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Challenges of Mothers Raising Children with Physical Disabilities and Spirituality as a Coping Mechanism: The Case of Cheshire Ethiopia

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Signed by the examining committee

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Examiner (Internal) _____ Signature _____ Date _____

Examiner (External) _____ Signature _____ Date _____

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Abstract

The study explored the challenges of mothers raising children with physical disabilities and the role of spirituality in coping. The study used a qualitative approach to gather data from an organization known as Cheshire Ethiopia. The participants selected were service users of the organization where their children had physical disabilities such as Cerebral palsy and Spina bifida. The study collected data by interviewing the mothers and key informants in the organization. The key informants were rehabilitation workers employed within the organization responsible for assisting parents and children with counseling and physiotherapy. The study found that mothers had challenges related to their marriage, finances, occupation, social stigma, and isolation. The results also revealed that the most widely used coping mechanism was spiritual coping. Mothers used prayer, faith, and hope in God to cope with challenges they encountered in their day-to-day lives. Spirituality also benefited the mother's ability to find meaning in the child's disability, grow personally, and become a better person.

Key words: Mothers, physical disabilities, challenges, spirituality and coping

Contents

Chapter One

Introduction

1.1. Background

Mothers of children with disabilities face numerous challenges in raising their children. The responsibilities associated with being a caregiver can be overwhelming, physically demanding, and may cause dysfunction in the family and social relationships, and have a negative impact on the caregiver's employment (Brannen & Heflinger, 2006; Seltzer & Heller, 1997). As a result, the likelihood of parents of children with disabilities experiencing depression, physical problems, and wellbeing is higher (Feldman, et al., 2007; Ones, et al., 2002). These challenges included, caring for a child with disabilities may lead to more stress, health risks, and marital conflicts compared to families raising a child without disabilities (Feldman et al., 2007). In the context of Ethiopia, the problems may be higher as disabilities are associated with bad luck or curse. This, along with poverty, low levels of awareness, and stigma, exacerbates the burdens mothers experience in raising a child with disabilities. To go through the challenges, mothers use different coping mechanisms, such as spirituality.

Spirituality is a powerful, unique aspect of human life that is used worldwide to cope with a variety of stressful life events, to speed up healing, and to find meaning in the struggles of life. Spirituality also helps to have a positive acceptance of an illness or disability of oneself or other close persons in a family.

Regarding the meaning of spirituality, it may be difficult to define as it goes beyond religion, tradition, and culture. According to Canda (1999), Fitchette (1993), and Gaventa

(2001), spirituality is defined as “the area of life that includes the need to find meaning in our existence; a search for fulfilling relationships between oneself and others, the universe, and reality as one view and understands it; as well as the way that we respond to the sacred." It is also defined as a transcendent relationship with something greater than the self (Marcoen, 1994). These definitions provide what spirituality means from different angles, but it is also important to distinguish it from religion. Religion “involves the patterning of spiritual beliefs and practices into social institutions, with community support and traditions maintained over time” (Canda, 1997, p. 303). Religion differs from spirituality as it “involves beliefs, doctrines, and rituals that distinguish one group from another” (Koenig, 2004, p. 76). Across many traditions and cultures, religion may involve following the teachings of God as the Creator, Buddha, Muhammad, Confucius, or others.

In the context of Ethiopia, many denominations, such as Christianity, include the teachings of God. Though Christianity is a religion, it is also a way of exercising one’s spirituality. Spirituality involves focusing on the inner self, whereas religiosity is a set of activities that one follows as a member of a particular denomination. Spirituality also includes these activities, but it involves turning inwardly to our hearts in search of meaning in a higher power, 'God'. Thus, what happens in the hearts of people makes the essence of spirituality different from religion (Legere, 1984). This search for meaning often leads to a connection or a relationship with a divine being (God) and shapes how we think, react, and handle or cope with stressful situations.

Since the majority of Ethiopians have adopted a certain faith, it has been embedded in most of their lives. Therefore, the researcher chose to find out the challenges of mothers raising a

child with physical disabilities and spirituality as a coping mechanism. As the majority of Ethiopians are Christians (2007 Ethiopian census, 2012), the researcher chose to examine spirituality as a coping mechanism in a Christian setting.

1.2. Statement of the problem

Families experience profound and long-lasting consequences when they raise a child with a physical disability. (Simmerman et al., 2001; Martin & Colbert, 1997). Mothers of children with physical disabilities bear a lot of stress and burden. Several pieces of research in Ethiopia studied the stress or challenges parents experience as well as the coping mechanisms caregivers adopt to manage difficulties. Some of the researchers, such as Aynalem (2014), Soliyana (2015), and Helen (2016), studied the challenges parents face and their coping mechanisms, particularly for families with autistic children. Although such studies were conducted, there is limited research concerning physical disabilities such as cerebral palsy and spina bifida and their effects on parents. For this reason, the researcher explored the challenges of mothers raising a child with cerebral palsy or spina bifida and the role of spirituality as a coping mechanism.

Mothers of children with special needs experience challenges due to the new demands of caring for the child (Angold et al., 1998). They experience financial difficulties, problems in their relationships within the family or other networks, and parenting distress. The expectations of the mothers are also impaired as the future becomes uncertain, which can lead to fear, anxiety, and stress (Gona et al., 2011). The effect of having a child with physical disabilities is multidimensional and reciprocal, affecting the whole family system and the relationships between the family members (Harris, 1994; Rodrigue et al., 1994). The diagnosis of some

physical disabilities is considered to be permanent chronic conditions that may need continuous support that could go beyond the age at which the child is expected to become independent.

Mothers also face social isolation and stigma due to the behaviors children with physical disabilities show that may not conform to the expected norm of society. Moreover, the physical appearance of a child with a physical disability, along with the lack of understanding of the public, may arouse hostile reactions toward the child with the disability (Gill & Liamputtong, 2011). As a result, mothers may feel that they have to withdraw from such situations or reduce their interaction with others, thereby isolating themselves from the general public. Social isolation is worsened when caregivers experience multiple kinds of negative responses from the community. These issues decrease the chances of parents getting enough social support from the community.

As mentioned above, mothers of children with physical disabilities face an immense amount of stress and burden in their lives. Mothers may experience depression, anxiety (Dyson, 1991; Emerson, 2003), higher levels of hopelessness, failure, guilt, less parental skills, and decreased marital satisfaction (Rodrigue et al., 1990). To manage such difficulties, mothers use different coping mechanisms, particularly in Ethiopia, where individuals may use spirituality, family, or social support. Though this is present in Ethiopia, there is limited research that explores how mothers use spirituality as a coping mechanism. Consequently, this research explored how spirituality helped mothers cope with the challenges that arise in the caregiving process.

1.3. Research questions

1. What did the mothers experience following the diagnosis of their child?

2. What are the challenges mothers face in raising their child with a physical disability?
3. How do the mothers use spirituality to cope with stress and challenges?
4. Which coping strategy is commonly used among the mothers?

1.4. Objective of the study

General Objectives

- To identify the challenges mothers face in raising a child with physical disabilities and how mothers use spirituality as a coping mechanism.

Specific Objectives

- To find out what the mothers experience after the diagnosis of their child.
- To find out the challenges mothers face in raising their child with a physical disability.
- To identify how the mothers use spirituality to cope with stress and challenges.
- To examine which coping strategy is commonly used among the mothers.

1.5. Significance of the study

Perceptions of illness and disability are associated with religious or spiritual beliefs (Zhang & Bennett, 2001). The last two decades have shown that there is a relationship between religiousness, spirituality, and coping with stress (Pargament et al., 2013). In times of crisis, spirituality (connecting with God) may serve as an energetic and harmonious life force to bring hope and motivation toward change and coping (Dreyer, 1996; Golberg, 1998). "A strong spiritual connection may improve one's sense of satisfaction with life or enable accommodation for disability" (Delgado, 2005, p. 157). People often look to spirituality or God to find answers to their questions and to find the meaning and purpose behind their struggles. Supporting

individuals in their spiritual identity and sense of worth fastens healing and fosters a healthier lifestyle (Bergin et al., 1994; Richards & Potts, 1995). Individuals who have a positive spiritual identity experience and enjoy being connected to God's love and draw their sense of worth from that spiritual reality (Richards & Bergin, 1997). Therefore, spirituality provides better mental health and a positive outlook on life. This leads to inner peace and comfort, resulting in greater success in coping. Hence, spirituality can also influence how mothers cope with the challenges they face in raising a child with a physical disability.

Spirituality also plays a role in the social work practice. Since spirituality is at the center of the lives of many people and its reach is so vast, including and integrating it into approaches to therapeutic interventions with clients is suitable (Weinstein, 2008). As practitioners of social work, we must look at an individual as a whole, and that means including spirituality. Therefore, spirituality is responsible for many positive aspects of human life. Consequently, the researcher believed that it is important to explore this personal reality (spirituality) that brings forth healing, success in coping, comfort, and inner peace.

1.6. Limitation of the study

The study is limited to the mothers of children with physical disabilities, particularly cerebral palsy and spina bifida. The research was also undertaken on a single study site and does not represent a larger population. The study also focused on coping mechanisms among Christian mothers and did not include other religious faiths, such as Islam. Since the views and perceptions of different faiths are very different, including other religions, the research would be unable to focus on one type of faith. In addition, Christianity was found to be the highest in Ethiopia (2007 Ethiopian census, 2012). For this reason, the study limited itself to Christian faiths only.

1.7. Operational Definitions

Mother: a primary caregiver of a child related by birth.

Diagnosis: the process by which the mother of a child receives official statement by medical practitioners that indicates the child's disability.

Physical disabilities: an impairment caused by a delay or incomplete development of the mind and/or body.

Cerebral Palsy: a type of physical disability that affects the muscles, movement, and posture.

Spina Bifida: a type of physical disability caused by damage to the spinal cord that may or may not cause physical disabilities.

Challenges: a problematic situation that arises in the caregiving process of a child with a physical disability.

Crisis: extreme challenges occurring after the child's diagnosis.

Spirituality: a personal relationship or connection with God that can be exercised individually or in social institutions.

Coping: a process of managing situations that are problematic and unexpected.

Coping mechanism: a tool or method used to adapt or manage through difficult situations.

Adaptation: adjusting to the child's disability and the associated challenges.

