisleder, 2011). These mothers' competence can be challenged in a wide range of tasks, including their caregiving skills (for the child with disability, other siblings of the child, and other family members), parent-child bonding,

and other social roles (e.g., wife and wage-earner) she plays within the family contexts (Lewis, Kagan, & Heaton, 2000; Pelchat, Lefebvre, & Perreault, 2003; Warfield, 2005). The cultural ideology of gender roles and responsibilities is essential to mothers' experiences of caring and parenting children with disabilities (Bruce et al., 1996; Burnes et al., 2008; Gray, 2003; Lewis et al., 2000).

The meaning of illness and the resulting implication for identity are also contextually situated and culturally constructed (Gray, 1993). Because of the nature of 'courtesy stigma', relative and parents of child with disability adopt a wide range of strategies for information control to manage (potential) stigma (Goffman, 1959, 1963). This means that the parents have the option of 'passing' in some contexts as long as the reality of their affiliation is not known to the public. For example, mothers of children with disability reported that their employment status is an important source of family income and is shaped by their personal aspirations and their sense of self-identity (Shearn & Todd, 2000). A working mother may choose to conceal their identity of a mother of a child with disabilities to avoid potential discrimination and biases in a workplace. As a matter of fact, passing is possible in many situations when the mother is not accompanied by her child with disability or when the child's disability can be sufficiently disguised or mitigated (e.g., having a bad day or feeling sleepy). Nevertheless, the same working mother may adopt a proactive, assertive parenting role as a mother with disabled child when interacting with health care professionals and service providers.

The temporal timeframe in an illness trajectory has been acknowledged as an important factor in conceptualizing the meaning of illness and the resulting implications

for identity management. Charmaz (1987) suggested that illness defines an individual's self-images along three time dimensions: the daily round, the life structure, and the life cycle. Thus illness demands an individual changing, adjusting or refocusing on his or her time perspective, which in turn leads to change in self-concept. The impact of time is manifested through the effects of illness on daily activities; time spent and required to manage illness, the orientation on future life, and the expectations of self at different stages of the lifespan (Charmaz, 1991, 2002a; Hawley & DeHaan, 1996). Mothers of child with disability usually spend most of their time taking care of their child, which can create disruptions to their routine, taken-for-granted day-to-day activities (e.g., trading their leisure time for therapy sessions or other intervention programs) (S. E. Green, 2002; McKeever & Miller, 2004).

Parents usually acknowledge the loss of their dreamed child upon hearing the diagnosis, which implies a long-term or life -long period of coping with their child's disability (Barnett et al., 2003; Klein & Schive, 2001; Moses, 1988), acknowledging the continuing and on-going changes and challenges to their identity management as they adjust to and cope with their child's challenges in different stages of life. Time is an important marker in understanding one's illness and designating significant turning points in one's illness experience. These turning points could be argued as stages of grieving of mothers of child with disability. For example, Birenbaum (1970) argued that parents of children with disabilities may go through cycles of experiencing different affiliations with their disabled child, feeling more comfortable and wiling to bear the burden of a courtesy stigma at certain times than at others. From this perspective, these mothers strategically control and manipulate information to control their 'discreditable'

identities (as opposed to the 'discredited' identities; Goffman, 1963) as they consider, balance, and negotiate the needs of their children's (including the disabled child as well as other children who develop typically), family priorities, and their own personal agenda.

The meanings associated chronic illness or any type of disability is also related to another dimension of an individual's identity - individuals' need for control. The experience of chronic illness or disability strips away multiple sources of an individual's perception of control within the individual's own life (Thompson, Dorsey, Miller, & Parrott, 2003). Severe and chronic illness frequently accompanied by physical restrictions, which in turn makes individuals lose control over certain aspects of their life. For mothers of child with disabilities, this might imply diminishing certain social relationships, losing employment, participating a series of activities before the birth of their child. Charmaz (1991, 2002b) argued that the struggle of claiming control is reflected in individuals' desire to control and define their identities. Individuals strive to achieve a balance between controlling the illness and being controlled by the illness (Charmaz, 1991). This struggle of control is manifested in experiences of managing daily life, dealing with illness, and making sense of it. Similarly, the aspiration for and the struggle of control experienced by mothers of child with disability is reflected in their efforts to manage their daily life, deal with their child's disability, and make sense of having a child with disability.

Within the tradition of interactionists, research on individuals with disability or chronic illness deal with disruptions and losses centers on reconstructing the meaning of his or her life to position and understand the illness in terms of one's self and one's life

(Fife, 1994). Researchers have explored the processes, relationships, ad interactions between identity and chronic illness in different ways. Charmaz (1987) investigated how people with chronic illness seek to reconcile their previous identities with the changed circumstances in which they find themselves. Charmaz defined preferred identities as implicit or explicit objectives for personal or social identity that individuals with chronic illness strive to achieve. The development of a preferred identity is geared toward leading a normal or previous life, avoiding dependence, reducing stigma, and creating or maintaining a valued identity (Charmaz, 1987). Charmaz identified four stages of identity construction: (a) a supernormal identity, which characterizes that individuals are determined not to let the illness stop them from being better than ever; (b) a restored self, which states that individuals are not quite as optimistic but typically deny that the illness has changed them; (c) a contingent personal identity, suggests that individuals admit that they may not be able to do everything they could previously do and they begin to confront the consequences of a changed identity; and (d) a salvaged self, a final stage that represents the development of a transformed identity that integrates former aspect of self with current limitations. In addition, Charmaz has used the concept of identity hierarchy to describe the process whereby individuals choose different types of preferred identities (Charmaz, 1987, 1991).

Subsequently, Charmaz (1991) identifies three ways individuals with chronic illness choose to respond to their illness: embracing illness, incorporating illness, and containing illness. Embracing illness involves individuals' taking their images of self from the illness; the illness lends meaning to one's life. Incorporating illness involves individuals' recognizing the illness and living with it, it becomes a part of one's self.

Containing illness involves keeping the illness hidden, at least in public, if not also form one's self, which might arise out of fears of loss and rejection due to the stigma of the illness.

In Charmaz's (1987) stages of identity change, individuals do not necessarily go through each stage even though the stages are categorized in descending order according to the interpretation of how difficulty they are to achieve and the extent of acuity demanded. The metaphors of identity change created by Yoshida (1993) illustrate the movement back and forth between the non-disabled and disabled aspects of the total self, which were influenced by loss, sustainment, integration, continuity, and development. While studying adults with traumatic spinal cord injury, Yoshida uses the metaphor to conceptualize the reconstruction of self and identity. The five dominant identities identified are the former self, the supernormal identity, the disabled identity as total self, the disabled identity as an aspect of the total self, and the middle self. These metaphors to certain degree resemble the stages of identity change proposed by Charmaz. Yoshida suggested that identity reconstruction is a continuous, evolving, dual-directional process.

Traditionally, research focusing upon the experiences of mothers of disabled children has been examining the additional stress, burden, and problematic consequences of having a child with disability (Helff & Glidden, 1998; S. Ryan & Cole, 2009). In recent years, research findings in parents' experience of raising a child with disability have geared toward a more positive tone, recognizing the positive impacts of parenting a child with disability (Blacher & Baker, 2007; S. E. Green, 2007; Helff & Glidden, 1998; Stainton & Besser, 1998). Scorgie and Sobsey (2000) suggested that

dimensions of positive perceptions and experience are encountered by the vast majority of families of children with disability.

The changing finding also is reflected in how parents of child with disability are portrayed in the literature. For example, Darling (1979) argued that parents are often caught in a 'no win situation': they are characterized either as unable to cope or those who appear to be coping well are considered to be deluding themselves about the extent of their child's difficulties. Taylor, Bogdan, and Lutfiyya (1995) also argued that parents who construct positive, non-grief stricken images of their family life are often seen to be 'denying reality'. However, a growing number of studies have successfully challenged the images of 'delusional,' 'grief-stricken' parents, noting that parenting a child with disabilities can entail transformative, positive experiences for both the families and individual parents (S. E. Green, 2007; S. Ryan & Cole, 2009; Scorgie, Wilgosh, & McDonald, 1999; Stainton & Besser, 1998).

Mothers of child with disability have been conceptualized in different ways. Parents for Inclusion, an organization that supports parents of disabled children, suggested that parents and professionals should be allies to young disabled people (Inclusion, 2015). Despite the considerable and on-going stress involved in parenting a child with disability, many parents argue that their experiences have been positive and transformative (Galvin, 2005; B. Gill, 1997; S. E. Green, 2002; Hornby, 1992; Scorgie & Sobsey, 2000; Scorgie et al., 2004; Steele, 2000). For example, Scorgie, Wilgosh, and McDonald (1996) found that parents of children with disabilities experience transformation in different areas: personal transformation (e.g., changes in self-identity), relational transformation (e.g., changes in the way one relates to others), and

perspectival transformation (e.g., changes in one's assumptions about life and what is important). Seligman and Darling (2009) argued that some mothers change their role from advocate to activist, which is partly catalyzed by the experience of complex interactions with professionals. These mothers may feel that the role of activist, although challenging, is compatible with the role of 'good mother' (Ryan & Cole, 2009; Todd & Jones, 2003). Scorgie and colleagues' concluded that parents of child with disability arrive at a more positive state through three processes: (a) the need to form new identity (e.g., a new parent identity that included an emphasis on competence in parenting a child with a disability), (b) attempts to derive meaning from the situation, and (c) the development of a sense of personal control (Scorgie et al., 1999; Scorgie et al., 2004).

E. Constructing Identity through Narrative

In Burner's (1990) view, self becomes defined through the constant act of negotiating and renegotiating meaning, both by individuals and cultures, and human experiences become endowed with meaning through narrative interpretation. The study of narrative explores the stories that people tell as a means of understanding the way that they experience the world around them (Connelly & Clandinin, 1990). In everyday life, individuals create private and personal stories that connect different events in order to give coherence and direction to their lives and as a means of developing their identities (Hsieh, 2004; Polkinghorne, 1988). According to Polkinghorne (1991, p. 136), "These are stories about the self. They are the basis of personal identity and self-understanding and they provide answers to the question of who am I?"

Identity is a complex construct, and it requires an ongoing process to construct or carve out one's identity. Some scholars have investigated this process through narratives (Galvin, 2005; Harter, Scott, Novak, Leeman, & Morris, 2006). Within the tradition of medical sociology, narratives have been essential to researchers' understanding of individuals' understanding of their experiences, sense-making process, and identity construction (Bury, 2001; Kleinman, 1988). A narrative is "a discourse featuring human adventures and sufferings connecting motives, acts, and consequences in causal chains (Mattingly, 1998, p. 275). Narratives are essential to individuals' sense-making process as they reflect their experiences of trauma, allowing them to find meanings and closure to their suffering (Charmaz, 1999b; Pennebaker & Keough, 1999). Charmaz (199(Charmaz, 1999b, p. 374) noted:

Stories of suffering are consequential. The words, characters, action, plot, and point shape meanings of the storyteller and for his or her audience. A story provides a way of making sense of suffering, of locating self in life, and of coming to terms with an altered existence.

Charmaz (Charmaz, 1999b, p. 365) claims that "[Suffering] is of the self and it is social. As suffering spreads out, it shapes social relations and limits social worlds." As stories of suffering are generated and revised, individuals (re)constructs themselves through narratives, strategically evoking and manipulating the ambiguity and overlapping boundaries of multiple identities. Somers (Somers, 1994, p. 606) noted,

It is through narrativity that we come to know, understand and make sense of the social world, and it is through narratives and narrativity that we constitute our social identity… all of us come to be who we are (however ephemeral, multiple and changing)

by being located or locating ourselves (usually unconsciously) in social narrates really of our own making.

Somers, and other theorists, have positioned the integral link between narrative and identity. People construct identities by locating themselves or being located within a repertoire of employed stories (Somers, 1994). Mathieson and Stam (1995) suggested that conversations become narratives when they are part of the search for personal identity. Both Somers and Ricoueur proposed and advocated the term narrative identity, describing how the self comes to be through the processes of telling personal and private stories (A. W. Frank, 1995).

The connection between narratives and identity explains why stories are a valuable means of understanding experiences in individuals' lives, such as the significant experience of a chronic illness or a disability. Riessman (1993) explained that individuals often tell stores when there has been a gap between ideal and real and between self and society. Telling stories to one's self and to others reaffirms relationships with the self and with others, an also provides guidance for others. Narratives both reflect and shape the illness experiences (Kleinman, 1988). Indeed narratives are integral to the process of making sense of the past, present, and the future.

Avery (1999, p. 118) has argued that the "disability story of parents needs to be heard." Stories provide insights to identity transformation as individuals reflect on critical, life-changing incidents, constructing meanings through evoking cultural resources and repertoire (e.g., meanings of motherhood). In addition, Vanderford and Smith (1996) argued the temporal timeframe constructed in the illness narratives often are structured in a before-and-after format in relation to the critical event. In this study,

I am particularly interested in my participants' identification, understanding, and interpretation of various critical events that trigger their identify dilemma or identity transformation.

Chapter 3: **Research Method**

To understand mothers' experiences of grieving over a lost child who they had dreamed about and their own identity loss; and to unfold how they find themselves and reconstruct their identity when they finally came term with accepting the child and the life change; I argue that the starting point of understanding must be the mothers themselves. Mothers' narratives and stories about their life experience caring for a child with Down syndrome will provide answers to these processes and questions.

Following the traditions of illness narratives (Bury, 2001; A. Frank, 2000; Kleinman, 1988), I adopted a qualitative, social constructionist approach. Qualitative approaches provide opportunities to explore the complex perceptions and multivocality embedded the narratives of the mothers of children with Down syndrome as they reflect on their situations, challenges, and life transformations. Qualitative methods provides insights into lived, embodied experiences (L. Green, 1998; Merleau-Ponty, 1982; Murray, 2000; Pitaloka, 2014), providing insights into individuals' sense-making processes of their personal journey (Boydell, Goering, & Morell-Bellai, 2000; McKevitt, 2000; Ochs & Capps, 1996). The detailed narratives also empower participants as they (re)gain their voices in the processes of data collection and analysis (Barry, Stevenson, Britten, Barber, & Bradley, 2001; Grover, 2004; Larkin, Watts, & Clifton, 2006).

In-depth individual interviews with mothers were used to collect the information from mothers about the birth, the diagnosis of their child with Down syndrome, their perceptions of being a mother, challenges faced in the journey of raising their child, and social support received in their grieving and coping process with the diagnosis. All

stories generated by mothers were in response to a set of open-ended questions asked by the researcher.

A. Participants

The participants for this study are mothers of children with Down syndrome residing in West Michigan area. The researcher recruited 20 mothers for in-depth individual interviews for the study. The ages of the mothers in the study ranged from 26- 48 years old. Regarding different cultural or ethnic backgrounds, 1 was identified as African-American, 1 as Mexican-American, 1 as Native-American, and the rest of 17 as Caucasians. While looking at this sample, it is definitely not a great representation of a diverse group in terms of ethnicity. However, it should be noted that West Michigan is a region in the country that is more homogeneous comparing to other parts of the country. The researcher also collected other democratic information about the participants. It has been noticed that these mothers were also different in terms of their educational backgrounds, family backgrounds, professional backgrounds, and religious backgrounds. Among all the participants, 3 mothers have a Masters' degree; 14 mothers have a Bachelor's degree; 3 have an Associate's degree. Before the mothers had their babies, only 5 mothers didn't work and were a full-time house wives. The rest of 15 all worked either part-time or full-time outside of their houses. The professions ranged from school teachers, physical therapist, nurse, sales representative, web-designer, to sports trainers. In terms of religiosity, the sample consisted of mothers who identified themselves as Christian, Catholic, and non-religious. All the mothers in the study were married except 1 was single mother.

In this study as previously described, mothers of different ages, different ethnicities, and different professions were recruited and welcomed to the research. However, due to the nature of the study which looked into mothers' experience of having a child with Down syndrome, going through different stages of grieving to finally accepting the reality and finding themselves again, mothers who were in the study need to meet one recruitment criteria: the age of their children with Down syndrome has to be 5 years old or younger. It is well recognized that how long the grieving process will last for each individual varies, the period of 5 years seems to be a relative and reasonable time length for most families or mothers to pass through different stages of grieving and hit on the road to accept the diagnosis of Down syndrome and their children as well. In addition, with in-depth individual interviews, it requires mothers to constantly draw themselves back to the past live experience, the younger the age of their children, the easier the past experience recall for those mothers. In that sense, it will increase the level of accuracy of all stories shared by the mothers. The majority of mothers in the study have at least two children with a few exceptions of only one child in the family. The ages of all children with Down syndrome in this study ranged from 10 months to 5 years old.

When it comes to the question of when the mothers found out their children were confirmed with the diagnosis of Down syndrome, 6 mothers had received the diagnosis during their pregnancy while having their prenatal genetic testing done; all the rest came to found out their children's diagnosis after the birth of their children. Some of them were delivered the news right after the babies were born, some were aware of the diagnosis several weeks later after their babies got home.

Some of the mothers in the study had their children with Down syndrome work with either an occupational or a physical therapist through the state-funded early intervention system called Early-on Program once a week. Only children who are under 3 years old are qualified for the service. For those mothers whose children were over 3 years old, their children either went to a preschool or kindergarten under the inclusive programs or in the early childhood centers. These programs are usually half-day programs.

B. Recruitment

Participants for the study were predominantly recruited from a non-profit organization, the Down Syndrome Association of West Michigan (DSAWN). The association was formed in 1985 by six couples who had children with Down syndrome. In addition to providing support and sharing knowledge with families, DSAWN also aims to advocate for individuals with Down syndrome and their families, to promote public awareness and support lifelong opportunities for individuals and their families. Currently, DSAWN has more than 430 members including individuals with Down syndrome, their families and their friends. The Association serves 12 counties in West Michigan working with more than 400 community partners that range from medical professionals to educational groups. The typical programs and events the Association sponsored and organized include to name a few, mothers' support groups, fathers' support groups, sibling groups, the medical conferences, feeding clinics, cooking capers, summer picnic, and Christmas party. The Association also provides different financial assistance for families in need to support their children's therapeutic and educational services. Myself, currently the researcher, I have joined the Association

since 2011 after my son was born and diagnosed with Down syndrome. I have been engaging in a variety of activities and workshops organized by the Association.

I contacted the Coordinator of Family Services of the Association first to explain to her in a detailed manner about what the study is, why it is important, and the specific procedures involved. I clearly communicated to the Coordinator that her help from the Association was crucially needed in recruiting the mothers for the study. With her confirmation and support, the flyer containing the study information and my contact information was posted at the Association's website. There is also a private online Facebook group created and administered for parents of children with Down syndrome only in West Michigan. I am also a member to that group. With the awareness and approval from the group administrators, I posted a study flyer with my contact information on Facebook to help recruit mothers to the study. Majority of mothers in my study were recruited through the above venues. They either contacted me via email or phone.

Additionally, I contacted the chief Association nurse who supervises the Feeding Clinic for children with Down syndrome to obtain permission to speak with families at their biweekly meeting regarding my study. In the meanwhile, I called my son's school, which is a center-based early childhood program for children with different disabilities, to present myself in one of their parents support groups promoting my study and recruiting mothers. During my presence at different recruiting places, I always began with a brief personal story sharing about my life experience with my son and his diagnosis. Overwhelmingly I felt welcomed, understood and immediately connected to those parents. Then I introduced my research as one that is derived from

my personal experience and pursuit of understanding what is like to be mothers of children with Down syndrome. I also communicated to them that as a researcher, I would like to hear, to understand, and to appreciate their live experience about raising children with Down syndrome from their own voices. I shared with the participants that their stories would be unique and valuable to not only help future mothers who are going to walk in the similar paths, but also bridge the gap of how the overall society understand and perceive our children in general. Of course, before I left the group, I made sure to explain the amount of time that would take them to participate in the study together with a brief overview of the procedures involved. I also distributed hard copies of my study flyers with my contact information for them to reach me directly once they decide to participate; or have any questions about the study.

Lastly, I recruited a few mothers via word of mouth. Every time after I finished my interview with a mother, I sincerely and directly asked her to share my study information with other mothers of children with Down syndrome they know. The same study flyer containing the research information and my contact information was handed to the mother for her to help with recruiting other mothers. All mothers participated in my study contacted me either via email or phone initially indicating their interest in the study. Then I took several attempts back and forth to schedule and finalize an in-depth individual interview with each of the mothers at their convenient time and preferred locations. Among all 20 mothers, only two phone interviews were conducted with the preference of the mothers. The rest was all face-to-face interviews.

C. Data Collection Procedure

Before I started recruiting the potential participants, making attempts to contact them, and conducting all interviews, The Institutional Review Board application was submitted and approved by the Institutional Review Board (IRB) office at the University of Oklahoma (OU). Before each individual interview, participants were given a copy of the consent form informing participants (a) of the purpose of the study; (b) of the procedures involved; (c) that their participation in the study is voluntary; (d) that they may choose to withdraw from the study at any time without any penalty; and (e) that they may request results of the study. I also assured the participants that all the information they offered in the interviews would be kept confidentially. If no questions were raised, participants were instructed to sign the consent form and they each also received a copy for their record.

All interviews with mothers were conducted at a time and location that was convenient and preferred by participants. The location for the interviews varied, ranging from the coffee-shops, the mothers' homes, my own home, and DSAWN office room. All these places ensured the privacy and unhurried conversations. The interviews done at the mothers' homes were usually with their children with Down syndrome or other younger age siblings around. Upon collecting the signed consent forms from the mothers, I went ahead asking the mothers to provide demographic information, such as age of mother, age of child with Down syndrome, number of other kids, ethnicity, educational background, religion, and occupation of mother. Once I finished collecting the demographic information, I officially began my interviews with them. I adopted the pre-established interview protocol asking the mothers a series of open-ended questions and, in responding to these, each mother generated an extensive and detailed narratives

and stories related to the birth, diagnosis of her child with Down syndrome and their experience in coping with the diagnosis and raising their children as a mother. The length of each interview conducted with the mothers varied from 60-90 minutes. There were several interviews lasted longer than this due to the constant interruptions from their children.

It should be noted that, while the questions on the protocol provided a framework for soliciting and facilitating conversations with mothers, the interviews were not strictly directed by these questions, nor were the questions necessarily asked in the particular order. I aimed to generate rich data by respecting and following an organic flow of discussion while maintaining focus on my research interests. Once the interviews began, the issues raised or topics proposed by the mothers actually served as starting or turning point for further inquiry. During most interviews, I was closely listening to their narratives and performed lots of further probing for either more information or clarifications. To a great extent in all these interviews, mothers were the active agents who determined what they wanted to focus upon while sharing their experience in raising children with Down syndrome. The interview protocol only served as a guide to fill gaps in conversations or to generate thought in areas that were not be spontaneously raised by the mothers. At the end of each interview, I made effort to encourage each mother to contact me if they wanted to add any other information that they couldn't recall during the period of the interview. All interviews were audio-recorded and stored safely for data analysis.

