ADDIS ABABA UNIVERSITY

COLLEGE OF SOCIAL SCIENCES

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GRADUATE PROGRAM

VIEWS FROM IN: FAMILY EXPERIENCES OF LIVING WITH A PERSON DIAGNOSED WITH CHRONIC ILLNESS: THE CASE OF ADDIS ABABA, ETHIOPIA

By

KALEAB FIKRE

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A THESIS SUBMITTED TO THE DEPARTMENT OF SOCIOLOGY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF ARTS IN SOCIOLOGY

BY: KALEAB FIKRE

SUPERVISOR: KIBUR ENGDAWORK (PhD)

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This is to certify that the thesis prepared by Kaleab Fikre, entitled *Views from In: Family Experiences of Living with a Person Diagnosed with Chronic Illness:* The case of Addis Ababa, Ethiopia and submitted in partial fulfillment of the requirements for the Master Degree of Arts in Sociology complied with regulation of the University and meets the accepted standards with respect to originality and quality.

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Abstract

Chronic illness is generally long term, not curable, results in limitations in daily life. It often makes patients more dependent on their healthy family members' care. Thus, families living with a chronic patient often experience overall altering on their personal as well as family life. This study aimed to reveal the family experiences of living chronic illness. The study was based on the family system theory, social ecology model, and the concept of family resilience.

The research methodology of the study is based on the philosophy of qualitative research design. The study draws on multi-method fieldwork, using semi-structured interviews, diaries, and informal dialogue. Field notes and reflections over field observations were also included. The study mainly used the above-mentioned methods to obtain data from the key participants of the study, non-patient family members living with a family member with chronic illness (aged 19-31). Twenty family members living with a person with chronic illness from ten families participated in the study, thirteen females and seven males. Purposive sampling was used to select the participants. The data were analyzed using thematic content analysis.

The study reveals that the presence of chronic illness had an altering effect for the family as a whole often changing the physical, emotional, and behavior of both the patient and non-patient family members. Furthermore, it also had significant altering effects on family function and inside-out social interactions. But, the study indicated that the family's illness experiences were not solely understood based on the presence of chronic illness. Rather, there were other ecological factors: including, the family characteristics. Notwithstanding all the challenges and changes, families often involve in different relational coping resources to be able to adapt and make adjustments and maintain the balance and function of the family system.

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ABBREVIATIONS

WHO - World Health Organization

LMICs - Low- and Middle-Income Countries

HIV/AIDS - Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome

EPHA - Ethiopian Public Health Association

Chapter One

1.1.Background of the Study

The World Health Organization (WHO) defines health as a "state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity" (WHO, 2011). Thus, chronic health condition encompasses more than simply the physical illness processes of the body and affects every aspect of the individual life, (i.e. physical, mental, and social wellbeing) and the people living around. Chronic illness is generally long term, not curable, results in limitations in daily life, may require special assistance or adaptation in normal functioning, and is an ongoing health condition (Clare, 2013; Midence, 1994; Boice, 1998). Similarly, chronic illness defined as a health problem that requires having, at least, a health problem for 12 months' duration in any one of the following spheres: functional limitations, dependence on compensatory mechanisms (medications, special diets, equipment), or service use beyond routine care (physical therapy, special education arrangements) (Burns, Sadof, & Kamat, 2006).

Even though the above definitions appear descriptive, chronic illness is not easy to define since it refers to multiple types of diagnosis. Thus, chronic illness is conceptualized in different ways. There are studies that give emphasis on specifying the type of illness that fall within the category of a chronic illness, such as cardiovascular disease, diabetes, cancer, sensory and nervous system disorder (Ayalon et al., 2008; Kilian, Matschinger, & Angermeyer, 2001). Other studies emphasized on specifying the use of phrases, such as acquired disabling conditions (Livneh & Antonak, 2005), having at least one chronic condition (Burns, Sadof, & Kamat, 2006; Riley, Russell, Glasgow, & Eakin, 2001), and having a health problem that lasts three months or more and affects a patient's normal activities (Compas, et al., 2012) to indicate the features of chronic

disease. Some studies (Adegbola, 2006; Clare, 2013; Midence 1994) associate the concept of chronicity with the irreversible state of a disease for which there is no cure. In the light of the aforementioned definitions, this study characterizes chronic illnesses by at least three important features. These are: chronic illnesses are prolonged in their duration, chronic illnesses do not resolve spontaneously, and chronic illnesses are rarely cured completely.

Even though chronic illness is a widely used and broad term that addresses many different facets of illness WHO and other institutions report high prevalence rates, globally. Global prevalence of chronic illness is increasing, and is seriously threatening the health of the global population (Bauer, et al., 2014; Nuget, 2008; WHO, 2011). As per WHO (2005) report, of a projected 58 million deaths from all causes, deaths due to chronic diseases account for 35 million. In its 2010 report on the global status of the challenges chronic disease pose, WHO again noted that that non-communicable conditions, such as cardiovascular diseases, diabetes, cancers, chronic respiratory diseases, asthma, and arthritis, accounted for nearly two-thirds of deaths worldwide (Bauer, et al., 2014; EPHA, 2012; Kiflie, Jira & Nigussie, 2011; WHO, 2011; Wonde & Boru, 2019).

Chronic illnesses are often associated with developed countries. Nevertheless, chronic illness is becoming the dominant health system's burden in many developing countries (Nuget, 2008). WHO (2005) reports that the impact of chronic illness in many low- and middle-income countries (LMICs) is steadily growing. This is indicated by the rising numbers of patients with such chronic illness (van Olmen, et al., 2012). For instance, according to WHO's report, of all deaths presented by chronic diseases, more than 80% occurred in low-income and middle-income countries (Bauer, et al., 2014; WHO, 2011). Moreover, in most developing countries the poorest people have the highest risk of developing chronic disease (Suhrcke, et al., 2006).

Though less well understood, chronic disease, such as heart disease, stroke, cancer, and diabetes, already have a significant impact on those low-income and middle-income countries. The significant attention paid to health problems, such as malaria, tuberculosis, maternal health problems and HIV/AIDS, has led to underestimating the prevalence and the significant impacts of chronic disease in many low- and middle-income countries (LMICs) (WHO, 2011).

Africa bears a significant proportion of the global burden of chronic diseases, along with poor countries of Asia and Latin America. Furthermore, Africa faces a double burden – both infectious and chronic diseases. Meaning, the raising number of chronic diseases co-exists with an ever greater burden of infectious disease, which still accounts for at least 69% of deaths in the continent. Notwithstanding the epidemiological evidences demonstrating the chronic illness burden, Africa is least able to cope with the resulting holistic crisis related to the poor socio-economic conditions of the continent (Aikins, et al., 2010).

In Ethiopia, like in many developing countries, there is a lack of reliable data about chronic illness. This is, according to Ethiopian Public Health Association (EPHA), partly related to the nature of the diseases and the less attention given to chronic diseases in general (EPHA, 2012). Nevertheless, like many developing countries, Ethiopia is a country in transition, facing the consequences of epidemiologic, demographic, economic and nutrition transitions that will continue to favor the chronic diseases epidemic (EPHA, 2012),.

Ethiopia is challenged by the growing magnitude of chronic illness, which created a double burden on the population and the health system already hard hit by acute illnesses (Kiflie, Jira & Nigussie, 2011; Wonde & Boru, 2019). Though, the contemporary Ethiopian society is experiencing the double jeopardy of chronic and infectious illnesses, studies (e.g. Fikru et al.,

2009; Kiflie, Jira & Nigussie, 2011) show that chronic illnesses are not receiving sufficient attention at policy and intervention practices in Ethiopia. The Ethiopian healthcare system is designed primarily for prevention and control of acute illness while giving less attention to or neglecting chronic illnesses. The health policy and strategies are overwhelmed with controlling infectious illnesses and seems unprepared to confront the devastating problems of chronic illness (Kiflie, Jira & Nigussie, 2011; Wonde & Boru, 2019).

In Ethiopia, chronic illnesses are viewed as illness of the affluent. For instance, the 1993 Ethiopian health policy characterized chronic illnesses as diseases related to affluence and ageing. Contrary to the rhetoric, chronic illness is not merely the problem of elderly and affluent segments of the society. Chronic illness is a national public health problem affecting people from all social backgrounds as a result of unhealthy lifestyle (Wonde & Boru, 2019).

There is consensus among experts that chronic disease, such as cardiovascular disease (CVD), stroke, hypertension, diabetes, and cancer, are becoming rampant health problems in Ethiopia (EPHA, 2012; Wonde & Boru, 2019). For instance, EPHA, (2012) and Wonde and Boru, (2019) indicate that the magnitude of CVDs and contributing conditions including obesity and diabetes have increased in the past couple of decades. The hospital based analysis in 1984 indicated that cardiovascular disease have been among the list of the ten most top causes of mortality in Ethiopia (Wonde & Boru, 2019). Recent hospital-based studies indicate that the prevalence of cardiovascular disease (7.2%); cancer (0.3%); diabetes (1.2%); and asthma (3.5%), (Misganaw, et al., 2014). Furthermore, WHO (2011) estimated that 34% of Ethiopian population is dying from non-communicable diseases, with a national cardiovascular disease prevalence of 15%, cancer and chronic obstructive pulmonary disease prevalence of 4% each, and diabetes mellitus prevalence of 2%. As per Misganaw, et al (2014) and WHO (2011) chronic illness is becoming

important health issues that need the attention of researchers and policy makers in order to mitigate the rampant increment and looking for possible interventions.

Bio-medically, though, what is affected by the disease is an organ system or possibly multiple organs. In reality, the impact reaches much further into the ecological context. A chronic illness impacts nearly every aspect of an individual's life and leaves a devastating imprint on the lives of everyone around. When someone contracts a serious chronic illness, it affects not merely the physiology of the patient but also impacts the patient emotionally, cognitively, and behaviorally, often changing their day-to-day routines, plans of action, feelings and meanings about self, others, and life itself. The whole of the person with a chronic illness can profoundly be affected psychologically and in social functioning (Patterson & Garwick, 1994).

In the past, individuals with such chronic illnesses never live long enough. However, because of advances in research and treatments in the area of chronic illness, living shorter life span because of diagnoses with chronic illness is become no longer the case. Chronic illness was often seen as an experience in which the individual passes through a serious of stages, depending on their conditions, at times improving and at times getting worse. Unfortunately, even with the new research and treatments available, the specialized and time consuming care needed to cope with a chronic illness can be emotionally and physically exhausting for the family of a person who is chronically ill (Patterson & Garwick, 1994). Studies (Newbould, Taylor, & Bury, 2006; Newcom, 2004; Patterson & Garwick, 1994) indicate that chronic illness is not merely the individual case or medical issue rather it disrupts family as well, in terms of, for instance, role disruption. What happens to the individual does happen to the family as well. In other words, the chronic illness happens to the family; not just to an individual merely. Chronic illness lasts long enough to become life itself (Öhman & Söderberg, 2004; Patterson & Garwick, 1994; Pierret,

2003). Thus, in the long course of illness experiences, those persons in the immediate surround, especially intimates, such as families with whom there is a bond of caring and mutual support that has a history and a future, cannot escape the effect of chronic illness either. The effect even goes further to the community and society as well, since it costs the society with higher health care cost and the potential reduced level of productivity for a functionally impaired person (Patterson & Garwick, 1994).

Even though the impacts of chronic illness goes further beyond the patients, less attention have been given to the people living with a person diagnosed with chronic illness. Having this research gap in mind, this study focuses on filling the gap in the area of chronic illness by revealing the family experiences of living with a person diagnosed with chronic illness from non-patient family members' perspective.

1.2. Statement of the Problem

Methodological changes from the physiological disorder (medical model) to psychosocial model led researchers, especially social science researchers, to conduct a series of studies on issues that are related to chronic illness putting it in its psychosocial context. For instance, one common issue in the area of chronic illness is a study on patients' illness experiences (Anderson & Bury, 1988; Pierret, 2003). These studies indicate that feelings such as, shock, anxiety, denial, depression, anger/hostility, and maladjustment to the everyday life immensely affect patients with chronic illness. Other studies made in the area of chronic illness by social sciences researchers focus on the impacts of chronic illness on the patient (Bailly, et al., 2015; Kuyper & Wester, 1998; Lee Strunin & Boden, 2004). For instance, these studies indicate that patients with a chronic illness may miss school more often and experience difficulties with concentration and

mental functioning due to certain medications and stress related to their illness. Chronic illness as socioeconomic burden (Aikins, et al, 2010; Nuget, 2008; Suhrcke, et al. 2006) is also another area of study made by social science scholars. These studies indicate that people with a chronic illness are shown to experience functional limitation, financial burden, sibling resentment, frequent hospitalizations, and grief (Manion & Cloutier, 1996). Coping strategies, intervention, adaptation, and treatment of chronic illness (White, Richter, & Fry, 1992) are also few to mention that social science researchers have made attentions in the area of chronic illness shifting the approaches from physiological disorder (medical model).

Though, in the field of chronic illness, the documentation of the problems faced by the patient, and to a lesser extent their families, has usually dominated the research agenda (Bury, 1991). Studies have mostly focused on exploring the experiences, perspectives, and problems that the patient has faced (Bailly, et al. 2015; McNamee & Mendolia, 2014; Paterson, 2001) and explore what it means to live with chronic illness, giving insignificant attentions to the perspectives and experiences of the families living with their a chronically ill-family member.

Similarly, there are few studies (EPHA, 2012; Kiflie, Jira & Nigussie, 2011; Fikru et al., 2009; Wonde & Boru, 2019) conducted in the area of chronic disease and chronic illness in Ethiopia. Though, most studies, like studies conducted elsewhere, in the area of chronic illness are conducted either with problem oriented approaches focusing on the perspectives and experiences of the patient, giving less emphasis to the everyday experiences non-patient family members. One good example is a study conducted by Wonde & Boru, (2019) on patient's experience and related perils of living with chronic illnesses. They indicated how chronic illness exposes patients for several personal and family problems. Wonde & Boru's study further showed the devastating impact of chronic illness on the livelihood of the family. A study conducted by the

Ethiopian Public Health Association (EPHA) in (2012) is the other study shown in the area of chronic disease. This study was commonly oriented towards investigating the prevalence of major chronic disease at country level. Besides, the study focused on providing the common risk factors related to chronic disease in Ethiopia.

Although there have been pieces of literature that studied families living with a person diagnosed with chronic illness, most have focused on the specific issues, such as family interventions to the patient, the burden of chronic illness on family, etc., which were mostly related to the problems families have experienced (Given, Given, & Kozachik, 2001; McNamee & Mendolia, 2014; Thorne & Paterson, 1998), rather than the totality of experiences.

In spite of the study gaps found in the areas of family experiences of living with a person diagnosed with chronic illness, studies (Öhman & Söderberg, 2004; Patterson & Garwick 1994) indicate that when someone contracts a serious chronic illness, it has a direct menacing effect in the overall functioning of other family members and their life course. Once diagnosed with a chronic illness, it is not unusual for an individual's family members to feel anger, denial, self-blame, fear, shock, confusion, and helplessness (Ellenwood & Jenkins, 2007). Studies (Compas et al., 2012; Cohen, 1999; Krats, et al, 2009; Lohnberg, Howarth, and Clay, 2008; Murray et al., 2007) indicate that the effect goes further to the family functions (role disruption among non-patient family members) and families' in-out social relationship. When a member of a family suffers from a chronic illness, the family dynamics may drastically change (Murray et al., 2007). For instance, as per Williams et al., (2009) the burden of having a chronic disease in a family produces dire changes in almost all areas of life, including financial, physical, emotional, social, behavioral, and personal domain. Financially, as a family, lack of insurance or being underinsured can produce huge amounts of strain when medical bills are piling up. Physically,

the family may not be getting enough sleep each night or not have their normal routine with all members present in the home at a given time. Emotionally, the stress and uncertainty about the future, an upcoming procedure, or extensive worry about the ill family member may dominate each member's thoughts. Socially, families may either feel isolated and alone from extended family members and friends or be overburdened by the extra attention that they are receiving. Behaviorally, family members may be pulled in different directions than normally expected, such as going to the hospital or picking up the siblings from school early and missing work. Each member of the family is affected in some way by chronic illness whether he or she is the patient, mother, father, grandparent, or brother or sister. Chronic illness often results in worry, stress, disruptions in routine, change, financial constraints and more; these types of effects notably manifest themselves in the physical, social, financial, emotional spheres (Williams et al., 2009).