Chapter Two

Literature Review

This chapter aims to review works of literature related to physical disability, challenges, and coping mechanisms. The chapter begins with the definition and cause of physical disability so that any ambiguity related to its meaning may be clarified. Two types of physical disabilities were also included in the literature review; Cerebral palsy and Spina bifida. Then it carries on with the literature that studied the lives of parents as well as mothers of children with a physical disability, the associated challenges they face, and the process by which caregivers develop coping mechanism(s) to deal with the challenges that occur in their lives. Then it elaborates specifically on literature related to spiritual coping and how it benefits individuals. Although there are different kinds of coping mechanisms individuals adopt, this chapter particularly focused on spirituality as one of the coping mechanisms used, as it is the main topic of the study.

This study also selected the theory of the Double ABCX model as its guide so that it can best explain what the mothers experienced during the diagnosis of their child, the challenges they experienced afterward, and their coping mechanisms. The theory had three parts: pre-crisis, crisis, and post-crisis. These three stages explained the initial challenges they faced during the diagnosis (pre-crisis), the challenges they experienced that led to instability within their family (crisis), and the coping mechanisms or resources they used during and following the crisis (post-crisis).

2.1. Definition and causes of physical disabilities

Definition

The definition of people with physical disabilities is a broad category of individuals who have delays in behavior, language, or body because of mental or physical impairments that manifest before the age of 22 (CDC, 2019). Physical delays include blindness or hearing loss, while mental impairments are associated with intellectual disabilities. The problem can also be both physical and mental.

Though there are different types of physical disabilities, the study included the following types since they were the disabilities found on the study site:

Cerebral Palsy

Cerebral palsy is an impairment of the muscles that is caused by damage to the brain. The damage may occur before, during, or shortly after birth. It may also happen before the age of 5 because of an accidental injury or illness such as meningitis (Porter, 2009). It involves muscle stiffness in the legs and/or arms and movement difficulties in half or all over the body (Jansheki, 2020).

Spina Bifida

Spina bifida is a physical disability caused by a defect in the development of the spinal cord. Children with spina bifida have an incomplete closing of the neural tube in the spine, leading to an improper formation of the backbone and the surrounding membranes that protect the spinal cord (CDC, 2019).

Causes of physical disabilities

Certain works of literature suggest a connection between genetic and environmental factors, including exposure during pregnancy. However, these factors do not show a close connection that could prove the cause (Finucane, 2012). Additional kinds of literature link physical disabilities to trauma to the brain and the nervous system. The Alta Regional Center states that childhood accidents, medication poisoning, hereditary disorders, malnourishment, and other factors were listed as causes of physical disability.

2.2. Models of Disability

Several models were proposed to define disability and its effects in the lives of individuals with impairments. Three models were found to be prominent and still have influence in the society. These models are religious/moral model, medical model, and social model.

Religious and/or moral model

This model aims to portray disability as a punishment from God for one's sin or sins committed by ancestors (Henderson & Bryan, 2011; Pardeck & Murphy, 2012). This model has a negative consequence for the family and the individual with the disability, excluding them from participating in their community (Rimmerman, 2013).

Another aspect of the moral and/or religious model views disability as a test of faith, in which individuals believe that their disabilities are a chance to be saved by showing perseverance and endurance (Niemann, 2005). Additionally, this model, discussed by Black (1997), mentions that the difficulties disabled people experience are opportunities provided by God for personal growth and character. Though this model is not as prominent as it was in the past, individuals

still experience negative views associated with their impairments (Henderson & Bryan, 2011; Rimmerman, 2013)

Medical model

Midway through the 1800s, the medical model of disability began to replace the moral and/or religious model. According to this model, disability is viewed as a medical issue that an individual has. The medical problem is the result of a defect in the bodily system and is considered problematic and pathological, needing a cure or treatment to eliminate the impairment (Olkin, 2001; Stone, 1986).

The medical model of disability is also described as the "personal tragedy, which suggests that a disability is some terrible chance event that occurs at random to unfortunate individuals" (Guevara, 2020, p.10). This negative view of disability has also led practitioners to perform questionable medical procedures such as forced sterilization and euthanasia (Carlson, 2009). In addition, terms such as 'invalid', 'cripple', 'spastic', 'handicapped', and 'retarded' are all drawn from the medical model (Creamer, 2009, p.22). The medical model views disabled individuals as in need of fixing and does not address the issues that contribute to the disability (Kasser & Lytle, 2005).

Social model

Though the medical model still has its effect on how disability is viewed and solutions are found, a modern conceptualization of disability called the social model is also observed. This model shifted the responsibility from the individual to the society, stating that it is society which disables people with impairments and that the focus should be made on changing the society as

opposed to adjustment and rehabilitation of the individual (Shakespeare, 2006). The social model, compared to individualizing methods, views disability in the context of a harsh and excluding social environment (Marks, 1997).

It follows from the analysis that individuals with physical impairments experience oppressions that affect different sectors of life, such as housing, education, work, etc. The problems individuals with impairments experience are seen as symptoms of oppression and exclusion in different areas of life. This model seeks to build a democratic organization of disabled individuals, which tackles maintaining a clear understanding of disability and the amendments required to overcome the challenges (UPIAS, 1975).

2.3. Parenting a child with physical disability

Being a parent, as most view it, involves a transition in one's life and includes growth and change (Demick, 2002). Parents experience changes mostly and are affected when they realize that their child has a disability (Graungaard & Skov, 2007). On the contrary, some parents and mothers report having positive experiences and adapting well to challenges in raising a child with physical disabilities (Emerson et al., 2006; Hassal & Rose, 2005). For example, most parents can cope and shift their focus from the child's impairments to addressing the needs of their child (Beresford, 1996; Rentnic et al., 2009). They also come up with and employ a variety of coping mechanisms to deal with the difficulties that may arise in raising their child (Glidden & Natcher, 2009; Lee, 2009). Some literature states that raising a child with disabilities involves both challenges and great love, or joy (Bayat, 2007; Blacher et al., 2013). It was also found that it strengthens the bond and connectedness between families (Bayat, 2007). Parents also report that it helped them have more tolerance, self-understanding, personal growth, and strength

(Hasting & Taunt, 2002; Scorgie & Sobsey, 2000). Furthermore, parents, particularly mothers, expressed that it is emotionally rewarding to raise their children (Green, 2007).

Though there are positive aspects to raising a child with a disability, especially in the Western world, in Ethiopia, parents face a lot of barriers and challenges. Children with disabilities and their family members often experience bullying, stigmatization, and discrimination (Kinnear et al., 2016). Disability, along with poverty, worsens their situation, making them more vulnerable and isolated (Trani et al., 2015). This, as a result, increases social exclusion among children with disabilities (Chamberlain et al., 2007). This shows that parents need continuous support in taking care of their child with a disability even after the child reaches adulthood (Aldersey et al., 2017; Bayat, 2007).

2.4. Challenges/ sources of family stress

Families who raise a child with a physical disability report experiencing higher levels of psychological stress (Baker et al., 2003; Dyson, 1991; Emerson, 2003). Most of the issues begin at the diagnosis stage, where parents learn that their child has a physical disability. When this happens, the expectations, dreams, and plans they made concerning their child and family seem darkened. For most parents, the diagnosis of their child's disability is a starting point for something they may have never known before (Bingham et al., 2012). After the child's diagnosis, parents have to seek out new expectations about their child, what their role is as a parent, and the support services they need (Russell, 2003). The parents could have difficulty finding suitable and affordable child care, and the decisions they have to make concerning work, education, or other matters could also be affected (Naidoo, 2016). This can cause an immense amount of stress on the parents, affect their mental and physical health, and trigger guilt or blame

(Reichman et al., 2008). Other contributing factors increase stress on families, such as severity, type of diagnosis, age of the child, and unknown etiology (Minnes et al., 1989; Hauser-Cram et al., 2001; Donovan, 1988; Goldberg et al., 1986).

The severity of the diagnosis can add to family stress (Minnes et al., 1989). The severity of the diagnosis has a negative effect; as the severity of the diagnosis increases, so do the maladaptive behaviors (Baker et al., 2003). The maladaptive behaviors disengage the parents, affecting siblings or typically developing children (Martin, 2001).

The type of diagnosis also leads to increased stress since different disabilities have their characteristics and challenges. For instance, Donovan (1988) found that both parents of children with physical disabilities and autism spectrum disorder had higher levels of stress. Nonetheless, compared to parents of children with other kinds of disability, parents of children diagnosed with autism experienced more stress. This was due to the aggressive behaviors associated with autism.

The age of the child also impacts the levels of stress in the family. For instance, a study conducted by Hauser-Cram et al. (2001) found that parents whose children are older and diagnosed with physical disorders experienced more distress than those with younger children due to the changes occurring in their development.

The other contributing factor leading to stress was unknown etiology. Goldberg et al. (1986) stated that families with an unknown etiology had more stress than those who knew the cause behind the disorders experienced by their children. Perry et al., (2004) also agreed that those diagnosed with physical disability of an unknown etiology had poor family dynamics. This was due to the perception of the parents about the diagnosis. A study done by McCubbin and

McCubbin (1989) demonstrated that families receiving a diagnosis of Down syndrome were more optimistic about the diagnosis than families who received a diagnosis of autism.

2.5. Impacts

As mentioned in the previous section, parents or caregivers experience lots of stress due to different reasons related to the physical disorder. Living with a child with a disability can have an impact on the entire family (parents, siblings, and extended family members) (Reichman et al., 2008). Some report having a positive and joyful experience raising their child. Others also stated that it encouraged them to be more aware of their inner strength, improve family cohesion, and be more connected to community groups or religious institutions (Naidoo, 2016).

On the contrary, parents may experience loss of hope for the future, fear, guilt, disengagement within the family, loss of job, less or no time for other activities, loneliness, and so on. Moreover, other family members, such as typically developing siblings or other relatives, may also be affected.

Different studies show that siblings of children with physical disabilities experience more behavioral problems, lower self-esteem, and depression compared to siblings of children without any physical or developmental disorders (Boyce & Barnett, 1993; Hannah & Midlarsky, 1999; Nixon & Cummings, 1999). Typically, developing siblings can internalize problems in childhood and later continue or manifest them in adulthood (Petalas et al., 2009; Wolfe et al., 2014). This happens as the siblings adjust to the problem negatively, thereby also affecting the sibling with the physical disorder.

On the other hand, some other studies also showed that having children with a physical disability could positively affect typically developing siblings. This is due to a positive adjustment to new roles associated with the diagnosis of a physical disorder in a sibling. These new roles involve caregiving and influence the typically developing siblings to be kind and empathetic (Cuskelly & Gunn, 2003). The roles and responsibilities given to the typically developing siblings foster their maturity and make them more accepting and altruistic of others compared to their peers (Howlin, 1988). Typically developing siblings may also go into caring professions as adults as they become benevolent because of their siblings with a physical disability (Cantwell & Baker, 1984).