D. Research Questions

The research questions for the study are:

1. What are the specific turning points that prompt the mothers of children with Down syndrome to re-evaluate and re-construct their identities?
2. How do mothers' grief and grieving processes shape their identity transformation?
3. Are certain processes of grieving and identity transformation more adaptive than others?

I have also included my interview guide in Appendix A. The interview questions are organized into three categories: initial adjustment and concerns experienced by mothers of child with Down syndrome; identity and stigma management; and reconciling their identities.

E. Procedure for Data Analysis

All 20 interviews were transcribed verbatim and filed in my computer. The length of the transcribed interviews varied from 20 to 35 pages long. I adopted grounded theory in analyzing my interview data. The grounded theory encourages researchers to remain close to their studied world and to develop an integrated set of theoretical concepts from their empirical materials that not only synthesize and interpret them but also show processual relationships (Charmaz, 2006). In other words, grounded theory allows the researcher to get close to their participants' worlds and play an active role in interpreting and understanding the data gathered and analyzing the data systematically. It is a general methodology for developing a theory that is grounded in the data systematically gathered and analyzed. Grounded theory is essentially a constant comparative analysis, because it focuses on the interplay of data collection, analysis, and theory development.

As it is mentioned above, the core of grounded theory is a constant comparative analysis, which systematically compare the codings and concepts emerged from the data (Glaser & Strauss, 1967). Through the comparison between or among codings, concepts or themes, well-defined categories will emerge. This comparison is not a one-time event, but a continuous process performed throughout the whole data analysis process till the theory is derived. I began my initial state of data analysis by reading repetitively and extensively through all of the interviews searching for commonalities in the core experiences and shared perspectives of the mothers at different stages of their lives raising a child with Down syndrome. In other words, I was looking for the emergent themes from the mothers' narratives. This is the open-coding stage which I made notes of all themes or patterns in the narratives with a non-discriminate manner. These themes are identified and coded based upon not only the frequency but also the consistency of commonly shared experience emerged from the narratives. For example, several major themes emerged consistently from all interviews: a) negative reactions to the diagnosis; b) impact of their children's diagnosis; c) major stressors experienced; d) social support received (or not received); e) turning point to accept the diagnosis and their children; and f) understanding of parenting (implies comparison before and after they had their children).

Following this, I conducted focus codings to identify all narratives that echoed the above themes. With further examinations and constant comparisons of all identified narratives, more abstract stratifications or conceptual perceptions of categories were identified. Basically, I used focused coding to pinpoint and develop the most salient categories to a broader and conceptual level. For example, after examining all the

narratives from two initial themes (impact of their children's diagnosis and the major stressors experienced) coded in the open-coding process, I have identified the salient category or higher conceptual level of those two initial themes as experiencing different types of loss, particular identity loss after the mothers were informed of their children's diagnosis of Down syndrome.

Finally I adopted axial coding, a process for me to go back and forth trying to relate elevated or salient categories (described above) and their properties to each other. The ultimate goal was to make sure the categories and their properties/dimensions were coherent and fit back to the data as well. For this study, the axial coding helped me to examine how the diagnosis of Down syndrome of their children changed the mothers' lives and their identities; how the experience of raising up a child with Down syndrome transformed the understanding of their lives and meanings of being a mother.

In the data analysis process, I made use of NVivo 8 as the data analysis software to label the codes derived from the narratives and to identity the relationships among different categories of codings. The final conceptual categories of codings based upon constant comparisons among all narratives, are identified and described below.

1. Initial Reaction to the Child's Diagnosis: This category described the normative initial reactions to their children's diagnosis of Down syndrome, which was typically negative and devastated. This code also entailed the descriptions of non-normative response to the diagnosis of the mothers and how family coped with the so called tragedy.
2. Identities Loss: This category included any aspects of narratives that suggest the identity loss experienced by the mothers of children with Down

syndrome at the early stage of grieving process. The identity loss was not explicitly expressed and identified by the mothers in the sample, but rather imbedded in the stories shared. Codes of the understanding of the nature and expectations of being a mother; codes of the general society's perceptions of the motherhood were described in this category as well. As a matter of fact, some subcategories adopted the direct statements by the mothers in the study clearly expressing the motherhood identity loss.

3. Discovered Transitional Identities: Realizing that the mothers couldn't be the dreamed mothers to the dreamed children, all narratives in which mothers described the major tasks and roles they tended to play while caring for their children were coded here. At this point, facing the medical needs and critical care demands, the mothers perceptions of who they were and what they were doing were described in this category as well.
4. Key Events or Turning Points for Identity Reconstruction: Any narratives of at what points or what made the mothers in the study want to change how they perceive themselves and accept their children totally were coded here. Throughout all the narratives, clear timelines were hard to recall exactly. Instead, the key or major events that inspired the mothers pursuing that change were described by the mothers.
5. Finding Peace with Their Newly Established Identity: This category described the understanding and meaning of motherhood shared by the mothers in the study. All aspects of narratives evolving around being a

mother to a child with Down syndrome and the dramatic change they have experienced in the process were coded here.

Chapter 4: **Initial Reactions to the Child' Diagnosis of Down Syndrome**

All parents desire to hold a healthy baby in their arms after hearing that high-pitched cry from their baby which officially announces the arrival of the new addition to the family. This baby also comes with an exciting future life plan that fills with their parents' dreams, hopes, and expectations. New parents are showered with joy, excitement, and heartfelt congratulations from all their families and friends. In contrast, for the parents who received a different announcement, the diagnosis of disability for their children, that future picture about a new family with a new life is distorted, shattered or vanished right away. This is mostly often considered to be a traumatic experience, which brings a tremendous amount of sadness, challenges, and a huge interruptions of the existing lives of family members. In this section, the initial reactions to the child's diagnosis of Down syndrome are identified and discussed. The analysis and discussion of the wide spectrum of initial emotional reactions to the diagnosis of Down syndrome is organized into the two dominant categories: a) normative reactions to the child's diagnosis; and b) exception to the norms: why and how. Among all the stories regarding how the mothers reacted to the diagnosis initially, some of them resemble the early research findings, which depict the mothers in a negative and devastated situation; others open a new world to the society which contributes to the challenge against the normative and unhealthy assumptions about how the mothers react to and perceive the diagnosis.

A. Normative Reactions to the Child's Diagnosis

Mothers in this study often shared their stories with a thorough and detailed recalled account of how the mother was informed about a diagnosis of Down syndrome.

Some of them were informed of their children's diagnosis through the phone calls from their doctors' offices; some of them were informed in their doctors' offices; some others received the diagnosis during the morning rounds in hospitals. While listening to each of their stories, you could definitely feel as if they were back to that place (either hospital or doctor's office), that moment (in the morning, in the afternoon, or at night), and that environment (anxious, exciting, or saddening), in which the diagnosis was delivered. For example, one mother said during the interview:

> And it's so weird though because I can still see her, the doctor, you know, I can see the pink cashmere sweater she had on and her pearl necklace. I can still smell her like it's that moment, it's almost like it's just engrained in you. It's so weird. (Lucy)

Fourteen mothers in the study were informed by their doctors with a suspicion of Down syndrome with certain markers shortly after the birth of their children, which was confirmed through several (genetic) tests. The rest of 7 mothers received a prenatal diagnosis of visible fetus abnormalities through ultra sound and a confirmation diagnosis of Down syndrome proved with prenatal genetic testing. Regardless of whether there was a prenatal or postnatal diagnosis, all mothers recalled the event vividly and described their most immediate reactions to it in great detail. The majority of the mothers in the study shared that they had reacted to the diagnosis of Down syndrome in a highly negative manner. This echoes the early research findings which state that parents of new born children with developmental disabilities typically express their first response to the diagnosis as "devastation" and "lost" (Huang et al., 2011). Some metaphors used in some mothers' narratives completely reflected their negative

emotions and responses to the diagnosis. For example, a mother described the moment when she received the news, she said, “The sky just fell!” Another mother felt robbed, “The joy was robbed!” Some made a references to initial feelings of “devastation,” others described emotions of sadness, anger, fear, guilt, or rage. In the following passages, the most commonly recognized and expressed reactions from the mothers to the initial awareness of their children’s diagnosis of Down syndrome are described. Even though previous literature has demonstrated a wide spectrum of feelings, emotions, and reactions from mothers of children with disabilities. The descriptions of the feelings, emotions and reactions of the mothers in this study need to be honored indeed because during the majority of interviews, the mothers made a very legitimate comment claiming that they longed to share their stories and be heard. In the following analysis of their initial reactions to their children’s diagnosis of Down syndrome, their words and narratives from their stories were adopted to show respect to their voices. While examining in detail about narratives offered in those interviews, a wide range of negative reactions to the diagnosis has been identified by different mothers.

A. 1. Being Denied of Presumed Moment of Joy

The nature of mothers’ immediate negative reactions to the diagnosis of Down syndrome is reflected vividly in above metaphors. For example, some mothers described their very negative initial emotions upon receiving the diagnosis using the above mentioned metaphors.

> So I was very blue and when my family visits, I would cry and it was very, very hard. It was very hard to take it and I remember being, now that I look back on it, I am so sad that it was such a hard time instead of a joyful time to welcome our

child. I just feel like we were robbed of a joyful welcoming for her because and then we're so dismayed with the diagnosis and just kind of wanted to deny it. (Ann)

The result came back on like Monday, but they couldn't get me in for an appointment all week, and then it was Friday. I'm like, "I'm not going another weekend. Just tell me what that test says." Over the phone, they told me the result. And then I just said, "Okay!" and hung up the phone, and then I was like bleeaaah. The sky just fell. Yeah. So we cried for the whole weekend, I think we just went into the doctor. (Mary)

So I was very angry and I said "just tell me the answer right now." And she nodded that yes, he has Down syndrome. And I got up and left. I handed Nathan (her son) to my mom very quickly and I just ran out. And I locked myself in the bathroom on the NICU and I just cried and cried and cried and cried and cried. The hardest I've ever cried in my life. Andy (her husband) eventually came and found me, in the bathroom, and that was probably the worst moment: the finding out. And I was just beside myself. I felt like my life was over you know I didn't expect that and I... [Crying](Megan)

Mothers in general reported having experienced similar emotions that ranged from feelings of devastation to feelings of anger or rage at being told that their expected "perfect" child now becomes an "imperfect" one.

A. 2. Inability to Process Information or Emotions

Having learned that their children would have certain degree of mental/cognitive impairment and that the Down syndrome was not curable, most mothers were in shock.

Usually this shock brings temporary shut-down from parents, evokes mixed or unsure feelings about how they perceive the connection between their newly born babies and themselves, and leads to the escape of the reality. One mother said,

> After I heard it from our OBGYN, my mind went blank. I couldn't talk and think. I couldn't hear any more about what they said. I only heard that my daughter has Down syndrome. I couldn't remember anything else in that room. I felt blank. (Helen)

Another mother recalled her emotional reaction toward her newborn daughter's diagnosis as "a huge below". And that blow totally blew off her mind and she suddenly lost her English and started talking in Spanish crazily, which nobody could understand her except the husband:

> Oh, of course, I was crying. It was a huge below. And I remember I couldn't even speak in English. I didn't realize that I was just talking in Spanish crazily. And then my husband is like, Maria, you're talking in Spanish. Because it was in my brain, just talking faster and kept asking, "Are you sure?" But everything was in Spanish. And I remember their faces just, like, looking at each other like, okay, we don't know what she's saying. I don't remember exactly what I said either. Because just – I switched. (Maria)

Some mothers in the study clearly recalled that mixed feelings of whether that baby belonged to them, and the unsure feelings of whether they would love the baby. Having carried those babies during the entire pregnancy, mothers have also grown intensively connected or bonded with their babies in all aspects of their lives presently and extensively to the future. The mothers and the babies are one, they know each other

and they feel each other. However, the shock of the diagnosis actually changes the cards in their hands. Those cards are their newly born babies. Now those babies are not familiar to them, are not known to them, and that chain bonded them together has been cut off. The mothers are landed in a different place, trying to making connections to strangers. To love or not becomes a question. For example, one mother in the study shared,

> I was scared of him. I thought he might turn out to be a strange creature. I tried to resist touching him. I didn't believe that he was my own baby. You know what I am saying. It was really hard. I wanted to look at him, but at the same time, not want to. (Dawn)

Other mothers expressed their guilt and regret about the thoughts they had during the interviews about receiving the shocking news about their sons' diagnosis while in the hospital room:

> I was in a complete shock. I screamed on top of my lung inside and said a lot of things that night. And my husband said "you know you still love him don't you?" and I said "I don't know." I didn't know anymore. See, I loved that child I thought I'd given birth to a couple of days ago, but this was a completely different child in my head and I didn't know. And—[sobbing]. And then I – I just cried and cried. (Megan)

> Once we found out I almost felt disconnected with her when I was pregnant. Yes and it was really – and thinking back I was like that was so – the same thing, I felt guilty and angry with myself for just kind of feeling that way but I felt like once I found out, it was just like – it just wasn't the same for me and, that's exactly what

it was like I don't feel like I know who you are anymore and it was such a weird – I don't know if weird is a good word for it but it was almost like an out of body experience even when I had her. (Angela)

A. 3. Questioning Individual Responsibilities and Faith

One mother in the study made a quite alarming and explicit comment:

I don't think any mothers, regardless of how many kids they have, they will hold up that baby book going through every single page, learning about everything. Let's face it, who wants to spend time dwelling on those scary and bad medical or genetic issues described in that book and say, let me educate myself and be prepared? You just want happy things and happy thoughts. (Kim)

It is universally true that being pregnant, anticipating a healthy baby, caring and raising a normal or a good child in future is the top priority and concern for all parents. In that sense, parents, especially mothers tend to be very competent and active in seeking and obtaining answers to how to raise a "normal" child. Mothers are way less prepared for a different set of questions and are chaotically engaged in searching for the answers as well. With the diagnosis of Down syndrome for their children, that most frequently asked question of how to raise a "normal" child now is converted to a daunting question of how did this happen to me or my baby! It is extremely common to hear through all narratives that mothers were voraciously asking questions of why and how; and desperately to be given an answer upon receiving the news.

Some of the questions derived from those narratives contain the accounts for self-blame. It is commonly seen that the mothers tended to blame themselves for the diagnosis. Some of them even thought they did something to cause the down syndrome

of their babies. Given the sudden and hard-to-prepared situations that mothers of children with Down syndrome are facing upon the delivery of the diagnosis, mothers with limited information and knowledge regarding the diagnosis will naturally fall into the trap of self-blaming to make sense of the diagnosis. For example, a mother in the study responded,

> [How did you react to the diagnosis?]
>
> Pretty poorly. I was pretty emotional. I – a lot of crying and yelling. I was – I didn't know anything about it, really, so I thought it had been something I did while I was pregnant. So I was yelling or saying a lot of things, like "What did I do?" (Emily)
>
> What did I do wrong? Why did you put me in this situation? I don't have the patience. And for the longest time I really didn't have the patience. Like why me? What did I do? (Rocky)

Other questions identified from the mothers' narrative accounts expressing their initial reactions to the diagnosis are self-comparisons to others and accusation of fair game either from life or God. Basically the pictures they tend to get about are older mothers they know having healthy babies; ill-behaved mothers such as those on drugs, or not taking care themselves having healthy babies; and those who don't want babies end up having healthy ones. For example, some mothers in the study wondered,

> I was, I felt very sad and I, it was very, very difficult. I have, she's my only child. I come from a family of women that have kids when they're older, that have lots and lots of kids and none of them had Down syndrome so how could mine? I kind of felt very sad about that and kind of think of myself, thinking why did we get

dealt this hand when it was just our one and only child, you know. So I felt kind of singled out that way. (Ann)

I just cried, I just cried. I cried and cried and wondered why. You know, eh, I, I went through a lot of stuff just to have a second child, And I wondered why God, Yeah, Why, why me and what did I do, you know I ate well and I tried to exercise and you know it wasn't like I did drugs or drink or anything through my life, I just, you know, you go through all those things. (Teresa)

I prayed. I prayed hard. I would go to my doctor's appointments, and there are women who don't even want kids and they give them a perfectly health kid. That was what was going through my mind. There are people on drugs and living on the street and you give them these healthy babies that are doing great and then I go to the doctors, I take my vitamins, I watch what I'm eating, I am exercising, I am doing everything I am supposed to be doing. Why me? What the heck did I do to deserve this? That was my initial..... (Rocky)

I think because my husband had been through his cancer, and we went through that. And then part of that – because of the type of cancer he had, we found out later he couldn't have children. So then we still had to go through fertility treatments and all of this. It was a long process for us to have kids. And then it was like we've been through all of this plus – Like, what did we do? It was like, haven't we been through enough? Which I feel so bad saying sometimes, but it was really..... (Angela)

These narratives shared by the mothers clearly depict a wide range of emotions and reactions during the initial diagnosis of Down syndrome for their children. Of

course, the mothers of children with Down syndrome are not the only ones that might experience and demonstrate all those emotions while reacting to the initial diagnosis for their children. The fathers are most likely accompanying the mothers while the diagnosis is presented to the family either during a prenatal or postnatal testing.

A. 4. Coping as a Family

Although the mothers are the focus for the study, those fathers have been asked and talked about by their wives with the prompt question of *"How did your husband react to the diagnosis?"* during the interviews. In general, the majority mothers recalled and described that their husbands reacted to the diagnosis very differently from them. They tended to be less emotional, less vocalized, and more passive and reluctant to talk and ask questions about the diagnosis. For instance, one mother said,

> He kind of shut down almost, just very quiet and just trying to figure out if he could be a father to her. So he had a very hard time. We both did and I would just say that he more shut down. He didn't really wanna talk about it, just took him a really long time to process all of that. Yeah. (Ann)

Talking to all these 20 mothers, it is commonly seen that husbands were characterized as sad individuals in silence and overtly avoiding discussing the diagnosis with their wives and other family members except one or two being equally devastated as those mothers. Surprisingly have they never realized how their reactions to the diagnosis of Down syndrome will implicitly but profoundly impact their wives emotions on the moment the news was delivered? Some mothers have felt there could be a "rift" between them and their husbands watching how their husbands react. For example,

> So that was the worst moment when they first told us and I was just absolutely devastated, like I'd never been devastated in my life. Yeah, so that was the worst. But you know Andy handled it completely differently and at the time I wanted him to be upset like I was, but he wasn't and I didn't understand that. So I kept looking to him. I needed reassurance that it was going to be okay and he couldn't say that, you know. (Megan)

Another mother has yearned for her husband's understanding in regards to her emotions. As a matter of fact, her husband needed to feel what she felt, also to cry her cry. When she didn't see those, it was hard for her to understand. That emotional miscommunication to certain degree can turn into a "rift" as she described in the narratives:

> But at the time I wanted him to feel the same way I did and I didn't think he was going to understand why I felt so upset. Just like during my pregnancy he never understood why I was so anxious and I always felt like it kind of annoyed him. I was always constantly talking about how something was wrong. So now here I am, crying in the bathroom and he doesn't feel the same way I do. And I felt like it was going to kind of be like a rift between us. (Kim)

All the descriptions or narratives generated by the mothers regarding their initial reactions to the diagnosis of Down syndrome for their children indeed echo the findings of other studies that claim that mothers usually react to the diagnosis with extremely intensive sadness and distraught. Their reactions of feelings and emotions are often in no difference from those associated with bereavement of losing their actual children forever.

However, with the shift in emphasizing on hearing the mothers to voice their own interpretations and understanding of their situations (Scorgie et al., 2004), we have learned that how people, family and our society view children of Down syndrome have become more positive than before. In this study, those typical and general assumptions of how the mothers react to the initial diagnosis have been investigated and analyzed. As the literature suggests that there is considerable variability in individual responses and coping strategies to the presence of a child with disability as well as a wide range of outcomes for families of children with disabilities.

B. Exception to the Norms: Who and How

Some of the study's participants do not conform to the norms described earlier. In fact, it has been extremely encouraging and exciting to have some mothers in the study walked you into a totally different emotional or reactional zone when they initially received the diagnosis of Down syndrome for their children. This group of mothers mirrored a different emotional reflections and it is an eye-opening experience to actually see the clear contrast between this group of mothers and the rest. As a matter fact, they describe their initial reactions as calm, not angry; manageable, not helpless; hopeful, not devastated; prepared, not lost. These mothers who are exceptions from the norms include: a) individuals with backgrounds in health care or special education; b) individuals who familiar with life with disabilities; and c) individuals who are finding silver lining.

B. 1. Individuals with Backgrounds in Health Care or Special Education

As a rule, we humans prefer the known to the unknown, certainty to uncertainty. So not knowing what to do, not knowing what's going to happen, not

knowing what other people are thinking and feeling, all these situations are ripe to breed anxiety and fear in anyone. The diagnosis of Down syndrome definitely can raise many fears to mothers. This can make mothers feel as if their lives are out of control and that they don't know what the future holds for their children. It's normal to be afraid of the unknown. The unknown and the uncertainty can make people feel angry, afraid, anxious or irritable. These feelings and emotions has explicitly expressed and seen from the mothers in this study. Facing this type of diagnosis, it is often the not-knowing that's the worst.

The mothers in my study who had the knowledge and the understanding about the diagnosis of Down syndrome and the experience working with them or others with different disabilities had already peaked into their children's potential future outlooks. In this sense, the degree of the unknown and the uncertainty about what future holds for them and their children has dramatically decreased. Instead of being in complete shock, they tended to be less frightened, but more prepared. Their professional experience has assured them the certainty and competence that they could cope with the diagnosis and moved on. For example, one mother reflected in her narratives:

> You know, I just said, okay. I was gonna go into pediatrics and I was in physical therapy school, that was my plan. And I had done a lot of work with Easter Seals, kids with Down syndrome, kids with many different physical impairments and different abilities and disabilities. And so it didn't frighten me really because I had a lot of experience with it. I think for my husband it took a little bit longer for him to understand what it meant and he kinda had his own process of kinda trying to figure it out and come to terms with it. But I think because of my physical therapy

> background, it didn't. Yeah, it didn't frighten me. His immediate medical needs frightened me because I just wanted him to be okay. But the long term wasn't really that scary for me. (Cathy)

The above excerpt showcases us how powerful that professional experience in determining the mothers' initial reactions to the diagnosis. As she shared, her initial response was not as traumatic as other mothers, but she did have certain worries and scares that she needed to deal with. Her child's immediate medical needs were her top concerns. She didn't lose herself in that big picture of future, but coping with what was needed right now. Another mother in the study who was a special education teacher had also responded to the initial diagnosis of her son in a similar manner.