Since chronic illness is usually not curable and last long enough to become life itself to the patient and family as well (Öhman & Söderberg, 2004; Patterson & Garwick, 1994; Pierret, 2003), it is significant to understand thoroughly how the chronic illness affects the non-patient family members. Apart from revealing the changes created, it could also be vital to understand the coping strategies a family used to bounce back from all the effects created because of living with a person diagnosed with chronic illness. Hence, this research emphasizes on revealing the family experiences of living with a person diagnosed with chronic illness from non-patient family members' perspective.

Understanding the totality of experiences that non-patient family members encounter in their everyday familial life emanated from living with a person diagnosed with chronic illness is not only vital to understand and reveal the situation but also to look for further appropriate strategies that can be developed to meet family needs.

1.3.Objective of the Research

The general objective of this study was revealing the family experiences of living with a person diagnosed with chronic illness.

1.3.1. Specific Objectives

In attempt to achieve the main objective, this research specifically aimed to:

- Describe the major physical, emotional, and behavioral changes brought about by the chronic disease on patients and their family members from non-patient family members' perspective;
- Explore changes in the family functions and family inside-out interactions due to a family members' chronic illness;
- Assess the coping strategies of family members use to deal with effects linked to chronic illness.

1.4.Scope of the Research

The research targets the non-patient family members living with a person diagnosed with chronic disease in Addis Ababa, Ethiopia, with special focus on Tikur Anbessa Specialized Referral Hospital. This place was chosen because of the various services provided to treat chronic disease and the chronic ill-health experiences which make it appropriate place for the research. The focus of the research was the family experiences of living with a person diagnosed with chronic illness from non-patient family members' perspectives.

1.5. Limitations of the Study

This study has provided some essential features regarding the family experiences of living with a person diagnosed with chronic illness. It was a qualitative research study, thus generalizability was not a goal. However, there were several limitations recognized in this study.

First, this study was conducted using a cross-sectional research design. That is, data collection was conducted with once-off a gathering of data at a single point in time. Since the purpose of the study was revealing family experiences of living with a person diagnosed with chronic illness, experiences are an ongoing process that requires spending some time closely with the participants of the study to have a comprehensive understanding of their everyday ongoing phenomenon. Therefore, considering the ongoing nature of the problem, future studies should consider longitudinal studies to comprehend the various stages of the illness experience. This would help to convey a better description of the illness experiences and thus provide a more accurate representation of the phenomena.

Secondly, the participating families in this study were represented by family members other than parents. It means that the study did not include the perspectives and experiences of parents who could have influences on the illness experiences of other healthy family members. Therefore, to keep the balance and credibility of the study, future studies should consider including parents and other healthy family members together to reveal their experiences of living with a person diagnosed with chronic illness.

The third limitation of this study was lacking the voices that the broader society has regarding the perspectives on chronic illness and chronic patients. The study identified the socio-cultural perspectives towards chronic illness and chronic patients as one major barrier to get access and

obtain relational coping resources. Nevertheless, this finding was only based on the thoughts, experiences, and perspectives of the participating families regarding the socio-cultural barrier. This could influence the finding of the study negatively lacking the voices of the broader socio-cultural perspectives. Hence, future studies should consider trying to figure out the socio-cultural perspectives towards chronic disease, chronic illness, and chronic patients by including the voices and perspectives of the broader society which could provide accurate information to reach a state of balance.

The final potential limitation of this study was the inability to include the perspectives of health professionals, especially physicians in the area of chronic illness, regarding the challenges non-patient family members' experiences of living with a chronic patient and interventions used to support them. Notwithstanding the study's plan and efforts to include health professionals, the outbreak of Covid19 made their participations very difficult. So, it could be good to include and ask health professionals working in the area of chronic illness to understand as well as inform the family experiences of living with a person diagnosed with chronic illness.

Therefore, future studies should attend to the limitations of this current research to obtain a better understanding of the family experiences of living with a person diagnosed with chronic illness.

Chapter Two

Literature Review

2.1. Introduction

This chapter focuses on presenting the theoretical underpinnings of the research synthesizing them with the literature related to the family experience of living with a person diagnosed with chronic illness. The theoretical underpinnings are organized based on the objective of the research. The final section closes the chapter with a brief presentation of the theoretical framework of the research.

2.2. Theoretical Underpinnings of the Research

Theoretical concepts can be helpful to lift the empirical experiences up into serving the important task of providing insight and understanding. Although theories can help in guiding the way of thinking and approach in a research process, at the same time, they are challenged by their inadequacy to capture the complexity of social reality (Nilsen, 2005). Thus, this research will employ different but interrelated theoretical underpinnings to look at and into the complex family experiences of living with a person diagnosed with chronic disease. In the following sections the chapter deals with the theoretical underpinnings that could be relevant and will use to guide this research.

2.2.1. Theorizing the Illness Experience

Anyone at any age could be affected by chronic disease and illness experiences since the causes are either genetic or hereditary dispositions, birth traumas and other conditions present at birth, accidents and injuries, diseases and illnesses, or conditions associated with the aging process (Livneh, 2001). Nevertheless, the responses to chronic illness can be influenced by the

characteristics of the patient, the illness itself, and the family and social environment, and the effectiveness of the medical, social, and environmental support (Midence, 1994). As per Frank (1995), people tell their own illness experiences, but composing and combining narrative types that culture makes available. The narrative types include: restitution, chaos, and quest. As per Frank, the narrative types somehow fit one or another type of individual's illness experiences. Furthermore, in any illness, all the three narrative types are told alternatively and repeatedly. At one moment in an illness, one type may guide the story; as the illness progresses, through other narratives. Understanding the different types of narratives encourages giving better attention to the stories ill persons tell and aids listening the ill (Frank, 1995). This section discusses the illness narrative types based on the works of Frank (1995), '*The Wounded Storyteller.'*

The restitution narrative dominates the stories of most people, particularly those who are recently ill and often the less chronically ill. According to the restitution narrative, anyone who is sick wants to be healthy again because contemporary culture treats health as the normal condition that people ought to have restored. Thus the ill person's own desire for restitution is compounded by the expectation that other people want to hear restitution stories.

The plot of the restitution has the basic storyline: "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again." This storyline is filled with talks of tests and their interpretations, treatments and their possible outcomes, competence of physicians, and alternative treatments. The narrative lays the modernist expectation that for every suffering there is a remedy. The remedy that medicine offers is the focus of the narrative. The restitution narrative does not only reflect a "natural" desire to get well and stay well. People learn this

narrative from institutional stories that model how illness ought to be told. The emphasis of the narratives is on life after treatment: returning to "I'm fine!".

The restitution story is about remaking the body in an image derived either from its own history before illness or from elsewhere. The plot unfolds in three movements. First, the ill person is shown in physical misery and, often though not always, in social default. Some activities with spouses or children get canceled or work missed. The second movement introduces the remedy. As in the naming story, a helper may be involved in bringing the remedy, and also as in the naming story, a subplot may involve the sufferer's initial rejection of the remedy and thus of the helper. Eventually the remedy is taken, and the third movement shows physical comfort restored and social duties resumed. The success of the remedy validates the helper, and a hint of renewed romance may close the story. The restitution story usually demands adherence to some regimen, and this medical (or alternative) compliance demands a disciplined body. The narrative is not about capability to generate self-stories but the expertise of others: their competence and their caring, affects the cure. That is, in the restitution narrative the active player is the remedy: either the drug itself or the physician (Frank, 1995). In concur with the restitution plot; Parsons describes illness in its restitution plot in his theory sick role. Parsons argues that the role or action of the sick person involves others expectations for behavior. Like Frank's restitution plot, Parsons "sick role" theory also depicts patients as passive recipients of the medical prescription to get their healthy life again. In other words, the drug or the physician dominates the illness experience narratives.

However, restitution stories no longer work when the person is dying or when impairment will remain chronic. When restitution does not happen, other stories have to be prepared or the narrative wreckage will be real. That is, the chaos stories.

Chaos is the opposite of restitution. Its plot imagines life never getting better. The chaos stories reveal vulnerability, futility, and impotence instead of modernist bulwark of remedy, progress, and professionalism. While restitution stories reassure (however bad things look) a happy ending is possible. The chaos stories, on the contrary reassure that life is no more getting a better ending. Chaos stories are also hard to hear because they are too threatening. The anxiety these stories provoke inhibits hearing. The chaos stories cannot be told in words. In other words, they are difficult to express in words. Those who are truly living the chaos cannot tell in words. In the chaos narrative, troubles go all the way down to bottomless depths. What can be told only begins to suggest all that is wrong. Chaos is told in the silences that speech cannot penetrate or illuminate. The chaos narrative is always beyond speech, and thus it is what is always lacking in speech. In other words, if one cannot tell enough of its own story to formulate its needs and ask for help; often, they cannot even accept help when it is offered.

The chaos story presupposes lack of control, and the ill person's loss of control is complemented by medicine's inability to control the disease. Chaos stories remain the sufferer's own story, but the suffering is too great for a self to be told. The voice of the teller has been lost as a result of the chaos, and this loss then perpetuates that chaos. Those living chaotic stories certainly need help, but the immediate impulse of most would-be helpers is first to drag the teller out of this story, that dragging called some version of "therapy."

Restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest.

The quest narrative speaks from the ill person's perspective and holds chaos at bay. The enacted stories of people's lives: involvement in patient advocacy is one enactment of a quest story; making significant vocational and personal changes in one's life following illness is another. It is an attempt to create a new relationship to illness. This could be accepting the illness and making significant changes in one's everyday life paths following illness. The most extreme change is the claim to have become someone else.

Quest stories tell of a search for alternative ways of being ill. As the ill person gradually realizes a sense of purpose, the idea that illness has been a journey emerges. The meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking.

The sticking point in quest stories is the notion of hero; what sort of "heroes" do ill people take themselves to be? Illness stories include some number of "I conquered ...stories." It is an attempt to show the lived experiences and share the strength with other people. One problem in chronic illness is a patient's silence, which could result in isolation. Nevertheless, if silence is to turn into action, people become visible to each other. Hence, the quest story makes illness a social issue, rather than personal affliction. In general, it is the totality of self-reinvention following massive trauma or catastrophic illness. Meaning, it is not only about survival but it also about a feeling of rebirth and living experiences. Quest stories could show that anyone can step beyond the limits brought by the chronic disease brought about. Being open to crisis as a source of change and growth and valuing contingency even with its suffering are the bases of the communicative body in quest stories. Quest stories witness how society has added to the physical problems a disease entails, and calls for change, by showing solidarity with the afflicted.

Even though the aforementioned narrative types are about the experiences and perspectives of the patient on the ill-health experiences, in this current research the narrative types were used to examine the non-patient family members' experiences of living with a person diagnosed with chronic illness looking at their restitution, the chaos and quest plot.

2.2.2. Family System Theory

Family systems theory was developed during family research for emotional problems. Part of the effort was directed at extracting facts from the morass of subjectivity, discrepant explanations, and verbal dialogue that is common in psychiatric research. Eventually, the research included the approach that attempts to study the functional facts of relationships among the family members. It focuses on what happened, how it happened, and when and where it happened, insofar as these observations are based on the fact of relationships (Bowen, 1974).

Family system theory, as a form of general systems theory, focuses on what goes on at the family level, rather than merely examining family members individually. In order to understand a family behavior, this approach addresses communication, transactional patterns, conflict, cohesion, separateness and connectedness, and adaptation to family stress. For instance, in families raising children, family systems theorists consider how mothers, fathers, and all children interact to shape the behaviors of individual members and how individual members contribute to family life on the whole (Fingerman & Bermann, 2000).

Family system theory rests on the basic assumption about relationship processes within families, and holds that the experience of one family member affects the experiences of other family members (Bavelas & Segal, 1982; Murray, Kelley-Soderholm, & Murray, 2007). In concur with this assumption, studies in the areas of chronic illness (e.g. Cohen, 1999; Compas et al., 2012)

indicate that being diagnosed with a chronic disease can be a major upheaval for the rest of the families' lives and often leads to many dysfunctional changes or experiences. In other words, roles are often altered or adjusted to provide the necessary care to patients with chronic disease (Martine & Colbert, 1997). Families with chronic illness are fundamentally forced to cope with extraordinary circumstances (Eiser, 1994). Thus, being diagnosed with chronic illness places enormous demands on the families and can become the basic organizing principle of family life (Cohen, 1999). For instance, after diagnosis, families begin to experience the longevity and ongoing difficulty of managing the medical diagnoses (i.e. medication adherence, hospital visits, etc.), in addition to managing normal family life, such as keeping up with daily household chores, schoolwork, jobs, and social activities, etc. (Bouma & Schweitzer, 1990; Williams, 1997). The changes faced by families are multifaceted and can include stress related to daily functioning: disease-specific symptomology, treatment and demands, family strain, structure, function and interpersonal conflict; and stress related to uncertainty and loss (Compas et al., 2012).

The family system theory assumes that family systems are made up of sub-systems consisting of dyadic relationships influencing the entire family unit (White & Klein, 2008). Confirming this assumption, studies in the areas of chronic illness (Cohen, 1999; Compas et al., 2012) argue that many illness factors and caregiving burdens increase parental strains. Parental distress is associated with having an impact on the familial relationships; for instance, between patients and non-patient family members. Compared to parents with healthy conditions, parents with chronic illness report higher levels of role strain, higher stressors associated with the parental role, as well as frustration and conflict about the division of labor and expectations (Lohnberg, Howarth, & Clay, 2008). This can be indicated when the presence of chronic illness in a family greatly

affect family relationships. A study by Murray et al. (2007) demonstrates that parents reveal stronger emotional responses towards a member with a chronic illness than the healthy members. A study by Alderfer et al. (2010) also indicates that non-patient siblings often report spending less time with parents, which makes them feel neglected, ignored, and uncared for. This could be related to parental difficulty of attending to the needs of both their sick and healthy children, which can lead to overwhelmed, guilty and excessive feelings of worry (Alderfer et al., 2010). As a result, in many cases, this leads to disconnections among family members (Murray et al., 2007), especially between parents and children.

Systems theory assumes that all people in the family unit play a part in the way family members function concerning each other and in the way the symptom finally erupts. The part that each person plays comes about by each "being himself" (Bowen, 1974). Contrasting this assumption, in families with chronic illness, the experience leaves family members to play not only their roles rather a change in functions of one family member is automatically followed by a compensatory change in another family member (Bowen, 1974). Studies in the areas of chronic illness (Bouma & Schweitzer, 1990; Krats, et al, 2009; Williams, 1997) indicate that in any family, parents, for instance, with chronically ill family member often involve in many roles, including as doctors, police officers, role models, cooks and many more roles. Besides the typical parenting roles, parents also become care coordinators, medical experts, systems advocates, personal ambassadors and representatives for their chronically ill family member (Krats, et al, 2009). This is basically because of, in most cases, the inability of patients with chronic disease to do things that are typically taken for granted (bathe, dress, eat, move, follow directions, communication) on their own (Martin & Colbert, 1997). Though, challenges are common in such situations. According to Murray, et al. (2007) some of these challenges are: tension in family relations, time

management struggles, disrupted family activities, disconnection from social networks, and high medical costs. Similarly, many areas of family life, such as daily routines, financial decisions, careers, developmental transitions, friendships, school performance, parenting strategies, and sibling relationships can be affected by the illness (Murray et al., 2007). For instance, a study by Alderfer et al (2010) reveals the impact of chronic illness on siblings' school performance. They argue that school performances are impacted because healthy siblings' get fatigue due to changes in their routine, experience great amounts of worry and lack of attention from their parents. Sibling's desire to be with the patient instead of at school is also another factor that affects the school performance of healthy siblings.