2.6. Coping mechanisms

Coping mechanisms can be defined as "our efforts to master the demands of stress and include the thoughts, feelings, and actions that constitute these efforts" (Hutchison, 1999, p. 137). Based on the work of McCubbin and Patterson (1981), the coping style of families is classified into internal and external strategies. Internal strategies mainly involve thought processes or cognition, such as passive appraisal and reframing or redefining the problem or situation. External coping strategies involve more behavioral attributes or actions, such as seeking social or spiritual support.

According to Lazarus, there are two essential concepts to stress. The first is *appraisal*, which involves the person's evaluation or judgment of the situation as to whether it is important or insignificant. It also refers to how an individual interprets or perceives a situation or an event (Folkman & Lazarus, 1984). The theory explains that there are two types of cognitive appraisal, namely primary and secondary appraisal. The first one involves the individual identifying the

meaning the stress has for him or her, and the second one involves determining whether there are sufficient resources available to cope with the situation. The second concept of stress is coping, which involves the efforts (such as thought and action) the individual takes to manage the stress (Lazarus, 1993). Then an action is taken, such as seeking information, social support, or other means to cope with the situation (Folkman & Lazarus, 1984).

Parents, as well as mothers of children with a physical disability, may have positive or negative appraisals, or both, in dealing with the challenges associated with raising their child (Trute et al., 2007). Having a positive outlook or perception of the situation can help reduce the stress in the family, improve their mental well-being as well as their physical resources, and protect against clinical depression (Gupta & Singhal, 2004). Using positive appraisal and seeking social or spiritual support have been cited as effective problem-solving strategies that help alleviate stress (Bingham et al., 2012; Gupta & Singhal, 2004).

Spiritual coping

Individuals use different coping mechanisms to deal with a particular event or situation. This section deals with spirituality as one of the coping mechanisms or resources to cope with stress. For example, Belavich (1995) stated that prayer and faith in God were the most common coping resources used in times of stress. Prayer involving talking to God about a particular situation that is troubling and seeking guidance from God or the clergy were the coping resources cited in the study.

Pargament et al. (1990) also stated that 78% of the sample in their study mentioned that religion and faith in God were the highest coping mechanisms used. In addition, Neighbors et al. (1982) reported that the most frequently used coping resource among blacks was prayer. This

helps individuals perceive situations as a lesson from God rather than punishment (Belavich, 1995). It also facilitates individual's ability to see and know that there is a higher power than them that could help them deal with the burdens they carry. In another study, Mabel (2017) reported that mothers who had a child with an intellectual disability used hope and support from family members, spiritual beliefs involving prayer, and other religious activities to cope with stress and challenges. This is because spiritual coping strategies help the individual find meaning and purpose in difficulties, contributing to self-empowerment and strength to cope with the current stress until he or she adjusts to the situation (Baldacchino & Draper, 2001). This also contributes to increased inner strength and personal awareness, resulting in inner peace (Delgado, 2005).

Spirituality is also cited as a source of social support. In times of stress, caregivers of children with disabilities may not get enough support from their families. According to Gunderson & Pray (2006), faith communities are the ones that provide more support to caregivers during times of crisis. In a study by Masuku & Khoza-Shangase (2018), caregivers drew their strength and encouragement from church members who consistently supported them through different activities such as prayer, house visitations, financial aid, encouragement, and messages of hope and love. In the study, participants gained support from spiritual fraternities and fellowships of the church. Hence, faith-based fellowship among members also increases social support (Büssing et al., 2005; McNally & Mannan, 2013). Zambrani (2010) also stated that spiritual support is the best for addressing and dealing with problems from the core, helping the caregiver see the situation from a broader perspective and, in turn, find long-lasting solutions.

2.7. Conceptual Framework

This research used the theory of the Double ABCX model of Hamilton McCubbin and Joan Patterson (1982, 1983a, 1983b). This theory used Hill's (1958) ABC-X model of family stress and coping as a foundation. Hill's model consisted of variables that were applicable until a family reached a state of crisis or instability. On the other hand, the Double ABCX model added post-crisis variables to show how families recover from crisis and why some are better at adapting than others (Patterson, 1988).

This research selected the Double ABCX model as a guide since its center of idea involves family (mothers and children), coping, and adaptation. The theory talks about how families transitioned between three stages: pre-crisis, crisis, and post-crisis, and how they coped and adapted after a crisis occurred. This research is also intended to study how mothers of children with physical disabilities cope with the challenges that happen and pile up (aA) after discovering that their child has a disability. This can either become a crisis or not, depending on the existing or new resources (bB) the mothers have access to and their perception or definition of their situation (cC). The theory mentioned different levels of resources, such as individual, familial, and communal. This research is also intended to use spirituality as a resource, either at one or all of the levels (individual, familial, or communal, such as church affiliation), for coping and adaptation. The variables such as aA, bB, and cC of the Double ABCX are thoroughly discussed in the following paragraphs.

The Double ABCX model consists of three main parts: pre-crisis, crisis, and post-crisis. Just as in Hill's (1958) model, the pre-crisis consists of the variables a, b, and c, where 'a' is an initial stressor, 'b' is the existing resource, and 'c' is the perception or definition a person has

about the stressor. The theory included individuals, familial relationships, and social and community resources.

The second part, crisis, is labeled as ‘x’, while Hill’s formula ends here, the Double ABCX model continues to include post-crisis variables. The post-crisis includes variable *aA*, which is the stress that piles up on top of the initial stressor. This pile-up was included to show the additional stressors families experience after the initial stressor. The next variable, *bB* is the existing and new resource, while *cC* is the definition the family has about the x, aA, and bB. This part also continues to include coping and adaptation to the post-crisis variables.

Coping is the interaction between the pile-up (aA), existing and new resources (bB), and the overall perception (cC) of x, aA, and bB. When the family’s perception of the situation is positive, they can cope better. The coping ability of the family also determines how well it can adapt to the situation. This leads to another point called adaptation, which is the outcome resulting from the change or stressors within the family. There are two levels at which adaptation can function: (1) between the members of the family; and (2) between the family and community. When there is stability between members of the family and the family and community, it is called bonadaptation, while the negative end is maladaptation, represented by xX. This shows a continuous imbalance in one or both levels of functioning.

The following figure shows how the three main parts (pre-crisis, crisis, and post-crisis) take place for a family in crisis.

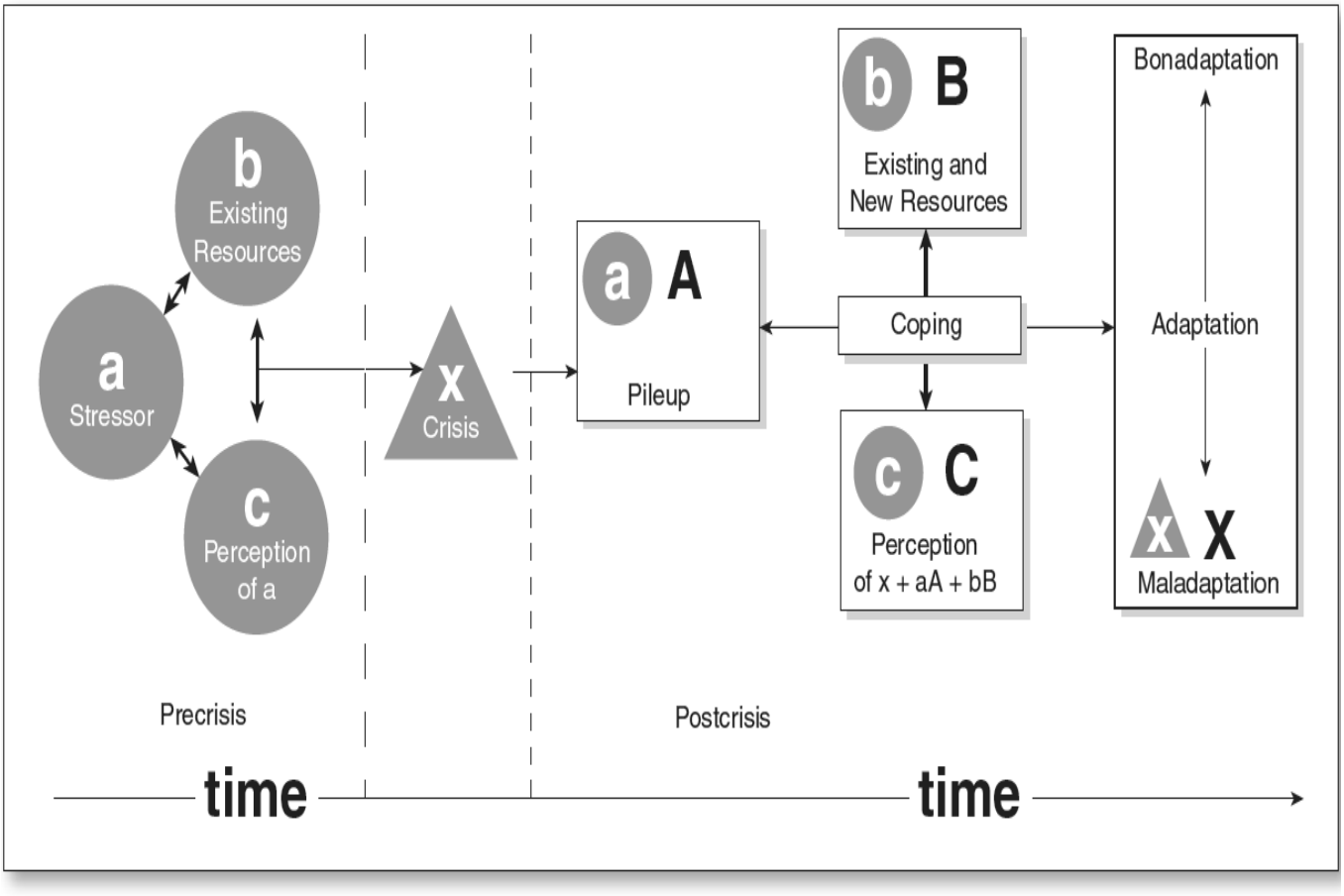

Figure 1.The Double ABCX model (McCubbin and Patterson, 1983a).

The variables are also explained in relation to this study:

Precrisis

- *'a'*, the initial stressor or the diagnosis of the child.
- *'b'*, the existing resource the mothers had before they reached crisis.
- *'c'*, the perception the mother has about the child's disability.
- *'x'* crisis refers to the multiple challenges that occur as a result of the diagnosis.