> I have been a part of special ed since I was young, helping with Special Olympics when I was in middle school, then coaching and obviously (now) I'm a special ed teacher. So I handled it much better than a lot of my friends did. I'm like, "Okay, let's do it." My biggest problems were the medical issues. As far as education, worrying about the future, I've known people with Down syndrome from the time they were itsy bitsy all the way up to full-grown adults. Worked with the whole range. So it wasn't, as far as worrying about the future, not a big deal. I was more worried about the medical aspects of it with the heart surgery and all that. (Emily)

The two mothers cited above both commented that their children's immediate medical needs were the top worry. They both considered the medical aspects as short-termed issues. When those issues are resolved or fixed, they are certain and fearless to face their lives with their children in the long-term aspect. What both mothers had demonstrated is the great combination of problem-based coping and emotional

adjustment after receiving a critical and dreadful diagnosis of their children. Without the initial shock, anger, and guilt, they could devote more energy to prepare for the future needs of their children. For example, one mother in the study who was both a social worker and a special education teacher immediately moved to the stage of searching and rationalizing what she could do to help her daughter.

> I've taught children with Down syndrome before but not many. Not many at all. Yes. Yes. And there was a theme for me. I tend to pick up a couple of things in my head and it'll stick with me. It's – teaching all those years, the one thing that I still say is it doesn't matter what you teach them, it's the time you spend with them. And so I just knew that right away in my head, that I was just gonna be with her as much as I could possibly be with her. Because in my past experience, that's what had made the difference for special populations, you know. And so, I was really – kept saying that to myself. But I did, I thought of all of the kiddos that I had taught in the past. Some that were succeeding with what they wanted to do if you spent a lot of time working with them. (Deborah)

The above excerpt also implies that the mothers had not only presented themselves in such a calm and prepared manner, but also gained certain control back for their own lives and their children's as well.

B. 2. Individuals Who are Familiar with Life with Disabilities

As explained earlier, people tend to become shocked, fearful, and anxious when facing a situation that is unknown and uncertainty. Typically when people are situated in a new, strange or unfamiliar circumstances, the level of the unknown and the uncertainty increases, which will prompt people to react with certain emotions.

Different from those mothers whose professional backgrounds to certain extent aligned with their future family lives, the mothers who had different degrees of personal interactions with individuals with disabilities had not conducted full pledged calmness and fearlessness; but not as devastated and hopeless as other mothers. The mothers who had a family member(s) clearly identified that the Down syndrome or disabilities in general was not something new to them or their families. For example,

> I have my mother's sister, my Aunt, does have special needs. It wasn't something she was born with. She had really high fever when she was little. And back in the early '50s there wasn't much they could do, and so it ended up causing some brain damage and stuff. So my family's grown up with – [It's not something totally new to you?] Right. It wasn't really new. So we were familiar with Downs Syndrome, and stuff. I think that wasn't even the part of it that was hard for us, it was the heart. (Susan)

Another mother in the study talked a lot about her uncle from her father's family who happened to have Down syndrome. She recalled the inconvenience and challenges the family had to deal with, but concluded in a very positive note that her uncle was very capable and had a very good life, and she really enjoyed him.

> Yeah, yeah it wasn't (that hard) and I had my own experience with my uncle and um you know they were fairly good experiences and he's still part of our life and my mom and dad had that, cause he was on my dad's side of the family and my husband's side of the family didn't have any experience with anyone. My uncle just passed away last year and was 65. He lived in a group home and you know my dad and his brothers and sisters would visit him and he had a very active life,

> he did special Olympics, he worked non-stop, he took vacations with everybody, went on cruises, he was in a bowling league, so active..... But I think if you try to look too far it does get to you, it is hard and you worry about the things and that and the future ..... (Amy)

The above excerpt illustrated a great reference point for the mother to understand her new situation and her daughter's diagnosis. With the experience of her uncle's life, this is so-called new or unexpected circumstance is not new or unfamiliar anymore. Instead, she felt more grounded while reflecting the snaps of her uncle's life. She also found her coping strategy from her uncle's life story warning herself not to look too far into the future, but focusing on the present, the medical needs of her daughter.

B. 3. Finding Silver Lining

Among all 20 mothers, two mothers recalled that they were sad and shocked when they were informed of the diagnosis of their children. But that initial dramatic and traumatic reaction to the diagnosis was quickly receded or removed from the reality that at least their children would have a chance to live with the diagnosis of Down syndrome, not the other type of diagnosis which will definitely take away the lives of the newborns. The mothers were put into a totally different perspective picturing having a child with Down syndrome is much better than completely losing a child in their arms. To them, this is just worse comparing to the worst they could get into. Throughout the interview, I have also noticed that the mothers tended to change their perspectives when they were given the opportunities to see something different, either could be the diagnosis, the types of medical issues, or other harsh trials other mothers have to go

through. That perspective change is so helpful to bring them back to the reality and make adjustment sooner upon reacting to the saddened news of their children's diagnosis. For example, Corea, the mother of a daughter with Down syndrome recalled:

> Well, I think I cried. I know I cried but it didn't last very long. I mean, literally, it was a few minutes and then I was very happy because, for our situation, she either had Down syndrome or she wouldn't live. If it was (Down syndrome), and so if that was the case, then they were pretty sure that they knew what it was and that she had a good survival rate. However, if they didn't come back with Down syndrome, they thought – they were really concerned with the condition of the heart because it may lead to something else. It might have been a different trisomy, one that would lead to only living for maybe a few hours or a few days. Maybe a few months after her birth. So when we realized it was the 21 instead of 18, we were elated that we got to keep her. That was all that mattered. (Corea)

As Corea commented, what really matters eventually is her daughter will be alive and she will have a baby to take home comparing to going home with empty arms and crib.

In discussing their initial reactions to their children's diagnosis, the mothers always went further to add their own explanations of why and how they felt that way after they received the news from their doctors. The majority of the explanations of the nature of their initial reactions is evolving around the fear of change for their life, their family and everything. Many of them truly believed that every single change would be negative and bad. Everything at that moment and into future all looked dismayed, gloomy, and darkened. Some of the beliefs was from the little and limited knowledge

about the diagnosis and the potential or real life outcomes their children would bring. Comparing to those mothers who had significant contact or interactions with individuals with disabilities prior to the birth of their child, the fear of unknown had dominated their thoughts and finally paralyzed them. Most of them made the point clear that they hardly ever known or even seen anybody with a disability before. This also conveys the belief that individuals with a disability are not visible, or supposed to be invisible. When I asked the mothers how they thought the society views children with disabilities in general, the answers offered were more negative, unwelcomed, mistreated, different than other groups in the society. The perception they have possessed from the society and culture about individuals with disabilities absolutely offered them a lens to interpret their children's diagnosis as negative and fearful.

Chapter 5: **Lost and Found – The Transformed Identities**

Every single one of us will experience grief at some stage of our lives. Among a few universally recognized and shared emotional states, grief is usually acknowledged and validated through certain prescribed rituals and ceremonies. For example, a Christian funeral or Hindu cremation exemplifies the socially instituted ways for people to express their sorrow. Grief is generally defined as a personal and emotional reaction to a significant loss, most commonly the death of a loved one or an involvement in some unforeseen tragedy. But how does grief gets enacted when nobody has literally died? This is the ultimately dilemma faced by the parents of children with Down syndrome in this study. Physically they didn't lose their newborns; their daughters and sons were right here with them. Psychologically the babies they had anticipated for 10 months were not showing up. It should be noted that physical loss is not the only type of loss that brings about grieving. Grieving is also a natural process for parents to respond to the diagnosis of Down syndrome which wipes away their dreams, hopes, and expectations for their children. It is in this sense that grief is actually associated with the psychological loss that parents tend to experience.

When it comes to examining and understanding the grieving process of any types of loss, it is critical to realize that no two individuals will experience and express their grief in an identical way. There is no absolutely "right" way to go by while grieving over the loss since the whole process is an intense individual experience. Regardless of its personal nature, there are five commonly identified and agreed-upon stages which most people go through (Prigerson & Maciejewski, 2008) on the road to coping and finally accepting the significant loss. These stages have been described in

details in the literature review of the study: denial, anger, bargaining, depression, and acceptance. In this study, stories shared by the mothers of children with Down syndrome entailed various descriptions of the grieving process that they had gone through. All the stages mentioned by the mothers were consistent with the five stages identified. Some of them only went through one or two stages before they came to term with their children's diagnosis; others almost underwent all stages to fully accept the diagnosis and their children. The stages of grieving identified by the mothers were definitely not in certain orders. The mothers also found themselves occasionally bouncing back to the same stage of grieving even though they had passed that stage previously. All these findings have confirmed that the nature of the grieving process is more of "cyclical" but not "linear" (Ruscher, 2012).

The following passages discuss how the mothers of children with Down syndrome transform their identities going through the grieving process about their psychological loss of the dreamed children, coping with non-stopping and intensive daily challenges of their children, and finally find peace and reconstruct their identities. In this section, the discussion about the identity loss and identity transformation is situated in the mothers' grieving process.

The analysis of the narratives in the stories generated by the mothers regarding the grief and their identities interruptions, loss, and transformations can be understood and conceptualized as: 1.) grieving over their psychological loss, which leads to discovery of their identities (former self) loss at the early stages of grief; 2.) Forming the transitional identities (middle self) to cope with the loss and daily challenges; 3.) Key/peak events that evoke and motivate the mothers to reconstruct their identities; and

4.) Finding peace in their new identity for the ultimate good, the mother they wanted to be.

Hearing and analyzing the stories from the mothers in the study, it is overwhelmingly to acknowledge that the majority of narratives depicted pictures of the mothers' "former self" vs. "new self". For some mothers, "new self" comes relatively earlier, others rather late. After walking the journey with their children, not only did the mothers finally find the real peace with their children's diagnosis, but also reconstructed their identity as mothers and sought the real meaning of the motherhood.

A. Early Stage Grieving: Lost Identities

Grieving is often recognized as a natural process that families may go through in order to deal with a multitude of emotional upheavals and uncertainties faced ahead. Families of children with Down syndrome need to grieve the child they had thought they would have. In the meanwhile, critical to the loss of the child, there is also other psychological loss the parents need to grieve about as well. In the study, the mothers of children with Down syndrome had predominantly voiced their heart-wrenching loss of hopes, dreams, expectations and beliefs for their children's future. For example, some mothers clearly depicted the anticipated future for their newborns and later on claimed to be a nightmare instead of a good dream:

> I was so, we were so happy that we have a baby finally. I don't know, I picture myself like, maybe like taking her – like very happy, you know? Because since I don't work, I'm a stay-at-home mom. Taking her to classes, you know, like ballet class. Like gymnastics, whatever. And then going, you know, meeting other moms, having play dates. I think, of course, going to school and going to college

and all this. And getting married. And the whole, you know, the whole fairy tale. (Marie)

Like I wanted, him and El are going to be such good buddies. They're going to be out playing soccer all of the time. Well he has downs syndrome, you know? So he clearly is not going to be able to go out and play soccer cause I, that's what I thought. Downs syndrome, so which, you know, obviously not ..... (Tina)

I remember, yeah. So I just think, like, oh my goodness. This is sick. She's gonna be sick all the time. She's gonna – we're gonna spend our life in the hospital. I mean, I'm not gonna – I don't know, maybe my dreams are not coming true. Or her dreams or something like that. So I was just crying and crying. I was like, oh, that's it. And then I remember thinking, oh please, let this be a bad dream. And just, I want to wake up. This is a nightmare. To be honest, I took it the worst. (Marie)

The above excerpts explain the well-painted picture by the mothers for their children are raptured. All the dreams and hopes these mothers had for their children with Down syndrome are not different from other mothers of children with no disabilities. With the diagnosis, these dreams and hopes suddenly become irrelevant and lost in their sadness. Another mother in the study had vividly described this type of loss as:

Your brain is picturing this a family picture in a frame. And now this person looks different than you thought they would. And then this gripping coming to grips with the idea that it never was that kid..... (May)

This psychological loss described by the mothers not only makes their babies look strange and different in their eyes, but also makes themselves feel different about being a mother to a child with Down syndrome (J. Gill & Liamputtong, 2011). The above excerpts have also suggested what Trainer (1995) claimed that the mothers tend to grieve the loss of their children and the family and life "normalcy" simultaneously which these mothers are typically not consciously aware of. Not being able to have a play date, play with other siblings, go to college, and spend time in their own house is indeed unacceptable in most families. Additionally from the perspective of a mother, such a loss may profoundly change how she views herself, how she performs her roles, and who she would like to be in the process of responding to the loss and coping with substantial interruptions in their lives and at the same time trying to raise their children with Down syndrome.

"Self" is seen as an essential part of us universally. It is something that we must all possess and a characteristic that we must all develop. Upon examining the literature about "self", it is not surprising that some argues self is an unformed and unfixed concept which tends to evolve and change over time; some debates that self is relatively stable; and others claim that self is comprised of multiple facets (Giddens, 1991; G.H. Mead & Morris, 2009; Terracciano et al., 2010). Drawing from the previous research about "self" and theoretical framework of understanding identity, the discussions about the identity (self) loss and rebuilt for the mothers of children with Down syndrome in the study are situated and contextualized in their narratives evolving around their daily activities and interactions either with their children or other people in their lives. This interactional approach acknowledges and addresses the development and transition of

identities through interactions over time (Hsieh, 2004). As I have shared previously in this section, the mothers in their stories were constantly referencing their "former self" while talking about their "new self" in their journey of raising their children. For example, one mother described her identity as following:

> So yeah, I do have struggles. Because I mean I know my role. I know, I know what, I did know what defined me prior to Brady and it's not what defines me anymore. And it's funny, you know, I had mention how different my home was and how, how organized I was and you know I'm not those things anymore. I was, and I'm not now. And I think it's probably for the best. You know, I've had to learn to let go of a ton, a ton. And yeah, some days I do look in the mirror and you know you kind of wonder if you're looking at the same person that you thought you were looking at. Because you, you know, you can see the same person but yeah, heart is not, I don't know. It's, it's bizarre to even try to explain because it, it doesn't make sense. Like I know I'm the same person that I was but I'm not. You know, like, I'm, now I'm Brady's mom. And Brady's mom come with a lot more than it did when I was Collin's mom. (May)

The above shared narratives from May's story explicitly demonstrated that identity change is not a one-time occurrence, but rather an over-time change. Her narratives also implied the multiplicity of identity construction. In addition, Understanding "self" with this approach allows the mothers in the study vocalizing their own understanding of self from their own perspectives and orientations. This ultimately enables mothers to reflect on who they are, whom they choose to identify with, and what they choose to be as they go through their daily lives. The analysis of the

narratives in the study outlines two major categories of identity loss pertaining to different types of psychological loss of their children at the early stages of grief: a) I barely recognized that person; and b) I just wanted to be his/her mom. I purposefully cited the original expressions from the mothers to capture their heart-felt identity loss.

A. 1. I Barely Recognized that Person

In all the interviews conducted, I didn't ask specifically the question about what the mothers were grieving about after being informed of their children's diagnosis of Down syndrome. The word of loss was not even mentioned in any questions. The concept of loss for their babies and their self were emerged to the surface naturally when the mothers were telling the stories about how they took the diagnosis and reacted upon it. For instance, one mother commented:

> I think more in the beginning I felt like it, you'll probably hear from people, it's more, felt like it was more like a loss. And I really felt like that. Like I, my healthy baby died. You know? My, my good baby died. (Tina)

Another mother in the study directly confirmed the loss of her son and further expressed the loss of herself.

> I remembered telling myself "I don't even recognize that person." Not to the point where I've lost myself, but that I'm not the same person. (May)

It is quite common we, as individuals, do not deliberately stop or pause to reflect upon the question of "Who am I?" very often when we go about our daily lives. But we tend to feel secure and anchored knowing who we are. Social identity theory defines personal identity as a set of idiosyncratic traits and personality characteristics (Hogg & Abrams, 1988). Not surprisingly we tend to believe that our certain personality traits or

characteristics are relatively stable given the truth that our sense of self is constantly evolving. Some mothers in the study were quite sensitive to and aware of the changes of their relatively stable personal identities or personality characteristics when their life encountered a disruption due to the psychological loss of their expected babies, and subsequent changes and challenges of taking care of their children with Down syndrome. Several mothers during the interviews articulated:

> Probably, if you would have asked any of my friends prior to Brady, "Who was the most on time, organized, detailed person, cleanest house that they knew, it would have been my name. And now, I'm lucky if I remember to pick up the kids up from school. (May)
>
> Mother: I looked back at pictures when I was pregnant, I barely recognized that person.
>
> Interviewer: You do see yourself different, right?
>
> Mother: Oh, yeah. I was sassy and nothing could hurt me. I was on top of the world, and then now I've been through so much in my life and now as you saw me now.....(Mary)

These excerpts from the interviews present us their well-understood and deep-believed personal characteristics loss pertaining to the loss of their dreamed children in a very indirect way. Grieving over their children with Down syndrome, shouldering extra loads of responsibilities, and wrestling with unanticipated challenges, the layers of their identities were peeled off one after another. In coping with the loss and the change, the mothers need to adjust their lives and expectations as the first mother claimed to be lucky to be able to pick up her child.

When examining the mothers' personal identity loss, it is critical to recognize that usually an individual's personal identity manifests in their social identity as well. In other words, we can't clearly draw a distinctive line or boundary that separates an individual's personal traits from their social identities, which is defined by the memberships of certain social groups. Thus the meanings of personal identity are constructed and understood within certain social contexts and through certain social interactions. Self is a social being, but not an isolated physical being. The self, described by the mothers deemed to their personal traits in the previous examples, also reflected their self in their designated social circles, such as friends, families and coworkers.

Narratives shared by the mothers in the study predominantly surround over their role loss, which leads to their identity loss in their own social space. In the previous discussion about loss and grief, we learn that physical loss, the tangible type, is easy to identity and the corresponding emotions regarding the loss is quick to be validated. In the opposite, the psychological loss, the intangible type, is relatively difficulty to discover and validation of emotions solicited from this type of loss is hard to be sought out. In other words, while the mothers in the study were grieving over the loss of their dreamed child, they were more likely grieving over certain hidden psychological loss, such as natural behaviors and interaction patterns they used to engage in their social space, or certain set of roles which they miss performing. All these are considered secondary loss imbedded in the grief over the major loss of their beloved children. Examining the stories, I have discovered that so many narratives of the mothers were

about their grief over the collection of secondary loss, which has a great impact on how they view their "self" while referring back to their former "self".

It is important to recognize that identity is not fixed. Rather, identities are multi-dimensional, multi-level social constructs to be negotiated within the parents' social network (Tracy, 2013). Hearing and analyzing the stories form the mothers in the study, their families, their friends, and their colleagues were all important parts of their life. How did they see themselves is always contextualized around these people. In other words, their social identity is reflected through who they have relationship with, who they interact with, and what roles they enjoy taking. In this sense, the collection of secondary loss that they were dealing with includes: self in friends' eyes, self in family circle, self in careers, and self in marriage.

A.1.1. Self (loss) in friends' eyes

When the question was asked about who they chose to share their children's diagnosis first and who they had received support in their grieving and coping process, their social network of friends were mentioned all the time. The friends comprised most part of their life before the birth of their child. It is amazing that these mothers noticed the dynamic change right away in their relationship and interactions with some of their friends. For example,

> I didn't go out that much with my friends. And they've had to do some adjusting as well around me because I won't talk about the same things. I won't see things exactly the same way that, you know, our friendships were built on. (Emily)
>
> And it's hard for me because some days I just want to shake people and say, "Why can you not understand where I'm coming from, why can't you see what I, you

know, that I went to three therapies this day and the pulmonologist for, you know, why can't you just understand that I can't go to dinner with, why does this have to be an issue." And I was a lot, I did have a lot more time, you know, prior to Brady, you know, my life was different, and I was able to see friends more, you know. We, yeah, we did a lot more than we do now. And I don't think they can, I don't think they can see the full picture so I want to shake them. And say put a camera in my house and follow me around town for a day, just a day. (May)

The narratives given by the mothers described how their interactions with their friends changed after they had the children. It is arguable that this kind of change will also occur to any women who just become a mother. However, it should be noticed that the mothers in their narratives implicitly expressed the nature of their interactions and relationships with their friends has dramatically changed. To certain degree, the mothers felt frustrated and not being understood. What the mothers really needed during that time is understanding, not defending themselves against the issues of why not being able to meet their friends for dinner, or not seeing the things their friends tend to see. Because of the diagnosis of their children, the mothers needed to manage lots of medical needs and grieve over their loss at the same time. As some of the mothers in the study mentioned that they didn't even have enough time to grieve on top of all other medical issues they had to deal with. They were busy and tired all the time. To keep up with or maintain any relationship or friendship, it requires you to invest your time and energy in. But to these mothers, that was too luxurious to do it. Eventually, some friends stayed and others became distant from their lives. Among the narratives about

friends, one mother told the story about how her best friend reacted to her child's diagnosis becomes the rapture point in their friendship:

> But I remember, she called me and then she's like, "Well, honey, I heard about it and I'm sorry. You know, God gives you sometimes good things and other times not very good things." And I'm like, "What are you saying?" Like, she's not a good thing? So I remember just – I didn't say anything because I was just listening to her but when I hang up I'm like, really? Especially because she had a baby a year before, right about the same time. So I was like, how did she tell me this? (Maria)

The above excerpt demonstrates that the mother didn't not only lose her dreamed child, but the best friend at the same time. This best friend in the conversation didn't not offer the support, instead devalued her loss and her child as well.

A.1.2. Self (loss) in family circle:

At the early stages of grieving process, the mothers of children with Down syndrome typically and heavily rely on their immediate families for support to cope with the diagnosis. Most mothers in the study felt very satisfied and blessed that their families were there for them when they needed. Their immediate families provided all kinds of support such as instrumental, emotional and informational support. In terms of who provided the most of support to the mothers in their families, the majority of mothers agreed that their own mothers were the ones they leaned over for help and comfort most of time. For example, several mothers shared in the interviews:

> Interviewer: So, in addition to your husband that who you had at that time for support, you know. Or was there anybody there that you felt was most helpful.

Mother: Um my mom, she had the same kind of you know "I'm sad for you." She is a retired special education teacher. My mom did a maters program on um where in the family dynamic does the Down syndrome child fall. And then here is her daughter, having this fella, you know. She said there were lots of great things about him. Yeah, so she was an incredible amount of support. (Lucy)

My mom, I will give her credit, she also didn't really have any experience with children with Down syndrome. She sure did a lot of research and a lot of reading and a lot of talking with people in the six months before Brady came around, so I will give both sides of the family credit for making an effort. (May)

I called my mom a lot, we talked a lot. Sometimes I just called her to cry. I have a wonderful mom. She would come over to take care of the stuff around the house, you know, cleaning up, doing laundry, cooking, lots of stuff..... (Teresa)

The support provided by their mothers during the early stages of grieving process meant so much to them. For some mothers, that harsh, sudden, and dramatic diagnosis of their children totally knocked them off. That initial shock could certainly paralyze those mothers and left them unable to function normally. Having the support from their own mothers actually helped them stand back on their feet.