Moreover, family systems theory highlights the integral influence of the family system on each member's development (Murray, Kelley-Soderholm, & Murray, 2007). All systems seek to establish and maintain balance, but can adapt to changes and grow stronger (Butler, 2010). Despite the changes, the family systems theory assumes the strengths of the family relationship in terms of cohesion, flexibility, and communication, which are keys for the family system to function in positive ways. However, when a family system is out of balance (not cohesive, not flexible, not communicating), the system weakens and sometimes collapses. Thus, families are expected to become more flexible and cohesive to cope with life's bumpy terrain (Olson & DeFrain, 1997). For instance, the introduction of chronic illness is an obstacle that could lead a family system out of balance. Thus, upon the introduction of chronic illness, Cohen (2004) indicates that every member of the family becomes a vital player, and the whole is greater than the sum of its parts. Family system theory asserts that family's burden is equal to each family member's burden. Nevertheless, in a given family system, certain individuals may be viewed as more important than others, certain individuals as more obligated to assist the family, and certain

individuals as more competent than other individuals (Fingerman & Bermann, 2000). For instance, variables, such as age and gender play an important role in how families adjust to illness (Williams, 1997). In contrast, Alderfer (2010) states that, concerning developmental stage, adolescent siblings seem to show the poorest adjustment compared to adults, school age, and preschool children. Houtzager et al's (2004) uncovered that siblings (of children with chronic illnesses) aged 7-18 years experienced more cognitive and especially more emotional problems than their peers. Concerning gender, Alderfer (2010) found that females exhibit more distress than males. Similarly, Houtzager et al. (2004) found that girls with an ill sibling are mostly at risk for difficulties in social relationships. Family systems theory correspondingly considers within-family differences (Fingerman & Bermann, 2000).

Recently there is a tendency among family practitioners to use systems theory to assist families in dealing with chronic illness and other family crucibles (Bohn, Wright, & Moules, 2003). There is growing understanding and interest among practitioners who recognize the impact of chronic illness on families, to execute treatment plans for the entire family, rather than simply for the individuals (Atwood & Gallo, 2010). Thus, the view of family as a system will be helpful to guide this research since the research is about experiences of family members living with a person diagnosed with chronic illness.

2.2.3. Ecological Model

Many researchers have used the ecological theoretical model in relation to families with a person living with a chronic illness because this model best addresses the contextual factors associated with a chronic illness and how the illness affects the individual and the family (Kazak & Christakis, 1994; Vinson, 2002). The ecological model is useful for examining the reciprocal

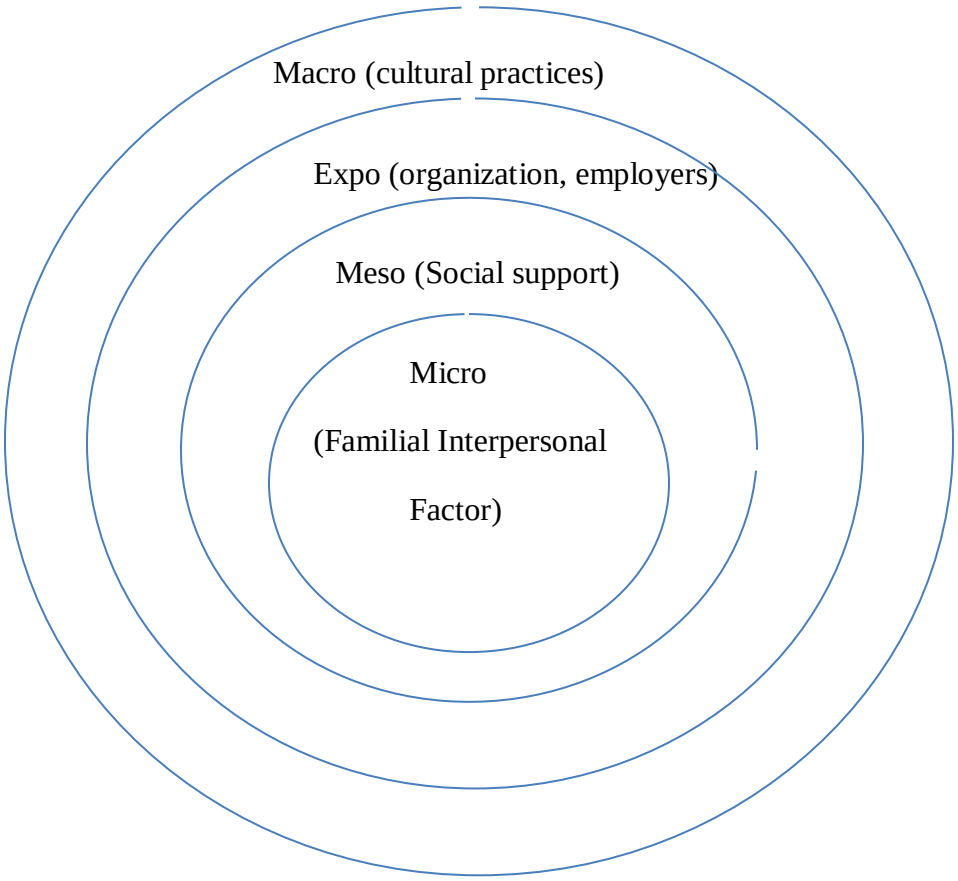
impact of chronic illness on individuals and internal and external systems to the family (Kazak & Christakis, 1994). Thus, the model explains that events external to the family unit are just as influential as the activities inside the family unit and inside the individual family member (Bronfenbrenner, 1986). For example, a patient's behavior problems are not solely based on the presence of a chronic illness, but are also influenced by stresses within the family and the functioning of external factors such as health insurance policies and social supports received from family, friends, and medical professionals. The ecological model acknowledges that external factors are associated with living with a chronic illness and considers how these factors can affect individual and family functioning.

According to ecological theory, family and individual functionings are embedded in the following four systems: the microsystem, mesosystem, exosystem, and macrosystem. The ecological model views these four different systems as constantly interacting and influencing each other (Bronfenbrenner, 1986). The microsystem is the individual level that includes the settings that the individual experiences and creates as a day-to-day reality. This level includes such factors as the physical and mental health of the individual, the people with whom the individual living with a chronic illness resides, and the financial viability of the family.

The mesosystem is the relationship between many other microsystems (Bronfenbrenner, 1986). This level includes the extended family, friends, and other areas of emotional or instrumental support for the family and individual living with a chronic illness. The mesosystem also includes the interaction of doctors, nurses, pharmacists, employers, and schools in the lives of the individual and family. Families living with a chronic illness may have more interaction with the mesosystem than families not living with illness, due to the demands of the illness. For instance,

parents may need to take additional leave from work to care for a patient experiencing an acute illness episode; this episode may also necessitate interaction with medical professionals and schoolteachers.

Figure 1: Depiction of the Ecological Model



The exosystem and macrosystem are further removed from daily family interaction, but continue to have great influence over family functioning. The exosystem has power over individuals' lives, but individuals possess little control over that system (Bronfenbrenner, 1986). For instance, the policies towards employee leave and health insurance in the workplace are included in the

exosystem. Additionally, Medicare, Medicaid, and health insurance companies are in the exosystem and create policies that delineate the cost, availability, and procedures for obtaining medical treatment for those living with a chronic illness. The macrosystem represents the broad ideological and institutional settings of a particular culture or subculture.

The macrosystem includes societal and cultural prejudices and stigma towards individuals living with a chronic illness (Dowling & Dolan, 2001). Historically individuals living with an illness or disability were considered defective and generally lacking ability to function in society (Disability Social History Project, 2001; Morgan, 2001; Russell, 1998). Although these beliefs have been changing in recent years, their historical legacy continues (Dowling & Dolan, 2001). The influence of the macrosystem on the other systems and its reciprocal relationship to the ecological model is displayed in the following example. The stigma and stereotypes of illness in society (macrosystem) may affect an employer's choice of medical insurance (exosystem), the social support from extended familial (mesosystem), and the individual's personal beliefs about the illness s/he must live with (microsystem).

The ecological framework also addresses risks and protective factors present in the four systems. Risk to the individual and family may be directly related to the presence of a chronic illness (Cadman, Boyle, Szatrnari, & Offord, 1987). Additional risks might include external issues such as societal stigma, federal policy regulations, and types of health coverage, as well as internal aspects such as economic strain, health stress, parental psychological distress, and patient's behavior problems. Unfortunately, for individuals and families living with a chronic illness, relationships with health care providers, insurance companies, and government agencies are often the most stressful (Doherty, McDaniel, & Hepworth, 1994).

In contrast, protective factors may help to remove risk from families and individuals. Creating a shared family view of the illness is often a protective factor. For example, the impact of the illness on the family tends to decrease when the parents of a patient living with a chronic illness have a shared view of the illness, its management, and its impact on the family (Knafl & Zoeller, 2000). Protective factors might also include attending support groups, having helpful extended family and community support, and/or medical professionals who are willing to educate and work together with the family. Finally, positive parenting may act as a protective factor and help to reduce the risk of patient's behavior problems.

2.2.4. The Concept of Family Resilience

The notion 'resilience' is defined as the ability to withstand and rebound from crisis and adverse conditions (Walsh, 2003; Luthar, Cicchetti, & Becker, 2000). The concept 'resilience' was initially perceived as an innate characteristic that resilient persons were acquired through their resourcefulness or good luck. The focus of earlier studies on resilience was mostly on the personal strengths and inner fortitude of individuals who thrived in spite of destructive family environments. Overtimes, as the knowledge base on resilience expanded, studies recognized the significance of the interaction between nature and nurture in the resilience paradigm. However, the views researchers had on family influences were still deficit based and pessimistic, which blinded them to family strengths. It thus was believed that families contributed to risk, but not to resilience. Studies tended to dismiss the family as hopelessly dysfunctional and rather searched for extra-familial sources of resilience to counter the negative influence of the seemingly noxious family (Walsh, 2003). Later, studies indicated that resilience involves a relationship between several risk and protective processes over time and increasingly noted the role both family and larger socio-cultural factors played in the resilience process (Hawley, 2000; Walsh, 1996).

However, a small amount of research was discovered during literature search that has focused on family resilience within families and individuals who are experiencing chronic illness.

The concept of family resilience starts with the hypothesis that quest why some families are shattered by crisis or persistent stresses, while others emerge strengthened and more resourceful (Patterson, 2002; Walsh, 1996). Shifting the perspective from viewing families as damaged to seeing them as challenged, and concept affirms family's reparative potential. The concept family resilience corrects the tendency to think of family health in a mythologized problem-free family. Instead, it seeks to understand how families can survive and regenerate even in the midst of overwhelming stress. A family resilience perspective affirms the family's capacity for self-repair. Family resilience is founded on the conviction that both individual and family growth can be forged through collaborative efforts in the face of adversity (McCubbin & McCubbin, 1996; Walsh, 1996).

The concept focuses on key interactional processes that enable families to withstand and rebound from the disruptive challenges they face. The key variable in family resilience is a family's in-out relationship in the face of adversity. The concept focuses on the crucial influence of relationships and social support (Walsh, 1996). Likewise, Lohnberg et al. (2008) have specified that the most prevalent predictors of well-being in families with a chronic illness: flexibility, integration into a supportive social network, balancing the demands of the illness and family needs, effective communication, and the encouragement of development and growth within the family. Family resilience is presented, involving processes that foster relational resilience as a functional unit. The concept family resilience involves family patterns, communication and problem-solving processes, community resources, and affirming belief systems. Of particular

importance is a coherence that assists members in making meaning of their crisis experience and builds collaboration, competence, and confidence in surmounting family challenges (Walsh, 1993).

The concept considers the family as a potential source of resilience: that is, as a resource. As a resource, meaning, the family emotional climate, such as warmth, affection, emotional support, and clear-cut, reasonable structure plays a key role in family resiliency (Walsh, 1996). Similarly, studies (Cohen et al., 1995; Williams, 1997) in the area of chronic disease have shown that family cohesion and adaptation play the biggest role in mediating the impact of illness on healthy siblings, which may include shared affection, emotional bonding, mutual understanding, helpfulness of members etc. Furthermore, in her review of the literature on siblings and chronic illness, Williams (1997) indicated that family and parent variables are present and key to adjustment to illness. For instance, absence of parental depression, good marital adjustment, and effective parent-sibling communication about illness are predictors of positive sibling adjustment, whereas high family stressors and lack of family cohesion and expressiveness contributes to several adjustment problems of siblings (Williams, 1997). Williams (1997) further indicate that holding a negative perception of the experience and lacking confidence plays a role in coping efforts, likewise impacting the family as a whole. Galloe et al. (1993) found that parents who are overwhelmed with the demands of care and saw it as a burden increases family stress and are less likely to have relatives' support. A study by Donoghue & Siegel (2000) also indicated importance for families to express appreciation for each other, especially when chronic illness alters an individual's ability to contribute to family life in normative ways. Though, when parents are unable to provide this climate, relationships with other family members, such as older siblings, grandparents, and extended kin can serve this function (Walsh, 1996). As indicated in

the aforementioned section, families with chronic disease in most cases could experience difficulty to attend the needs of both their sick and non-patient family members. Consequently, lack of attention in the family leaves non-patient family members to look for support at the community level (Alderfer et al., 2010; Hollidge, 2000).

The concept family resilience extends the relational resilience to the community level, indicating supports provided by friends, neighbors, teachers, coaches, clergy, or mentors as keys in family resilience. The availability of community resources and a family's outreach to use them are essential for family resilience, providing practical assistance, social support and a basic sense of connectedness through friendship networks, and religious or other group affiliations (Walsh, 1996). However, the intense demands of care for patients with chronic illness make friendship and looking for community service more challenging and difficult (Martine & Colbert, 1997). Furthermore, social isolation may also occur when the communities avoid the family with chronic illness due to beliefs and misconceptions about the disease (Martine & Colbert, 1997). Lacking community response to hardships, family disruption may be inevitable no matter how strong the intra-familial capacities (Walsh, 1996). Research indicates that the larger the available social network together with community support to families with a person with chronic disease, the more effective it is at reducing stresses (Bruns, 2000). Needed community services may include educational consultation and training, family social support, financial assistance, in-home professional assistance, information dissemination about available services, medical care, recreational programs, support groups, therapeutic services (occupational, physical, and speech), and transportation (Cole, 1986; Crnic et al., 1983). Thus the concept assumes that in order for a successful adaptation the family requires both intra-familial and environmental relational resources (Walsh, 1996).

The concept of family resilience extends strength-based approaches in ways that have important research utility. First, it links family process to challenges: assessing family functioning in social or relational context and whether it fits varied demands. Second, a family resilience approach incorporates a developmental, rather than cross-sectional, view of family challenge and response over time, considering how relational resilience processes vary with different phases of adaptation and life-cycle passage (Walsh, 1996).

Interactional processes as cohesion, flexibility, open communication, and problem-solving skills are essential in facilitating basic family functioning and the well-being of members. Key processes in family resilience include: (1) shared acknowledgment of the reality of loss; (2) open communication for sharing the experience; (3) reorganization of the family system; and (4) reinvestment in other relationships and life pursuits (Walsh, 1996).