Postcrisis

- *'aA'* new challenges that pileup on the initial stressor.
- *'bB'* either existing or new resources of the mothers.
- *'cC'* perception of the challenges/crisis, pileup, and the resources the mother holds regarding the child's disability.
- *'Bonadaptation'* a balance between the family of the child with the disability and the community.
- '*Maladaptation xX'* imbalance between the family of the child with the disability and the community where the mother is unable to cope.

Chapter Three

Research Methodology

3.1. Research Design

This study used a qualitative research approach to gather rich, detailed, and meaningful data from the study participants (Creswell, 2007). This particular research approach was important for this study, as the topic considered involved the experiences of mothers following the diagnosis of their child and also the way they cope with the associated stressful events or situations that occur. The qualitative research approach was conducted in such a way that the researcher could gather data related to the mother's experiences and challenges they face and how the coping mechanisms they adopt help them manage the struggles that occur daily or have occurred in the past.

Among the types of qualitative research, this study conducted a single case study on a particular organization known as Cheshire Ethiopia. The researcher decided to do a case study as it provides an in-depth understanding of an issue, whether on a single or several programs (Creswell, 2007). The researcher chose Cheshire Ethiopia as it is responsible for caring for individuals with physical disabilities. It was convenient for the researcher as the organization did not only focus on a single type of physical disability. It seemed suitable for the researcher to include other physical disabilities to see how they affected mothers and children differently.

3.2. Study Area

The study was conducted on a non-profit organization known as Cheshire Ethiopia, established in 1962 by the grandchildren of the late Emperor Haile Selassie with the technical support of Captain Leonard Cheshire (Cheshire Ethiopia, n.d.). It is an independent local non-

profit organization, staffed by Ethiopians, and registered as an Ethiopian Resident Charity. The organization focuses on providing physical rehabilitation for children with disabilities in different locations, such as Menagesha, Hawassa, Dire Dawa, Harar, and Addis Ababa. The organization selected for this study is located in Addis Ababa known as the Reed House Pediatric Center. This rehabilitation center started operating in October 2010 and provides physical therapy for children with physical impairments residing in the capital. The researcher chose this site because it was suitable to find mothers who were raising children with physical disabilities.

3.3. Research Participants

The participants of the study were mothers who were raising a child with a physical disability. The mothers selected for the study had children enrolled in the physical rehabilitation service Cheshire provides and were sixteen in number. The parents that most attended the services were mothers (single or married) and a few fathers who attended irregularly. As a result, the research participants selected were mothers only. The disabilities the children had consisted of cerebral palsy and spina bifida. The study included all of the disabilities mentioned but, more importantly, focused on children with cerebral palsy, because it was found to be the highest in number within the Reed House Pediatric Center. The study also included five key informants working for the organization as rehabilitation workers. The researcher included key informants as they would be able to provide information about what they observed among the parents while working in the organization and also to know how the services they provide benefit the parents and children.

3.4. Sampling technique and inclusion criteria

This research paper used the judgmental or purposeful sampling technique to include individuals with particular characteristics, such as being the mother of a child with a physical disability. This type of non-probability sampling was selected as it would enable the researcher to choose mothers with specific experiences and characteristics. Therefore, the study purposefully chose characteristics that included participants who were Christian (married, divorced, or unmarried) and raising a child with a disability. The key informants were selected based on their frequenct contact with the mothers and hence were believed to have more observation and information regarding the situation of the mothers and disability of the children.

3.5. Data Collection Instruments

The sources of the data collection included primary and secondary sources. The researcher reviewed literature related to disability, coping, and spirituality to look at the relationship each had with one another. As for the primary source of data, the researcher selected a semi-structured interview as an instrument to grasp a detailed description of the experience of mothers raising a child with a physical disability. Due to the current situation with the coronavirus (COVID), the researcher was unable to interview the mothers face-to-face and had to interview them through phone calls. Though the researcher was unable to observe the participant's facial expressions and body language, it helped the mothers freely talk about sensitive subjects as they were in their private space. On the other hand, the key informants were available to interview in person. Accordingly, the interviews were undertaken until the data reached saturation.

3.6. Procedures of data collection

The data collection began by contacting the person in charge of leading the team at the Cheshire Rehabilitation Center. The researcher had a brief meeting with the team leader to get acquainted with the organization and its services. The researcher also took the time to establish a rapport with the rehabilitation workers and gather information from the observations they had while working in Chesire. Due to COVID, the researcher was constricted from contacting the mothers in person and therefore opted to use phone calls to gather information. The researcher was permitted to obtain the phone numbers of the mothers enrolled in the program. Consequently, the researcher asked the mothers for consent and interviewed the mothers until the data reached saturation.

3.7. Method of Analysis

The type of analysis selected for this study was thematic analysis to determine the relationships and similarities between the data set that are coherent with the research questions (Braun and Clarke, 2006). The researcher first transcribed the raw data gathered from the interview and labeled the participant's name with a number. After that, the data gathered from each participant was reviewed, and notes that were relevant to the research questions were highlighted. Then the researcher grouped the similar data and labeled the categories. Next, the categories were reviewed again to find patterns, meanings, and relationships among each theme or category. Then the categories were given new names that best fit the data and were described in the findings.

3.8. Trustworthiness of the study

To ensure that the research is trustworthy, the study employed triangulation as a strategy to test the validity of the research. Triangulation is a method that involves the use of multiple sources to check and increase the validity of a study. Accordingly, the researcher conducted semi-structured interviews, reviewed documents, and interviewed experts or key informants from the organization. This was done for the researcher to compare and contrast the data gathered between the participants and the key informants, as well as the documents reviewed. The data gathered from the key informants helped the researcher look for areas that were in agreement and areas that were not consistent with the overall data. However, not every piece of inconsistent data was omitted from the study, as the experience of each participant was just as useful and meaningful as the others.

3.9. Ethical consideration

Ethical consideration involves respecting the rights and choices of participants, whether or not to partake in a study. The researcher took steps such as informed consent, confidentiality, and anonymity to ensure adherence to ethical guidelines. Since the interview was conducted over the phone, an informed consent form was read to the participants to ensure that they were willing to participate in the study. The names of the participants were also kept anonymous by assigning numbers to the individuals. The researcher also chose a setting where the information gathered would be private and not prone to being overheard by others around. In addition, the researcher made sure that the location the participants were in was comfortable for them to share their stories, and any information that the individuals did not want to disclose was kept confidential.

Chapter Four

Findings of the study

This chapter presents the findings of the study beginning with the socio-demographic characteristics and living conditions or state of the mothers during the data collection and their attendance in the organization. Then based on the research questions as well as the theory of the Double ABCX model the findings were presented in three major sections that discuss the experience of mothers after diagnosis, the associated challenges they faced and their coping mechanisms to manage the difficulties that arose in raising their children with physical disabilities.

4.1. Socio-demographic characteristics of the participants

The participants in the study consisted of 16 mothers and 5 key informants from the organization ranging from age 23-38. The majority of the mothers completed their education until the tenth grade and often engaged in low-income jobs before having their child. Four of the mothers were divorced or were single while the rest were married. The highest faith that was found among the mothers within the organization was Orthodox while a few were protestant.

The key informants selected were those who worked in the organization as rehabilitation workers who provided physiotherapy to children with disabilities. Hence, of all the workers in the organization, they had the most contact with the mothers. For this reason, they were selected as key informants as they were able to give information concerning what they observed during their close contact with the mothers while working in the organization. Table 1 illustrates the socio-demographic characteristics of the mothers while Table 2 shows the characteristics of the key informants.

Table 1: Demographic information of the mothers participating in the study

No	***Age***	***Education***	***Occupation***	***Marital status***	***Faith***
1	32	9th grade	Laundress	Single	Orthodox
2	23	5th grade	Housewife	Married	Orthodox
3	32	10th grade	Nanny	Married	Orthodox
4	25	8th grade	Housemaid	Divorced	Protestant
5	31	4th grade	Housewife	Married	Orthodox
6	38	10th grade	Housewife	Married	Orthodox
7	38	8th grade	Housewife	Married	Orthodox
8	34	10th grade	Housewife	Married	Orthodox
9	30	10th grade	Janitor	Divorced	Orthodox
10	26	10th grade	Housewife	Married	Orthodox
11	27	8th grade	Housewife	Married	Orthodox
12	30	Diploma	Housewife	Married	Orthodox
13	33	10th grade	unemployed	Single	Protestant

14	28	5th grade	Housewife	Married	Orthodox
15	24	8th grade	Housemaid	Divorced	Orthodox
16	27	8th grade	Housewife	Married	Orthodox

Table 2: Demographic information of the key informants in the study

No	***Age***	***Gender***	***Occupation***
1	34	Female	Assistant rehabilitation worker
2	36	Female	Senior rehabilitation worker
3	35	Female	Public health worker
4	36	Female	Assistant rehabilitation worker
5	35	Female	Assistant rehabilitation worker

Living condition of the mothers

The mothers under study were those who were working in low-income jobs and some living in the poorest situations due to their low educational status. They manage to earn a living by working as a housemaid, cleaning, washing clothes, or working in daily labor jobs such as on construction sites. The mothers get support from Cheshire through the services that provide

physiotherapy for their children. The key informants mentioned the following regarding the situation of the mothers.

> *The mothers seeking service within this organization are those with low incomes and working in informal jobs. They live in the poorest situations and sometimes we may even assist them with transport cash for them to come and have another session with us. Some mothers are unable to afford sanitary materials (diapers) for their children. So they have to go through these conditions as well while trying to take care of their child's disability.*

Some of the parents were also stay-at-home mothers who quit working from their jobs to give their children full-time care. Others were single or divorced mothers who were left by their husbands after discovering that their child had a disability. For instance, mother 9 mentioned the following about her living situation.

> *I live in a house where some of it is covered in plastic and cardboard. Rainy seasons and cold weather are the most difficult time of the year for me and my child. My child suffered from pneumonia and flu multiple times because of this.*

4.2. The experience of mothers after diagnosis (pre-crisis)

This section is aligned with the theory of the Double ABCX model to describe what the mothers experienced during the diagnosis and a while after diagnosis. This stage is known as the pre-crisis stage since the diagnosis is the initial stressor the mothers experienced before they reached in a state of crisis. In this accordance the experience of the mothers during and a while after diagnosis is explained in the following paragraphs.

The diagnosis stage and the process afterward, as the mothers explained, was the most difficult time they had to pass. They had to go through different stages to accept that their child

had a disability. Concerning what the mothers felt, the following arrays of emotions were commonly experienced among them.

- They were scared, shocked, and felt grief.
- They were in doubt, in denial, and had unrealistic expectations.

At the beginning of the diagnosis stage, some of the mothers mentioned that they were anxious and felt grief. Mother 6 and 13 respectively mentioned the following about how they experienced grief and shock when they first found out that their child had a disability.