Besides the support from their mothers, they also talked a lot about support received from other family members such as their brothers, sisters, and extended families. It is interesting but not surprising to see the different types of support offered between these family members. Their brothers mainly provided more of instrumental support. Their sisters had done both instrumental and emotional support. It is crucial for the mothers to have the support they need during the early stages of grief. The support

received from their family members absolutely reflects the relationship they have with those members. Generally speaking, the closer the relationship, the more support provided, which in turn helps the mothers to cope. More importantly, that close and positive relationship claims that they are part of the family; and they and their children are one of them as the other two mothers explained:

> On the day we found out the diagnosis, my family, my aunt and uncle were in town. And they, we tried going to dinner together. On the way there, we changed our mind, got off the highway, then we called them and said we can't go, we need to go back home. And after that it was like everybody that came up to us said, "This baby is a part of our family and we take care of our own." (Lucy)
>
> Yeah. I think that overall we've had just most people that know about him. Especially our close family have all just been like, "Hey he's ours. We love him to bits." (Kim)

However, it is not always the case that when the interruptions occur, in this case, the diagnosis of Down syndrome, the family will be immune from those interruptions, and the relationship among members will remain unchallenged. As a matter of fact, some mothers in the study experienced the other way around, which adds the relationship loss to the list of their psychological loss of their children. In their narratives, you could easily taste that disappointment, sadness, and loss. For instance, one mother in the interview recalled how difficult her mother made the situation and the diagnosis:

> I um, stayed up all night and sobbed and um then the next day, told my mom, who didn't react very well so then that made it a little bit worse. But as soon as I

> told my mom she said, "(gasp), what did you do? You were in that farm house, those cats died. What if, you know, you guys should have never been in that farm house. You shouldn't, you know, what, what was there that um did this to the baby?" And she's a nurse as well, but she still had that reaction where Down syndrome is not caused by anything except for genetic factors, but that was her reaction. So instead of having a, "it's alright honey, we'll get through this," you know, it was not, not what I was hoping for. (Tina)

The story Tina shared above regarding how her mother reacted to the diagnosis indeed adds extra stress and frustration on top of handling her son's diagnosis. She expressed her disappointment of not receiving the comforting and supporting message from her mother, instead, what she received was a blame or accusation. During the interview, I further probed to ask her how she felt about her mother's reaction. She commented as below:

> Well, I was very frustrated and I was very sad and defensive too, a little bit, because I actually went to asked the nurses what did I do, you know, how did this happen. I knew nothing of Down syndrome. Did I do this? You know, what happened? And they told me no and so defensively, I told my mom, it's not my fault, you know? I didn't do anything. But she, it took her a while to come around. (Tina)

Several other mothers in the study expressed their frustration of dealing with certain family members while trying to process and cope with the diagnosis. The frustration usually emerges from the lack of understanding and emotional support from those members. These mothers articulated that they felt singled out and more

disconnected to some of their families. They saw themselves different from other members because the relationship was interrupted or totally lost. These mothers described that compounding feelings of losing their dreamed child and seeing themselves drifting away from the family circle is heart-wrenching.

One mother in the interview shared an unbelievable story about the initial reaction from her mother after she was informed of her daughter's diagnosis during her pregnancy:

> Oh, I went right away. [After she was told that her daughter had Down syndrome] I think it was, like, two seconds and I was on the phone. And I called my parents and my mom – Bla Bla Bla. My mom was planning a baby shower for me at the time and she was like, "Well, should we stop the baby shower?" And I got really mad at her. I'm like, "Well, what the hell? Is this a baby?" (Corea)

The mother above insisted having a baby shower on her own for her baby. Later she explained that her mothers' response really hurt her feelings. From that point, she said she just expected things going different directions between her and the family. During the conversations with her, I could still remember how upset and resentful she was while talking about her mother. She recalled that her mother would go shopping for her daughter, but all beautiful clothes her mother bought for her daughter would only hang up in her mother's house. Fancy things such as cribs, toys the grandmother got for the little girl just had to stay with grandmother. Her daughter could only wear them and play with them when they visited grandparents. She made it very clear that her parents had hard time accepting the diagnosis and her daughter:

> I was angry. So what's the point of buying stuff for her, then she couldn't actually have them. When you go to my mother's house, Cindy got her own room with everything. She even built a wardrobe for her. I don't see the value of it. That's not for her. We just stop going to her house. It hurt so much. (Corea)

We could imagine what looked like in the end. The mother admitted that she hadn't been to any family reunions, holiday gatherings, or any celebration events in her family in last three years. She made it very clear by saying that, *"Now we are on our own!"*

Another mother in the study voiced her frustration and trust issues about her own mother in caring or babysitting her child. As we know, that trust is essential to any relationship:

> People always asked me, "Why he cannot eat?" To them it's so easy and natural, but they don't understand that kind of frustration. Eating stuff is really frustrating to me too. I've caught grandma coming behind me and putting stuff on her finger and sticking it in his mouth because she didn't believe me. I got so scared to leave him with anyone. What if they did the same thing to him, and that would cost his life, you know. (Mary)

What the mothers had shared in her story had also occurred in my own memory of that relationship loss between me and my mother-in-law while I was grieving over my son's diagnosis. Honestly I still could feel the pain, anger, and breaking up when I shared with her about the story that my mother-in-law refused my son's picture. All the early stages of crying, anger, sadness, and distraught are actually the compounding effect of everything that the mothers has lost in a very rapid manner.

The sadness about this mother-daughter relationship loss is not the only type of secondary loss discovered in the study. The relationship between them and their siblings is another escalated loss. Don't get me wrong here, most mothers' siblings were very supportive and helpful in the grieving and coping process. Some others had experienced tension and conflicts with their sisters in the mist of coping. The tension and conflicts are generally derived from what the mothers called "jealousy", "self-centeredness", and "judgment". For instance, one mother told the story about how she and her older sister had stopped talking and interacting due to her sister's immaturity in understanding her situation and her needs.

> I think I'm less tolerant with negative people, too. I'm just done with them, like my sister hasn't been great. She's always jealous that my mom's helping me so much and not spending time with her daughter. I just cut her out. I don't care anymore. I don't have time for all her drama. Yeah, I just stopped dealing with her. She always called for something that is so trivial to me like her daughter had choir concerts at her school. She had four of them in one month, and my mom was gonna be missing one because she was gonna be watching our kids. That was not acceptable to her, and I'm just like, "You're ten years older than me. Why are you acting so immature?" So just things like that, it just makes me more tired, so you just don't deal with it. So I'm all done with pleasing you. (May)

Another mother in the study described the deep felt tension between her and her sister-in-law. That tension emerged after the birth of her daughter. The mother's sister-in-law was in health care field and she couldn't get around of the idea of raising a child with Down syndrome. The mother recalled the short exchange between them two:

> I remembered that my husband's younger sister was not taking it well. When she came to visit me, she said she couldn't imagine how I could live with a child like this. She would make sure and do everything to have options. Once I heard that, in my mind, I said to myself that she was not asked for sure to babysit any of my kids. No way. I don't trust her. End of the story. (May)

A.1.3. Self (loss) in career trajectories

Unfortunately, these secondary loss does not come one after another at a given time with a warning sign. That's why you heard the mothers in their narratives saying that everything changed after the diagnosis of their children. The mothers in the study all were used to the roles they performed in their life. As I have described in previous chapter, the mothers who worked either part-time or full-time had totally stopped working to care for their children with Down syndrome. Those 16 mothers who worked before their children were born, they stated that they really enjoyed working and had certain visions in their careers. As a matter of fact, most of the mothers had decided to come back to work after their maternity leave. The diagnosis and the medical complications with their children had left them no choice to give up their career. But the decision didn't come along easily and it became an internal struggle to some mothers. The struggle came from the discrepancy between what they had envisioned and what had happened in reality. For example, one mother expressed:

> I was like all these moms balance all this stuff, and they are totally fine, they can do it. It's like I balanced working, and getting my master's, and doing this and that, this should be okay. And it was really, really hard for me to just give that up,

and say I can't do it, I can't do everything. I was stuck and didn't know what to do. (Angela)

What has been described above indicate that working or having a career is part of the mother's identity and that is how she sees herself over years, and she will continue seeing herself doing it in future even with a baby planned along the way. Some mothers recalled how proud and excited they were about their achievement in their career, and that was just blown away with the diagnosis of their children. One mother who was about to start her own counselling business after she completed her master's degree and fulfilled her practice hours regrettably commented:

I finally got married, had a family, done with my education and about to jump into a great career. Then this happened. Instead of moving on, I got stuck. I wondered what was the value of my education. No more private practice, this is my career now. (Kamilla)

Another story told by the mother also reflected the struggle about giving up their career. This is where I see Stryker's identity theory (Sheldon Stryker, 1987) come in play and explain how the mothers feel the way they felt debating whether to go back to work or not. The theory states that individuals have distinct component of self, that self is called identities tied to the roles the individuals play in the social space. The roles these mothers played before the birth of their children were also closely connected to what they did for a living. Somebody was a sales manager, somebody was a practitioner, somebody was a nurse and almost each mother had a role they perform in any profession. In this case, it's not surprising to see mothers of children with Down syndrome are more likely to subject to the role dilemma of being a professional or

leaving the profession to care for their children. One story told by one mother illustrated the dilemma:

> I tried to set up a time to talk to my boss, but she was just always too busy. I think her (my daughter) first initial heart surgery and everything kind of threw everything off. I didn't know what to do. You know, I was stuck. It's like I needed to take care of my kid, but then I felt like I was abandoning everybody, my coworkers, and that kind of stuff; just kind of leaving them high and dry because they were totally expecting me to come back. I had agreed on to help set up the new office..... (Angela)

The mother in the above story did end her career and spent all the time taking care of her daughter. The previous literature on families of children with disabilities has repetitively confirmed that mothers are the dominant caregivers to their children. In addition to the routine care for their children's daily needs, they have to manage the medical needs, handle therapies and later on educational needs. It's not strange that you hear the mothers always say that they don't have time, no time at all. As Rocky claimed in her narratives:

> I stopped working. I'm just starting to go back to work. So I'll be back to work part time. But I went from working 40 plus hours a week before, I worked my butt off. I never stopped working before Elle (her daughter). I felt that I had almost lost my identity. That, I just was it seemed like for the longest I was just in doctors' appointments and therapies and everything and what happened to Rocky? What happened to me? And it felt like I no longer had an identity. (Rocky)

To a mother who has been committed her time to the career before the baby comes, it is typically hard to make the adjustment to take care a newborn. It is extremely challenging for a mother of child with Down syndrome to digest the diagnosis and adjust to the numerous interruptions that lead to a dramatic change. The adjustment always comes with certain types and forms of sacrifice. To the mothers of children with Down syndrome, one sacrifice they have to undergo is to give up their career. According to Shearn and Todd (2000), mothers of disabled children work substantially less than those of other mothers. Moreover, previous research indicates that the employment status of a mother does not only affect the family financial situation, but also influence the mother's personal aspirations and her sense of self-identity. All the accounts collected in the interviews are the examples of identity loss caused by losing employment status.

A.1.4. Self (loss) in marriage

In discussing their initial reactions to their children's diagnosis, the mothers also talked about how their husbands responded to the diagnosis as well. In my first part of findings of the study, the initial reactions of fathers are generally described as more silent and less emotional comparing to the mothers. Some mothers were very concerned about their husbands' reaction just because they didn't scream, cry and get angry. They wanted their husbands to feel and express themselves the same way as they did, in that case, the mothers knew that they were feeling the same way, sad about the same thing, and devastated about their future. To certain degree, it is a comfort for these mothers to see their husbands' reactions echo theirs, which suggests that they are together for this. Other mothers in the study were so worried that their husbands would left or escape

from the trauma due to the diagnosis and foreseeing changes in their lives. The accounts from one mother directly highlight her immediate concern and worry that her husband would leave her because their daughter has Down syndrome.

> (After the diagnosis), I was sitting there, my mind went crazy, my heart sank, and there, I was thinking my marriage would be done. What Dick thought about this? He didn't wanna have kids, it was me. I wanted a baby so badly and just because of this, we went through counseling, other things, finally took us several years to have this baby. Now he must be mad at me. Just because I wanted a baby, not him..... (Teresa)

The excerpt above indicates a concern and worry of marriage loss for some mothers in the study. It is absolutely true and well-acknowledged that traumatic events such as the diagnosis of disability for their children, will really strain the couple's relationship or create tensions between the husbands and the wives. It is not surprising to see some husbands walk out the marriage and leave their wives and the children to move on. Among all the mothers interviewed, it is very impressive that all mothers survived their marriage except for one whose husband couldn't handle and cope with the diagnosis as the mother recalled:

> It was very difficult and I think put a lot of stress. A lot of stress. We are friends but I think that this was really difficult on that relationship which was not – how do I do this without being, like, overly personal about it? We didn't have a long and strong relationship before I got pregnant and so it was already built sort of on a little bit of a rocky place. And we made a valiant effort at it but I think the diagnosis affected me. I'm sure it affected him, but it affected me to the point

> where I didn’t blame him or anything, but it completely altered the course of my life in a way that initially I couldn’t quite get over with him. So, you know, we’re in a pretty good place in terms of being able to raise our son together. (Ali)

Certainly the mother, Ali, experienced the loss of marriage following the psychological loss of her newborn son. In her accounts, the stress of digesting and coping with the diagnosis of her son is overwhelming to both of them to the point that the husband couldn’t handle it any more. For certain individuals, choosing to escape from whatever they are facing is one of the most common coping strategies, and it is also an easy way out. As Ali mentioned, she couldn’t get over the fact that her husband had left her at the very beginning. Since then, one more loss was added to her life in addition to the loss of her son. During the interview, she opened herself up and cried while looking back to her son’s diagnosis and her husband’s leave at the same time. She described in her accounts that she cried so much and screamed so much.

According to the loss literature, having a disabled child considers a loss to the parents, whose healthy child never comes. Similarly in a marriage, divorce is a loss to the couple, whose husband or wife leaves. The identity of being a wife or a husband is determined by the mutual reflective roles the couple play and intertwined with their relationship. Let’s say, if the husband leaves, the couple relationship is not existing anymore. Then her identity of a wife disappears. The mother, Ali, quoted above had experienced the identity loss for a wife since her husband chose to leave the marriage. When she was grieving over her son’s diagnosis, she was also grieving over her identity loss as a wife.

The rest of 20 mothers in the study didn't go through divorce in marriage as Ali did. Nevertheless, they all experienced other types of loss in their marital relationship with their husbands. These loss includes the time spent doing things together with their husbands, understanding and support from their husbands. These are all important in defining the identity of being a wife.

The majority of mothers in the study agreed that they stopped spending time with their husbands at the early stage of grieving and coping process. Time seems to be a huge monster that robs away all things that a wife would enjoy doing with their husbands, to name a few, going out for dinner, seeing a movie, taking vacations, or just simply sitting around each other to chat. All these seem to be too greedy for the mothers. The following accounts from the narratives of the mothers indicate the loss of a wife's role in their marital relationship:

> Yeah, I would love to go out with my husband for the night and be crazy like we were, and now we can't even watch a movie because I'm so tired. The other day, he asked me, "You wanna watch a movie tonight?" "No, I'd rather go to bed. Good night." You know? You are tired, you have no time. (May)
>
> I just feel like we don't do things together. Even before we had kids, we did everything together. I mean, I still consider him my best friend, but I think about we'd get up on a Saturday, and we'd go for breakfast. We would just do stuff together. We did everything together. I would hang out with him more than I'd hang out with my friends. And I feel like now, we don't have the time. And we don't have a babysitter. And it's so expensive. By the time you hire a babysitter, and then if you do go out, and then I'm usually worrying about the kids because I

feel like if we do have a babysitter, do they understand everything about them? (Lucy)

After I had Sarah, I stopped my practice. We were told that she needed at least 2 or 3 heart surgeries. I couldn't work, but we have to pay the bill even with our insurance. Bill (her husband) just had to work long hours, and I didn't get to see him very often. Sometimes I really need somebody to give me a break, but nobody, he got home late and I was just lonely. We didn't even have the time to sit down for a meal. Those are long days. Now Sarah is 3, before she turned to 3, Bill and I had never gone to a restaurant together. (Kamilla)

These excerpts indicate that the mothers never got a chance to do what a typical wife does with her husband. Who doesn't like going to movies, enjoying a meal, and just hanging out with their husbands? Caring for their children with Down syndrome literally takes away their role of being a normal wife as other mothers of children without disabilities. The findings about their role loss as a wife could be explained by the salience concept in identity theory, which argues that an individual's particular identity will be determined by the person's commitment to that role and their interpretation of the contextual demands (Tracy, 2013). The mothers in the study generally commit most of their time and energy caring for their babies with tremendous demands. Those demands limit their role of being a wife.

Time issue is one side of the story that prohibits the mothers from spending time and doing things together as a wife with their husband. But there is another side of the story that deserves our attention as well. Several mothers in the study expressed their husbands' disconnection to their world, less understanding about their feelings and

emotions, lack of validation for their work at home. For example, the narratives given by some mother state:

> And I just feel like I get irritated with him more. I feel like we just – not that we argue all the time, but I just feel like he irritates me because he doesn't understand. And I just feel like we don't have that closeness like we used to. And I'm hoping that – I mean, obviously, we have to work at it. (Lucy)
>
> I cried a lot at the very beginning. My husband never cries and I think he doesn't like me crying. He would ask me, "Why you are crying?" He just doesn't understand. I tried so hard not to cry before him. (Ali)

We argued almost every day about everything. Something that I don't understand, why when he got home, he said he needed a break from his work. What about me, do I ever get a break? No. He went out to have a drink with his friends, I got to stay home with the baby. I just didn't get it, why he could just walk out like that? (Kamilla)

The above mothers are not the only ones who complained how frustrated they felt about the relationship and interactions with their husbands. Yes, for sure, the mothers are facing the time constraint in spending time with the husbands, but they still long for that closeness, that connection with the husbands. Even though the mothers bear most of caring responsibilities for their children, they still wish the husbands could understand what they have gone through on daily basis. The mothers actually seek more emotional support and validation from their husbands. From a wife's perspective, a husband should perform his role with these responsibilities.

A. 2. I Just Wanted to Be His/Her Mom!

One question in the study asked the mothers what they had envisioned of being a parent/mother before their children were born. The answers given by the mothers range from how busy they would be, what things they would do with their children, to how to care for their children. For those mothers who had more than one child, they tended to go more in detail telling me that they would do what they had done with their older children for the newborns. Others who were first time mothers, they usually referred to their own mothers to model parenting. Ultimately, two major beliefs are embedded in those narratives and hold deeply by the mothers: a) No mothers envisioned themselves being parents of children with Down syndrome; and b) They all believed whole-heartedly that once their babies were here, they became a mother.

Certainly no mothers would like to have this type of envision of having a child with a disability; quite in the opposite, they would like to indulge themselves to envisioning the exciting, happy, and surprising moment of becoming a mother to the child they've been waiting to meet for so long. Meanwhile, those envisions extend and expand to the future pictures of how their lives would look like, what dreams they have for their children, what plans they had designed for their families. Sadly, for some mothers in the study, that moment disappeared rapidly without knowing what really happened; for other, that moment had never come. The door to the expected motherhood seemed to be shut closed and the journey of the motherhood seemed to end abruptly. Everything then started going downhill. The baby was not the one they had just met, just held, just kissed, and just celebrated for a short while ago. That normal and healthy baby turned to a strange and unknown little person right there in front of

their eyes; then away went that strong-held belief and understanding of the motherhood – a typical and normal mother formerly perceived.

Upon the finding out and delivery of the diagnosis for their children, a parade of celebration to welcome the new addition to the family turns out to be a devastated mourning about the loss to the family. The mothers didn't get to take their babies home with them, instead, most mothers spent a period of time (ranges from several days to several months) with their newborns at the Neonatal Intensive Care Unit (NICU) for more tests or keeping them stabilized. The constant and regular hospital stays and visits deprived the bonding opportunity between the baby and the mother. The diagnosis of their children shifted their life course and what they had believed shattered into pieces.

In my interviews, the mothers strongly believed that our society in general still perceived individuals with disabilities in a very negative manner. They worried that their children would be stigmatized, stereotyped, and discriminated. The sad and helpless pictures of their children being laughed at, bullied, and isolated from the rest of their peers and the society were constantly depicted in their minds. Goffman (1963) identified a group of stigmatized individuals who are a particular stigma as what he called the "own" group. The other group is the "wise", that is considered to be normal people who feel they can related to the stigmatized individuals. In this sense, the mothers in the study fits perfectly into the "wise" group with the situations they are in. Ali et al (2012) claims that the "wise" also experience the similar loss and courtesy stigma as the disabled individuals and those with chronic illness. The stories and narratives offered by the mothers in the study were indeed no different from narratives of those individuals with disabilities or chronic illness. The type of illness these mothers

had is one that is called “deep illness” (Bosticco & Thompson, 2005) because the bodies, minds, and emotions of these mothers had remarkably showed the signs of the illness of bereavement. In my previous discussion about the initial reactions to the diagnosis, and the loss they experienced, the mothers were perfectly considered to be unhealthy and had lost the identity of self. Charmaz (2002b) argues that chronic illness separates the person of the present from the person of the past, and influences images of self-envision for the future. The mothers of children with Down syndrome in the study announced again and again that their former self had gone and they couldn’t recognized themselves (in previous discussion).

However, along with all types of loss the mothers experienced, the loss of the preconceived mother identity becomes an immense struggle they have to face while caring for their children. In other words, the identity of being a mother as others was spoiled; and this happens when an individual’s “actual social identity” does not match their “virtual social identity” (Goffman, 1963). The “virtual social identity” of being a mother after the baby comes to the world is always enacted in particular and socially agreed-upon rituals and heart-warming future dreams for the newborns. In the following passages, the expectations the mothers had of themselves and their newborns are discussed. The disparity between the “actual social identity” and the “virtual social identity” is discovered.

A.2.1. Self (loss) in the expectations for the newborns

One of the most exciting things that each expectant mother enjoys doing during that 10-month pregnancy is to weave dreams, craft hopes, and form expectations for their newborn. The mothers in the study went through the same route to indulgingly

create the perfect future picture for their children. For example, one mother noted in the interview:

> Yeah, I think I spent a lot of time, not so much thinking about how I would parent but as what kind of child he would be. You know, I really thought he would be super smart and super; you know, outgoing and athletic and sort of that – I know he was going to be a boy, so I just kind of had those classic perceptions about him..... (Emily)

The mother, Emily in her narratives explicitly expressed her expectations about her boy. In her mind, being smart, outgoing and athletic are the characteristics of the boy. With the diagnosis, the super smart part is taken away since children with Down syndrome have different degrees of cognitive impairment; being athletic is hopeless due to the low muscle tone that each child with Down syndrome is challenged physically.