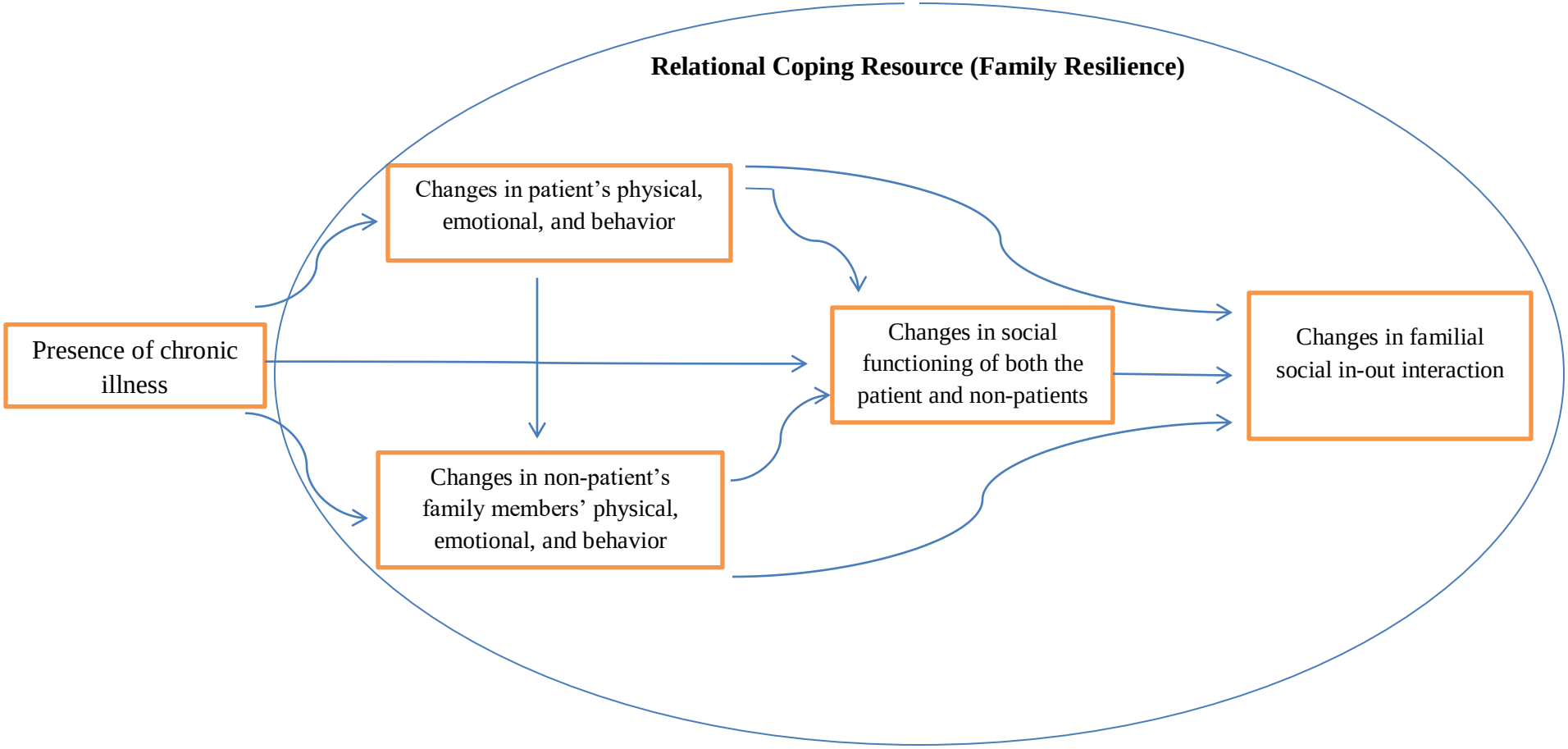
This research intended to use the family resilience concept together with related literature to explore the family's in-out social relationship and the extent of its maintenance of their resilience to the experiences of living with a person diagnosed with chronic illness.

2.3. Theoretical Framework of the Research

The theories and model mentioned in this particular chapter helped to shape the theoretical framework that will be employed in the current research. As shown, the presence of chronic illness is hypothesized to affect the overall familial phenomenon, including the physical, emotional, and behavioral aspects of both the patient and non-patient family members. Furthermore, the social functioning and familial social in-out interactions could directly be affected by the presence of the chronic disease in the family. Nevertheless, the framework does

not imply that all the strains that family experience because of living with a person with chronic illness, personal as well as social behavioral strains are created solely by the presence of illness, just that the illness has some impact upon these variables. According to the framework, the family experiences of living with a person diagnosed with chronic illness is intermediated by several other factors. For instance, physical, emotional, and behavior changes of the patient due to the ill-health condition directly influence the physical, emotion, and behavior of non-patient family members as well. The physical, emotional, and behavioral changes created by the ill-health condition directly influences the social functioning of both the patient and non-patient family members. Changes in physical, emotional, and behavioral; and social functioning also influence the family social in-out interaction as well. The framework posits that a successful adaptation or family resilience requires both intra-familial and environmental relational resources. Lacking community support for hardships produced by the presence of chronic illness, family disruption may be inevitable no matter how strong the intra-familial capacities. The theoretical framework hypothesizes that familial relational resources will moderate each of the previously mentioned relations. The following figure will show the theoretical framework of this current research.

Figure 2: Theoretical Framework of the Research



Note: the research hypothesized that the relational resources or families resilience capability will moderate each of the above variable relations.

Chapter Three

Research Methodology

3.1. Introduction

This chapter focuses on the methodology that was followed in the research. The chapter first explores and discusses the decision to adopt a qualitative research design for the proposed study. It also briefly describes the research area. A brief account about the research participants, and the techniques used to recruit follows. Subsequently, description of the research methods used to gather the necessary data to achieve the objective of the research will be provided. The chapter also briefly describes the method employed for analyzing the collected data. Finally, the ethical issues are presented.

3.2. Research Design

This research was based on a philosophy of qualitative research design. This research considered qualitative research design as the most appropriate method. The rationale for choosing qualitative research design lays in its paramount usefulness for the following reasons. First and foremost, it promotes an expansionist stance for holistically exploring the matter at hand compared to the quantitative designs which would have limited the focus of the study. Secondly, where the language used in quantitative research is predetermined for the purpose of determining hypothesis validity, qualitative research prides itself in the knowledge acquired through the connotations, emotions, and meanings communicated through language. Thirdly, qualitative research provides contextual information that is often absent in quantitative work. Moreover, qualitative research provides rich insight into human behavior, that is, the human side of an issue, i.e. often contradictory behaviors, beliefs, opinions, emotions and relationships of

individuals (Crang and Cook, 2007; Guba & Lincoln, 1998; Vanderstoep and Johnston, 2009). Hence, a qualitative research design approach was chosen to reveal the family members' experiences of living with a person diagnosed with chronic illness since the goal was to get into the experience of the participants and see it as they see it.

More specifically, the phenomenological method was selected. Phenomenology refers to a philosophical method of recording and interpreting the 'lived experiences' of certain individuals through detailed descriptions and conversations. This research utilized phenomenological methodology with an aim to expose, and reveal certain elements of particular situations that are universal to that unique cohort (van Manen, 1997). The phenomenological method views things in a way they are experienced in the world (van Manen, 1997). To know well and understand the phenomenon that is being explored, individuals have to be in and experience the world. In order to reflect, the experience must have already passed or been lived through in order to gain a retrospective perspective (van Manen, 2014). Phenomenology attempts to demonstrate how an individual's own words, concepts and theories can shape and structure the experiences as they live them (Wertz, 2005).

Phenomenological research methods are directed at providing an in-depth and interpreted understanding of the social world of the research participants by learning about the sense they make of their social and material circumstances, their experiences, perspectives and histories. Phenomenology focuses on how family members experience the phenomenon of chronic illness in their family context. Phenomenological method was used to explore how individuals construct meanings out of their experiences of everyday life, and how these individual meanings shape group or cultural meanings. Phenomenologists maintain that human experience makes sense to those who live it. The method maintains that reality resides in the interpretation or consciousness

of an experience. Hence the outputs that include detailed descriptions of the phenomena being researched grounded in the perspectives and descriptions of participants. Understanding the constructs, concepts, ideas or thoughts people use in everyday life to make sense of their world and uncovering meanings contained within conversation or text is the concern of qualitative research design (Johnston and Vanderstoep, 2009).

Phenomenological methodology best supports this research, as it allows diversity in responses from the research participants. It ensures that each unique family experience is accounted for and gives them the opportunity to tell their own experiences of living with the person diagnosed with chronic illness. This particular methodology captures the lived experience of each individual. In addition, there is the ability to report findings from both individuals and families as a whole (Wertz, 2011).

3.3. Research Site

This research was conducted in Addis Ababa, Ethiopia. Addis Ababa is a big city with a dense population, and a center for many hospitals or health service centers, both public and private. Though, the research limited itself at the public hospital. A public hospital was selected because it serves a large number of patients from different socio-economic and cultural backgrounds, and the extended and variety of services provided to the patients with chronic disease in comparison to private health service centers. More specifically, Tikur Anbessa Specialized referral hospital was used as a place to initiate the study. The place was chosen because of the presence of various services provided to treat various types of chronic disease and chronic health experiences, besides the reasons mentioned above.

3.4. Research Participants

The research aimed at revealing the non-patient family members' experiences of living with a person diagnosed with chronic disease, giving emphasis to an insider's perspective. Hence, the study targeted non-patient family members' who are living with a person diagnosed with chronic illness. The study attempted to contact 14 families, of which 10 were successfully contacted. From the 14 contacted families, 4 were not interested in participating after the study was explained. The study included two non-patient family members from each successfully contacted family to achieve variation and maintain an in-depth understanding of the phenomena studied. Thus, the numbers of research participants' were 20 in total. Of all the research participants, 13 were females and the rest 7 were males. The participants included were between the ages 19-31. The families included in the study were families with cancer (5), diabetes (3), and hypertensions (2) patients. The number of non-patient family members and families included in the research was determined by the amount of data collected from each non-patient family member. That is, as per Dawson (2007) the research continued recruiting research participants and collecting the data until the saturation point was reached or it becomes saturated (participants no longer provide additional understanding of the phenomenon studied). In qualitative research, it is believed that each participant has experienced the phenomena to be studied (Creswell, 1998) since the firsthand experiences in common across participants allow for the development of themes in the process of data analysis (Babbie, 1999).

Table 3: Participants Information (N - 20)

Sex	Frequency	Age	Frequency	Types of Diagnosis	Frequency	Time since diagnosis	Frequency
Male	7	19 – 22	7	Cancer	10	5 months-1 and half years	10
		23 – 26	7	Diabetes	6	2 years – 5 years	8
Female	13	27 – 31	6	Hypertension	4	6 years – above	2

3.5. Methods to Recruit Research Participants

Non-probability, purposive sampling was used to identify potential research participants because it was believed to lead to the information-rich participants. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research (Patton, 2002). Hence, purposive sampling was used to select the participants. Non-patient family members who were attending a family member's medical treatment at Tikur Anbessa Specialized referral hospital were intentionally selected. Notwithstanding purposeful selection, all potential study participants were invited to participate in the study of their own free will and consent.

In this research, chronic illness meant that an illness that can last for an extended period, at least three months, often for life, and cannot be cured (Midence, 1991). The criteria to be part of the research were (1) a family living with a person diagnosed with chronic disease; (2) since the research was about non-patient family members experiences of living with a person diagnosed with chronic illness, it has to be at least three months and above since the person got diagnosed with chronic illness; and (3) the participants must be families, including housemaid, to a person diagnosed with chronic illness and still part of the household. Thus, all the research participants were those who met the criteria sat above.

The initial recruitment phase was started by presenting the official letter of support taken from Addis Ababa University, sociology department; and by introducing Tikur Anbessa Specialized referral hospital, the research and publication office, about the research as well as the overall objective of the study in order to gain access to the setting and initiate the process of selecting

the potential study participants. Following, a nurse who was able to provide help in the process of identifying and contacting potential research participants were contacted.

Therefore, the initial recruitment began by providing information about the overall objective of research and the purpose, i.e., academia, to the potential research participants with the help of a nurse. Once each potential participant had agreed to participate in the study, contacts were made via phone to make a time and select places that were suitable for them. In all cases, the participants were given information about the research and the overall objective before the interview to take place.

3.6. Data Collection Tools

This research was based on multiple research tools to collect the data needed to achieve the objective of the study. As Denzin (1978) indicated, using multiple research tools together to investigate the same phenomena made it very important to increase the depth of understanding of the family experiences of living with a person diagnosed with chronic illness. Besides, using multiple research tools enabled to triangulate and offset the weakness of one method by the strength of the other. Thus, in this research, data collecting tools: semi-structured interviews, diaries, informal dialogues, and researcher's field notes were used to collect the data necessary to accomplish the objective of the research. The following sections elaborate more on the research tools the study employed.

3.6.1. Semi-Structured Interview

Semi-structured interview was developed to facilitate and organize the data collection. A semi-structured format was developed for the interview, as it was deemed to elicit and specific enough to elicit the detailed information necessary for analysis across participants, yet flexible and open

enough to allow participants to tell their stories. As a result, probing questions were used to ensure enough information on the topics covered by the semi-structured interview and to increase understanding of the participants' experiences (Hill et al., 1997).

Semi-structured interview interviews were used to have conversations with 20 research participants. The interviews were held basically to reveal the non-patient family members experiences of living with a person diagnosed with chronic illness. Initially, the research used interview guiding questions that were prepared before the fieldwork. The interviews were estimated to take between 40 to 60 minutes at a location of participants' choices. Interviews were held in mutually agreeable locations, such as Public Park (e.g. Addis Ababa golf club), to ensure ease and comfort of the participants throughout the interview process. The participant's social situations were considered by offering them environments that suited them. An interview at a cafe was the least preferred option as they do not offer much privacy and are often noisy. The purpose of the interviews was to ensure that participants were given a chance to voice their experience and to further explore the insight and knowledge that the individuals have of the particular experience. Semi-structured questions provided research participants the opportunity to describe and explain their personal experience. Furthermore, conducting face-to-face interviews allowed getting non-verbal messages of the participants (such as emotions that were clearly visible to be observed throughout the interview), which significantly increased validity of the interview and the data collected. The interviews were conducted in Amharic, a local language. All interviews conducted were recorded with an audiotape.

As Kvale and Brinkmann (2014) argue using semi-structured interviews give opportunity to go beyond the already defined interview questions by providing a flexible environment. Kvale and Brinkmann further argue that semi-structured interviews go beyond the spontaneous exchange of

views in conversation, and become a careful questioning and listening approach. Thus, the method helps to obtain a thoroughly tested knowledge since the knowledge is going to be constructed in the interaction, interchange of views about a subject of mutual interest, between the interviewer and the interviewee (Kvale and Brinkmann, 2014).

3.6.2. Diaries

Diaries are a typical research method used to record particular information in relation to some aspects of a specific event or experience. Diaries are also used to explore thoughts and feelings in relation to a particular phenomenon, in the case of this research, non-patient family members' thoughts and feelings related to living with a person with chronic illness. Diaries allow for freedom of expression and for the recording of information at the time of, or shortly after, the event or experience (Ross, Rideout, & Carson, 1994).

Diaries, self-report instruments used repeatedly to examine ongoing experiences, offer the opportunity to investigate social, psychological, and physiological processes, within everyday situations. Instantaneously, diaries recognize the importance of the contexts in which these processes unfold (Bolger, Davis, & Rafaeli, 2003). Thus, diaries were designed to capture the little experiences of everyday life that fill most of working time and occupy the vast majority of conscious attention (Bolger, Davis, & Rafaeli, 2003).

A fundamental benefit of diary methods is that they permit the examination of reported events and experiences in their natural, spontaneous context, providing information complementary to that obtainable by more traditional designs. Another benefit is the dramatic reduction in the likelihood of retrospection, achieved by minimizing the amount of time elapsed between an experience and the account of this experience. The data from diaries reflects people's usual

experiences in their home, work lives, and the typical ways of handling the challenges and possible responses. A prime advantage of this method is that participants can prospectively unfold a series of events and perceptions relevant to their subsequent action rather than rely on recall of the past events (Bolger, Davis & Rafaeli, 2003).

This research used a diary method with three participants, who document their everyday experiences of living with a person diagnosed with chronic illness. Data was obtained about an individual and the family health processes which surround health and illness. Diary-use allowed documentation of challenges and associated coping strategies by the individual or family experiencing them within their own frame of reference. Diaries were completed at home, without supervision, and days were chosen as representative of usual or typical days. Selection of the particular days on which to record was left to the discretion of participants. The research did not attempt to impose a standardized method of recording. Rather participants were given the opportunity to select their own method of diary keeping.

The method was used to understand the quality of life of non-patient family members living with a person diagnosed with chronic illness. Participants were asked to record any experiences related to ill-health conditions in their house and their response to the problem they faced. This provided insights into the everyday experiences and possible response to the experiences faced. The research included those participants who agreed to record their everyday life experiences related to living with a family member diagnosed with chronic illness and continued to record until the end of the diary period.

One of the major challenges of the diary research method was fatigue, a lack of willingness to complete the diaries in the same details as time passes (Ross, Rideout, & Carson, 1994). One of the possible solutions, Norman suggests is, asking respondents to complete a randomly selected

days. Thus, recognizing the commitment required for diary keeping and the potential for fatigue, data collection were restricted to 2 days per week. The documentation of diaries was kept for the maximum of two weeks. Additionally, telephone contact was made 48 hours prior to the scheduled day of completion.