> *I was shocked when I first found out! Since she was my second child, I did not expect that this would happen. I saw that she was losing a lot of weight and was not able to eat. Then I took her to the doctor and found out about her disability. It was so hard and painful for me to accept that my child had a disability.*

> *I felt an immense amount of grief as if I was losing or saying goodbye to someone I once had in my life. I thought I would never see any change in my child but as time went by and as I knew more about the disability she had, I learned to accept it.*

Other mothers experienced doubt and denial and had unrealistic expectations of their child's disability. This particular information was according to what the key informants observed while working in the organization. They stated that the mothers seek solutions for their child's disability in several places before deciding to get treatment either from the doctors or from the organization. Some mothers try to take their children to traditional healers while others in search of a cure, take their children to religious places. The key informants also mentioned that mothers experienced denial due to the biases attached to being a mother to a child with a disability such

as bad luck, curse, or sin. The negative views or perceptions of the paternal relatives are also another factor for the difficulties the parents go through in accepting their child's disability.

4.3. The stage of crisis

After discovering their child's disability, mothers experienced several shifts within their family life that led to instability (crisis). They experienced problems in relationships with their family, neighbors/friends, and occupation. Regarding this stage, two groups of mothers faced the challenges differently: the married and divorced. The second group also consisted of single mothers as they did not have a partner that would support them in caregiving.

Based on the interviews, married mothers faced several challenges in their families to accommodate the new situation associated with their children. It was apparent that most of the mothers had to quit their jobs after they discovered their child's disability. The following is what mother 7, 8, and 11 mentioned about having to leave their jobs:

> *I used to have a business before I had my child, but I could not continue as my child needed special attention.*
>
> *I used to work in a hair salon but I had to quit my job so I could take care of my child.*
>
> *I used to do tailoring before I became a housewife. I had to stop working after I found out that my child had a disability.*

As for the other mothers in the second group, they experienced challenges in their marital relationships that led them to be separated or divorced. Since they were not able to afford the rental fee, the mothers went through different consequential events. Based on the interview with

the mothers and key informants, several consequences were commonly found because of the divorce/separation.

The first one is that they could no longer afford to continue living in their home. Following a divorce, mothers may become homeless because they cannot afford to pay rent. The key informants also mentioned that some mothers may start begging on the street if they are not able to find a job suitable for them. For instance, mother 9 had an experience of homelessness and shared her story as follows:

> *My husband left me when he found out that our child had a disability. I could not afford to pay rent for the house I was living in so I became homeless. I was in great need and distress about my child's situation and how I was going to take care of her even though I had no job or place to stay. But thank God someone found me crying on the street and offered me a place to stay.*

The mothers who experienced the second consequence were forced to leave their rental houses and started working as housemaids to have a place to stay and be able to care for their children while working. On a similar note, Mother 15 mentioned the following:

> *The diagnosis stage was very devastating for me. When my husband heard, he left saying that he had to go somewhere far for work. Then he switched off his phone and I never heard from him again. Then I had to start working as a housemaid as it was a job that would allow me to stay with my child and work at the same time.*

The mothers that belonged to the third consequential event had support from their family members following their divorce or since the beginning of their child's birth. For instance, Mothers 1 and 13 are single mothers who live with their siblings.

Overall, following the diagnosis, the mothers experienced different arrays of emotions such as grief, denial, and doubt. The mothers were also encumbered by changes they had to go through because of the child's disability leading them to experience crisis or instability within the family. As mentioned above there were two groups of mothers who experienced the changes differently. As these changes arise, the changes themselves have their resulting consequences and challenges. These challenges were additional stressors the mothers experienced and this was known as the post-crisis stage concerning the Double ABCX model. Therefore, in the following sections the challenges as well as sources of the mother's difficulties that arise after discovering that their child has a disability are discussed.

4.4. Challenges of mothers in raising a child with development disability (post-crisis)

In this section mothers in both groups, married and divorced experienced challenges from the beginning of the diagnosis (pre-crisis) and throughout the rearing of their child (crisis and post-crisis). There were four challenges found among both groups of mothers: marital, occupational and financial, societal, and challenges associated with the specific type of physical disability. These challenges are discussed in the following sections.

4.4.1. Marital challenges

As it was discussed in the previous section, the mothers in the second group reach a state of divorce for various reasons. At the beginning of the diagnosis stage (pre-crisis), such mothers

go through conflicts with their husbands. The sources of their conflict were found to be related to (1) blame shifting and (2) the thought of rearing a child with a disability as burdensome.

At the beginning stage, when parents discover that their child has a disability, they are often encumbered by questions of how the child acquired the disability. When these questions do not get a satisfactory answer, the fathers particularly might shift the blame to the mother, making her the cause/fault of the child's disability. Based on the interviews from both the mothers and key informants most fathers blamed the mothers for their child's disability and as a result, divorced their wives or randomly left without any warning or sign. For instance, as mentioned in the previous section mothers 9 and 15 experienced a similar situation where the father left after discovering that their child had a disability. In addition, paternal relatives also play a role in the divorce by telling the husband to separate from the mother when they also assume that it is her fault for the child's disability.

The other source of the divorce between the spouses is when the father begins to believe that raising a child with a disability is burdensome and decides to leave his wife believing that it is easier. After such cases, most mothers end up leaving their homes and also struggle to find a job suitable for them as a child with a disability needs special attention. This challenge leads the mother to experience another occupational and financial challenge while raising her child. This specific challenge is discussed in the next section.

Married mothers may also experience challenges related to less satisfaction or communication with their husbands when rearing a child with a disability. Most mothers after diagnosis are forced to quit their jobs so they can be the primary caregivers of their child. When these changes unfold the mother has to depend entirely on her husband to provide the necessities

of the family. The key informants mentioned that after a child with a disability joins the life of the family, most mothers tend to get overlooked by their husbands. Although the father may be able to provide for both the child and the mother, he may not understand or notice the needs of the mother. As a result, the mother may get overlooked or may feel too dependent on the husband. For instance, Mother 8 mentioned what she felt about being a housewife:

> *I am not okay with not being able to work. I could not get a job because I had to take care of my child at home. I feel bad about it most of the time and it makes me feel unhappy that I have to always be dependent on my husband*.

4.4.2. Occupational and financial challenges

As discussed above, after the diagnosis of the child's disability mothers experience marital challenges and may end up getting divorced. The next phase is for the mother to find a suitable job for her child. Mothers struggle to find jobs that would allow them to bring their children to work. Since a child with a physical disability needs full-time special care, the mother would have to stay with the child at all times. Especially if the severity of the disability is higher, the mother would have a hard time leaving her child to another person. As a result, most mothers are forced to choose occupations such as housemaid. Their educational level was also another factor as to why they chose such jobs. For instance, mothers 4 and 15 experienced a similar situation. Their statement is written as follows:

> *I usually work part-time housemaid jobs as it is easier for me to work while my child stays next to me. It is still hard to find such jobs easily but that is what I mostly do.*

After my husband left me because of my child's disability, I had to start working as a housemaid. It is a difficult job but, this is the job that is better for me and my child.

As for the other divorced/single parents, they have someone who can look after their child at home and so can work. Mothers 9 and 13 have a relative or a close friend they live with who can assist them when they need to work. There was also another participant, Mother 1 who started living with her sister due to the coronavirus (COVID) pandemic. What she said is written as follows:

I used to make a living by washing clothes from different houses but after the pandemic, I could not find any job. But my sister took me in and now I am staying with her.

For mothers unable to find a job or do not have any relatives or friends who can support them, the key informants mentioned that they may get supported by a non-profit organization. The worst case is that they may become beggars on the street if they cannot find any support.

Concerning the married mothers, since most of the participants have low-income jobs as well as their spouses, the family may experience financial challenges when the mother quits her job. This causes the family wage to decrease, making the whole family dependent on the father to be the breadwinner of the house. Moreover, caring for a child with a physical disability has additional expenses and affects the finances of the family.

4.4.3. Societal challenges

Mothers raising a child with a physical disability face many societal challenges. They may experience social stigma and neglect, and at other times mothers may isolate themselves from the public to avoid stigma from society. Therefore, based on the information gathered from

the mothers and key informants, the societal challenges that were found in the study are discussed below.

Decreased participation in social activities

When a child with a disability joins the family, mothers are forced to make many changes. In those changes, mothers may become unable to be part of the social activities they used to engage in. Taking care of a child with a physical disability requires special attention and may need full-time. Having to stay with the child at all times forces mothers to disengage from the different activities they used to partake in. The frequency of engagement with other people slowly decreases, and at other times, they may be forced to stop. For instance, Mother 3 experienced such problems, and she explained it in the following statement:

> *At first, I did not have any social life. I stayed at home with my child all the time. Staying at home made me sad as I saw my child like that. All I thought about was what my child was going through, and it stressed me out. And since I did not have anybody to talk to throughout the day, I felt like I was losing my mind. And whenever someone came to our house, I did not know what to say or how to say anything properly. Then Cheshire found me a job at a school and a way for my child to learn there. After I began working in the school, I started to meet other people, and in time I also made some friends. Then, I saw many changes in myself. I felt free to talk with people, and then I got better and better mentally.*

Overall, most mothers experienced less engagement in social activities as they had to stay with their children all the time. Whether married, divorced, or single, they had to care for their child and had low participation in social activities. For example, mothers 4 and 15 worked as

housemaids, so they did not get to meet family, friends, or others as much due to the nature of their work. As for the other mothers, they mentioned that they always have to stay with their children, and this resulted in less participation.

Social stigma and Isolation

Mothers of children with disabilities face several challenges from the general public in the form of stereotypes, neglect, stigma, and isolation. The stereotypes may come as judgmental attitudes by associating the disability of the child with a curse, bad luck, or sin. The way others view them, such as close family members and friends, may change because of such misconceptions. These misconceptions can also affect how in-laws interact with the mother and the husband. For instance, it was found that in-laws also play a part in divorcing the mother. The in-laws may advise the husband to leave his wife, believing that it is her fault that the child has a disability.

The key informants also mentioned that mothers as well as people with disabilities tend to get neglected in different spheres of life, such as the occupational world. For instance, a mother of a child with a physical disability may have a hard time finding a job because an employer may assume that she is incapable of undertaking the job regardless of her ability to do so. Other times, employers may also choose not to hire such mothers out of fear of what others will say. The problem lies in the fact that mothers, especially singles, may need to take their children while working. This may make the employer uncomfortable and cause them to not hire such mothers.

For instance, mother 16, although she is married, faced such challenges and talked about her experience trying to find a job.