> I picture myself like, maybe like taking her –like very happy, you know? Because since I don't work, I'm a stay-at-home mom. Taking her to classes, you know; like ballet class, like gymnastics, whatever. And then going, you know, meeting other mom, having play days. I think, of course, going to school and going to college and all this. And getting married. And the whole, you know, the whole fairy tale. (Maria)

The above excerpt displays the mother's expectations for the activities, education, friendship, and typical life course that her daughter will engage in. With the diagnosis, all these expectations and hopes seemed to be impossible. In her narratives, she called what she had hoped for her daughter a fairy tale, which implies that these hopes would never come true. The mothers who had more than one child in the study

also had a set of future expectations and hopes for their newborns and their older siblings. For instance, one mother raised her concerns about the brotherhood of her boys:

> This changes the whole game. This changes everything. This changes our future. Now we're going to have this child with us forever. Now we're, he's not going to be able to play with his older brother. I thought they were going to be best brothers, but now they're not. You know, I, um, yeah. Thankfully, I think I got passed that soon and just tried to focus on the positive. (Tina)

In the narratives of Tina, the mother sincerely expressed her loss about seeing the brothers play as other brothers and having them be each other's best friend. The brotherhood is considered to be an essential part of the boys' lives during the course of growing up together. Some mothers in the interviews indicated that one of the reasons of wanting to have more than one child was to give a companion to their only child and a friend to grow up with. As a matter of fact, most of mothers had a relatively large family with several siblings to grow up with. They enjoyed the relationships with their own brothers and sisters. When it comes to their own family, that influence of brotherhood and sisterhood is so strong that they want their children to experience that as well. As Tina expressed, the diagnosis of Down syndrome challenged and distorted her preconceived idea of what the brotherhood really meant.

A.2.2. Self (loss) in the expectations of desired physical interactions with their newborns

Nothing is comparable to the joy and excitement that a mother experiences on the moment she gets to hold the newborn in her arms. That joy and excitement plus

content, satisfaction and fulfillment of being a mother continues to manifest in a variety of routine interactions between the mother and the baby. There are a series of socially constructed and deeply shared physical interactions that are expected and longed for by a mother. These include but not limit to bringing the babies home, cuddling them, nursing them, kissing them, talking to them, smiling at them, bathing them, and playing with them. The mothers in the study were in no exceptions in expecting all those interactions with their children and were ready to begin the bonding process immediately. Unfortunately, the majority of the mothers encountered huge interruptions and obstacles while desperately trying to establish the physical interactions with their children due to the medical complications of the diagnosis. These complications range from congenital heart disease, thyroid disease, seizure disorders, congenital intestinal obstruction, Hirschsprung disease, sleep apnea, celiac disease, hearing and vision loss, hypotonia to leukemia. Among 20 mothers, only 4 mothers of children with Down syndrome did get to take their babies home after one or two days of hospital stay. The rest of the mothers remained in hospital because their babies had various medical complications that required further observations, diagnosis, and procedures. For some mothers, the stay was just a week or two; for others, the stay lasted for months. Neither short nor long stays in hospital, the mothers felt fearful, stressed out and empty. Given the fact that they hadn't had enough time to process and grieve the diagnosis of Down syndrome, suddenly they were crushed again with second round of crucial delivery of medical crisis for their babies.

In the interviews, I asked the mothers to recall what stressed them out the most at the early stages of the grieving process. The medical issues and concerns were the

major stressors. Because of the medical issues, the mothers didn't get the opportunity to experience and enjoy the long-expected physical interactions with their babies. What they typically got was just watching their babies in the cubical warmer at NICU. For example, several mothers in the study recalled:

> So as a new mom I was grateful that I had him. And so I guess my grief was more looking at people who could just have a baby, take the baby home and just be together. (Cathy)
>
> He was fine when he was born. The Apgar score was 8 and 9. Then 15 or 20 minutes later, they noticed that he started turning blue and had hard time breathing. They rushed him to NICU and I had a C-section with lots of pain medicine. I couldn't walk down there. I was so scared and I thought he was gonna die. They finally wheeled me there to see him. My heart sank when I saw him all tube up. I cried and cried and helpless. He stayed there for two weeks and came home with us with a breathing machine. That was hard..... (Tina)
>
> I was under lots of medicine and when I woke up, my husband told me the diagnosis of Down syndrome for him. I burst into tears and asked to see him. He told me he was at NICU and the doctors suspected him having a heart problem. I was like, like I didn't get to hold him, you know I was asleep because of the medicine. (Maria)
>
> She was born with a very critical and scary heart condition. We were told during my pregnancy we needed to fix her heart, maybe, they say, several weeks after she was born. Then this happened, they said she couldn't wait that long, they flew

her right away to Ann Arbor for the surgery. I was scared to death. My husband drove there to meet them. I had to stay, I had a C-section..... (Kamilla)

The above accounts in the mothers' narratives suggest the loss of the desired physical interactions with their babies. The early anticipated picture of going home with their babies and holding their babies in the arms was ruptured. Instead, they sadly watched their babies being taken away for treatments and surgeries. As the mothers recalled, they were just not together and that hurt them so much.

The mothers in the study all expected to breast feed their babies and they considered it a significant part of mothering experience. It is also extremely important to help the mothers bond with their newborns. As a matter of fact, expectant mothers are all encouraged to breast feed their babies not only just for bonding, but also for the health of the babies. Not being able to nurse the babies was a huge frustration the mothers expressed. For instance, one mother commented:

> I think it was kinda back to that feeding stuff. I think you have expectations that you'll go home and you'll have this baby and you'll nurse this baby and it'll be great and whatever. And it just didn't go that way. And it was just so much harder than I anticipated. But, yeah, really I think it always came down to the feeding issues for me. So I was a little bit resentful of the situation just because here I am with this stupid pump and it's making me hurt and it's frustrating, you know. I finally stopped pumping at 5 months. I am so sick of the pumps. (Cathy)

There were only 5 mothers in the study who nursed their babies, the majority of these babies had no health complications as severe and critical as other babies. It should be noticed that babies with Down syndrome have low muscle tone. It is usually difficult

for them to “latch on” for feeding at first. Additionally, these babies tend to be sleepier than others. Usually it requires more effort for the mothers to keep trying to get them nursed.

Cathy, the mother articulated her resent to the pump, and frustration of not being able to nurse her baby boy. This was not what she anticipated as a mother. Thus, one of the expectations of being a mother is to being able to nurse your baby. We could clearly sense her loss in her narratives.

Another mother also identified a commonly seen and practiced routine for her and her baby was of great importance, but did not get performed. Having a baby first, showing your baby to others and taking your baby to places are what mothers tend to expect. Taking the baby out gives the mother a chance to claim to the public that she is a mother:

> Honestly, Will really never left the house until he was about 8 months because he was so susceptible to RSV with the heart and we spent 8 weeks in the hospital doing heart surgery. So lots of time to recover, but it was hard because you didn’t really get to be- you were a mother at home, but you know how you’re proud of your child and you want to take them to places or you see moms go to the zoo or - that definitely was what I wanted to do, but I couldn’t. (Kim)

The loss of the physical interactions discussed in the above accounts from the mothers is remarkably important in defining what the motherhood is in their eyes. It should be pointed out that on the one hand, the medical issues interrupt the normal and expected bonding process between the mothers and their babies; on the other hand, the medical treatments, procedures, and equipment really takes away the images of a baby.

The mothers in the study talked about how difficult to see their babies being tubed up, taped up, and covered up after surgeries. One mother shared:

> When my husband wheeled me into the NICU, I saw this poor little thing laying there, eyes closed, there were tubes everywhere. She was constantly poked on her feet for blood testing. I couldn't believe she is my baby. Her face was taped up, she got Ng tube for feeding, oxygen tubes, central lines and all hooked up with monitors. It's hard to explain the picture, there is no word to describe what I saw. Or I could say it's hard to see a baby there. And you felt very strange. (Kamilla)

With the description above from the mother, can you imagine how hard it will be for her to try to hold the baby with so much medical stuff in between! As she admitted, the baby was buried under those medical equipment. That's why she didn't see a baby. In this sense, the medical stuff not only makes the baby look strange and different, but also serves as a barrier for mothers to enjoy the babies physically. The following accounts vividly explain how the mother felt about holding her baby:

> And I still just, I have my moments is she's up in the middle of the night, keeping the oxygen on, and at that time, she had a heart monitor, and you look at your baby who is 2 months old and is tubed up and with monitors and you can't even go and pick her up right away to comfort her. When you hold her, you always worry about whether the tubes are in place, whether the monitor is working? It's all stressful..... (Rocky).

Now let's turn our attention to those mothers who did get to take their babies home because their babies with Down syndrome didn't have the complications of medical issues. It's reasonable to think that they would have more physical interactions

with their babies, and experience less difficulties in bonding with their babies. That does not mean they are free from frustrations in seeing who they are and who their babies are when they began the journey. These mothers did experience similar frustrations as others did. When the other mothers were kept in hospitals with their babies, these mothers went home and started early interventions and therapies for their babies to reconstruct a potential future in the long run. The frustration still remained as that they couldn't enjoy the baby as typical mother. For example, one mother complained:

> Yeah, the feeding thing is crazy. And we did have to stop feeding therapy because it was just crazy. It was so crazy. What the Early-on people wanted to do was teach me to do the things but I already had way too much to learn. You were busy with stuff, but not with your baby. I swear to you, if one more therapist told me, just do this while you're changing his diaper. You do that while feeding him..... I mean, we could have had a 50 minutes diaper changing routine if I did everything they said I was supposed to do when changing his diaper. So that kind of stuff got irritating. And then all I wanted to do was enjoying him, but I can't. I just wanted to be his mother, you know? (Ali)

What Ali shared above in her accounts, I believe, is what all the mothers in the study are seeking for. The journey of being a mother entails so many expectations and challenges for the mothers of children with Down syndrome. We learned previously that an individual's virtual identity is about the expectations one might have of himself and herself. So far, the excerpts from the mothers' narratives and stories demonstrate that these mothers want to be a mother of a healthy, smart, and athletic child; a mother

who will witness her child graduating from college and walking into marriage; a mother whose children are wonderful loving brothers and sisters; a mother who will take their baby home holding him or her in the arms; a mother who will nurse and show off the baby; and a mother who will spend time with the baby. However, the diagnosis of Down syndrome for their children changed the expectations they have for their children and for themselves. The claim made by the mother, Ali, in the above excerpt accurately displays the disconnection or disparity between their virtual identity and their actual identity. In this case, self, of being the mother as they expected was gone or spoiled. In the same manner, the understanding of the motherhood is contested and problemized. For example,

> I would say the first 6 months of her life was learning how to cope and learning how to understand and going through that grief. And learning how to be a mom and how to be a mom to her in particular and how to approach this whole business of Down syndrome. (Angela)
>
> I just know that everything changed the minute that she came into our house. I just remember our house was never the same and not in a negative way necessarily but I do feel like and I wonder how to describe that in particular to myself as being a different person. I feel like a totally different person because now I'm a mom, you know, so it's I feel different in that way in terms of being a mother of a child with Down syndrome, that's how I'll never want or know. I don't know how to do it! (Emily)

These narratives from the mothers illustrate the meaning of the motherhood is changed or distorted by the diagnosis of their children and the compounding medical

complications. That once strongly-held belief of what defines a mother is not helpful to the mothers of children with Down syndrome; in the complete opposite, it creates confusions and challenges for the mothers to makes sense of their new identity of mothers of children with Down syndrome. Kelly (2005) raise the same concern that many parents of impaired children face a set of challenges in understanding the relatively taken-for-granted sense of what means to be a "parent".

In discussing the analysis of the narratives of the mothers, it is evident that at the early stages of grieving process the mothers in the study were grieving over their psychological loss of their babies, but also grieving over their own identity loss as a friend, a sister, a colleague, a wife, and most importantly a mother. All these roles they are expected playing undoubtedly defines who they are. With the diagnosis of Down syndrome for their children and medical complications, the mothers in the study always suffered from deciding who they wanted to be as described in the following excerpt:

> I feel trapped. You know? I can't live my own life at all. Not have any identity at all. And I'm anxious all the time that if I do sometimes choose to be myself and I'm actually choosing to let the possibility of her dying happen. And I can't live with that. And it makes me cry..... (Kamilla)

The above example painfully shows that the mother couldn't be the person she wanted to be. She couldn't help with the situation and she didn't have the choice and control over what she needed to face very day. As Thompson et al (2003) argues that the experience of chronic illness or disability strips away multiple sources of an individual's perception of control with the individual's own life. The individual's need for control is another dimension of an individual's identity. Hearing and analyzing all

the accounts in previous passages about the identity loss for the mothers, we could obviously see that they all lost control over numerous things and aspects of their life due to the diagnosis of their children. They couldn't get the dreams they had for their children back; they couldn't fix the medical issues their children had to dealt with; they couldn't take their children home enjoying them as other mothers; and they couldn't continue their careers. The loss of control over their lives during the early stages of grieving process made them lose their confidence and competence in taking care of their children. Some even claimed to be a failure.

> But it was still – like that first time we had to change her Ng tube I'm like, I don't know what I am doing. I'm not – they showed me once in the hospital how to do this. There were definite moments where I wasn't sure if I was doing everything right. And then she came home with second heart surgery, I felt totally incapable of caring for her. (Angela)
>
> Every time I tried to change his feeding tube or cleaning up the site, he coughed, gaged. He is looking at me like, "Why are you doing this to me?" And I think the worst probably was peeling the tape off and putting the tube in. But I remember being in the room, and just like jumping up and down like, "I can't do it! I can't do it anymore!" I lost it. (Jessica)
>
> What's the word I'm looking for – confidence? Because you know, you feel so unsure of yourself, and am I doing this right? And it's hard seeing your child on oxygen, and all of a sudden, one day you're sent home with him. So I think my confidence level as a mother certainly was not there for a long time. (May)

> I failed my mom, my husband, my family, everyone. Because, oh, you have a kid, yes, but she has problems. And I was like, okay, I'm failing to be a mom with a typical kid. How can I fail this? You know, especially if you live in a society or you grow up when you have to be, you know, like, not perfect but always trying to do your best. When I was growing up, I always – I'm the oldest one of five siblings. And, you know, I was always the one with the best job, the best grades, everything. So it was like, all my best was gone, I couldn't even do anything to change it or make it better! (Maria)

At the early stages of grieving over the loss of their babies due to the diagnosis, it is common to notice that people around the mothers and the mothers themselves generally agree and recognize the identity loss of being a typical mother as others to their children. The analysis of narratives in this session reveal that typical motherhood identity is not the only type of identity loss experienced by the mothers. As a matter of fact, the mothers were undergoing and suffering from a collection of identity loss. These loss adds the compounding effect into the grieving process. In addition, these loss usually occur simultaneously without awareness by the mothers; which inevitably push the mothers to the edges of losing confidence, hopes and controls over their lives. The frustration and dilemma of not being able to be the person they wanted to be, in this case, being a stranger to their children and an unknown person to themselves perpetuates themselves to perceive their lives as a total failure.

B. Forming the Transitional Identities: Coping with the Loss and Everyday Challenges

All mothers in the study acknowledged that they definitely went through the grieving process such as denial, anger and depression. The only difference among the mothers about their grieving process was that for some mothers the early stages of grieving process lasted relatively short (e.g. several weeks to several months) comparing to those whose grieving process extended more than a year. The mothers agreed that they really needed time to grieve over the loss of their babies, even though they didn't articulate that they were simultaneously grieving over the collection of the secondary loss which is ultimately and closely related to their identities.

All the accounts or narratives of the mothers in my interviews didn't identify or recognize each specific stage of their grieving process with a clear time line. We have to understand that those early stages of grief were actually very chaotic and the mothers were often in a highly emotional state of mind, which is quite natural to lose the sense of time. That is where you heard the mothers described as if the time stopped right there, and days seemed to be as long as years. It should also be pointed out that neither did all mothers go through each stage of grieving process, nor did they follow that particular stage orders. Nevertheless, the deep experience of grieving over their loss over time helped to bring them back to the reality check, that is, times goes by, and their life needs to move on. When I asked the mothers how they understood parenting after they moved on from early stages of grieving of being denial, angry, despaired, devastated, and hopeless, the overarching response or answer offered by the mothers could be well described as what one mother claimed, "It doesn't feel like parenting at all!"

So far in the analysis of the narratives of the mothers' at the early stages of their grieving process, the mothers generally perceived their children being different from what they expected, they also viewed themselves as an unknown individual to themselves and a stranger to their babies. Their narratives were so powerful and undeniable to break the truth that they didn't possess the identity of being a real or a typical mother as they anticipated. Birenbaum (1970) argues that parents of children with disabilities may go through cycles of experiencing different affiliations with their disabled child, feeling more comfortable and willing to bear the burden of a courtesy stigma at certain times than at others. The affiliations the mothers in the study experienced with their children at the early stages of grieving to certain degree, were described as strangers not mothers. When they moved on with their lives of having their babies home to cope with daily challenges and provide care to them, they had experienced a different set of affiliations created between the mothers and their children. It seemed to be a seemingly argument that they got to be somebody or someone in the mist of their chaotic lives. In this sense, I argued that the mothers were actually forming a set of transitional identities which helped them to make more sense of their life experience and prepared them to finally reach the acceptance stage of their children and their own life. Upon analyzing the narratives from the mothers, three set of transitional identities were discovered: a) mother as a personal healthcare provider; b) mother as a resilient fighter; and c) mother as a knowledgeable educator.

B. 1. Mother as a Personal Healthcare Provider

Taking home a sick baby with critical medical conditions was an overwhelmingly dreadful experience to the mothers in the study. Most mothers

interviewed had voiced that enormous fear they had to face when they were told to handle the medical care of their babies after they got home. They were already stressed out just by watching their babies suffer at NICU, and now they were own their own performing all kinds of required medical care to their children alone without any assistance of professional care providers. What typically happened was that medical staff in hospitals would train parents in using oxygen machine and vital monitors, practicing Ng tube insertion, operating timed-feeding pump, and delivering all kinds of medications. Parents, particularly mothers were the ones who were put on the spot of taking care of all these medical care routines. They had to continue doing all these until some of the major medical issues could be resolved later on through surgeries. Additionally, the mothers were responsible for keeping up the weekly doctor visits and early intervention therapies. Ultimately the early stages of not knowing who they were and what to do with their lives, now shifted to shouldering medical responsibilities of their children without an escape. One mother in her interview claimed:

> In some ways, it doesn't feel like parenting. It feels like monitoring. You know, you haven't had a, we haven't quite, now we're almost there, I feel. But we're not quite there as where other parents are yet. We're still hospital staff and caregivers and on-call nurses and doctors and therapists and researchers. And I don't feel like a parent very often. I feel like I'm trying to keep a life alive all the time. (Corea)

In her excerpt, she directly stated that what she was doing was definitely not what a typical mother would do. She also indicated that being a mother to her was a different, longer but difficult process than she anticipated. She claimed that she was not quite there yet; she compared herself to other mothers of children without Down

syndrome and medical issues again confirmed her current identity was shifted to be a medical staff instead of being a mother. In her narratives, there was a slim of hope and light she saw and felt about – they are almost there.

All the identities the mother believed of having really summarized the general feelings about the majority of mothers who had to deal with medical issues of their children with Down syndrome. What they were taught to do for their children was the duties of nurses, but this nurse didn't work by shifts, always was on call and needed to be ready at any minute. If things didn't go well, then they had to be a doctor trying to diagnose about what went wrong. To certain extent, they were no different from doctors because what those doctors do is to keep people alive; and this was exactly what the mothers were doing at home with their babies. Another mother commented:

> And to me I see that not as parenting and I see what we're doing as just trying to keep her alive and safe and get to the next step (Usually the next step is to have all needed surgeries done.). So I only see things in small increments. Today, and tomorrow. I don't see 8 years, 9 years. I'm not thinking about her graduation or where she's going to college or who she's marrying. (Maria)

The above accounts confirmed that those previously possessed expectations and hopes for her daughter's future were absolutely died out. The once-believed typical mother identity was not there anymore. The predominant and crucial role she needed to perform was to keep her daughter alive as the commitment for a professional medical doctor has for his patient. Another mother in her narratives summarized her parenting experience as the following:

> I don’t know if things have been – I mean they’ve definitely been different than what I thought. I didn’t realize in two years she would get so sort of like, you know. (She survived two open heart surgeries.) I felt like I had a degree in cardiology and therapy. I know it was gonna be lot of work. I didn’t know it would be this mentally tiring. (Angela)

Regardless of whether their children had a critical medical condition or not, the mothers were all involved in therapies offered from the Early-on intervention program which teaches them simple and relevant stuff to work with the children around the house to help them reach certain mile stones and minimize both cognitive and physical delays. As a matter of fact, this once a week home visit or therapy was considered way too less to help the children moving toward the pre-set mile stones for any of their babies with Down syndrome. Therefore, the majority of mothers were advised either by the pediatricians or the specialists to engaging in more therapies, such as Occupational Therapy (OT), Physical Therapy (PT), Feeding Therapy, and Speech Therapy, to minimize or counter against the foreseen delays. The mothers showed up to those therapies, learned the techniques, and were told to practice those with their children at home every day in order to see the effect. Adding to their previous identity of medical staff, now another layer of identity was added on, the personal therapist to their children. For example, one mother expressed in great frustration:

> We had done several session of intensive feeding therapies trying to get him to eat. When we did that, you know, we didn’t have a lot of time, instead of going down there 4 times a week, you know having feeding and PT done, it was just insane. I asked the Mary Free Bed to schedule back to back, you know, to save

> time, only going down twice and got them all done. But the frustrating part was he didn't gain weight, you went back to the doctor's office, they weighed him, you know, nothing, not an ounce; they asked how I did the stimulation to his face, tongues, and lips at home. It was just crazy. I couldn't keep up with. They always said easy, 5 minutes here on her lips, 5 minutes there on her face, 5 minutes here to stretch a big C. I admitted, I didn't do it every day before every feeding, you know, there were days I couldn't get myself together. You know what I am saying? I don't want to be his therapist, that's why we paid money to have them do it. (Tina)

A typical mother does not need to worry about doing everything to keep their child alive; a typical mother does not need to learn extra therapies to ensure that their child will reach the designated developmental mile stones. Instead, they will take most of their time in adoring their baby, studying their baby, and playing with their baby. To the mothers of children with Down syndrome in my study, these were not part of their job descriptions at all. Their role responsibilities were more align with the medical staff.