3.6.3. Informal Dialogue

Informal dialogues were held with potential research participants throughout the research process. Most informal dialogues were held at Tikur Anbessa Specialized Referral Hospital, a place where the research initiated the process of conducting the study. Informal dialogue with the research participants was helpful to create opportunities for making acquaintances and mutuality about the research problem as well as the building rapport and confidence about the overall research processes. The close interactions maintained through informal dialogue enabled holding, casual conversations on topics of particular interest to the research (Punch, 2001). Furthermore, informal dialogues with research participants created an opportunity to make participants ready for further research activities, including getting easy access for other data collection tools, especially for semi-structured interviews and diaries. Informal dialogues were kept with researcher's own field notes immediately after the interaction with research participants happened.

3.6.4. Field Notes

Field notes were also taken as part of researcher's self-reflection on every field activities with research participants and the gatekeepers of the research sites and participants, for instance Tikur Anbessa Specialized Referral Hospital, that has some kind of control over both research sites and participants to conduct or not conduct the research. Field notes were concerned in writing

researcher's self-reflection: for instance individual interviews as well as informal dialogues. Emotions, facial expressions or body languages and all the challenges of field research, the processes of getting consents from each participant, and many more events were included in the field notes. Mostly, field notes were written at home, or quite places as soon as possible when they were fresh in mind. Since it was unlike the conventional methods, such as interviews which use tape-recorder, it was required to convert field notes to a typewritten document immediately after the interview or interaction with research participants. Lloyd-Evans (2006) indicated that writing notes while they were fresh in mind makes it much easier to remember. In this manner, immediate perceptions were retained and utilized in the analysis.

3.6.5. Secondary Data Sources

The research also used secondary data from different sources, including books, articles, research publications, and other relevant unpublished materials, including information from the Tikur Anbessa Specialized Referral Hospital, especially about the magnitude of the problem of chronic illness and if there is any intervention programs that have been done for non-patient family members living with a person diagnosed with chronic illness.

3.7. Method of Data Analysis

Analysis in phenomenological research is not to tie all loose ends together rather to describe and understand the experiences of the participants (Dahl & Boss, 2005). Thus, in the first stage of data analysis, all recorded interviews were transcribed, first in Amharic, and then in English to get the experiences of research participants with its full account. The crucial part of data analysis was creating a list of coding categories after the data collection. In order to do this, for the patterns and consistency within the collected data as well as identifying the themes was carried

out (Bogdan and Bilken, 2007). Furthermore, key words and phrases that represent the topics and themes were identified and used as coding categories. Developing a list of themes and sub-themes eased sorting the collected data, which was crucial in the data analysis process. From this process, the meaning units were listed, and then clustered into common categories or themes. The clustered themes and meanings were then used to develop the significant themes of the phenomenon. The findings were then written up alongside the references to the literature.

3.8. Ethical Consideration

Ethical issues are common in all research activities with all kinds of people. Nevertheless, the sensitiveness and the ethical complexities of conducting research on some research subjects leave researchers to be more cautious. Recruitment of participants, sampling, and data collection require careful attention to ensuring voluntary informed consent and protecting the confidentiality and privacy of all parties involved. This was mainly aimed at protecting the research participants emotionally, physically, and mentally from any kind of harm. Thus, this research has given huge considerations throughout the research process to the ethical principles, such as seeking consent, respecting the privacy and confidentiality.

3.8.1. Informed Consent

One of the basics in research activities particularly in fieldwork is securing the consent of the participants and institutions that have a stake in and responsibility for the potential research participants with which the researcher is planning to conduct the study. Informed consent means that a study participant has agreed to be part of research, after being cognizant of and understanding of who the researcher is; the aims, methods and processes, topics, the usage of

data, and withdrawal from the research at any time (Beazley et al. 2009). But, seeking consent does not just focus on giving information but also in the ways that participants understand.

"*Consent should be obtained from the participants in person, and after a participant was given the opportunity to hear information about the project, they should be given the opportunity to ask questions or raises concerns"* (Sime, 2008:6). Vakaoti (2009) argues that participants consent to participate should be attained for each specific research tool. Although the provision of information about the research may help participants in determining whether to become study participants, in practice it is quite difficult for any participant to understand the full implications of participating in research. Therefore, the role of 'process consent', whereby the consent of research participants is obtained in negotiation as an ongoing process rather than something that it is assumed on the basis of initial consent, is necessary (Sime 2008). Consent needs to be taken from the participant in person after getting them aware of the research and the researcher and in process they should be given an opportunity to ask questions or raise concerns (Patton, 2002).

Accordingly, this research obtained the consents of each possible research participant and for each research tool. As cited in Sime (2008), this research obtained the consent of the potential research participant as an ongoing process rather than something that was assumed on the basis of initial consent. In doing so, the potential research participants were informed about the overall aspects of the research, including the objective of the research, methods used and processes, and about the right to withdraw from the research at any time for any discomfort. The research also obtained the oral consent from the concerned bodies to get access to, for instance Tikur Anbessa Specialized Referral Hospital, which the research used to initiate conducting the research. All consents were documented using voice recordings.

3.8.2. Respecting for Person

This qualitative study aimed at revealing the non-patient family experiences of living with a person diagnosed with chronic illness. Meaning, individuals (the primary research participants) were contacted and asked to provide personal and family related information about their experiences of living with a chronically ill family member. Accordingly, privacy, avoiding undue interference in the personal affairs, was taken as a vital ethical issue that should be considered in this research activity. This included recognizing rights of research participants to control all personal information they provide. According to Admassie (2010) research participants are entitled to exert control over whether or not to make sensitive information about them available to others. Respect for a person requires a commitment to ensuring the anonymity of research participants in order to protect them from exploitation of their vulnerability to ill-health family conditions. The standards focused on protecting participants from any harm during the research, and ensuring that consent was obtained, and then the risks posed modest. The dignity of all research participants was respected. Thus, adherence to this principle ensures that people were not used simply as a means to achieve research objectives. Research participant's right to privacy were valued by rendering personal or family data anonymous. This makes the research feasible without limiting the productivity of the research. Therefore, in this study, the research participants were informed not to talk and expose matters that they have made it private in order to avoid negative feelings for them and others as well. Furthermore, as part of the research responsibility, the research confines itself to the social and ethical principles so that it will not infringe on the private matters of the research participants.

3.8.3. Confidentiality

Confidentiality, having participant's identity and other details secret when reporting, is also one of the vital ethical concerns in research activities (Morrow & Alderson, 2011). Ennew et al (2009) argue that collecting participants' names is irrelevant in social research. They further argue that research participant's identity should be protected by changing their names (or not collecting names at all) and if necessary, the name of their community, in the research report and other publications. It is also accepted that the researcher is responsible to provide participants information about their rights to confidentiality before taking part in the research (Kirk, 2007).

Thus, in this particular research, the participants received assurances that the information they give will be confidential and utilized for the research purpose. Moreover, personal computer was used to keep all field documents, including interviews and diaries, and secured under lock. The study will not reveal the names, and images of the research participants while reporting the findings in any scientific publications in order to protect the research participants from any kinds of harm on their current as well as future lives. Since the study's focus was describing family's experiences of living with a person diagnosed with chronic illness, while reporting the finding, the study uses the descriptions including their personal information such as anonymous names, age, or sex.

Chapter Four

Chronic Illness Directed Changes

4.1. Introduction

The study aimed to reveal family experiences of living with a person diagnosed with chronic illness. This chapter analyzes the data gathered on the major physical, emotional, and behavioral changes brought about by the chronic illness on patients and the family members of the patients. Notwithstanding the focuses, the chapter begins by giving brief descriptions of families included in the study, especially outlining their characteristics in terms of family structure; and their accounts of diagnoses to chronic illness. Besides, the chapter gives brief discussions on the non-patient family members' onset and later illness experiences, having Frank (1995), restitution, chaos, and quest plot in mind.

4.2. Family Characteristics

This section presents a summary of the study participants' family composition and their accounts of diagnoses to chronic illness. Even though families included in this study were nuclear in structure, looking at participants' background information, the study identified two categories of nuclear families in terms of their composition, which has shown a significant impact on the illness experiences of family members of the chronic patient. The first category was a nuclear family also known as a conventional family that comprises both parents (mother and father) and their children. The second category was a single-parent family which refers to a divorced family, (i.e. a parent (father or mother) and the children) or a widowed family (i.e. one of the parents (mother or father) dead and the children).

Of the ten families included in the study, three of them correspond to the conventional nuclear family category. For example, an excerpt from a female participant reads “I used to live with my parents, siblings, and a housemaid. It is the mom who got a chronic illness (diabetes)” (P11, 27). A description from a male participant living in conventional nuclear family elaborated “It has been almost a year since dad’s diagnosis with cancer was known” (P8, 28). Similarly, a female participant living with her parents with chronic illness says “My parents have a chronic illness, diabetes” (P14, 23).

All participants included in this study have parents, (either father or mother, or in some cases both), who were diagnosed with chronic illness notwithstanding the difference in types of illness diagnosed. Even though, the presence of all family members had its advantage to keep the healthy functioning of the family system. The study indicates that having a family member diagnosed with chronic illness changes the overall family system of inside-out social interaction and the function each family member has to play to make the family system functional.

The other categories of nuclear families included in the study were divorced families. This consisted of a parent (father or mother) and children. Two of the participants’ families correspond to this category of the nuclear family. While talking about their family composition and family member’s accounts of diagnoses to chronic illness, for example, a male participant elaborated “My parents got divorced. So, I’m living with mom (who has a chronic illness, cancer), siblings, and housemaid” (P4, 31). Similarly, the other male participant from the divorced family said, “I am the firstborn to my family and have a younger brother. My parents got divorced when I was eleven. Since then we haven’t lived together. I used to live with my mom who had a chronic illness, cancer, and younger brother” (P1, 27)

Divorced families commonly experienced many challenges and changes in their family system, mostly role disruptions. As a result, each member in a nuclear (divorced) family expected to live up with additional compulsory responsibilities, which included both emotional and instrumental, to keep the functioning of the family system. Besides the challenges and changes created by the divorce, having a chronic patient within the family significantly shifts the roles previously carried out by each family member: both the patient and their family members. Often family members of the patient have to take over the roles previously carried out by chronic patients. For example, a male participant elaborated how the role shifted to the healthy family members because of mom diagnosis with chronic illness (cancer) and said, "Mom used to be the strongest woman who holds the entire house in accord…but after her diagnosis with cancer that role play has shifted to us (me and my brother)" (P2, 27).

The study indicated that the participants' included in the study have parents with chronic illness. Thus, besides the absence of a father or a mother in the family, having a family member diagnosed with a chronic illness puts non-patient family members' under more pressure or compulsory responsibilities to keep the family system functional. The next chapter discusses role changes diagnoses to chronic illness brings about, specifically on the family function and family inside-out social interaction (see chapter five for more).

Of the families included in the study, five of them belong to a nuclear family with either mother or father died. Of the five families who belong to this category, for instance, an excerpt from a male participant reads "It has been one and a half years since mom died. Now, I and my siblings are living with our father. Our father is diabetic" (P12, 22). Similarly, a female participant elaborated

> …mom diagnosed with the same chronic disease (cancer) about ten months after our father died of cancer. It was a horrible experience for us (me and my siblings) to hear such a chronic health problem after our father's death (P7, 24).

The other categories of nuclear families were single-parent families consisting of father or mother and their children whose mother or father is dead. The study indicated that besides parental losses, a family member's diagnosis of chronic illness was a horrible experience since the illness removes everyday freedom once again. This is because, like divorced families, besides the absence of a family member, having a parent diagnosed with chronic illness causes role shift (role disruption) that each family member is supposed to play in the family system.

The study indicated that the healthy function of the family system can be influenced by several factors: for instance, the compositions of the family. In addition, having a person diagnosed with chronic illness significantly alters the function each member is expected to play to the family system. Concurring to this finding, previous studies indicated that the illness-causing situations directed family members of the patient to play not only their roles rather changes in the role of a family member is automatically followed by a compensatory change in another family members (Cohen, 1999; Compas et al., 2012; Martine & Colbert, 1997). It means that family members of the patient have to take over the roles previously carried out by the chronic patient. As a result, the increase in responsibility brought about by taking the role of the dysfunctional family member in addition to their role often leaves the rest of the family members with a reduction in their various inside-out daily activities. This finding is consistent with the basic assumption that view family as a system that can experience change brought about by the changes that a family member encountered (Bavelas & Segal, 1982; Murray, Kelley-Soderholm, & Murray, 2007). As

Bowen (1974) indicates the changes that a family as a system experience in one family member automatically leads to compensatory changes in other family members.

Anyone at any age could experience chronic illness since the causes are either genetic or hereditary dispositions, birth traumas, and other conditions present at birth, accidents and injuries, diseases and illnesses, or conditions associated with the aging process (Livneh, 2001). Even though what is affected by the disease is an organ system or possibly multiple organs of the diagnosed person, the impact reaches much further into the ecological context. Chronic illness impacts every aspect of life and leaves a devastating imprint on the lives of everyone around, mostly on non-patient family members. Consequently, the presence of chronic illness leaves non-patient family members to various experiences created by or related to a family member's diagnoses to chronic illness. However, illness experiences vary during the onset and over the course of life with chronic illness. In the following section, the study briefly discusses non-patient family members' initial and later illness experiences related to a family member's chronic illness.

4.3. Illness Onset Reactions

Improvements in modern health care have enabled people to survive more health crises, and spend less time in medical centers. As a result, the majority of medical care and treatments take place at home causing family members of the patient to assume a more caregiving role (Patterson & Garwick, 1994). However, the onset of chronic illness and the course of illness leave family members of the patient to experience and frequently react to the illness creating challenges and changes. The study indicated that the onset and later illness experiences of the chronic health condition rely on factors, such as the types of the disease diagnosed; prior knowledge about the

illness; and the patient behavioral changes related to the diagnoses to chronic illness and related painful experiences.

When someone develops a serious chronic illness, it affects not only the patient but also significantly alters the lives of everyone around, often family members of the patients, in every aspect of their everyday life. As a result, when someone hears about the onset of the illness, everyone's desire and hope are to be healthy or to get health back. As Frank (1995) describes, restitution was the expectation that other people want to hear. However, the study showed that the non-patient family members' onset reaction to the chronic illness depends on factors, like the types of the disease diagnosed, prior knowledge about the illness and its treatment, and patients' behavioral changes following the diagnoses with chronic illness. Recounting about their onset experiences to a family member's diagnoses with chronic illness, the study participants' elaborated on how their experiences were chaotic. For instance, a male participant said, "When we heard mom's diagnoses, first time, we fall into anxiety anticipating the future hassle we are going to face" (P8, 28). Another male participant also said, "Mom diagnosed with cancer and we didn't see any hope; so we thought that our mom was going to die anytime sooner" (P1, 25). Similarly, an excerpt from a male reads "We were shocked. The absence of treatment intensified our level of concern. We (I and little brother) were depressed" (P2, 27).

The study shows that upon the onset of chronic illness to a family member, non-patient family members often experience shock, hopelessness, anxiety, depression, and fear anticipating the hassle they are going to experience, chaos according to Frank's (1995). But, the chaotic feelings depend on the disease type diagnosed. Concurring with this study's findings, a study by Zimmerman (1993) has revealed that the onset experiences to chronic disease largely depend on each disease's clinical expression, chronicity, severity, and the associated hardships imposed on

individual families since the impact of each disease has great variability. For instance, in cases like cancer, as per Alderfer et al., (2010) and Williams (1997) patients often experience feelings of intense worry, loneliness, fear, grief, hopelessness, helplessness, anger, and depression instead of hoping to get well, restitution. Similarly, this study has revealed that family members living with a person diagnosed with chronic diseases, such as cancer, experience the feelings of chaos instead of restitution upon the onset of the illness.

Moreover, prior knowledge about the illness and its treatment has an impact on patient's and non-patient family members' onset experiences, whether restitution or chaotic. The study was able to reveal how prior knowledge about the illness and its treatments was significant on the family's onset experiences to the chronic illness created to one of their family members'. An excerpt from the study participants' reads:

> You know, we didn't know anything about the disease (cancer) and its treatment, and so there was no way for us to be optimistic when we heard the onset of the disease for the first time (P8, 28).