I used to work as a part-time housemaid. I also washed clothes, but now I had to stop. People do not like seeing a child with a disability while you are working. I tried to find a job through agents, but they were hesitant and told me that it may be unappealing for others. My child also has difficulties swallowing and may vomit while eating. I knew people would not like that, so I stopped looking for a job. Other times, people may also be worried for my child in case something happens while I am working.

Single mothers who are employed may also face stigmatizing comments and attitudes from the public while working on their jobs. It can also happen when mothers have to take their children with them when traveling if they do not have support at home. Due to a lack of awareness, people comment on the mothers, saying, "How could you bring the child out here?" or "You are making the child suffer by carrying him around." If the child is older but has to be carried, people might say things such as, "He is a grown child; why don't you put him down?" or make remarks about how she handles the child. Therefore, the mother has to bear these negative perceptions of people while making a living. It is also true for any mother who has to take her child while taking transport or moving to different places for other reasons. It may not apply to every society, but it is common in most places.

The other issue found was that mothers isolated themselves from society. For instance, public comments may happen in social gatherings, markets, religious places, or at work, where people use verbal cues and sounds that indicate that they are sorry about the child's disability and cause the mother to become insecure. As these comments and gestures continue, the mother is forced to avoid these situations and, in turn, may isolate herself from society. For instance, Mother 3 mentioned what she experienced in public.

I have met people who did make pity sounds when they saw my child, but it honestly hurts me every time I hear such words. It is like going back all over again after trying to be so strong, and I would prefer not to ever hear such a word.

Sometimes family members or friends may also indirectly isolate the mother by overly treating her. For example, relatives or friends may not invite or advise the parent not to be part of certain events, thinking that they are benefiting the mother by not being a burden, but in turn, it is hurting the mother and her family. The statements may come in as "You have to take care of your child at home", "You have a lot to do, so you do not need to come," or “You are busy; I do not want to bother you, so there is no need for you to come,” and so forth.

Overall, married mothers, as well as single mothers, face societal challenges in the forms of stereotypes, neglect, stigma, and isolation in public places, at work, and even sometimes from close family members, friends, or neighbors.

4.4.4. Challenges associated with the specific type of physical disability

There are many challenges that mothers face concerning the type of disability their child has. Though the specific disabilities considered in this study are known as physical disabilities, the severity and characteristics differ among the classifications. For instance, spina bifida can be diagnosed right after birth, but cerebral palsy may not be diagnosed immediately. Based on the data gathered from the interviews, it was found that the doctors may not have enough awareness of disabilities such as cerebral palsy, which could affect the detection of the disability after birth. For instance, mother 10 mentioned the following about her encounter with the doctors regarding cerebral palsy:

My child had epilepsy, so I had to take him to other doctors for treatment. As I told them what kind of disability my child had, they asked me what cerebral palsy meant. Then I noticed that most people had more awareness of autism compared to cerebral palsy, and I learned about it because my son had it.

Due to a lack of awareness, most mothers do not know when their child has cerebral palsy. Other times, the signs are observed as the baby develops and not immediately after birth. It may take six months or a year to notice signs such as difficulty swallowing, muscle stiffness, poor muscle control, etc. If the mothers take action quickly and take the child to the hospital, he or she can receive the treatments. After the diagnosis, the child needs physiotherapy since the problem is mostly related to movement and posture. If it is done earlier, the chance of the child improving faster increases.

Concerning rehabilitation, the time it takes to recover for children with cerebral palsy is longer compared to children who have spina bifida. There are different types of cerebral palsy: spastic, dyskinetic/athetoid, ataxic, and mixed. Among these, the most severely affected are those with spastic quadriplegia, characterized by muscle impairment in all parts of the body, including the arms and legs. Other types do not affect all the body parts but are related to involuntary movement, poor balance, and poor coordination. Based on the data gathered from the interviews, those with spastic quadriplegia had more difficulties and took more time to recover. The other types may take six months to see changes, but quadriplegia may take two years or more. The mothers also struggled more with this type, as it involves contracted muscles. As a result, she is unable to carry the child on her back, and she would need to carry the child in her arms. It may not be an issue for infants, but as the child grows up, it becomes difficult for the

mother. If the child gets treatment quickly, the burden on the mother decreases, and the time it takes the child to recover is improved.

4.5. Coping mechanisms

Mothers use different coping mechanisms to manage the difficulties that arise in raising a child with a disability. Among all the participants, the researcher found that spiritual coping was a common coping mechanism. The other coping mechanism found was the support the mothers received from the organization. The following sections go over these two coping mechanisms the mothers employed.

4.5.1. Spiritual Coping

The data gathered indicated that spiritual coping was the most commonly found coping strategy. The mothers were asked about the strategies they used for coping and what they experienced after using those strategies. Mothers used prayer, hope in God, and reading or listening to scripture in church or at home. This connection also served them as a source of meaning for their child's disability and an opportunity for self-improvement and personal growth.

Prayer and hope in God

Almost all of the mothers stated that they used prayer to cope with the challenges they faced because of their child's disability. In stressful times, mothers talk to God or call out his name in search of comfort, meaning, and peace. The mothers expressed that they felt hopeful, peaceful, and joyful in their hearts after prayer. Prayers differed according to the mother's view or perception. They expressed that they called out to God or cried out to him, others said that

they talked to God as a close person and that he did not seem distant but was there for them in the midst of difficulties. For instance, mothers 1, 3, 6, and 8 mentioned the following about how praying has helped them to cope with the challenges they face.

> *I usually pray when I am stressed. I feel so much more hopeful after I pray, and I also feel joy in my heart.*
>
> *My hope is in God; I read the Bible, and also go to church. I feel very peaceful after I pray, and I also like spending time with others in the church talking about God. Doing these things helps me get through difficult days. I personally like the verse 'Through him all things were made'.*
>
> *I pray and tell God about the challenges I go through. To this day, it is God who gave me strength to keep going. I feel peace in my heart when I pray, and I also read the Bible.*
>
> *I pray when I go through tough times. I tell God about the things that trouble or concern me. I feel hope and peace after expressing my concerns to God.*

Source of meaning

The mothers also mentioned that they found meaning in their child's disability because of their belief or relationship they have with God. The mothers expressed that through prayer and connection with God, they were able to see their child's disability in a positive and meaningful way. They stated that it helped them to draw closer to God and become hopeful. Mothers 7 and 11 mentioned the following about the meaning they found in their child's disability as well as the ways they connected with God.

I cried out to God, and I felt hopeful and believed that my child would be fine. I spend most of my time in church. I feel peace in my heart after going to church and hearing the word of God. Though it was hard at first, I realized that my child's disability has brought me closer to God and made me more reliant on him.

I get through tough times mainly through prayer. I believe that I will see changes in my child in the future. I learned to see that my child is a gift from God, and even with the difficulties my daughter goes through, I believe that she will be in a better place someday. My child's disability helped me draw closer to God and be hopeful.

Other mothers also mentioned that their child's disability helped them to be patient and more reliant on God in times of difficulty, and also to believe that hardships happen for a reason. Mother 9 talked about what she felt regarding the challenges she went through.

I normally pray when I feel sad or pain, and I also take my child to church. The strength that I have is what God has given me. Through all that I went through, I learned to be patient and hopeful in God and that, though there are ups and downs, the tests that I face are for the good.

There were also mothers who saw their child as a gift from God. They believed that God chose them to be mothers to a special child and that they were lucky to have been chosen. For instance, mothers 3, 11, and 12 mentioned the following:

It was very hard at first, but as time went by, I learned to focus more on what God has given me than on the things I do not have. It helped me see that my child is a gift from God and that I am very lucky that God chose me to be a mother to this child.

I felt a lot of grief at first, but the difficult times helped me learn that she is a gift from God and to be hopeful for the future. The challenges also helped me draw closer to God.

I usually pray when I feel stressed, and though there are tough times, it helped me see that God would not have given me this child if I was not able to handle it. It also helped me become a stronger person.

In general, spirituality as a connection with God helped the mothers see their situation positively and find meaning in the difficulties they faced. They stated that it helped them draw closer to God, to become hopeful and patient, and to see their child as a gift.

Source of Self-improvement

Spirituality was also found to be a source of self-improvement for mothers raising a child with a disability. They believed that what happened was the will of God and that it was for them to become stronger and better. The mothers stated that through the journey they went through with their children, they learned to be better people and became more compassionate and empathetic towards others. Mothers 11 and 12 shared the following about what they learned from raising a child with a disability:

I believe that I am stronger now than I ever was. I used to get annoyed and frustrated by little things before, but I learned to be thankful for what I have, whether it is small or big.

I did not care much before when I saw people who were in trouble or when I saw children with a disability. But after my child's diagnosis, I learned to be understanding towards others. When I look at parents who have a child with a disability, all I think

about is how I can help them. I go over and offer help and advice to other parents. Because of what happened, I learned to be compassionate toward other people.

4.5.2. Organizational support

The other coping mechanism found aside from spiritual coping was the support the mothers had from the organization. The organization is responsible for taking care of children with physical disabilities such as spina bifida and cerebral palsy by providing physiotherapy and counseling. Parents unable to afford are allowed to enroll their children in physiotherapy and trained to help their children at home. This physiotherapy assists children with physical disabilities that affect their posture, muscle movement, and coordination. Through time, children who regularly do the therapeutic exercises are able to sit, crawl, stand, or walk, depending on the severity of the disability. One of the challenges the mothers faced was associated with the severity and type of physical disabilities. After diagnosis, most mothers felt grief, shock, and denial and experienced emotional turmoil due to believing that their child would never improve. But when the mothers benefit from services that offer their children physiotherapeutic exercises that can improve their physical ailments, it can be rewarding and hope-giving to the mothers. Most mothers were thankful that they were seeing changes in their child and were hopeful for the future. These changes, as a result of the physiotherapy, helped the mothers cope with their child's disability. For example, Mother 1 mentioned the following:

I am really thankful; I have seen a lot of progress since the therapy. She was unable to loosen her hands, and her fingers were stiff, but now she can hold on to objects and stand.

The organization also served as a source of social support, especially for single mothers. The key informants mentioned that the support the mothers have with one another is better than what they receive from their families. Parents who have already gone through the process of accepting and helping their child can be great examples for other parents who are new and lack knowledge. When the parents see other children with disabilities ranging from minor to severe, they may feel thankful and less alone in what they are going through. Concerning peer support, Mother 16 mentioned the following:

> *I was so shocked when I first discovered that my child had a disability. I did not know what to do. I thought that my daughter's disability was something I could not handle. But after I went to Cheshire and saw all the kids with different disabilities, some too severe, I felt so much better. I was having such a hard time accepting my child's disability, but after seeing all those children, I knew I was not the only one going through this. I also saw that I should be thankful because they were kids who had more complications than my daughter.*

Chapter five

Discussion

This chapter deals with the discussion of the findings of the study in relation to the theoretical framework as well the reviewed literature. The chapter discusses how the Double ABCX model fits for this study concerning the experience of mother after diagnosis, the challenges they faced as well as the coping mechanisms commonly used.