B. 2. Mother as a Resilient Fighter

In addition to perform the roles of professional medical staff to keep their children alive before they could receive or handle the required surgeries, the mothers in the study had to become somebody who was armed with resilience, bravery, and persistence to fight for whatever they children were entitled to receive. During interviews, the majority of mothers deeply and painfully shared one of the toughest things they had to prepare to deal with all the time when it came to the care for their children, that is, fighting to get their children off the label of Down syndrome. Please do

not take the mothers' desire in a wrong way. Yes and truly their children have Down syndrome. But that does not mean their children should be just treated as a category, not an individual. In the narratives, the mothers voiced their concerns that their children were deemed to be a minority in the society. Not surprisingly, Saxton (2000) concludes that individuals with disability are considered to be a minority group which subject to the same forms of discrimination and stigmatization.

The biomedical framework of understanding disability prevails the view that disability is the outcome of biological impairment, which distinguishingly reflects the biological determinism, and in turn legitimatizes the commonly seen list of potential medical issues a child with Down syndrome would have. With this belief, the medical problems that a child with Down syndrome is battling with are normalized and to certain extent trivialized by the medical community. Basically it claims that if your child gets sick very often, it is just because he has Down syndrome. Over time in my study, I heard the resentment and disappointment the mothers expressed while they were trying to convince the doctors that something was wrong with their children and they deserved immediate medical attention. The answer they got quite often from the health care providers was because the baby had Down syndrome. The following story was from the mother who had to argue against the doctor's rationale regarding her baby boy's vomiting issue; and challenged the doctor with evidence to prove that the doctor should not normalize her son's condition without paying attention to the individual difference.

> You know, but he (my son) drips at night, and he's uncomfortable when he eats, and so then he can't sleep because he's like, "Uhhhhh" – I went to the GI specialist,

and all he says is, “Well, one day maybe he'll outgrow that.” “Uhhhhh” – and that was really hard, and so now I'm gonna go to a different specialist at U of M to see if someone can actually.....Everyone's like, “Well, one day.” I'm like, “No, I don't believe that.” We've been doing this “one day” since May. I'm like, “It's not.” I was telling the doctor, “He's vomiting, he's vomiting, he's vomiting.” Weeks, like 17 weeks, and “It's just reflux, Mom. In general, kids have this. With Down syndrome, he is more likely to have reflex.” I'm like, “It's not.”

I'm like, “He's painting the floor, literally the floor from where it starts there, the wood floor, all the way to the window would be all formula from one vomit. He would just be like, ‘Bleearrgh.’” It wasn't a little bit. It was all over the floor, and finally I took a picture of it. I'm like, “This is what he's doing. This is not reflux,” and then they're finally like, “Oh, yeah, that doesn't look like reflux.” I'm like, “I've been telling you.” So that stuff's tough, so when a doctor says, “Oh, one day they'll outgrow it,” or “Because he had Down syndrome,” I get angry. I'm like, “I'll go to the next one, then, someone that'll actually help me because obviously you don't care about him.” He just ..... (May)

Toward the end of the conversation, the mother claimed that her son was off the radar so many times because the doctors didn’t listen to her or treated him as what the label of Down syndrome suggests. In order to prove that her son didn’t have the normal reflux, she had to present her case with evidence. She had to fight, not just once, but persistently to convince the doctor that he was wrong. Another mother in the study had the similar experience when dealing with the eye doctor regarding the vision prescription for her daughter.

> When she was about 8 months old, we were referred to the eye doctor to get her eyes checked out. I was sitting there holding my daughter, she showed her different patterns, then, you know, squeezed eye drops to her eyes, she struggled and made a fuss about it. Then, out from nowhere, you know, she turned around and said, "Young lady, you just got yourself a pair of glasses." What? You know, I was, really an 8 month old baby wearing glasses? I couldn't picture that, I just asked her, so, so "What made you say that?" uhh, and "What's your proof?" She didn't give me a complete or satisfying answer. Then, you know, in my mind, I told myself, I needed a second opinion. I left her on that day and sought a second opinion, guess what, she didn't need that glasses at that time. And we never went back to her. (Kim)

Both mothers from the study had to make themselves stand up to either spoke for their children, or protect their children. While dealing with medical complications about their children, the only mission that each mother had was to make sure they were alive or not suffered. Additionally, some mothers had to fight with other groups besides the healthcare providers, which was described as equally stressful and frustrating experience. The insurance coverage for the medical care needed for their children was another hurdle they had to fight over to spare them from the burden of medical bills. As the previous research shows, financial burden is a huge stress for families of children with disabilities; and it only gets worse when the mothers withdraw from the working force. All the physical and psychological stress experienced by the families of children with disabilities cannot be attributed to the diagnosis of and the actual care needed for the children, but also to the constant fights and negotiations with different entities to

ensure the needs of their children. The following narratives from a mother who had fought her fight with the insurance company to demand the coverage for her son's treatment added another ordeal to her role as a fighter.

> And that's with Family Tree, we're paying all that out of pocket, and I asked our insurance, "Why are you not covering?" They said, "Well, they won't work with us, it's not we won't cover them. They won't work with us." I'm like, "Why do you think they won't work with you?" Because insurance only will pay half of what they need kind of thing, so it's tough that insurance has to dictate a whole bunch of stuff like his therapies. Why is insurance telling me what we can and can't have? That's so frustrating, too. We just got another bill from U of M still, and his surgery was in May. Oh, you still owe us another $800.00, and so I'm on the phone with insurance. "Why aren't you picking up this $800.00?" "Oh, well, it's – they charged you X-rays twice." I'm like, "They probably did it twice because he couldn't breathe." He needed. Me and my husbands had to do this all the time, we didn't take the no answers right away. We always call to demand the rationale. (May)

B. 3. Mother as a Knowledgeable Educator

In addition to being the medical staff and fighter for their children, the mothers in the study also commented that they had to learn so much information regarding everything that their children were going through. For the mothers who had no or limited knowledge about the diagnosis and the future outlook, they chose to read ferociously as much as they could to help them understand what was really going on and gave them a perspective to make sense of the whole thing. For the mothers whose

children were suffering from various medical complications, they researched madly about treatments and possibilities. For those mothers whose children were about to start pre-school or early-childhood education, they sought information and help from all kinds of organizations and workshops to educate themselves about what to prepare. One of the mothers clearly depicted that her life was going by stages which was determined by the needs of her son. Usually these stages are long and inquire lots of learning to be able to move on.

> It's just the journey, and we just keep going because that's what we need to do. I just always think that if we get through this, we'll be good. Then it changes. Like it was, "We'll get through heart surgery, and we'll be good." Now it's, "As soon as he eats, he'll be good." And then it'll just be the next thing. It'll be the school giving me a letter..... (May)

As shown above in the narratives, what the mothers/parents have to deal with at different time periods actually changes based upon the needs of their children or the situations they have to face. When it comes to the routine care, the mother becomes a personal healthcare provider; when it comes to the overlooked medical issue/need, the mother becomes a resilient fighter; and when it comes to facing the situations that demand the mother to educate themselves and others around, the mother becomes an educator, a very knowledgeable one. Among the interviews, I constantly heard the mothers mentioning that they had learned quite a lot over time in the process of coping with the diagnosis. Sometimes, they were stunned that they had never thought about they were able to learn so much in life before they had their children. One startling fact shared by the majority of mothers in the study revealed that the mothers were the ones

who were willing to devote themselves to get educated on all aspects of caring for their children. As one mother commented in her interview:

> Yeah, I still feel like that sometimes because there're still things where I feel like I have to deal with all – I took him to his appointments. He (her husband) didn't do any of that. I read all the handouts. If I asked him to read, he would say, "You read this", like this is stuff we need to do, these are behavior issues. I go to the workshops, conferences. He doesn't go to the conferences or any. (Lucy)

It is common among the mothers in the study that they were trying to take any opportunity to educate themselves about a variety of topics evolving around Down syndrome. Those topics range from medical care, intervention programs, community available resources, financial management and investment, and specialized workshops on particular issues. The mothers brought home the knowledge and information to better care for their children. We would assume that the information would be shared and relayed to their significant others. In reality, the information is usually digested and only stays with the mothers. This happens because most of husbands wouldn't take the lead in educating themselves and deemed the responsibilities and expectations to their wives. One mother commented in her interview:

> He does not read anything. He does not take them to any doctor, therapy, support groups, no. I always go to workshops and seminars by myself. I asked him to read, he said, as long as you know it, it is good. I got frustrated, I even highlighted the part, I wanted him to read. No, not reading it. (Tina)

Since the mothers were doing all kinds of learning to cope with the diagnosis and caring for their children, they were more knowledgeable than their husbands. The

responsibility of educating others around them automatically fell upon their shoulders. Most of the mothers in the study didn't actively seek the opportunity to educate others about their children, the diagnosis, and their needs; when the opportunity came up, they would take on the role of educators with no reservation. For example, one mother expressed in her narratives:

> And you know, you start to say things like, well, he's just steaming or she's just seeking sensory and you have to go back explain what that means. And you don't want to be rude to the people but you don't have any time to do this in details. You know, so you just kind of feel like not only are you educating yourself, your child, but you're educating your friends and family and often times your doctors. That's a lot of education for people who just learned this crap themselves four years ago. (Megan)

The situation the mother, Megan, referred to in the above narratives was some family relatives inquiring her son's diagnostic information. During some interviews, I asked the question of how they responded to the questions regarding their children, such as behavioral issues, language issues, or anything people noticed differently. Most of them confirmed that it was hard to answer or explain to the people, including certain family members and friends about everything such as why and how. It was very complicated to be able to understand their children from an outsider's perspective. Because as mothers, they learned so much over time, they saw the complete pictures, they understood everything behind it. Some mothers even mentioned that they got frustrated and wanted to educate others about the myths of having a child with Down syndrome:

> I, you know, I– I think just reiterating some of, you know, what we were just talking about. I think people often talk about how loving kids and people with Down syndrome are. You know, to the point where it kind of becomes a bit of a stereotype. And we know that that's not true. And so I think, I don't want to play in to the stereotype that, you know, he's happy all the time because he certainly is not. I think is something that I don't know that people fully understand. So I would hope that people would learn. (Angela)

Most of the mothers in the study had raised the concerns that people always thought that their babies or children with Down syndrome were happy, joyful, and loving comparing to most of children in general. As the mothers claimed, they truly believed that the depictions are stereotypes about their children. As a matter of fact, the mothers felt that frustration of not being understood that their children were not always happy and joyful, but they were actually having a wide spectrum of emotions ranging from being angry, violent, to being stubborn. The sad part as what Angela pointed out, most of time, people didn't recognize that part of their children and didn't even understand children with Down syndrome at all.

Another mother in the study particularly mentioned how much she needed to learn about school or education system for her son:

> It's incredibility difficult. And I think that is a huge – a huge, a huge, what's the word? A huge hole in parent services in this area. Until you go through it a few dozen times you have no idea what your kids are entitled to. How to get it? Who to ask for it? How to say no to a school when a school is telling you one thing and you disagree with it? Like, we don't get any of that and until you go through it a

bunch of times, unfortunately you don't. All these questions led me in the right direction for researching it on my own. (Emily)

The mothers whose children were over 3 years old in the study, they definitely needed to learn a different set of knowledge and information to prepare both themselves and their children for the future educational outlook and needs. Except for those who were social workers, special education teachers, most of the mothers had to do a lot of self-learning to figure out the educational system and what was the right program for their children. As Emily, the mother of a 3-year-old boy described, it was very difficult for the mothers.

It was also clear to a lot of mothers in the study that getting themselves educated about their children's diagnosis and all their needs was just the beginning of their journey. The next step came to educating others about their children and the diagnosis. Some mothers chose to educate healthcare providers about the diagnosis; some chose to educate teachers and children at school. For example, one mother in her interview shared that she went back to her OBGYN's office to educate the staff and the doctors there how to address people with Down syndrome; and what kind of information and resources the office needs to give out to the parents. In her narratives, she shared her story:

I've given her (the midwife) those brochures that talk about your baby might have Down Syndrome, because I just felt like she wasn't good in talking to my husband and I about the Down Syndrome. But we wanted more than that. I do feel like I try to educate anybody who I come upon. The other thing is, I don't like people

> call her the Down's. That is not the right thing. You see, even doctors do that. I am surprised that they didn't know that. (Ann)

For the mothers who had decided to drop their children to the daycare facilities, they had to educate the teacher, the staff and other kids in the room. One mother shared that she went to the daycare program where her daughter only stayed there two half days to do a short talk for the kids to understand her daughter:

> It's amazing that little kids notice the difference right away. They were similar age to her, but they kept calling her a baby. That hurts. But it's amazing that once I told them to look around to see who are exactly like them in the room. They couldn't find one, and I just went from there telling them everyone was different. They seemed to get it. Every time, there are certain activities there, I need to educate them why she couldn't do it. (Kamilla)

It is commonly recognized by the mothers that the first couple of years were extremely challenging and difficult for them to go through. Their lives were busy, chaotic, stressful, and interrupted. The majority of mothers described this period as trying to survive. On the one hand, they performed the role of private and personal health providers to ensure their children could grow big and strong enough to handle any of those required surgeries; they fought for their children to receive the appropriate care and medical attention/service that they deserved; on the other hand, they devoted themselves to educating others to understand their children. When asking the mothers how long they thought their grieving process lasted, not surprisingly, nobody went through the process as same as the others in the sample; and nobody experienced the grief as long as the others. Overall, the length of the grieving process varied from

roughly 6 months, 8 months, 12 months, and a couple of years. During all those time periods, the mothers had gone through a tremendous amount of challenges, borne an incredibly heavy responsibilities, and suffered a huge amount of identity loss.

Before the mothers walked into the stage of total acceptance for their children and their own life, the set of identities of medical staff, therapist, fighter, and educator has served as a strong anchor for them to: a) make sense of their life with a sick and disabled child in those daily chaos; b) help cope with the earlier identity loss; and c) lay a strong foundation to seek new meaning in life and reconstruct a new self.

The stages of the grieving process broadly and ambiguously outlines the time frame of how individuals go about to make sense of the loss and finally accept it. Time is of course an essential and critical element in understanding the holistic picture of the life change and self-identity change of the mothers in the study. As Charmaz (2002b) explains that the impact of time is manifested through the effects of illness on daily activities; time spent to manage illness, the orientation on future life, and the expectations of self at different stages of the lifespan. So far, what I have discussed in the analysis revealed that the mothers over time in the process of grieving and coping with their children's diagnosis had experienced dramatic life change which include interruptions on their daily activities, time spent to care for their children, future orientations and expectations for themselves, the children and the family. The loss of identity occurred at the early stages of the grieving process which pertains to their psychological loss and the collection of secondary loss. With the time went by, when they were highly engaged in caring for their children, particularly managing the critical medical needs, all the activities they conducted were around the care, and the identities

of personal healthcare provider, strong fighter and educator had been invoked and constructed to help them understand the diagnosis and cope with the loss.

Recognizing that they were not the same persons anymore after their children were diagnosed with Down syndrome, the mothers struggled the most to claim the identity of being a mother to their child. This identity of being a mother, a typical mother, was the one identity they were striving to perform, but lost right away after the birth of their child. The grieving process is vital and necessary for the mothers to continue their journey of making, unmaking, and remaking their identity. Each of the mothers in the study took various amount of time to grieve about their loss of the expected babies and their loss of self before they came to the point to accept their babies and remaking their own identity through the transformed life experience caring for their children.

C. Key/peak Events for Identity (Re)construction

In the study during the interviews, I wanted to know when they became to accept their children's diagnosis and their life as a mother of a child with Down syndrome. In general, I have found that recalling at what time they felt okay about the diagnosis and their life was quite a challenging task. As what they had shared previously about their grieving stages, there were no clear time lines or periods that they distinctively knew what stage they were at and how long those stages actually lasted. They could only remember roughly about how long they stopped crying badly and shifted their focus to take care their children's non-stop daily needs. That is why it is very important to keep in mind that for the mothers of children with Down syndrome, reaching a point of acceptance is not so clear-cut at all.

One of the theories on the grief process, chronic sorrow suggested by Olshansky (1962), argues that parents with disabled children might not necessarily go through the typical stages of grief outlined particularly for those who mourn the death of a loved one. Instead, the grief process of parents with disabled children is deeply imbedded in the notion of chronic sorrow because the source of their grief is not completed gone, but with them every day. In the study, the mothers agreed and recognized that the diagnosis of Down syndrome would be never fixed or gone away, there were still ups and downs in their journey of raising their children. Yes, the mothers in the study were facing the source of their grief, they also returned to their grief from time to time due to different triggers or circumstances (such as birthday celebration, a negative assessment report from the therapist, or a glimpse comparison to other typical children).

However, no mothers in the study actually described or demonstrated their life experience with their children in a sense of chronic sorrow after the early stages of grief. Coping and living with their children's diagnosis is a long term process. Although time doesn't necessarily heal all their wounds, it certainly helps to lessen their pain. No matter how many or what stages of grieving the mothers went through, one thing that was for sure, they were all walking toward the stage of accepting who their children were and who they were. Of course, this stage didn't come easily to the mothers and it was hard to identity at what time line the stage of acceptance occurred as well. But the majority of the mothers in the study could recall the key events or situations that inspired them and motivated them to rethink their lives, reevaluate their situations, and refocus their energies to get on with their lives.

In the interviews, I asked the mothers whether there was a particular event or situation that made them realize that was it- that was their child and their life and they were ready to move on after going through different and intense hurdles of trials. In analyzing and discussing the narratives regarding the key events or situations that definitely changed their perspectives, and inspired them to reexamine their lives, there are three major key events or situations identified by the mothers in the interviews, which they considered critical turning points in their lives for them to strive for the change for the good. These three key events or situations are: a) the resolution or the removal of medical issues; b) the inspiration of other mothers of children with Down syndrome; and c) the first accomplishment/mile stone of their children.

C. 1. The Resolution/Removal of Medical Issues

It was already devastating for the mothers to receive the diagnosis of Down syndrome for their children; and the critical medical complications together with the diagnosis even worsen the pain and the distraught the mothers experienced. As discussed in the previous section, the medical conditions, the treatments and the equipment all interrupted the normal bonding process and interaction patterns between a child and a mother. To certain degree, those were barriers and obstacles which prohibited the mothers to see their children as who they were; In the opposite, those treatments and equipment objectified the babies and turned the bonding process to a task-oriented process, which distorted how the mothers perceive their babies and themselves. Throughout the interviews, the mothers commented what a big release to see their children clean and free from breathing tubes, feeding tubes, and some other monitors! And how excited that they could actually carry and hold their children

without worrying about messing up with the medical issues. All these allowed them to see and enjoy their babies differently. For example, one mother described and shared deeply in her narratives about how things changed and turned around in her life after her daughter's heart was fixed:

> Yeah, I think definitely when the medical stuff was over I finally felt okay, now I can see who you are and I think it's because we can hold her so much more. We were so afraid to just hold her too tight and I think when that fear of "Are you gonna stop breathing?" kind of was gone, definitely that second heart surgery made it big once we got through the complications with that, life it easier. I knew you'd warm up, just kind of getting there. That was also huge, yes, those simple little bonding things that everybody gets with their new baby was all of a sudden – I remember those moments were very vivid the first time giving her a bath. I mean I can tell you the color of the towel then she had. It was such an exciting moment to do those things, our first walk or getting her dressed up in her little Christmas outfit and kind of having people ogle over her and that sort of stuff, just wonderful. Oh, forget to mention, especially the feeding tube, the whole year we were like 24 hours feeding her. So, there was no sleep or nothing. Now, there were things we did was sort of looking at the special Olympics website and all these other things that she eventually would be able to do that felt like it brought some type of normalcy to our life and everything and that kind of made us excited and things we could still do with her and why are we gonna all of a sudden limit what we would do as a family, we can do this stuff this is how we can kind of work it out and still do these things.....(Angela)

The extensive excerpt shown above resembles how most of the mothers felt about their life and their children after the medical issue was resolved. Previously, they were so busy caring for the children with their medical needs; now, they could hold their babies, hug their babies, and bathe their babies as much as they wanted without the interruptions of the medical concerns as described by Angela. This long-time yearned but lost intimated bonding now emerged and recreated between the mothers and the babies through what she called “little bonding things”. This type of reconnection with their children put the mothers into a new perspective about their life and granted them the opportunity and temptation to slowly peek into the things they could do together as a family in the near future. Moreover, these “little bonding things” were exciting and encouraging to the mothers because as what Angela claimed – they brought some type of normalcy into her life, which really reminded her that they should not limit themselves from what they thought they could do as a family, but with a strong belief that they could work things out eventually.

After the medical issues were resolved, most of the mothers felt they had some time to breathe, to sleep, and to relax a little bit. This relief and break definitely gave them time to recharge their energy and make adjustment to move on with their life with new perspectives and understanding for their children and their life. Another mother expressed in the interview about how she saw her baby was totally changed after her son’s tube was removed from his face:

> Before, there is something wrong with this kid because, apparently, because this baby, has a tube. But then after the surgery, he didn′t have a tube and I felt like he

was perfect, you know? He's fixed. He's fine, his heart's good. You just have a baby right in front of you. I didn't see the difference anymore. (Teresa)

The above accounts by Teresa also explained why the bonding was so hard to form between the mothers and their babies when they returned home from hospitals. The feeding tubes, breathing machines, and 24-hour feeding pumps, which they had to learn operating not only consumed their time and energy, but also distorted the baby image in the eyes of the mothers. After those were removed and fixed, what they got to see now was their baby, the perfect one. In the early stages of grieving, the mothers were mourning the loss of the anticipated babies who were deemed to be perfect. Now they actually found their babies again. This undoubtedly convinced the mothers that they could handle anything from now on and they were about to embark on a new journey.

C. 2. Interacting with Others with Shared Experiences

In the interviews, I asked the mothers what stressed them out the most and who was the most important person for support during their grieving process. The majority of mothers agreed that the medical complications and the unknown factors were the things that stressed them out the most; their mothers, husbands, and the immediate families were their great support. It is also well recognized throughout the narratives that the stronger support the mothers received, the less struggled the mothers tended to be; and the shorter the grieving process the mothers experienced. In addition to the support described above, most of the mothers agreed that they also received wonderful support from the Down Syndrome Association of West Michigan (DSAWN). The association provides several support programs specifically designated to the mothers in

addition to other supports such as workshops, seminars and etc. Three support programs were mentioned the most during the interviews: Mom, Inspiring Moms; Mothers Dinner Out; and the Facebook Support Group. The mothers acknowledged that these programs had offered them a distinctive and invaluable support which they couldn't get from other sources. Because the leaders, organizers and the members of the above mentioned programs were fellow mothers of children with Down syndrome. Those mothers shared the same journey and went through the similar trials as the mothers in the study. Some of the mothers sincerely claimed that the mothers from the support programs understood their life and situations the best. Participating and receiving the support from the support groups/programs offered by DSAWN, the mothers in the study felt connected, understood, not isolated and lonely in their journey of raising their children with Down syndrome.