> As persons with no medical background when we heard that she (mother) is suffering from a rare form of cancer we were terrified. Thus, during her early stages, my day to day life has been affected significantly (P2, 27).

According to the above two descriptions showed a lack of prior knowledge about the illness and its treatment leaves non-patient family members to the chaotic experiences upon the onset of chronic disease on one of their family members. In other words, despite the initial feelings of shock and frustrations, the study indicated that having some kind of prior knowledge about the chronic disease diagnosed helps to mitigate the impacts that the illness could create on the non-

patient family members' onset experiences when first heard about the illness. For example, a quote from a female participant reads "…dad is diabetic, and at the time we already knew that if he (father) follows medication and take care of things, we understood that things might get well despite the initial shock" (P11, 27). Similarly, a female medical student's excerpt reads:

> I'm a medical student at Black Lion specialized referral hospital. When I first heard mom's diagnoses to chronic illness (cancer) I went through all the ways to get health back. I had been the one following mom's treatment. Even though it's shocking and tough to pass through with such an experience, I was managed to cope with some of the onset challenges following all her medications (P3, 27).

It was noticed that people are quite quick to feel the hope of getting well or healthy, as per Frank's restitution rather than chaos experiences, if their prior knowledge about the illness and its treatment was good enough. Therefore, the study may indicate that people's prior knowledge about the illness helps not only to feel optimistic about getting back to normal, restitution but also to adjust the everyday life experiences to the problems they faced, quest, as per Frank (1995).

Illness induced behavioral changes were the other factor that significantly defines the non-patient family members' onset as well as later experiences to a family member's diagnosis with chronic illness. The study identified how non-patient family members' onset experiences were impacted by the illness brought behavioral changes. For instance, an excerpt from a male participant reads "Besides the chronic disease (cancer), the way mom behaves, the way she reacts for every little thing makes you cut your hope" (P1, 25). Similarly, a male participant with the same experiences of living with a chronic patient elaborated:

> The pain my mother suffered has made her hot-tempered and verbally inconsiderate which repelled both me and my brother away from her. Her unceasing complaints and physical limitations have made our life more straining (P2, 27).

Usually, chronic patients experience declines in communication, and other activities because of the chronic causing situations. Frustrations due to the illness make the patient's behavior strange for everyone around them, including their family members. As a result, the relationship between the non-patient family members and the patient often starts to cease. The study indicates that family members of the patient experience embarrassment because of the patient's behavioral problems, like the use of coarse language and hostile relationships within the family. This is often caused by illness-causing situations, which mostly leave patients for more intense feelings of hopelessness. Consequently, the way the patients behave and react for every little thing is in complete contrast to the way they used to behave previously. As per the above participants' accounts, in the first few days, or weeks patients diagnosed with chronic illness experiences were hot-tempered, verbally inconsiderate, and unceasing-complaints against everyone around. As a result, often the situation leaves family members to experience more strain, and become hopeless of getting well. Irrespective of the illness type, patients often experience an intense sense of insecurity and hopelessness upon the onset of the illness. This happens when the illness type is chronic, and the patient starts imagining life never gets better anytime soon. Therefore, non-patient family members often experience, as per Frank's description, chaos. It means that the anxiety patients provoke makes the non-patient family members feel and react in the same fashion to the illness-causing situations at home.

Following the onset experiences, whether it was intense, moderate, or normal, over time non-patient family members' reaction changes to the chronic ill-health condition in the same way or

differently. However, experiences and reactions largely depend on their level of understanding of the illness and its treatment; disease's clinical expression, severity, and the associated hardships imposed on patients and non-patient family members; and patients' response to their illness experiences as well.

The study has shown the changes created over the course of time on non-patient family members following their onset experience. The study specified how the non-patient family members' chaotic experience improved once the patient began medical treatment and related organizational supports, and the knowledge attained get better about the illness and its treatment. These factors give hope to anticipate a possible happy ending, restitution, according to Frank (1995). Excerpts from two participants read:

> Our initial reaction and feeling have changed over time. Her (mother) beginning of chemotherapy and the fast response of her body to the treatment was what changed our feeling initially. Besides, the fact that her staff and administration of the hospital where she worked over the years showed readiness to pay her salary throughout the treatment period while she in the hospital taking her treatment has boosted our confidence and relieved our financial stress somehow (P2, Female, 28).

> After a while, our anxiety becomes lessened simply because we heard that the chronic disease (hypertension) can be controlled by medical treatments and family and personal care (P18, Female, 21).

The above two descriptions make it clear that the disease's clinical expressions (i.e. fast physiological response to the ongoing medical treatment), changed the chaotic experiences that the non-patient family members faced when they first heard about the diagnoses. Besides, the

study showed that having improved knowledge about the illness and its treatment helped the non-patient family members to lessen the anxiety they had experienced when they first heard the illness. Furthermore, the study also revealed how the organizational support, in terms of, for instance showing a willingness to pay the salary of the patient boosted non-patient family members' confidence and relieved their financial stress.

However, moves from chaotic to restitution experiences or restitution to chaotic experiences due to the chronic illness depends on the type of disease diagnosed and the patients' reaction to the ill-health experiences. Here an excerpt from a female reads:

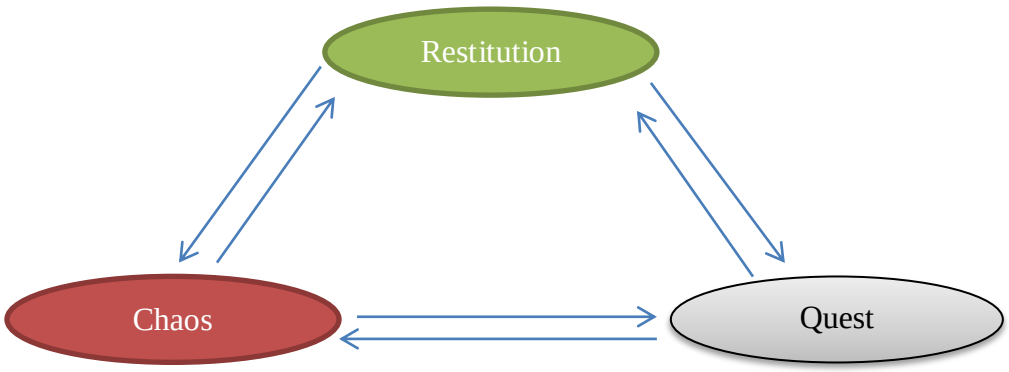
> My mom passed away after being diagnosed with cancer. After a while, my dad started to show the same symptoms and finally, we heard his diagnoses with the same type of cancer…so… it was clear we didn't see any improvement since then. We didn't anticipate anything better because we already know the thing that is going to happen. Yeah, it has been a tough experience for me and my family, in general. So we are just living accepting the truth (P3, 27).

The above accounts indicate how the onset illness experiences were influenced by the later thought of the same health problem. Death due to a chronic illness can result in chaotic experiences of vulnerability, futility, and impotence instead of imagining a happy ending in the later experiences of the same ill-health condition to other family members. Likewise, the study indicated how patients' intense feelings of hopelessness made things worse. Thus, as per the above participant's account accepting the realities of the illness sustain the chaotic experiences of healthy family members'. Moreover, the chaotic experiences brought about by the chronic illness significantly change the personal as well as family life endeavoring to create a new

relationship to illness, that is, a quest plot as per Frank (1995). This is accepting the reality of the illness and making significant changes in one's everyday life paths following the illness.

This study argues that there is no one way or a linear move from restitution to chaos and then to quest plot, as discussed by Frank (1995) when experiencing the chronic illness either by the patient or non-patient family members. Rather depending on the factors mentioned above, the responses or reactions to chronic health conditions could move from restitution to chaos plot and vice versa; restitution to quest plot and vice versa, or chaos to quest illness experiences and vice versa.

Figure 4: Chronic illness experience model



As it has been discussed in the aforementioned sections, having a person diagnosed with chronic illness in a family leaves non-patient family members for various experiences to the ill-health condition. As per Frank (1995) such illness experiences can be restitution, chaos, or quest. As has been discussed, upon the onset of the illness, patients experience either restitution or chaos depending on the factor, such as the disease type diagnosed; prior knowledge about the illness and its treatment; and patient's reaction to the ill-health experiences. These factors can also determine the reaction taken to the illness diagnosed.

This study so far as indicated upon the onset of the illness, both patients' and non-patient family members experienced chaos, anticipating the worst to come, when the illness type was chronic, such as cancer. A lack of prior knowledge about the disease and its treatment leaves also for the same chaotic experiences. Furthermore, the patient's behavioral changes following the diagnosis have also significant influences on non-patient family members' experiences. Nevertheless, during the course of the illness when the knowledge about the illness and its treatment gets improved, the illness experiences move to restitution, hopes to be healthy, or desire to get health back. Thus, this moves non-patient family members' chaotic experiences to restitution illness experiences. However, the case is not the same for families with chronic illnesses, like cancer. It means that family with chronic illness, like cancer, was not optimistic about getting health back. It might be due to the nature of the illness and the absence of treatments. Therefore, in most cases, both patients and non-patient family members with chronic diseases, such as cancer, overtime move from the initial chaos to later quest illness experiences. It means that people start to adjust their life to the illness instead of hoping or desiring to get health back, restitution.

Similarly, when the disease type is less chronic and treatable, (e.g. hypertension, diabetes, etc.) and get an improved knowledge about the illness and its treatment from the very beginning, the illness experience for both patient and non-patient family members, as per this study, is going to be restitution. However, when restitution does not happen or things get wrong, the experience moves to the chaotic experiences. It means that the illness experiences move from restitution to chaos.

Finally, there are also situations in which people re-bounce back to restitution, a desire to get healthy again after long time experiences of chaos and then quest. As discussed above, when people lose hope of getting health back, they often adjust their life with new realities. There is a

possibility, however, to re-bounce back to restitution from a quest, (i.e. a move from quest to restitution illness experiences) when the medicine in the area of illness gets improved or when illness's clinical expressions show positive results. This implies fast physiological improvement because of the ongoing medical treatment, or improved knowledge about the illness and its treatment, or other positive factors.

Therefore, this study claims that rather than following a linear move from restitution plot to chaos plot, and then to quest illness experiences, depending on various factors mentioned above, the illness experiences can move from one plot to another and vice versa, as shown in figure 3.

Whatever the illness experience is, chronic illness changes nearly every aspect (i.e. physical, emotion, and behavior), of the patients and leaves a devastating imprint on the lives of everyone around. The following sections discuss each of the changes chronic illness caused and attempt to link one another although it is difficult to separate one from the other. The section begins with the physical changes caused by chronic illness.

4.4. Chronic Illness and Physical Changes

The physical change was one of the major changes patients with chronic illness experienced and have been undergoing. The study found that patients with chronic illness exhibited various physical complications (physical changes) brought about by the illness. For patients with chronic illness, everyday health conditions, and the medications taken to cope and manage their health conditions causes drastic changes in their physical appearances. Study participants testified a variety of physical changes a chronic patient experienced since the onset of the illness. For instance, a male participant elaborated "The pain my mother suffered and undergoing every day has made her hot-tempered and often verbally inconsiderate" (P1, 25). A male participant also

said, “He (father) used to experience huge weight lose” (P16, 19). Similarly, an excerpt from a female reads “What has been disturbing is the physical change; especially when you see the everyday changes on her [mother] face.” Furthermore, a male participant elaborated:

> The disease gave her [mother] unusually big legs that made her feel unattractive and isolated. Her dressing style was dramatically changed. She also preferred staying home to avoid awkward confrontation and repeated inquiry into what happened to her and her legs (P2, 28).

The above testimony indicates that patients with chronic health conditions were experiencing various physical changes, which including physical pain, extreme weight loss, changes in their face, and swelling of legs due to the chemotherapy cancer patients undertake. The physical changes the patients experienced were mostly caused by changes in lifestyle, mainly diet. Most patients, for instance, diabetes and hypertension have to follow a specific diet plan to manage their health conditions. For instance, dietary restriction (e.g. a gluten-free diet) and monitoring insulin and blood sugar levels and adjusting dietary choices thereto urge the patients to change the lifestyle. This often causes a huge loss of weight that can be visible on the patients’ faces. Another factor that causes visible painful physical change is a medical process the patients have to undergo over an extended period of time: for instance, chemotherapy that causes swelling of legs.

Likewise, as a result of living with a person diagnosed with chronic illness, family members experience various physical changes. One of these physical changes was sleep deprivation. An excerpt from a female reads “Sleep deprivation is an issue, for me and my little brother, as her [mom] illness caused her sleepless we were also up with her” (P2, 27). Another physical change

reported was a huge weight loss. A female participant recounts reads "You know… […with tearful eyes]…I am losing weight since mom's diagnoses with breast cancer" (P9, 22). A female participant also recounted a strong feeling of a headache. "It has been a while since I started a strong feeling of a headache. Now, it becomes my usual experience most often when responsibilities at home and out become intense, and when dad's illness becomes anxious" (P3, 27). Another physical change reported was fatigue. An excerpt from a female reads:

> It has been a while since mom has been homebound under family care; and I am trying to be patient and calm under so much pressure…but, I feel exhausted physically with a lot of home chores and errands and with outdoor responsibilities, I have to undertake, in addition to the care mom looking for (P7, 25).

The study revealed the most common physical changes that non-patient family members often experienced: includes fatigue, headache, weight-loss, and sleep-sickness. These physical changes are often associated with the painful experiences that their patients were undergoing, excessive attention paid for patients', the overloaded responsibilities at home but also in outside activities, the caregiving burden. This goes in line with reports of how the caregiving burdens physically exhaust family members of chronic patients (Bouma & Schweitzer, 1990; Williams, 1997). This was frequently caused by the difficulty of managing the increased responsibility and obligations to take over the roles previously carried out by the patients. Thus, family members, as to Eiser (1994), are fundamentally forced to cope with extraordinary circumstances. Furthermore, the physical changes make many non-patient family members feel embarrassed to go to work, see friends, or anywhere else. The above testimonies along findings from similar studies and the records of the field notes (i.e. noticeably deep emotions on tearful faces of the research

participants' and body language) indicate how challenging the life course of the non-patient family members was.

4.5. Illness Produced Emotional Turmoil

Ramifications of having a close person who requires a lot of care and a great deal of attention are severe on non-patient family members of the patient. The presence of illness in a family causes huge emotional blow, especially, when the illness is chronic, permanent, or not curable. Chronic illness experiences cause emotional turmoil not only in the patients but also in non-patient family members.

Study participants reported the variety of emotional changes in chronic patients experience in daily life. This study noted that since the onset and in the course of illness, patients often experienced emotions, such as anger, grief, feelings of depression or down, hopelessness, anxiety, worries, and fear, among others. Most participants were able to describe moments their patients showed strong emotions of anger. For instance, a female participant said, "The illness changed my dad significantly. He was so interactive and smiley. But now, because of the pain, he was experiencing, he easily gets angry anytime" (P9, 22). Another excerpt from a female participant also reads "She [mom] often gets very depressed, stressed out, and worried a lot when things appeared just never going to get better" (P7, 24). Furthermore, participants also recounted the patients' feelings of anger. For example, an excerpt from a female participant reads:

> He [dad] often expresses his anger whenever he feels pain. Sure, we understand how things were changed very fast for him from a kind of strong gentleman to someone else who is looking at the care and attention of children (P10, 20).

The emotions were mostly caused, by factors, such as the painful nature of the illness, related illness experiences and its tough medical process; patients' inability to do things by themselves as they used to do in previous times; feelings of dependency on the hands of other, in the case of this study, children; and friends, neighbors, and others reaction and repeated inquiry of the patient's chronic health condition and patients attempt to avoid such inquiry. For example, a male participant elaborated:

> She (mom) preferred staying at home to avoid awkward confrontation and repeated inquiry into what happened to her and her legs. This often makes mom be emotional and unresponsive (P2, 27).

While giving the above accounts the non-patient family members were visibly emotional (e.g. tearful expression and body language) revealing how challenging the patients' emotions were to cope with at the time it occurs. It was apparent that many of the study participants would not like to remember such experiences of changes of emotion, and it had been extremely hard to see their patients' physical and emotional change.