5.1. Experience and challenges of mothers raising a child with a physical disability

Mothers, after the diagnosis, felt shock, grief, denial, and other arrays of emotions. According to the Double ABCX model, the diagnosis stage can be seen as an initial stressor event (a) (McCubbin & Joan Patterson, 1982, 1983a, 1983b). The initial stressor or diagnosis brought forth the array of emotions and difficulties the mothers experienced. The Double ABCX model has three stages: pre-crisis, crisis, and post-crisis. In the pre-crisis stage of the Double ABCX model, ‘a’ stands for an initial stressor, which is the diagnosis in this context, b is the existing resource the mothers had before they reached crisis, and c is the definition the mothers held regarding the disability of their child. The mothers in the study had low-income jobs, and some lived in poor conditions due to their educational status (pre-crisis stage). This showed that several mothers were already living in poor conditions before they reached a state of crisis.

The mothers' resources 'b' were severely affected because, before the crisis, they were already living in poor conditions. Their resources also determined whether they could avoid a crisis or not. As shown in the findings section, the mothers were divided into two groups: the married and the divorced. These two groups had different ways of using resources as well as how

they handled stressful situations. As for the married mothers, they had to quit their jobs after discovering that their child had a disability. The other mothers in the second group had to go through divorce or separation after the diagnosis of their child. In both of the groups, their resources (b) are lost or decreased due to the loss of a job or the loss of a partner. This affected how they dealt with the stressful event and their perception of the problem. This determined whether the mothers could avoid a crisis or not.

When the resources are not sufficient to combat the problem, it may cause the mothers to enter a state of crisis (x). For instance, the mothers who got divorced after the diagnosis of their child experienced crisis as the family was not in a state of stability. It led the mothers to lose their homes and go through many consequential events, such as going through a divorce, becoming housemaids, or moving in with a relative for shelter. The family members experienced changes in their lives as a result of the father abandoning the mother, which may have been detrimental to the mother and the child.

Concerning the married mothers, being unemployed and having to stay at home affected the mother's perception (c) in many ways. The mothers had to stay with their children at all times, thereby not being able to engage in social activities or any productive work. This made the mothers lonely and disconnected from society. Moreover, the financial difficulties they experience when the father is the only provider leads the family to crisis (x). This stage is marked by instability in the family members as well as in the society.

The difficulties the mothers experienced in both groups were also related to problems in the community, such as changes of heart in people and less support due to being a mother of a child with a disability. It can be associated with the community or relatives assuming that the

child's disability is the mother's fault or a curse, bad luck, or sin. These issues together made the lives of the mothers disconnected from the community and made the difficulties in the family increase, thus making the family reach crisis. According to the Double ABCX model, the crisis is followed by the stage known as post-crisis. This post-crisis stage is discussed in the next section as a challenge that piles up after the initial stressor.

5.2. Challenges of mothers raising a child with a physical disability

As discussed above, mothers reached a state of crisis or instability after the diagnosis due to changes (leaving a job, divorce, etc) that accompanied it. These changes also resulted in additional challenges on top of the initial stressor, hence being called pile-up (aA) in the post-crisis stage. This stage consisted of (aA) pile up, (bB) existing and new resources, and (cC) the perception the individual has about the crisis, pile up, and resources (McCubbin & Joan Patterson, 1982, 1983a, 1983b).

The pile-up 'aA' in this sense are the challenges the mothers kept on experiencing after the diagnosis of their child. As discussed in the findings, the mother experienced additional stressors or challenges, such as marital, financial, occupational, societal, and challenges associated with the specific type of physical disability the child acquired. These challenges pertaining to the Double ABCX model ‘aA’ or pile up are discussed in the following sections.

Financial challenges

After the diagnosis of their child, mothers, whether married or divorced, faced financial challenges as a result of losing a job or divorce. This challenge caused additional stressors to pile up since they live off of low-income jobs. This, in addition to the mother leaving her job,

increases the stress on families as the members would need to depend solely on what the father provides. As for the mothers who went through divorce, they also experienced additional stressors due to the loss of their house, money, and, most importantly, a family member. The mothers experience challenges in looking for a suitable job and a shelter. Being a mother of a child with a disability forces the mother to choose only specific jobs that will allow her to take her child to work.

These challenges also cause additional stressors (aA), such as health problems for the children living in poor conditions. Most of the children with physical disabilities experienced breathing difficulties as a result of living in a congested area. This issue is hard to resolve as the mothers cannot afford to rent or buy a better house. The findings of the study showed that the children suffered from frequent colds and sometimes pneumonia. Therefore, mothers of a child with a physical disability, whether married or divorced, faced financial and occupational challenges, which also caused other stressors to pile up (aA), such as health problems, due to the financial burdens they experienced. Other challenges are also discussed in the next section, such as the pressures they experience in society and how low social support and stigma interplay together to cause marital difficulties.

Low social support, marital challenges, and social stigma

Mothers of children with physical disabilities experience low social support, which contributes to marital challenges. The relatives of the mothers' were found to be somewhat supportive, but the paternal relatives were not as supportive and accepting of the mother or the child. This low support also contributed to some of the challenges the mothers faced in their marriage, such as abandonment, separation, or divorce. This affected the perception (cC) the

mothers have of their children due to the emotional difficulties they go through because of the separation. This separation may happen with or without any warning, leaving the mother in a state of despair or confusion if she waits for her husband to return. Moreover, the mother is also affected by the new encumbering changes; she has to face new life responsibilities, such as looking for a job and a shelter if she is without a family member who can support her.

For mothers with family members, the difficulties may lessen to some degree as they can work while someone looks after their child. But this is also exceptional in cases where the child's disability is severe and may need careful attention where only the mother can provide it. Then the mothers would need to stay with their child at all times, which can affect the mother's perception (cC) as well as emotion. This could lead the mothers (whether married or unmarried) to experience loneliness and depression due to being disconnected from society.

Social stigma was also one of the additional stressors or pile-up (aA) the mothers experienced while raising their children. The mothers faced difficulties related to superstitions, verbal cues reflecting pity, side talk, and neglect from the community. This affected how parents dealt with their needs and problems regarding their children and family life. It affected how the mothers perceived the disability of their children (cC), thereby influencing how they dealt with the diagnosis. This influence may lead mothers to lock up their children in their house, fearing what others will say or think of them. They also seek solutions or cures from traditional healers. As a result, the child's recovery from the impairment will take longer to achieve through physiotherapy.

5.3. Coping mechanisms

The mothers widely used spirituality to cope with the problems they faced in raising their children. Moreover, the organizational support they had from Cheshire also helped them cope.

According to the Double ABCX model, these two coping mechanisms can be used as resources, either existing or new resources (bB) to cope and adapt to the changing circumstances the mothers experienced. The support from the organization can also be seen as a new resource because the mothers discover about it after diagnosis. They did not have this resource at the beginning of their pregnancy or right after birth. However, the mothers learn about the organization that provides physiotherapy through other resources, such as health care. Therefore, this organizational support they have access to can be seen as a new resource (bB). These two coping mechanisms as existing and new resources (bB), are explained in the following sections.

5.3.1. Spiritual coping

Spirituality is a concept that is different among people's cultures, backgrounds, and experiences. To minimize the broad definition, the study chose the definition that held that spirituality is a relationship or connection with the creator of the universe, 'God'. This definition is also widely accepted in most denominations found in Ethiopia, where most people have adopted a certain faith.

According to the Double ABCX model, in the third stage (post-crisis), coping is mentioned as an interaction between the pile-up (aA), resources (bB), and perception (cC) of what the individual holds regarding 'aA' and 'bB'. In the context of this study, spiritual coping can be seen as an existing resource that helps the mothers cope. It can also serve as a resource that influences the mother's perception of the child's disability to become positive, thereby

contributing to better coping. For instance, McCubbin and Patterson (1983a) mentioned in their study that when the cC factor is positive, the family can cope better. Their study showed that wives who gave positive meanings to their situations, such as "the Lord's will" or "an opportunity for growth," were able to cope better (p. 97).

According to Legre (1984), spirituality is about what really happens in the heart of people. The mothers in this study experienced this connection and comfort in their hearts through prayer, reading the Bible, and worship. Similarly, Belavich (1995) also mentioned that individuals commonly used prayer and faith in God in times of stress and difficulty.

According to the mothers in the study, prayer meant seeking God for answers to their concerns and difficulties. It meant viewing God as a father or a close person they could talk to when they experienced stress or difficulty. This prayer was used as a resource as well as a coping strategy among all the mothers in the study. On a similar note, other studies such as Pargament et al., (1990) and Neighbors et al., (1982) also stated that prayer by faith in God was the highest coping resource used by individuals. Prayer, according to the mothers in this study, meant that they could give their burdens and concerns to God. This 'prayer' helped the mothers to be comforted, hopeful, and at peace in times of struggle. As the mothers continue to make this connection, their perception becomes better due to the source of meaning they draw from it.

Spiritual coping helped the mothers to view their child's disability positively and to draw meaning and purpose from it. It helped the mothers see their circumstances as an opportunity to become a better person and accept their child's disability as a gift. For instance, a study conducted by Houston (1999) about the lives of people who acquired disabilities talked about a woman named Elaine who had a disability for 16 years. She attended a healing mass, hoping that

her faith would cure her, but that did not happen. However, she gained such peace that she knew God was taking care of her, leading her to accept that her disability was part of who she was. Moreover, Belavich (1995) also mentioned that spirituality helped people see their troubling circumstances as a lesson, not a punishment. Some of the mothers mentioned that, through their experiences, they learned to be patient and thankful in the midst of hardship.

There were also studies conducted about the meaning spirituality provides for families of children with disabilities or people living with a disability. Skinner et al. (1999) and Do Rozario (1997) mentioned that families or individuals with a disability often have deep questions related to the meaning and purpose of life and how they can make sense of their suffering as well as their child's. For the majority, spirituality held the answer to these questions. It is also linked to Frankl (1959), who lived in a Nazi concentration camp, stated, "Suffering ceases to be suffering in some way at the moment it finds a meaning... and that through suffering one is given a last chance to fulfill the deepest meaning" (p. 114).