However, what really inspired most of the mothers to rethink about their life, reexamine their identity, and reestablish their perspectives was personally meeting and interacting with a mother of child with Down syndrome. It should be noted that most of the mothers in the study did not participate those support groups to meet other mothers during the early stages of grieving because of the medical challenges and restraint, and their overwhelming responsibilities and busy schedules. Some of the mothers got to meet other mothers introduced by or from their social network; some just ran into other mothers randomly while they were doing grocery shopping; some met other mothers through the DSAWN organized events or activities. No matter in what way and under what circumstance these mothers met, interacted and connected, the mothers in the

study were undoubtedly inspired by those mothers they met and that inspiration turned into comfort and motivations for changes in their life.

For example, one mother who was informed of her daughter's diagnosis of Down syndrome during her pregnancy contacted the other mother of a child with Down syndrome introduced by her colleague. In her interview, she explained that it took her about 5 or 6 months to grieve over her daughter's diagnosis without reaching out to other mothers:

> I think I went quite a long time, you know, right in the beginning, you know, I was reading things and everything was so negative that it was overwhelming that I just decided that I wasn't going to read anything. And I just kind of pushed it aside and I didn't read anything or look anything up. But I kinda, I'd have to say like, you know, closed off. I didn't reach out to anybody; I didn't reach out to the Down Syndrome Association or to anybody all through my pregnancy, so you know, it had been 4,5,6,7, almost 5 months, I, you know I didn't reach out. I just kinda kept it in and thought I'm having a baby that's what I wanted and I'm not gonna worry about all the other things. And then on, in my eighth month, um I decided to start reaching out. I started to feel a little better. I don't, I don't know if it was just the okay, you know, time went by and I was comfortable. I think I settled down with my emotions. One of my colleagues knew I was pregnant and my baby had Down syndrome. She said, "I would love for you to meet somebody, one of my good friends has a baby with Down syndrome." (Teresa)

The mother, Teresa, contacted the other mother through emails and got to meet each other. This meeting with the introduced mother unfolded the picture which was

full of surprise, and comfort. The meeting gave her new perspectives to look into her future life with her daughter. In her narratives, she described:

> She (The mother) was super sweet and open to have my family over to her house and have dinner and meet her family and her little girl. Her little girl's name is Rhi. So just me and Sarah (her older daughter) went to their house, and you know had dinner with them. Lindsey (Rhi's mother) was such a sweet women, she came out of the house and greeted us with Rhi in her arms. That day I got to see her (Rhi) in action. And her and you know at that time she was just starting to walk. Yes, you know, you could tell, she has Down syndrome right away, it could never be that truthful to me at that moment. After dinner, we started playing and doing stuff with her. Amazingly, I didn't see Down syndrome anymore in that little girl's eyes, face and I saw a real person. And after that day I was fine with it. I was fine with my pregnancy and I was fine with her having Down syndrome. (Teresa)

The above excerpt displayed that the direct interaction with the mother and the child of Down syndrome did not only offer the comfort to Tammy, but also changed how she saw the little girl with Down syndrome, that ultimately change brought her comfort and peace to know that she was welcoming a real baby girl and she was fine with it.

Another mother in the study recalled the stunning moment in her life when she unbelievably witnessed the joy, the smile, the hope from the mother she met at DSAWN Christmas Party. And on that day she told herself deep in her heart that she would love to live a life that would be different but good with her daughter. The story she shared about meeting the mother went as:

> When talking about Down syndrome and all the things I've gone through, it's with the moms that I met through the Down Syndrome Association. Ever since the beginning. I met one mom when Emilee was three months. It was at a Christmas party and the mom had a baby. I think she was like nine months. And we were talking and she was so happy and I remember that I wasn't happy. Because she was – I was – I was still a little hesitating. And I saw, she had a baby and she was so happy. And her personality is, like, very cheerful. I mean, and she's like, "Oh look, the baby!" So I saw her and I'm like, oh my goodness, I'm gonna be happy someday like her. I remember just looking at her and saying, oh my goodness, I'm gonna – look at her. She's so happy and she's so proud of her daughter. And I remember thinking, I'm gonna be like that one day. I say, I'm gonna be like her one day. You know, happy. And, yes, like a month later or two months or whatever, it was like, yes, I felt a bit happy with her. And every time I see her because we're still – I mean, she doesn't live close. It's like an hour from here but still every time I see her, it's like, oh my goodness, you have no idea how much you helped me. Just to be you. I said, to see you, how happy you were. And then Emilee and her daughter have been super good friends all the time and we went to birthday parties and trips and everywhere. And I really – it was a big moment for me. (Marie)

Meeting the mother at the Christmas Party, being inspired by her attitude toward, pride and joy for having her daughter, Marie was shocked and encouraged to change herself to be the person who was happy and proud. The mother she met on that

day became her role model that helped her and guided her through the journey to eventually reach that point of being happy with her daughter and her life.

Similar stories shared by other mothers in the study reflected the touching and inspiring moment they experienced with other mothers of children with Down syndrome. The mothers who looked up to those mothers who were positive and happy about their life and their babies to recheck their own life. In the meanwhile, they were heavily influenced by them and had the desire to be one of them because what they had seen from other mothers was not different from what they had envisioned about their life and their baby before the diagnosis and confirmation of Down syndrome for their children. Those mothers who inspired them presented themselves as a normal and typical mother; and this really helped them to envision themselves being normal again as a mother of a child with Down syndrome. As one of the mothers commented in here narratives:

> And she came in and I've never seen her since. So I don't know where she is. She came in, she talked about her experience. She held Cole, you know. And she – as you could imagine, she looked normal. She looked fine. That really gave me something, you know, to picture myself being a normal mother. (Ali)

The mothers in this study who got to interact with other mothers of children with Down syndrome felt that immediate connection with other mothers. How those mothers presented themselves and interacted with the mothers in this study has dramatic impact in striving for that normal and typical mother identity.

C. 3. The First Accomplishment/Mile Stone of Their Children

During the course of raising up a child, there are so many first times (e.g. first smile, first roll-over, first sit-up, first step, first jump, first word and etc.) spurred up that make the parents thrilled and proud about their babies. There is nothing comparable to that type of joy experienced for parents. Typically all those first times of the babies will emerge and show up at the designated time period marked or identified in the standardized growth/development chart. Not long ago there was a different chart specifically created for the children with Down syndrome because they could not reach or hit those markers as the typical children did. The mothers in the study had all seen that chart in their pediatrician's office given the fact that there is the new change initiated for adopting the standardized growth chart for children with Down syndrome. The mothers were all aware of the potential delays their children would encounter. This delay is also another unknown factor to the mothers since there is a wide range time of delay in all aspects of the children's development. Some delays could be several months; some could be years; and some could be life-long time. Some delays could be more on cognitive abilities; some could be physical mobility; some could be speech.

Because of all these delays, the mothers and the children were busy with all kinds of therapies to shorten and minimize those delays as much as possible. All they wish was one day their children could reach those mile stones one after another as the typical children but with a different time table. As you could imagine, how much the mothers expected seeing their children to reach certain mile stone and how exciting that would be. Some of the mothers in the study described that each achievement of their children, each mile stone reached were a huge thing for them to celebrate. However, the

first time achievement of their babies or the first hit on the mile stone was the biggest and most unforgettable event that not only made them cry, scream and clap to express their joy, but also rendered them great hope for their babies and their life. For instance, one mother recalled the moment her baby son first time latching on, even though it was delayed for several months, she felt that was a great turn in her life which gave her new perception about her identity of a mother and what is normal in her life:

> I knew breastfeeding was good for him, you know, he needed it. I was so sick of pumping, I went to a feeding group for a while. But it seemed hopeless to the point I wanted to give up. And suddenly one day, he just latched on, boom, that fast, you know. He's nursing. So at that point, it was like, okay, everything is pretty much normal at this point. Because that was my, in my mind that was the biggest disappointment for me that I couldn't nurse him. Yeah, we made, jumped this hurdle. We're feeding normally and just getting through day-to-day life and trying to sleep. And at that point I think it's just like being a mom of an infant. (Cathy)

In Cathy's narratives, she shared the great but hugely delayed mile stone – her boy was able to latch on and be nursed, totally shifted her perception about the life down the road and the sincere feeling of being a mom. This first achievement was described as such a huge hurdle in her life and for her son to overcome. Once this hurdle was removed, she started her first step into what so-called normal life with the belief that things would be ok.

Whether the mothers went home with their sick and heavily machine-bound babies or not, the overall picture of their life and the babies was dark, cold, negative and

hopeless. What they had to face and take care of every day was not the babies who they had depicted so many times in their dreams. They pleaded to hold the babies with close eye-contact and beams of smiles. They also longed for the connection and interaction with their babies. For the babies with critical medical issues, that connection began with the resolution of the medical issues. For the babies without other medical issues, but only the diagnosis of Down syndrome, that connection started with their first smiles their mothers spotted and cherished. That first smile was just like a beam of light lightening up their mothers' hearts and days. That first smile was also like a magic key to open up a whole different world for their mothers and themselves. Another mother in the study explained:

> I guess that would to be, you know, I think once she started smiling, and um just kind of being a normal baby, like a typical baby's smile. That moment, I didn't really see things wrong with her even though I knew there was, you know. Like she wasn't sucking. I couldn't believe my eyes, my heart you know, warmed up by her. I can't help smiling back to her with tears. I also kind of started seeing her personality come out. I saw her, she was just a lot she's just like any other child. (Dawn)

The above stories shared by both Dawn and Cathy have shown the impact of those important and vital first mile stones achieved by their babies. These mile stones shifted their perception of their own lives and their babies as well. These first mile stones were keys to interpreting their life and defining who their babies were. As discussed earlier, both mothers experience the identity change for their babies: from a

sick baby to the normal baby; from a baby with Down syndrome to the baby like any other baby.

D. Finding Peace: A New Identity for the Mother They Wanted to Be

Throughout all my interviews, the answer to the question of whether having a child with Down syndrome changed you (the mothers) and in what ways was unanimous - "definitely yes" but "very positive". It was encouraging and spirit-lifting to hear all the mothers in the study to describe how they had changed from one person to the other over the course of their journey with their children. The previously constructed images of parents of being delusional or grief-stricken in early studies were disapproved by the mothers in the current study. Those images could be true and found at the very early stages of grieving process. But the mothers did move on with their lives after the grief period, then to search for the meaning of their lives and reconstruct their strived identities. What the mothers had gone through in their life with their children could be described as transformative and positive, which also echoed some recent research about parents of children with disabilities. The mothers in the sample did experience different transformations focusing on different aspects of their lives discovered by (Scorgie & Sobsey, 2000): personal transformation, relational transformation, and perspectival transformation. Both the early literature on families and parents of children with disabilities and my research with the mothers of children with Down syndrome, one common but essential experience shared and identified by all parents is the loss of their anticipated children and their own identity of being a mother – the took-for-granted and socially constructed identity that confirms their motherhood. In the following passages, the personal transformation to this new identity of being a real and typical mother

distinctively with their own interpretation and understanding of what the motherhood really constitutes: a) motherhood is humbleness; b) motherhood is sacrifice; and c) motherhood is acceptance.

D. 1. Motherhood is Humbleness.

When the mothers in the study began their journey with their children after receiving the crucial diagnosis of Down syndrome, they normally had so many concerns and worries. Some of them were concerned about their children's health condition; some were about their children's future and their family's future; some were concerned about the judgment from others in society. All these worries, concerns and fear threw the mothers into a desperate situation of losing themselves in the mist of grieving and coping with daily demands. After going through so many trials, hurdles and struggles managing all kinds of daily demands and needs, they finally came term with their children's diagnosis and realized that this was their life and their children. From the early stage of not recognizing who they were to the current state of claiming themselves to be a real and normal mother in their own eyes, the mothers learned that they needed to be humble to allow themselves to be who they were and to be seen as who they were while walking the journey with their children. This humbleness offered them peace, comfort, and relief to face the reality and make the best out of it. One mother in the interviews shared at the very end of her stories about the importance of the humility of being a mother:

> It's like the humility of motherhood I call it. You just have to be humble to let people see you as the mess you are because, thinking of any other mothers, you

have small children. You're always gonna be a mess. For me, this maybe longer, but that's ok. (Ann)

Ann, the mother honestly admitted that she was fine with people seeing her as a mess, because that was who she was when facing up with so many challenges. She understood quite well even for the typical mother, they also couldn't spare themselves from being a mess from time to time. In my analysis I actually adopted the term "humble" from Ann, because it really reveals the truthful aspect of the state of parenting or mothering. This humility also extends further to examine the individual self to reflect how truthful the individual needs to be with themselves. For instance, another mother in her narratives articulated her regret of not being able to be herself humbly:

> And it was just such a joke to me when I think about my life, being a mother that like why the hell would I think that I would have something typical or normal? Nothing in my life has been that way. And I realize that Sarah's here to help me to embrace that. You know, and here I am chanting and telling special populations, "Be yourself. Be an individual." And for 40 years, I was afraid to do that. Even though I was leading the group, I wasn't being true to myself. You know? (Kamilla)

The above excerpt from Kamilla, the mother, indicated that she finally understood that nothing could be considered normal or typical in her life, which raised the question of whether typical or normal things actually existed in individuals' lives. After she had her daughter, she tried so hard to speak to the people with special needs that they needed to be themselves, not others. At that moment, she realized that she needed to be truthful to herself and be herself to begin with. Her narratives also

suggested that being typical and normal was relative. In her interview, she shared that she had learned quite a lot from her daughter and she would never be a typical mother, but only the mother to her daughter.

D. 2. Motherhood is Sacrifice.

Hearing the stories from the day one when they each became a mother to their child with an extraordinary flux of emotions of anger, devastation, disappointment, and hopelessness, all the way to the day when the mothers felt so grateful about having their children with Down syndrome, I personally witnessed the heart-wrenching but extremely heart-warming and encouraging experience of the mothers who walked the long and harsh journey with their children to become the type of mother they had never imagined and pictured through their deep self-reflective narratives. A woman becomes a mother right away after she gives a birth to the baby. However, being a mother, and what type of mother to a baby entails more endeavors than just giving a birth. In the study, the mothers of children with Down syndrome all considered their journey of being a mother to their child unbelievably demanding, challenging, and struggling. Nevertheless, not a mother in the study felt regretted and worthless to go through those trials. Instead, they described their journey with their children positively as a rewarding and life-changing experience that made them a better person and a mother. Of course, all these didn't come without the dedication and the sacrifice the mothers chose to made for their children. As discussed early, one of the biggest sacrifice was the loss of self in caring for the children. What the mothers had gone through and the sacrifice they had made so far was deeply reflected in Mother Teresa's quote, "A sacrifice to be real must cost, must hurt, and must empty themselves." The mothers in the study chose to

sacrifice their time, their sleep, their hobbies, their careers, their relationships, and their dreams to put their children's needs ahead of their own. One mothers in the study shared in her narratives:

> It was quite the time and so I think just motherhood – motherhood is sacrifice. Love is sacrifice. When you get married you're giving 100 percent of yourself to your husband and he's giving 100 percent of himself to you. And it changes everything else around you. All that selfish time, there's just no room for it, no place for it. Not that you can't have a healthy balance of time to do things for yourself or on your own but it's just different. You have concerns for others and you're giving yourself to others all the time. And so I don't know that it was really any different for Derek (her son) as it would be for any of the other kids. You just – I gave up some of my work time, which I really enjoyed; and sleep time and cooking time..... (Cathy)

The mother, Cathy, in her accounts adopted a parallel comparison, the love between the husband and the wife, to understand and explain what motherhood was. As a mother, no different than a wife, you need to give 100% of yourself to your baby. In this sense, you need to attend your baby's needs and concerns. She believed the sacrifice she made to attend her son's needs was similar to any other parents for their kids. To her, being selfish is not how motherhood is defined and understood.

When the mothers made that choice of sacrifice, they knew it wasn't easy but rather painful. As one of the mothers described, "If I could push the baby back to my belly, I would do so because it was so painful." But amazingly the mothers learned that they grew more in all those trials and deeply believed that with great belief that

parenthood or motherhood was an opportunity for personal growth for everyone. Another mother in her interview expressed:

> Parenthood is hard no matter what. It's not easy. It doesn't matter what, kind of, child you have. It's going to have some, kind of, challenges in some, sort of, way. It's a change and it's a period of growth for everybody and you just, sort of, have to let yourself grow and I think with Down syndrome if your child has something like that then really for both of you or all of you, maybe the whole family it's just an opportunity for growth. And I think that sometimes we get childish because we don't want to grow up. We want it to be easy. (Kim)

The above excerpt demonstrated that wanting things to be easy was not how parenting went in her perspective. Regardless of what kind of child you have, parenting is hard and challenging. According to Kim, parenting was a self-growing process which required an individual to move away from being childish to being mature. It was common among the mothers in the study that they claimed that they grew into a new person over the course of their journey with their children. As other mothers claimed in the study, that personal growth was gradual and the big part of that growth was to become less selfish.

> I like to think I'm more organized now than I used to be out of necessity. I think you get progressively less selfish as time goes on with your children because they just need more of you and you need to give more of yourself. And so my husband wants me to go dress shopping for my brother's wedding next month and I'm just like I don't know when I'm going to do that and it doesn't even sound very appealing to me to do. And so those things that used to be so easy to just run out

and do you just – they just become so low on the priority list you just don't – they just don't get done. (Megan)

As the mother shared above, her children needed more of her, that's where her sacrifice came in. If her children needed more, as a mother, she just should give them more of herself. In doing so, certain things were off her list of priority. This list can contain any plans, any activities, and any personal needs. And over time, she became less selfish and put her children's needs above hers. As described above, any of these changes didn't come along right away with these mothers. During the course over their journeys and trials with their children, they had understood and learned what it meant to be a mother for their children with Down syndrome.

Other mothers in the study who had experienced the similar growth were so thankful that they were taught by their children not only being selfishless to their children, but to other people who are in need as well. Therefore, the unselfishness nature of motherhood has perceived to be the ultimate meaning to their life. The mother, Tina, expressed as following:

It's much more powerful in that you know I'm thankful because that's taught me in those situations to do the same thing, whereas before, and I still do, probably use the "let me know if you need anything" type of, um, type of thing, but you know, when Tina (her friend) was diagnosed with cancer, and I have another friend that was just diagnosed with breast cancer, um, I don't ask them if I can cook them a meal, I just say, I'm bringing you a dinner over on Wednesday. You know? Whereas I don't think I would have did that before. So I think the selfish

part of you dies out a little bit more over time and you have to maybe work at it, work at attending to your own needs a little bit harder. (Tina)

The mother saw herself growing into a person who became less selfish and more sensitive to her friends' needs. She considered her mothering experience to be very powerful in teaching her to become the person who she is now. However she did recognize that she needed to work on attending to some of her needs as well. To all these mothers, motherhood is an active choice of being willing to sacrifice themselves, to learn to be selfless, to attend their children's needs with all their heart and soul. In the meanwhile, this understanding of motherhood has been transformed to be the meaning of their life.

D. 3. Motherhood is Acceptance.

The identity of a mother was immediately claimed by the mothers after their children were born; but for the mothers who were informed of their children's diagnosis of Down syndrome, that just brand-new granted mother identity was robbed away. In understanding all the loss the mothers had to grieve about, the identity loss of being a normal mother was the outmost dilemma that set the mothers to continuously search for over the course of accepting and raising their children. The identity of being a normal mother was constantly contested, challenged, and negotiated along the course of grieving, coping and finally accepting the diagnosis, their children and their life. Charmaz (1987) defines preferred identities as implicit or explicit objectives for personal or social identity that individuals with chronic illness strive to achieve. Comparably, the mothers in the study had strived to search and reconstruct their preferred identity of being a normal mother to their child in a great effort overcoming

the unsurmountable of trials. Watson (2002) argues that individuals with disabilities can achieve their self-identity through a reconstruction of what is being normal, but not through sidelining the impairment. That's why there are individuals with disabilities claiming themselves to be a "normal" person. Because they accept the difference of a body with impairment and regard it as normal to him or herself.

In the similar sense, I have found that the mothers in the study all proclaimed a normal mother identity to their child with Down syndrome. They indicated that they were mothers no different from other mothers. For example, one mother articulated in her interview:

> I think like – I usually don't think a lot about Down syndrome now. I used to think a lot more. But now I – you know, for me it' like, that's what she has. That's just part of her. Exactly, for me, I'm just a mom that struggles every day with something just like any – some days are very good and some others not that good. But I'm just a mom like any other mom. And I don't really think I'm a different mom just because she has special needs. I don't think so. (Marie)

The mother, Marie in her narratives explicitly pointed out that she saw her daughter first, not the Down syndrome piece. She made it very clear that Down syndrome was only part of her daughter. To certain degree, she turned the Down syndrome piece into a characteristic her daughter happened to have. As a mother, she accepted her together with her characteristic. Another mother added her comments conveying the same belief:

> You know, I can do fine without a lot of stuff and just being more content I think with maybe what I have. And I look around at my friends who their kids are

> involved in everything or I have cousins who they play piano and they play sports and they do this and they're just go, go, go all the time. And I think, you know, maybe our life will be a little simpler but that's okay. It doesn't matter if he doesn't have this degree behind his name because that's not what defines you as a person. (May)

The above accounts illustrated that the mother were content to be the mother to his son because she didn't focus on the disability her son has, but changed her perspective in seeing her son as a person who would not be defined by any particular things. As it is argued by Watson (2002) that the individual is able to set apart from his/her disability and construct a self-identity focusing on what he/she is able to do, and not the other way around. In addition, if an individual sees himself/herself as person first, but the disability as one of the characteristics as same as other characteristics people usually have to make them a distinctive individual. In this context, both mothers in their above narratives accepted the Down syndrome as one of their sons' characteristics, which might devalue their personalities; but totally see their sons as persons first. At the same time, they formulated both their identities and their children's identities based upon what they can do and what their children can do. For example, the Down syndrome doesn't define who their son is; and the degree doesn't define who they are either.

One mother also commented that she admitted her daughter's special needs-Down syndrome did identify her differently from other children, but she was totally okay and she didn't need to fight to say her daughter was as typical as other kids.