Likewise, non-patient family members inevitably had experienced the emotional turmoil the chronic illness created on their family members. As per the study's finding, the most commonly experienced emotional tolls faced were depression, anger, anxiety, sadness, hopelessness, and of course, fear, anticipating the future hassles. It was more of a chaotic experience than restitution. This study also indicated the various factors that caused emotional toll, including the immense pain patients, were experiencing; being unable at times to be part of various activities apart from caring or role disruptions; of course most often from their attempt to understand and trying to

deal and cope with the chronic health experiences they faced in one of their family members. Three examples read as:

> You don't know how awful experience it is when you see your mom on the bed suffering from the painful permanent ill-health conditions (P3, Female, 27).

> I have to take care of my dad with diabetes, and that is not a problem since it is something expected. However, when every day is as it comes, and if he is not well enough to do things by himself and needs my help then I am not able to do what I have planned (P11, Female, 27).

> The absence of easy treatment to the illness mom diagnosed has intensified our level of fear. Sometimes it makes you feel a mix of emotions; you were upset, frustrated, and angry when you want to see your mom back to health and when things get all wrong (P2, Male, 27).

The study revealed how tough it was to see illness break a person with an ill-health condition, and how life was gradually wasted away and the medical process being unable to do anything. Often people put their eyes on the physician wishing to get their patients' health back or get rid of their illness, restitution. However, when things no longer work and painful experiences remain chronic, chaotic experiences start happening bringing an emotional toll on the non-patient family members.

During the interviews, the emotional toll ensuing from having and living with a family member with chronic illness on the entire family was clear. Participants' tearful eyes, while describing the illness account, clearly indicate how dreadful the experiences they had were.

4.6. Chronic Illness Produced Behavioral Changes

In the previous sections, the significant physical and emotional changes were presented. Another change commonly experienced by both patients and non-patient family members is behavioral. The study suggested that changes in behavior often follow physical and emotional changes. As discussed in the previous sections, having a chronic illness or living with a person diagnosed with chronic illness contributes to various physical pains, weight losses, and other physical deformities. This study has also revealed that noticeable physical changes cause huge emotional turmoil in people with chronic illness and their families. Consequently, the combined outcomes of the physical and emotional changes are reflected in changes in behavior.

From the most commonly mentioned behavioral changes, here a male participant talk about the patient's unceasing complaints. "Aha, mom always complains. She complains about life, about God, about fate, about medication, and almost everything" (P1, 25). Similarly, a male participant said, "The disease particularly mutilated mom's spiritual understanding and devotion. She was the one who introduced our family to faith. Her trembling faith and unceasing complaints have left us" (P2, 27).

Others mentioned how the diagnosis of chronic illness made patients' angry over every little thing. For example, an excerpt from a male participant reads:

> Repeated inquiry into what happened to her and her legs made mom angry and hot-tempered. [It was an effect of the chemotherapy] Unfortunately, we are the one who commonly experiences mom's reaction for every little thing happening at home (P2, 27).

Another commonly mentioned behavioral change was the patients' preference to stay alone. This was often intended not to be seen and/or to hide their painful experiences and physical changes.

An excerpt from a male participant reads “The disease gave her unusually big legs that made her feel unattractive and isolated. Her dressing style was dramatically changed. And often she prefers staying at home and lonely” (P2, 27). Similarly, a female participant said, “When he (dad) became ill, he often used to hide his painful experiences at bed staying alone. He even often wants to avoid us” (P20, 21).

As per the above study’s findings, diagnoses with chronic disease significantly changed patient behavior. Restrictions from everyday life activities because of living with the chronic ill-health condition cause chronic patients to experience dramatic behavioral changes, for instance angry, social isolation or loneliness, complaining of every little staff, and so on.

In the same way, non-patient family members’ often experience various behavioral changes or toll throughout their course of life with a family member diagnosed with chronic illness. The study indicated that behavioral changes were felt often in relation to a family member’s chronic illness and related behavioral changes. Furthermore, the inability to participate in activities other than home chores and errands or lack of attention or carelessness to other outside activities was also another factor that often caused behavioral toll on non-patient family members. This was often directly related to care or attention paid to the patient living with chronic illness.

In general, as it has been discussed throughout this particular chapter, having a person diagnosed with chronic illness can be a serious upheaval for the family as a whole often changing the patients’ and non-patient family members’ physically, emotionally, and behaviorally. In other words, it means that how the experience of one family member affects the experiences of other family members (Bavelas & Segal, 1982; Murray, Kelley-Soderholm, & Murray, 2007) and the family system as a whole. Similarly, Williams et al. (2009) have demonstrated how a family

member's illness experiences could affect each member of a family whatever their position is within the family.

The study's finding indicated that those changes in the physical, emotion, and behavior caused by a family member's diagnosis with chronic illness had further challenges and changes in the family as a system, creating role disruption and changing family inside-out social interaction. The next chapter deals in detail about the changes created on the family system brought about by chronic illness.

Chapter Five

Chronic Illness Experiences of the Family System

5.1. Introduction

The previous chapter has shown the changes a chronic disease and illness experience cause on the physical, emotional, and behavior of patients and their family members. It has also shown the onset and later illness experiences that chronic patient and their families undergone. The study indicated that the changes a person experiences have effects on the family system, particularly in terms of its functions, that is, roles each member supposed to play, and the system's inside-out social interaction. This finding is consistent with other those from similar studies (Cohen, 2004; Donoghue & Siegel, 2000) that indicated the inevitable life-altering impacts of chronic illness for the family as a system.

Thus, in this particular chapter, the study emphasis two main themes: the challenges and changes that chronic illness brought on the family's system of function, and family's inside-out social interaction. The chapter discusses each theme successively.

5.2. Family as a System of Functions

Studies indicate that having a serious chronic illness has a direct altering effect on healthy family members' life (Newbould, Taylor, & Bury, 2006; Newcom, 2004; Patterson & Garwick, 1994). Chronic illness is known as long-term and incurable health impairment without a definitive treatment that requires lifelong support and care (Clare, 2013; Midence, 1994; Boice, 1998). Therefore, since the onset and in the course of illness experiences, the illness significantly affects the family system by altering the roles previously carried out by each family member, including the patient and other family members. The presence of chronic illness within the family leaves

healthy family members to assume more responsibilities because the roles previously carried out by the patient became unfilled. The study indicated that every aspect of the chronic illness has altering effects on the function creating role disruption and further changes inside family assuming healthy family members more responsibilities to play and keeping the family system functional. This was indicated in an excerpt from a male participant reads "Mom used to be the strongest woman who holds the entire house in accord…but after her diagnosis with cancer that role play has shifted to us (me and my brother)" (P1, 25).

The study has shown how the presence of chronic illness altered the functions of each family member, in terms of roles supposed to be played. Often, the role shifts cause the highest level of burden on some family members of the chronic patient. This concurs with the basic assumption that indicates how the presence of the chronic patient in a family significantly alters the family system changing the function of each family member supposed to play (Bavelas & Segal, 1982; Murray, Kelley-Soderholm, & Murray, 2007). Besides, this study revealed that the altering effects of chronic illness experiences go further to healthy family members outside roles or activities.

5.2.1. Role-Shift inside the Family

The study identified the reasons that cause the role shift to occur. Some of these include: the presence of chronic health condition, which is progressive in its effects; patient's inability to play the roles carried out in the previous time; the attention that chronic patient takes; and non-patient family members attempt to mitigate the effects chronic illness has on the family system. In other words, the roles shift occurs not only because of the presence of the chronic illness but also because of the desire to maintain the function of the family system. Consequently, role shifts

frequently caused family members of the patient to play further roles, including emotional and economic. One example reads as:

> My mom is a widow. Because of mom's illness, therefore, I and my little brother are no longer expected to play the role of children but also required to fill the emotional and financial gap created by the absence of a husband (P2, Male, 27).

There are studies that conform the informal caregiving role expected from that healthy family members' to provide the patient with chronic illness bearing a very high caregiving burden (Cohen, 1999; Compas et al., 2012; Martine & Colbert, 1997; Öhman & Söderberg, 2004). It means that the roles are often altered or adjusted to provide the necessary care to the patient with chronic illness (Martine & Colbert, 1997). Three examples include:

> Mom took all our attention. We all do things to make mom forget the pain of the illness and to see her happy faces (P13, Male, 28).

> Our dad was dead a year ago. So, we are no longer playing the role of children rather we all are playing also parenting role trying to fill all gaps taking care of mom who has cancer (P5, Female, 25).

> Dad has diabetes. He needs our very close attention and care. So, our attention have been focused on lessening things that make him angry and making food staffs in accordance with his doctor's prescriptions (P11, Female, 27).

The above cases show how healthy family members' shifting role was necessitated to keep the functions of the family system. Studies in the areas of chronic illness (Bouma & Schweitzer, 1990; Krats, et al, 2009; Williams, 1997) show that in any family with chronic illness, the illness

experiences lead other healthy family members to assume not only their roles but also change in the function of one family member caused by ill-health conditions automatically leads to compensatory changes in another family members functioning. As per the study, the presence of chronic illness made patients more dependent on their healthy family members, in the case of this study, often on children. Healthy family members treated and cared for the patients as if they were their children by making fun to help them forget their pain, preparing food and feeding, and helping to visit their medical process. The study indicated that there were also circumstances that let healthy family members play a role that is usually played by a doctor or other people in the health system. For example, an excerpt from a female participant reads "…You know, I had to get learned how to give the injection" (P15, 24).

Consequently, it leaves healthy family members to feel like a nurse who was responsible for the care at home. A feeling of being like a mother to their own mother or father was the most common expression used to show the real role shifts that healthy family members experienced, particularly females. For instance, a female participant elaborated "…I feel like I am the mother of the house" (P5, 25).

The finding has revealed that healthy family members struggle to make the home as a home. In spite of illness-causing troublesome situations, it was indispensable for participants to make the home still feel like home. Hence, the reorganization was needed to make the functioning of the family system possible. As per Levinas participants have taken the responsibility to make the home as home because home is where "the self is." There, one can feel joy and misery, intimacy, and gentleness and create a happy atmosphere. Thus, participants' total involvement led them to feel and act like nurses at home. They even felt like a mother to the ill person, as discussed above, when that person could no longer deal with the most intimate needs. Levinas further

posited that the relationship between human beings can be seen as a parental relationship. That is, regarding the other person as one's child involves establishing 'beyond the possible'. It is a state in which one can see the other's possibilities as own (Öhman & Söderberg, 2004).

5.2.1.1 Other factors that Influence the Roles Played Inside Home

Even though the presence of chronic illness has huge effects on the experiences of the family as a system, this study has identified other factors that affect illness experiences and caused role shifts for non-patient family members. This section briefly discusses two major factors: the household composition: (either conventional family type or single-parent family type, which consisted of divorced family and families with a parent dead) and gender.

As discussed above, in any family, chronic illness experiences alter the role each family member is supposed to assume and play in keeping the family system functional. However, the presence or absence of a family member increases or decreases the compensatory role shift each family member assumes. It means that chronic illness experience in terms of role shift at conventional family type, (i.e. consisting of parents, the children, and the housemaid) has shown some differences in illness experiences of the single-parent family type (i.e. consists of both divorced family and a nuclear family with a parent dead).

Participants, in the so-called single-parent family, described various roles they assumed, including managing their houses playing parenting roles and filling emotional and economic needs, in the absence of either father or mother due to divorce or death. For instance, divorced families may experience many challenges in their family system, mostly role disruptions compared to conventional type nuclear families. Therefore, each member in a nuclear (divorced) family has to live up with additional compulsory responsibilities, including both emotional and

instrumental, to keep the healthy function of the family system. In addition to the changes created in the family system due to divorce, being diagnosed with chronic disease(s) significantly shifts the role previously played by each family member, both the patient and other family members. Two examples read as:

> My mom is a widow. Because of the presence of mom's illness, therefore, I and my little brother were no longer expected to play only the role of children but also required to fill the emotional and financial gap created by the absence of a husband (P2, Male, 27).

> When mom became ill, she could not work for long attending her chemotherapy. So I had to work sometimes by being a waitress to cover some of our expenses (P7, Female, 24).

Concurring to this study's finding, other similar studies report that participants in a single-parent family and living with a parent with chronic illness involved in multiple roles inside the family. These are nursing roles, coordinating home activities like cooking and other chores and errands, personal ambassadors and representatives for their patient and the family, and many more roles (Bouma & Schweitzer, 1990; Krats, et al, 2009; Williams, 1997).

However, even though the challenges and changes were still there, the role shift, in the so-called conventional nuclear family was less anxious than in a single-parent family. Excerpts from participants read:

> It was a huge shock when we heard mom's diagnosis. She had been the one who holds the family. Our dad did not have much concern for things happening at home apart from his instrumental role. But, mom's diagnoses changed his behavior and attention to our family he did not have before. Now, we are really proud of having such a strong, caring father (P18, Female, 21).

> I [a female participant] can't even imagine our family's life in the absence of mom. Where could we get all the strength we had now to cope up with the painful experience of our dad undergoing if she (mom) was not there? Look, mom is the one who holds everything nowadays. Thank God (P11, Female, 27).

Despite the dire situation brought about by the illness, the presence of parents keeps the parenting roles one could play even though the other gets sick. It means that parents were still there playing parental roles, including emotional, economic, and social roles. The study has shown that notwithstanding their involvement in many roles, a healthy parent was the one who provided the family's economy and kept the sole representation of the family.

Another factor that was apparent from the participants' accounts was the differential gender roles played in the family even though the dire health condition affects the physical, emotional, and behavior of everyone in the family. In fact, upon the presence of chronic illness, the role of every member is vital for maintaining the family system (Cohen, 2004). However, the study indicated females exhibit more responsibility for roles played inside the family. The study indicated that home chores, like managing the house parenting roles, nursing the patient, preparing food, cleaning, hygiene, and other similar chores and errands were seemingly assigned or supposed to be played by females. However, this does not mean that men were entirely uninvolved. It does not also relate to their lack of interest. Rather it was often related to unfamiliarity in some areas of home chores and errands, such as cooking, cleaning, running the house, and other caregiving roles. For example, a female participant said, "…It seems home chores and errands are left to us [a female participate]" (P20, 21). Another female participant also said, "…He's [talks about her brother] worried about the pressure we were experiencing at home activities but didn't support" (P7, 27). Similarly, a recount from a female reads:

> We wish if we would have brothers' support. They know the pressure and the difficulties we are facing at home engaging to cover all the activities. But they are uninvolved. It makes you mad sometimes when you see their ignorance (P7, 24).

The study indicated that females were overburdened for more inside home roles expected to be played to keep functioning of the family system. As a result, females often exhibit more distress than men. Furthermore, females with an ill-family member mostly at risk for difficulties in maintaining their outside social interaction. This finding has been confirmed by many previous studies in the area of chronic ill-health experiences (Fingerman & Bermann, 2000; Houtzager et al., 2004) recognizing family variations within family members in terms of illness experiences but also roles played. The participants' accounts showed that men were highly involved in outside activities, especially by helping the patients to visit medical centers for their treatments.

5.2.2. Outside Role Limitations

The onset as well as later experiences of chronic illness, as discussed in the previous chapter and in the preceding sections of this chapter, had various altering effects on the physical, emotion, and behavior of patients but also healthy family members as well. The altering effects of chronic illness experiences had gone further to the roles each family member supposed to play at home, causing role disruption among family members. Participants' descriptions also showed how the presence of chronic illness altered roles played on their outside engagements. As per the study's finding, the changes that occurred on healthy family members' outside roles were partially outcomes of changes in the physical, emotional, and behavior of the patients and their family members. It was also the outcome of the role shifts that occurred inside the home. It means that physically related fatigue, headache, weight-losses, sleep-sickness, and emotionally connected depression, anger, anxiety, sadness, hopelessness, and fears had hugely taken the attention

supposed to be paid to the outside activities. In addition to this, the role shifts occurring inside the family system caused healthy members to play further roles, including emotional and economic, in addition to the roles played previously had also its negative imprint in outside roles or activities. Caregiving roles, for instance, healthy family members provided for patients bear a very high caregiving burden and further alter the roles expected to be played on outside activities. This was the bitter reality for families living with a chronic patient. For example, a male participant elaborated:

> When my mom became ill, she could not work anymore…then we faced many problems. It even caused my sister to become a waitress in addition to her school time to cover some of the mom's medical costs (P8, 28).