Mothers also learned to empathize with others going through difficult circumstances and become a better person. The mothers were also able to see their child's disability as a way that helped them draw closer to God and have a stronger faith. Similarly, in Cho et al., (2000) study, mothers who had spiritual beliefs expressed that raising their children helped them strengthen their faith and provided them with a chance to develop qualities such as patience and love. One mother stated, "If I had not had a disabled child, there would have been no way for me to know everlasting God truly, I would rather choose to know God than to have a normal child" (p. 245). Several studies also reported the initial denial, shock, and grief experienced by parents after discovering that their child had a disability. However, their spiritual faith helped them cope and

adjust to the crisis, enabling them to gain an immense amount of strength and peace (Rogers-Dulan, 1998; Cho et al., 2000; Bennet et al., 1995).

In addition, the mothers met in the organization to support one another regarding the disability of their child. This gathering also served the mothers as a place where they could share their thoughts about their faith and the lessons they learned through the troubling circumstances they faced while raising their children. This gathering is similar to church meetings or studies people hold in their homes as well as in churches. As a group, they supported and encouraged one another concerning their child's disability through their spiritual beliefs.

The mothers drew meaning, strength, hope, and self-improvement because of the personal relationship or connection they had with God. This connection helped them cope with the struggles they faced in raising their child. Through this connection, their perception, or cC factor, in the Double ABCX model is improved. That also influences how they use their resources (bB) and how they cope with and adapt to the situation. When their attitude or perception of the problem improves, they can help their children and use the resources available to them, such as the services Cheshire provides. Mothers who are in denial are not able to easily use such resources due to being unable to accept their child's disability. As a result, they often look for cures in other places and rather choose not to use the resources the organization provides. However, when the state of mind of the mothers is improved, they can successfully use the resources available to them. Then, the mothers start using the resources around them, which they may not have initially considered due to the change in their perception. Accordingly, spiritual coping was found to help the mothers accept their child's disability, find meaning from it, be strengthened and hopeful, and use the resources available due to the positive perception

they gain from it. Then the mother is better able to help her child by accessing the resources available, such as physiotherapy, and also by having the right attitude, which in turn influences her child and family positively.

The Double ABCX model also discusses about adaptation, which is influenced by how well a family copes. The model mentions two kinds of adaptation: bonadaptation and maladaptation. Maladaptation, represented as 'xX', is when an imbalance between the family of the child with the disability and the community occurs. This can be observed in the lives of mothers at the beginning of the diagnosis stage and after (pre-crisis and crisis), where many changes occur, such as loss of job, partner, higher expenses, stigma, etc. After these encumbering changes, mothers in the post-crisis period may have access to new resources and adopt a new set of beliefs, such as positive meaning-making, because of their spiritual beliefs. This can help the mothers cope with their child's disability, which in turn influences how well they can adapt to their circumstances. This successful adaptation is called bon-adaptation, where there is a balance between the family members as well as the community. Therefore, mothers, in the long run, can reach the bonadaption stage when their perception (cC) is improved, as it affects how well they can cope, which in turn influences how well they can adapt. Accordingly, spirituality was the most commonly found coping mechanism that helped to improve the perception of the mother (cC) and the use of existing and new resources (bB).

5.3.2. Organizational Support

Mothers who enrolled their children in Cheshire saw improvement due to the physiotherapeutic services they provide. Mothers in the beginning stage (precrisis) often lack knowledge concerning their child's disability and feel discouraged and alone. As the mothers get

access to the new resources (bB) Cheshire provides, they notice an improvement in their child's physical ailments and also get social support from other mothers who are having similar difficulties. The perception of the mothers (cC) improved when they got acquainted with other disabilities with different degrees of severity. Most mothers became hopeful when they observed that their child was not the only one experiencing such challenges. This helped the mothers perceive their child's disability positively, and the support they had with one another also served as an additional resource for coping.

Chapter six

Conclusion and Recommendation

6.1. Conclusion

This research explored the challenges of mothers raising a child with physical disabilities and how they used spirituality to cope with difficult situations that arise. It was important to seek out this topic, as mothers go through an immense amount of challenges in raising their children. The process they go through after discovering that their child has a disability and having to experience encumbering changes and challenges such as divorce, financial and occupational challenges, as well as low social support and stigma, are some to mention.

This research used the theory of the Double ABCX model as a guide to study the experience of mothers after diagnosis, the challenges they face, and the coping mechanisms commonly used among the mothers. The study explained the three stages of the theory: pre-crisis, crisis, and post-crisis. The mothers during the diagnosis were in the pre-crisis stage, as it was the initial stressor they experienced. This initial stressor brought forth many changes in the lives of the mothers, which led them to reach a state of crisis (x). After this stage, there is the post-crisis stage, which consists of the variables 'aA', which is the pile-up or the additional stressors or challenges they experienced after the initial stressor; bB, the existing and new resources they had, such as organizational support; and cC, the perception the mothers have about their overall circumstances.

Concerning the way the mothers cope, spiritual coping was found to be the most common among the mothers under study. Mothers used prayer, reading the Bible, and going to church as

coping strategies to get through the difficulties they faced in raising their children. Spirituality helped the mothers find meaning, purpose, and a source of self-improvement and become better people. Spirituality as a connection with God gave them hope, strength, and a sense of comfort in their sufferings, which made them empathetic and caring toward others. Spirituality helped the parents not only to cope but also to become a better and transformed person.

Spirituality also influenced the mother's perception (cC) and the use of existing and new resources (bB). Mothers who had a strong spiritual belief and faith were able to view their child's disability as a gift, thereby improving the cC factor of the Double ABCX model. Mothers who were able to view their child's disability positively were able to cope better, adjust, and adapt to their circumstances. Therefore, spirituality was found to help in coping, positive perception, and adaptation to the changes after the diagnosis of their child.

The study also explored disabilities such as cerebral palsy and spina bifida that may not be as widely known as other physical disabilities, such as autism. The paper sheds some light on how these types of disabilities affect parents differently. It also showed how each disability had its severe type and the effect it has on the parents, their work, and other spheres of life. In such contexts and associated difficulties, the role of spirituality in coping based on the Double ABCX model was studied.

6.2. Recommendation

Raising awareness

The most common problem found among mothers raising a child with physical disabilities was associated with a lack of awareness, neglect, discrimination, and social stigma.

The government or other sponsors can initiate disability campaigns to raise societal awareness to decrease social stigma and create a disability-inclusive society.

- Some of the mechanisms in which awareness can be created are mentioned below:

Awareness can be created specifically for disabilities that are not well known, such as cerebral palsy. Most people are not aware of this type of disability, which could make the issue go undiagnosed for a longer period of time. This is problematic if the child passes the physical age that is optimal for doing physiotherapy.

In addition, awareness can be raised specifically for developers and organization leaders or owners to be inclusive of mothers raising a child with a disability as well as for people with disabilities if they can do so. This is mentioned as most employers may believe that mothers of children with disabilities are incapable of undertaking a job even though they have the ability. Initiating campaigns through the media and forming available support groups for children with disabilities in the nearby Kebeles can also be beneficial. By creating support groups, people with disabilities can be empowered and strengthened by one another. It would also allow them to gain information regarding their rights and use them to the fullest. This will pave the way for children with disabilities to have a better future.

The local government can also initiate support with other partners and benefactors to include parents of children with disabilities, especially mothers (along with their children), in programs that teach vocational skills. There are various ways in which disability campaigns can be implemented. It can be done by including faith communities in the awareness-creation process. It is important since leaders such as pastors or priests have a positive influence on

society. Several points (such as teachings) are mentioned in which faith communities can be helpful to families or people with disabilities.

Firstly, faith communities can teach about the issues of disability so that problems related to social stigma (such as bad luck or sin) and discrimination are alleviated. It would also help in lifting the burden associated with stigma at work, school, and public places, thereby creating a better place, especially for single mothers to be more productive, for children to be confident, and that in the future, when they join the workforce or school, they will have lesser difficulties.

Secondly, include messages that teach that people with disabilities are capable and that their difficulties are just limitations and not who they are entirely. It is beneficial as some of the stigma was associated with words that show pity, making most parents and children insecure. Finally, incorporating teachings about marriage, family, and disability can also be beneficial. Since most marital problems are associated with blame-shifting, teaching parents about love, compassion, and empathy can help spouses understand one another, strengthen their bond, and cope better in times of difficulty.

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Appendices

Appendix A

Informed consent

Hello, my name is Yeabsira Amdie, and I am calling from Cheshire. I am a student in Addis Ababa University's social work department. I am currently undertaking a study on the challenges of mothers in raising a child with physical disabilities and the role of spirituality in coping. I received permission from Cheshire to give you a phone call. I would like to ask you several questions related to you as a parent and your child so that I can understand the experience you went through in raising your child. In addition, I would also like to understand how you cope with the challenges you face, whether they happened before or are currently happening. The research is purely educational, and your name will be kept private. If you are willing to participate, I can proceed with the questions that I have.

Appendix B

Interview guide for parents of children with Developmental Disability

A. Interview Questions

1. How did you find out that your child had a disability?
2. How did you feel when you heard the diagnosis?
3. How did you experience the pain or grief in raising your child?
4. What changes occurred in your living situation?
5. How did your parents, family members, friends or neighbor react to the diagnosis of your child?
6. What kind of challenges did you face at (a) home, (b) work or (c) public places?
7. How do you go through your daily care giving process with your child?
8. What stresses you out the most regarding (a) yourself, (b) your child and (c) the whole family?
9. How do you cope with the challenges?

For Spirituality

- What tools did you use?

If one of these is mentioned:

- *Prayer*: Do you see a difference before and after you pray? If so, in what way?
- *Meditation*: which biblical or spiritual concepts did you use and out of those concepts which ones helped you the most?
- *Support from other members in the church*: what did you gain from it?

Other mechanism

- How did using that mechanism help you?

10. Compared to other times did you experience more strength or resilience after using those tools? Or is it the same? Could you explain how?
11. Is there any meaning that you found from the challenges you faced?

B. Background Information

Name _____ Gender _____ Faith _____

Child Diagnosis _____ Date of Diagnosis Received _____

Marital Status _____ Employment position _____

Appendix C

Interview guide for key informants

1. What is your role in the organization? How do you undertake your roles?
2. How does the experience of the mothers look like in raising their child?
3. What are some of the processes mothers take in accepting their child's disability?
4. What are some of the major challenges they face in their marital life, work, and public places?
5. From your experience working here, how do you think the society views them?
6. Which developmental disability is the most difficult and challenging? In what way?
7. How do the mothers go through these challenges they face?
8. Do they use spirituality as one of the ways to cope up with the challenges? If so, how?