> We fight so much to be just like everybody else but the truth is that we're not. And that's okay too. You know, I don't need to fight to say my daughter is just like every other typical kid so she should be allowed all these things. Well, she has some special needs. So that does identify her differently. And that's okay. You know, technically everybody has special needs. (Kamilla)

The mother, Kamilla found complete peace with the diagnosis and the truth of her daughter being different from other kids. She claimed that she didn't need to fight to make herself and her daughter as normal as others because she honestly believed that everybody had special needs. By admitting that she was not like anybody, as a matter of fact, no two people are alike, she completely accepted her daughter to be the child with special needs. What she truly believed along with other mothers in the study actually challenged the socially constructed normalcy of being a mother and a child with special needs. What was normal to the mothers now is accepting the difference of who they are and who their children are; but not dwelling upon the disability and not allowing that disability to define their identities as well.

E. Summary

In the above chapter, the analysis of the narratives by the mothers has demonstrated a course of life changes and identity transformations from the early stages of grieving, negotiating, to the final stage of accepting their children, their lives and finding the meanings in what constitutes the motherhood. The accounts given by the mothers vividly illustrate that they have to get over different hurdles of loss, challenges, and trials to become the person they are content and happy with. Grieving over all kinds of identity loss and confusion about being a mother, a wife, a friend, a career woman;

establishing the transitional identities of a health care provider, a fighter, and an educator; experiencing the inspirational moments and events that awaken them to strive for new identity constructions; and eventually finding not only the peace in their life with their children's diagnosis, but also the deeper understandings and meanings of what mothers are really are in their perspectives. As it is discussed, the mothers in the study cam a long way in making sense of the diagnosis, negotiating their identities and redefining who they are in the process of coping with the diagnosis while managing all the challenges in their lives. Definitely the journey they have walked in is not easy at all. The descriptions of how desperate they felt about themselves and their lives while facing the surmount of stress and struggles speak to the truth that the diagnosis, the impact of family normalcy, and the identity crisis can be perceived as very negative and hopeless. But that is not the end of the story since the mothers are not isolated individuals exempting from daily interactions with other social beings in the society; they are not withdraw from providing care to their children either. Those formerly perceived negative outcome and hopeless future are subjected to the continuous contestation and negotiation in the process of grieving, coping and balancing their lives. It is through this journey full of challenges, trials and hardships, the mothers in the study found the peace and the meaning of their lives and ultimately reconstruct their identity of being the mother they wanted to be to their children with Down syndrome.

Chapter 6: **Discussion and Conclusion**

A. Discussion of Findings

Not only do the findings of this study lent support to what has been discovered in the previous research regarding the stress, the struggle, and the frustration experienced by parents of children with disabilities, but also contribute significantly to the existing literature and understanding about how the families grieve and cope with the diagnosis of Down syndrome; how the parents, in this case, the mothers make sense of the diagnosis; how the mothers suffer from the identity loss; and eventually find the meaning of their lives and the long expected motherhood while caring for their children. Over time, the research has been consistently dwelling upon the negative outcomes of having a child with Down syndrome in the family and leaving the mothers with the images of being devastated, lost, and suffered. In the contrary, this study together with others has shed a positive light on the experience of the mothers, which is considered to be a positive, rewarding and heart-warming journey. Most importantly, through this journey, the mothers have not only found peace with their children's diagnosis, but also found their long-lost children, and themselves again.

The findings of the initial reactions to the diagnosis of Down syndrome partially echo the commonly found negative emotions and responses from the mothers as indicated in other studies. The narratives shared by the mothers vividly express how traumatized and devastated they were upon receiving the diagnosis of their children. However, there is no reason for us to believe every single mother would respond to the diagnosis of Down syndrome of their children in the same or similar manner. Given the examples and analysis from the study, we know for sure that some mothers actually

responded with a more positive and constructive ways. Either negative or positive initial reactions to the diagnosis are, we need to keep in mind that both are normal and should be honored. Both reactions are live, honest, and truthful feelings and voices given by the mothers in the study.

As discussed in the analysis, the negative feelings and emotions were evolving around the fear of the unknown future and the limited knowledge regarding the diagnosis. They definitely need time to process, digest, and grieve over the loss they are facing. Recognizing the general emotions in responding to the diagnosis, both family members and health care professionals need to be sensitive to the types of support provided to the mothers. For example, when the mothers are questioning whether they have done something wrong to cause their babies to have Down syndrome, the health care providers need to affirm the mothers that they have nothing to do with the diagnosis and are ready to answer any other questions. For the family members, they need to give the mothers time and space to breathe over the diagnosis and offer them comfort and understanding, but not judgment or critique on what they need to do. The accounts from the mothers in the study generally portrayed the husbands' initial reactions to their children' diagnosis as saddened, but silent and less emotional. The mothers in the study particularly expressed that they felt uncomfortable, confused, disconnected, and to certain degree fearful about the way their husbands responded to this family crisis. In this sense, the husbands as what the mothers called the "strong front" for support, should validate the mothers' emotions through verbal expressions and be willing and open to talk about the diagnosis. This really helps the coping process in terms of making sense of the diagnosis and being able to move forward as a team.

The findings of exceptions to the normative initial negative reactions to the diagnosis teach the society a lesson that we couldn't make the bold assumption and the over generalization about how the mothers respond to the diagnosis initially. The narratives given by some mothers in the study showcased the complete opposite side of the previously portrayed emotions. In other words, we need to recognize and acknowledge that some mothers tend to respond to the diagnosis more positively than negatively. As it is discussed in the data analysis, mothers who were knowledgeable about the diagnosis and who had experience working with the individuals with various disabilities actually removed themselves from that initial sad, anger, and shock stage; but presented themselves with competence, calmness, and readiness to address all the needs of their children. The accounts in the stories shared by these mothers indicated that what they really needed is the informational support and instrumental support to address their children's medical needs. For health care providers, they should ask the mothers more questions before they offer certain kinds of support. For example, in one of the interviews, the mother expressed the awkwardness and her upset when the health care provider told the husband not to blame the mother, or not to be angry at the mother because she didn't do anything wrong to cause the Down syndrome. Both the husband and the wife felt offended by the comments made. Therefore, the health care provider needs to be cautious while trying to comfort the mothers. They should not assume that the mothers all respond to the diagnosis the same way; and indeed the mothers do not perceive the diagnosis as devastating and negative as others. The health care providers should stay away the over generalization and pay attention to the particular medical needs of the mothers. The mothers non-normative reactions to the diagnosis identified

in the study greatly challenge the long held belief and assumption that having a child with Down syndrome is a "tragedy".

The stories of the mothers in this study reveal that during the grieving process, the mothers are not only grieving over the psychological loss of their expected children, but also grieving over a collection of secondary psychological loss, which fundamentally defines who they are as a mother, a wife, a caregiver, a daughter, a sister, a friend, and a coworker. The findings supports certain aspects of the previous works of scholars who have claimed that: a) the diagnosis of their child not only makes the baby look like a stranger to the parents, but also makes the parents feel disconnected to the child and failed to claim the identity of being parents (Ali et al., 2012; J. Gill & Liamputtong, 2011); and b) the parents tend to experience role dilemma while trying to balancing the family life and providing care for their child. The narratives given by the mothers in this study point to a deeper and complicated level of understanding self (identity) loss in the grieving process. The mothers in the study spoke implicitly and extensively about their painful and miserable loss or struggles in all aspects of their identities they used to possess – the "former self". The analysis of their lost identities pertaining to their personality characteristics, their families, their friend circles, their careers, their marriages, and the long anticipated motherhood clearly conveys that grieving over the lost child is only part of this deep sorrow. It should be noted that most of time, all these identities loss occur simultaneously and usually are manifested in the expressions of worry, fear and doubt.

Furthermore, the narratives of the mothers regarding the collection of their loss in the grieving process indicated that they, as a matter of fact, didn't recognize all these

types of loss or didn't even realize that they were sad and devastated about all these loss together with their lost dreamed children. In all their narratives and stories, the most frequently used or mentioned word to describe all these loss is "different". After their children were diagnosed with Down syndrome, they felt the relationship with their friends were no longer the same as before; they experienced the breakdown in the closeness with certain family members; they sensed the disloyalty in their professions; they saw a different person in themselves as a wife and a mother. It is common to say that sometimes, the mothers don't even know what and who they are grieving about when all these losses show up at the same time. This sets the mothers to a chaotic and confusing situation, which makes them extremely stressful and tired. In this study, mothers who had experienced less identity loss in the grieving process, recovered from the so called deep illness; and shifted their focus to providing the care for their children faster than others.

The findings of the study demonstrate that the mothers of children with Down syndrome will experience different kinds of identity loss during the early stages of grieving. These identity losses are not being consciously aware of by the mothers. With the same argument, the mothers are also unconsciously grieving over all kinds of loss at the same time. As Seligman and Darling (2009) argues that unlike physical loss, it can be difficult for others to recognize or related to psychological loss, even among family members. The narratives shared by the mothers in the study further illustrate the insensitive or inconsiderate comments received from either their family members or friends. For example, the stories about how the mothers are frustrated with the questions asked by their friends such as why they couldn't come up and join them for dinner; or

questions asked by their family members such as why they couldn't come to certain family event. The comments indeed confirm the above claim that it is difficult for friends and family members to recognize the psychological loss the mothers are experiencing at the early stages of grieving. Not only did the mothers in the study felt the devastation of losing their expected children, they also experience the desperation of not knowing who they are any more. During the early stages of grieving process, it is extremely important to recognize and understand all these types of loss the mothers tend to experience and provide the appropriate types of social support that helps the mothers to cope with the diagnosis. The narratives cited in the study suggest that the mothers need the understandings from others but not questioning of why they couldn't do certain things as others; the stories shared also indicate that they need validations from their support circles but not judgment on what they do. For example, one mother in the study shared that she felt quite relief after hearing a successful professional woman telling her that she did what she was supposed to do with her situation. The mother recalled that was what she really needed after she became a stay-home mother from a professional woman.

The findings of the identity loss of the mothers really demonstrate that individuals' identities will change over the course of social interactions under contextual variations. What the mothers have experienced in this study are all manifested with and enacted in their interactions with themselves, their families, their friends, and their coworkers. The diagnosis of their children and the subsequent changes in their social interactions all result in shifts in identity claims. At the early stages of grieving process, due to the traumatic emotions and distraught, it is not surprising but

common to see that the mothers are more likely to fail to claim their identities because every identity they have before the birth of the baby is becoming problematic and confusing.

The findings of this study pertains to how the mothers engaged in making sense of their children's diagnosis, reexamining the meanings of their lives, coming to redefine the experience of raising a child with Down syndrome and finally reconstructing their new identity of being the mother they wanted to be. Consistent with the assumptions of social interactionist approach that identities are constructed and negotiated through social interactions over time (Galvin, 2005; Hsieh, 2004). It should be noted that identity is a complex construct, and it requires an ongoing process to construct or carve out one's identity. The narratives of the mothers in the study are examined and analyzed to help investigate how the mothers devoted themselves to making, unmaking and remaking sense of their identity in their journey of raising up their children.

As Avery (1999, p. 118) has argued that the "disability story of parents needs to be heard." The mothers in this study were the active agent participating in telling their own stories which illustrate how they negotiated the meaning of having a child with Down syndrome and reconstructing their identities while taking care of their child. The stories shared by the mothers regarding the set of newly established transitional identities in the coping process served as a middle ground which helps them move closer to the final stage of total acceptance of their children and eventually find the new self with new meanings. The narratives pertain to the transitional identities the mothers identified undoubtedly inform the nature of the self, which states that the notion of the

individual identity can't be separate from the daily activities or social interactions. This set of transitional identities of a personal health care provider, a resilient fighter, and a knowledgeable educator are derived from the deep sense-making of their engaged daily activities and interactions of taking care of their children's needs. In their stories, they clearly expressed how they perceived and understood themselves after they lost those long time believed identities. These identities are live, real and unescapable before they finally become content and satisfied with who they are and what their life is. The narratives pertaining to the transitional identities took a shift from the notions of suffering and devastation about the diagnosis to the understanding of how to manage the diagnosis. This process clearly demonstrates the sense-making of the diagnosis and the negotiation of identity change. With more understanding of what the diagnosis entails and what roles they need to play to address the immediate needs, the mothers actually begin to engage in a stage of meaning searching for their lives ahead of them.

As it discusses in the analysis, the most dominant and salient identity loss experienced by the mothers in the study is being a typical mother to the child. This motherhood identity has been pushed to the back stage or completely deprived because of the diagnosis and the corresponding demands of intensive care for their children. While the mothers are busy tending the medical care and educating themselves and others about the diagnosis, their narratives consistently prove that they didn't feel their babies were "normal" babies in their eyes; they didn't even see themselves as "typical" mothers either. However, this doesn't mean that the mothers are totally giving up searching or striving for their dreamed and ideal identity of being a typical mother. The narratives in the study generate stories which are evolving and unfolding through

different plots and time lines intertwined with the mothers' lives. The findings of key events that motivate the mothers to reconstruct their identities, particular being the mothers they want to be, once again highlight the fact that timeframe is an important factor in conceptualizing the meaning of illness and the resulting implications for identity management. The narratives in the study always capture the mothers' lives with their self-perceptions in the timeframes of the past, the present, and the future.

The fact of them being the mothers to the children with Down syndrome in this study is undeniable; but whether the mothers perceive and believe themselves performing the identity of a typical mother is always contested and confronted by the mothers. This in turn lends the support to the claim that identity construction is a process affected by the events, contextual variations, and time. The narratives given by the mothers didn't explicitly identify the time line or point when each of them elevated themselves to a different levels of sense-making of the diagnosis and identity negotiation. As Charmaz (2002b) claims that the impact of time is manifested through the effects of illness on daily activities, time spent and required to manage illness, the orientation on future life, and the expectations of self at different stages of the life span. Therefore, once the medical issues are resolved; once certain mile stones are met; and once the inspiration and encouragement received from other mothers; the mothers in this study started seeing more light, the positive one in their life and becoming motivated to seek and reconstruct their self, which is aligned more to their current situations. These key events are the impacts of time manifested in these mothers' lives. These key events also render the mothers to open a window to their future and their children's future; and see a different baby and a different self from their past.

The findings of the key events experienced by the mothers which motivate them to strive for the identity reconstruction are considered to be critical turning points in their lives which prepare the mothers to finally walk to the stage of total acceptance of their babies and themselves. These turning points present the opportunities for the mothers to reinterpret and challenge against the well-recognized and believed assumption that having a child with Down syndrome is a "tragedy". As a matter of fact, the mothers in this study changed their perceptions and rejected the notion that raising a child with Down syndrome was a negative experience. Instead, all mothers in the sample argued and defined their life journey with their children were definitely positive. It is easy to see the clear contrast and difference in terms of how they described the experience at the early stages of grieving and later stage of acceptance. The narratives cited in the study reveal the course of their identity transformations through constant collaborative meaning making in the ways that the mothers interact with their children, with their families, with other mothers who shared the same experience, and with health care providers.

Furthermore, the narratives of finding peace in their lives and reconstruct the new identity of the mothers they wanted to be emphasize on their own interpretation and understanding of what the motherhood really constitutes. In their descriptions of the present lives, the narratives shared by the mothers attribute all the challenges, stressors, difficulties and sacrifices to the essential motherhood experience, rather than to the mothering a child with Down syndrome. In other words, the mothers perceive themselves as "just being any typical mother" who needs to be humble about their life changes; who needs to be willing to sacrifice their time, their careers, their

relationships; and who needs to accept unconditionally who themselves are and who their children with Down syndrome are.

Finally, the findings of this study contribute to the literature of understanding the families of children with disabilities and the identity transformations of the parents in the process of raising up their children. As discussed in the literature review, the trend has been shifting from portraying families and mothers in a desperate situations as "grief-stricken" figures, to the self-depicting of positive, enduring, encouraging, and rewarding journey and experience. In this sense, the mothers are no longer perceived to be the one who suffered and lost; instead, they have grown to be a different mother who they love and enjoy being.

B. Conclusion

The findings of the study reveal that the mothers of children with Down syndrome usually experience different types of identity loss from the point they are informed of the diagnosis to the grieving process over the diagnosis and finally come to the term with their children's diagnosis and find themselves again in their lives. The narratives of identity loss indicate that in addition to the motherhood identity loss, we also need to recognize the concurrent identity loss of being a person who they used to be. These narratives also highlight the impact and the diagnosis has on the families and illustrate how the mothers perceive their children and their lives is contextually bound to their daily activities, struggles, and challenges in raising up their children. More importantly, how they make sense of the diagnosis, interpret the meanings of their lives, and reconstruct their identities are manifested through their interactions with others in their lives.

The narratives of the mothers in the study lend support to the notion that an individual's identity is not fixed, but constructed in and dependent on the social context and social interactions. In this study, the mothers were never isolated from social interactions with their families, their friends, other mothers, health care providers and their own children while managing the demanding care for their children. Situated in grieving over the loss, coping with daily challenges, and searching for the lost identities, the narratives have become essential to understanding the mothers' parenting experiences, sense-making process, and identity construction. Ultimately, by identifying the identity loss at the early stages of grieving, explaining the transitional identities established in the middle of coping, outlining the key events that motivate the mothers to redefine their lives, and highlighting the excitement of reconstructed motherhood identity, the findings of this study disrupt the picture of the negative and tragic outcomes the families tend to experience, and dispel the belief that the mothers of children with Down syndrome are different from others because of the disabled label of their children. The findings of the study contribute to further discussion and conversation about the meanings of having a disabled child in a family and challenge the socially constructed normative motherhood with a normatively desired child.

C. Limitations of the Study

This study focuses on understanding how the mothers of children with Down syndrome interpret and understand the diagnosis of their children and the subsequent life and identity changes in the process of raising up their children. In addition to the significant findings of the study, there are certain limitations that need to be addressed. First, the sample of the study was relatively small considering the total numbers of

mothers and families of children with Down syndrome in the State of Michigan and in the United States. The mothers in the study were more homogenous than being diverse. Considering the family background, age, education, profession, ethnicity and religion, there was some diversity. However, the majority of the mothers in the sample were Caucasians and from middle-class families. Second, the recruitment of the mothers in the study is center-based in the Down Sydrome Association of West Michigan, which potentially limit the participation of others into the study. Third, the narratives and stories examined and analyzed in the study regarding the parenting experience of the mothers are presented in the absence of fathers' accounts and perspectives. The role of fathers in the study was only described and shared to certain extent through the accounts of mothers. It should be acknowledged that exploring the experience of being a father to the child with Down syndrome will definitely enhance the deep understanding of the dynamics of familial experience in raising up a child with Down syndrome. In addition, the health care providers are vital in delivering the news and explaining the diagnosis to the mothers and the families in general. How they relay and convey the information to the mothers and the family will greatly influence their perceptions and coping mechanism after being notified of their children's diagnosis. In this study, the question of how the diagnosis is delivered was asked by the researcher, but not being explored and discussed in the analysis. Therefore, future research should consider or include both groups' perspectives and narratives to gain a better understanding of the parenting experience and the family dynamics in coping with the challenges of raising a child with Down syndrome.

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Appendix: Interviews

A. Category I: Initial Adjustment and Concerns

1. Where were you when you heard your child's diagnosis of Down syndrome?
2. How the diagnosis was delivered to you?
3. When you heard the diagnosis, what was your initial reaction/response to it?
4. Who was there with you when the diagnosis was delivered? And how did they react?
5. Have you ever had any interaction with or known anyone with Down syndrome before you heard your child's diagnosis?
6. What did you envision parenting would be like before your child was born?
7. What do you find most difficult or stressful in having a child with Down syndrome?

B. Category II: Managing Identities and Stigma

8. What did you envision parenting would be like after your child was born and diagnosed with Down syndrome?
9. How do you think the society views children with disabilities in general? And what are perceptions about children with Down syndrome?
10. What kinds of preconceptions have you had about children with Down syndrome before the birth of your child?
11. What kinds of concerns and worries did you have about your child?
12. After learning about your child's diagnosis, when was the first time you choose to tell someone who is not a family member about your child's diagnosis?
13. When you shared the diagnosis with people, what kind of concern you have most of the time?
14. How did you share the diagnosis with them?

15. Think about the initial three or four months of your life after the diagnosis, what did you really need or wanted to do?
16. In general parents of child with either medical issues or disabilities need to go through certain period of grieving process. Would you please describe or share with me about the grieving process you have, and that can range from your emotional upheavals to daily challenges and struggles.
17. Now looking back, do you think you have changed the ways that you tell others about your child's diagnosis? In what way? Why do you think you changed?
18. How did having a child with Down syndrome affect your relationship with your husband or any other family members?
19. How did having a child with Down syndrome disrupt/change your future plans for yourself and your family?
20. During your grieving process, who was the most important person there in your life? Why?
21. Can you think of anybody who was particularly helpful through your entire coping process? What kind of help did they provide?

C. Category III. Reconciled Identity

22. Do you have a particular event/situation that is when you first realized that is it. This your child and your life? What was it?
    a. Do you feel better or worse after that realization? Why?
    b. Do you think that you'd ever feel that you are in peace and have complete acceptance with your child's diagnosis? Why or why not?

23. If I ask you to describe or share with me the effects and impacts either positive or negative of having a child with Down syndrome on your personal life, what would those be?

24. If I ask you to describe or share with me the effects either positive or negative of having a child with Down syndrome on your family life, what would those be?

25. Does having a child with Down syndrome change you? In what ways?

26. Do you think having a child with Down syndrome impact your relationship with your other children? In what ways?

27. Is there anything you want to add or share in addition to those questions asked?

D. Participants Demographics

Demographics of the Participants

Name	Age	# of Children	the Order of the Child	Education	Religion	Ethnicity
Ali	28	2	2	Bachelors'	Christian	Caucasian
Amy	36	1	1	Bachelors'	Christian	Caucasian
Angela	35	2	2	Bachelors'	Christian	Caucasian
Ann	41	1	1	Associates'	Christian	Caucasian
Cathy	35	2	1	Masters'	Catholic	Caucasian
Corea	42	1	1	Bachelors'	Christian	Caucasian
Dawn	30	2	1	Bachelors'	Catholic	Caucasian
Deborah	34	1	1	Bachelors'	None	Asian American
Emily	37	3	1	Bachelors'	Christian	Caucasian
Helen	29	3	2	Bachelors'	Christian	Caucasian
Kamilla	42	1	1	Masters'	None	Native American/Caucasian
Kim	40	2	2	Bachelors'	None	Caucasian
Lucy	34	2	2	Associates'	None	Caucasian
Maria	38	1	1	Bachelors'	Catholic	Mexican-American
Marie	28	2	1	Bachelors'	Christian	Caucasian
Mary	31	3	3	Bachelors'	Christian	Caucasian
Megan	38	1	1	Bachelors'	None	Caucasian
Rocky	32	2	2	Bachelors'	Christian	Caucasian
Susan	45	3	3	Bachelors'	None	Caucasian
Teresa	48	2	2	Associates'	None	Caucasian
Tina	36	1	1	Bachelors'	Christian	Caucasian