The presence of chronic health conditions affects almost every aspect of a family. Difficulty with schoolwork was one aspect that chronic illness caused. This could be implicated by the amount of time absent from school and its further negative effects on academic achievement. A female participant also elaborated how the caregiving burden affected her schooling:

> I was studying medicine when mom became ill. When we heard mom's illness, I was the family's hope regarding mom's health and treatments. So, I went through all the ways to get mom's health back, even though the disease didn't give us time to get her back. After a while, she passed away. She took all my attention; I didn't give any attention to what I was studying. This finally had shown its impact on my final exit exam. You know, [with tearful eyes] I mean I didn't pass the exam (P3, 27).

The study has shown that poor school performance was associated with many factors: including illness related expectations, whether it was professional or not, related fatigue, other emotional

tolls, medical attendances, and caregiving burden needed to the patient. This has been mentioned and consistent with other studies and is reflected in how frequently the class students miss or leave classes to fail behind in school works, and have failing results (Boice, 1998; Houtzager et al., 2004). These studies further stated that some medications can cause attention issues, like the case mentioned above, which can cause problems on students' ability to retain information. Furthermore, stress related to a patient's illness can cause attention and concentration issues. Taken all together, challenges to academics can cause students to live a person diagnosed with chronic illness to attain lower results (Boice, 1998).

Another area that appears apparent in the life of healthy family members was the decision to quit a job in order to look after a person with chronic ill-health. Participants' description has shown that diseases, like cancer, diabetes, require serious attention from everyone around, especially close families. Therefore, the inability to attend to the needs of the patients on top of their outside jobs urges healthy family members' to quit their outside jobs, often formal jobs. One example from a male participant reads as:

> Especially during the early stages of the illness, the medical attention required was intense which forced my brother to quit his job and look after her [mother] (P2, 27).

Similarly, the study has also shown the dares non-patient family members faced related to their functional limitation to perform everyday activities at workplaces because of the illness patients experience at home. For example, a teacher at a private school said "I was frequently absent from school whenever things seemed worse. It has also reduced my social engagement [at school]. Whenever she [mother diagnosed with cancer] is home I can't stay late with friends" (P2, 27). A male participant also said, "During her early stages my day to day life has been affected

significantly. I have to make numerous phone calls to check up on her and much of my thought was engaged with her condition which caused a distraction in my work" (P1, 25). Another male participant said, "It had made me late comer often and an unusually absent from work. Thus, my focus was compromised" (P4, 31). Similarly, an excerpt from a female participant reads "Whenever she feels pain and needs care, I am the one who attends around her. For this reason, frequently I am forced not to avail myself for other activities" (P5, 25).

The above cases indicate how healthy family members' everyday outside activities can be compromised by patients' situation at home and the caregiving burden. The illness makes finding time to do even the most necessary daily activities hard due to the difficulty to leave the ill person alone or treatments. As a result, the study uncovered that failing to punctually attend working time or missing workplaces, and poor work performance or deliverance on different outside roles characterize the life of healthy family members living with a person diagnosed with chronic ill-health conditions. The study reveals that the patient's health conditions cause healthy family members to experience huge disorder in their everyday outside roles expected to be played.

To sum up, the burden of chronic illness on healthy family members is significant. Family as a system can experience many dares due to the presence of illness, patients' illness experiences, and subsequent turmoil on the physical, emotional, and behavior of healthy family members. Any family with chronic illness can experience role shifts. This implies that the presence of ill-health conditions alters the roles each family member has been playing inside family and outdoor activities. Consequently, each family member starts assuming more responsibilities in order to compensate for the roles left unfilled by the chronic patient and maintain the function of the family system. Role shift often occurs due to the caregiving roles healthy family members

supposed to provide to the patients. In other words, family as a system of function is expected to play the primary caregiving roles for patients with chronic illness even with a range of specialized services available today (Murray et al., 2007). These role shifts often force non-patient family members to miss work or other daily errands to help the patient attend, for instance, medical appointments or accompany the patients to procedures. This can limit career advancement, and take a financial toll. They are sometimes expected to learn how to navigate the medical system and provide support to the patients (Burns, et al., 2006). Furthermore, according to the above participants' account, the presence of chronic illness hugely impacts the family's social inside-out interaction often causing social isolation. The following sections analyze the changes chronic illness brought on the family's system of social inside-out interaction.

5.3. Family as a System of Social Interaction

This study indicated the huge impacts of chronic illness have on the family's system of social interaction. Familial interaction is very important and unique because it lasts longer, and the nature of the relationship is highly egalitarian. It plays an important role in each other's development (Barbara, et al., 2003). Nevertheless, the presence of chronic illness makes familial interaction different. As this study indicated, in any family, chronic illness significantly alters the social interactions peculiar to the natural family. Thus, another area of change occurring in any family with a chronic illness is on the system of social interaction, both inside the family and their outside social ecology. The study indicated that the presence of chronic illness and other related challenges, for instance, illness produced physical, emotional, and behavioral turmoil, either hold the family together creating a sense of We-ness or acts as sources of conflict-related to, for instance, role disruption produced ongoing conflicts in the family settings. Moreover, the study's finding indicates chronic illness can produce tolls in healthy families' outside social

interaction often causing social isolation. This finding is consistent with previous studies on the way, chronic illness influences the family's interaction with others (Barbara, et al., 2003; Williams, et al., 1999). In the following section, the study gives a detailed analysis of the subtheme, which focuses on changes in chronic illness, brings on the family's system of inside-out social interactions.

5.3.1. The Family inside Social Interaction

Despite the stress and strain produced by ill-health conditions, the familial social interaction is still there trying to keep the family system functional. However, social interaction has its own variety of characters. As most participants described, the ill-health condition often brings family members together against their common challenges by creating a sense of We-ness. However, family members' social interaction was strongly affected by the challenges and changes faced when a family member has a chronic illness. This study found that tensions in familial social interaction, often produced by factors, such as the role disruption triggered by caregiving burden; and patients' illness reaction to the turmoil they were undergoing. In the following section, the study analyzes chronic illness produced challenges and changes in familial interactions. The section begins with positive outcomes on families inside social interactions.

5.3.1.1. We-nesses

The illness, as per participants' description, created increased communication about the everyday conditions of the patients, treatments, family needs, cares, and other home-based activities and outside activities supposed to be undertaken to maintain the function of the family as a system. It showed the introduction of strong social interaction that holds family members together creating a sense of unity or we-nesses among family members. A recount from a female participant reads:

> We frequently communicate with each other about mom's illness, the medication producers, treatments, care expected to be taken, family needs, and other family staffs. These days, every phone call did include talks about our everyday conditions too. Now, we became very intimate and caring than before (P5, 25).

This study indicates that families inside social interactions were strengthened as a result of chronic ill-health conditions. It further showed some of the characteristics that indicate the strong nature of familial social interactions, including greater intimacies, togetherness, protectiveness, compassion, open communications, and cohesiveness. Participants expressed their joy in having had worthy interaction inside a home, even though their current situations and life was hard and involved greater responsibilities. For instance, a male participant said, "…In a way, it had made us more intimate and caring than ever" (P8, 28). Another male participant also said, "I have to make numerous phone calls to check up on her and much of my thought was engaged with her condition" (P2, 27). Similarly, an excerpt from a female participant reads "We often spoke about challenges, strengths, weakness, and keep appreciation for each other. I think it has made us caring" (P3, 27).

In spite of ill-health caused dares that affected each in a family, participants' descriptions showed that the challenges they faced brought healthy family members together against their common problems, in the case of this study, parents' illness. The finding implicated the family's sense of We-nesses through strong emotional responses towards one another. This was indicated by their numerous phone calls made on a daily basis to check day-to-day conditions they and their patients were facing, the share of emotion, including the strengthens and weaknesses, and appreciation is given for one another. The study revealed how it is important to talk to each other about shared thoughts, emotions, and everyday undertakings to cope with chronic illness-causing

situations. Family as a system of social interaction gives family members strength and a feeling of pleasure in being together. This was expressed from an excerpt of a female participant "… I am happy for we can talk and agree about such kinds of things, for instance, cares provided, division of activities at home. So it is quite a good thing. For it has joy" (P5, 25).

The study showed that positive familial attributes produced increased intimacy and care given to each other. Moreover, often there were individuals who were not only passive but also detached from the system of familial interaction, frequently spending more time for their outside activities. One example reads as:

> Mom's illness brought my brother back to family life. Notwithstanding his working character on outside activities, he was totally uninvolved in family time and spends more time away from home. But, now he is the one who helps mom to visit hospital and other appointments and kept family in check. Now, every time he is around (P17, Female, 26).

Frequently, the absence of some family members from inside home activities, spending more time outside, as discussed in the previous section, causes not only role disruption but also produces conflicts inside the house. However, as the study's finding showed the presence of parental illness contributed not only to bring some previously uninvolved family members into the family but also made them become active in the familial interactions taking further responsibilities. Therefore, the study would say that despite ill-health produced challenges, the increased familial social interaction causes family as a system of interaction to become more strengthened. This finding was consistent with previous studies that showed the positive outcomes a family experienced while living with chronic illness (Butler, 2010; Olson & DeFrain, 1997; Williams, 1997). For instance, compassion, a higher level of empathy, helpfulness, an

increased sense of responsibility, and care characterized families living with a person diagnosed with chronic illness. Similarly, according to Butler (2010), seeking to maintain the balance of the system, families adopt new family experiences and grow stronger. However, this does not mean that family as a system does not experience strains and stresses within the familial interactions. Rather, the study's finding here focused only to show chronic illness produced positive outcomes.

5.3.1.2. Strains within Family Interaction

As it has been said many times, in any family, the presence of chronic illness produces strain and stress within the family's interactions. In spite of the increased familial interactions (i.e. we-nesses, intimacy, care, and other positive outcomes), in any family, the presence of chronic illness has its own toll in creating an uneasy social environment or interactions inside the family system. The study's finding showed tensions in familial interaction, often produced by factors, such as the role tensions within the family or disruption triggered by caregiving burden; and patients' illness reactions, either to their physically related pains and changes, emotional or behavioral confusions undergone or undergoing.

Since the onset and over the course of illness experiences, patients often passes through various challenges and changes, either physical, emotion, or behavior. These experiences in turn leave both patients and their healthy family members for various reactions. Of course, reactions were different in each situation and mostly had anxiety, depression, fear, and hopelessness for the future. The illness produced challenges and changes, as study the indicated, have tolls in families inside interaction creating tension often in between chronic patients and healthy family members.

Participants described how illness produced strain and stress detached healthy family members from their patients though sometimes. For example, a male participant elaborated "The pain mom suffered has made her hot-tempered and often verbally inconsiderate which repelled both I and my brother away from her though shorter period" (P1, 25). Similarly, an excerpt from a male participant reads "…unceasing complaints and the physical limitations mom faced have made our life more straining than usual. So, sometimes we stay away until she gets calm" (P2, 27).

Similarly, the study revealed how illness produced strains caused patients to not follow medical procedures, which often causes conflict between patients and their caregiving family members. Besides, the study indicated that the patient's unceasing complaint about almost everything and their desperate reactions was the cause that produced tense interactions between healthy family members and the patients. An excerpt from a female participant, for instance, reads as "He [dad] often expresses his anger on us whenever he feels pain, which made sometimes to stay distant from our father" (P3, 27). A male participant also said, "We are doing all we can to get him out [dad] of the strains and stresses brought by the illness, despite his unceasing complains and disagreements" (P4, 31). Similarly, a female participant elaborated:

> Dad often says, 'I wish if I would die, die…die'. Oh, that makes me and my siblings feel mad. Moreover, he doesn't want to go and visit his doctor to get medical treatments. He is totally desperate about life. I don't know how we could continue like this. That was why we frequently involve in disagreements and sometimes conflicting (P3, 27).

The study has further shown how the painful experiences of chronic illness and related the patient's compliant contributed to marital divorce. For example, an excerpt from a female participant reads:

> Because of mom's illness, my younger brother together with his wife was living in a house with us, and in the process of caring for my mother, mom frequently complained about her daughter's in law, saying, 'she was uncaring'. So, after longer quarreling, my brother went through a divorce (P5, 25).

In any family with chronic illness, another significant factor that affects familial interactions was role tensions within the family or role disruption triggered by caregiving burden. As discussed in the previous section, since the onset of the illness and over the course of life, illness produces role shifts. Often, this resulted because the patients were not expected to play their normal roles and responsibilities. According to Parsons's sick role, the sick person is exempted from normal responsibilities, both at work and at home (Ritzier, 2008). Thus, chronic illness brings functional or role shifts within the family system letting healthy family members assume more responsibilities and preserve the function of the family system. The illness produces an increased burden on healthy family members, including the caregiving burden for the patient. However, the burden becomes higher for some healthy family members, especially for females than men. Therefore, the study has shown that the highest level of burden females assume often causes disagreements between or among healthy family members. For example, a female participant elaborated "We wish if we would have brothers support. They know all the pressure and difficulties we are undergoing at home. But they are uninvolved and seem careless. It makes you mad sometimes when you see their ignorance" (P19, 24). Similarly, an excerpt from a female

participant reads "…It seems home chores and errands are left to us. Thus, we often involve ourselves with some disagreements" (P20, 21).

The study discussed that, in any family, chronic illness produces a mix of experiences for the whole family as a unit. On one hand, the presence of chronic illness, as the study showed, contributes to the rebirth of the family's strength. This means, even though the challenges were still there, illness produces a strong sense of We-nesses that holds all together. This is similar to finding previous studies, which found illness produced increased intimacy or inside interaction, the higher level of empathy, helpfulness, care, and illness produced other family positive outcomes (Butler, 2010; Williams, 1997). On the other hand, the presence of chronic illness produces much turmoil that could negatively affect family interaction. It means that since the onset and over the course of illness, family experiences tensions on their inside social interactions produced often by the pain, and connected patients' illness reactions, either to their physical pains and changes, emotional or behavioral confusions they have undergone or undergoing; and role disruptions within the family or disruption caused by caregiving burden. This finding is also consistent with those in previous studies (Cohen, 1999; Compas et al., 2012; Martine & Colbert, 1997) that indicate the negative outcomes, including sibling conflicts, role tensions within the family, brought by the illness. In the same way, Lohnberg, Howarth, and Clay (2008) also reported that families with chronic illness experience higher levels of role strain, higher stressors associated with the parental role, as well as frustration and conflict about the division of labor and expectations.

In addition to the challenges and changes a family encounters on their inside family interactions, the study showed further impacts that chronic illness had on their outside interaction with others.

5.3.2. Family System's Outside Social Interaction

The impact of the presence of chronic illness in any family goes further into the family's social interaction with others, outside their environment. The changes illness brought on the family's outside interactions were partially the direct outcomes brought by changes encountered inside the family, in terms of physical, emotion, behavior, roles, and interactions changes on the patients and other family members as well. For instance, caregiving roles, attention paid to the patient, anxiety, depression, and other emotionally related changes often caused to have reduced outside social interactions. An excerpt from two participants account elaborated:

> Our attention was focused on treating our mom. So, it significantly reduced the communal engagement with friends and with others (P1, Male, 25).

> …because of mom's illness, often going to church and attending certain social events was compromised (P13, Male, 28).

The study found that patients often receive significant caregiving thought or attention from healthy family members. Therefore, healthy family members could not stay longer with their friends. One example reads as:

> Whenever she [mom] is home I can't stay late with friends because of the illness stoles all my thoughts (P4, Male, 31).

The social interaction healthy family members have with outsiders, for instance, friends or others, as the above participants' description, could be compromised due to the time required to care for the patients. Further attention could be the stress and strains of having a patient with

chronic illness spending a lot of energy and time caring for the patient have an impact on the social interaction that could be made with friends.

The study further indicated how the physical change brought by the medical treatments caused patients not to be only on the public but also avoid their social interactions often to avoid awkward confrontation and repeated inquiry into what happened to physical changes seen. One example elaborated as:

> Mom's societal engagement has shown a significant decline. The disease and related treatments [chemotherapy] gave her unusually big legs that made her feel unattractive and isolated. Her dressing style was dramatically changed. She also preferred staying in doors to avoid awkward confrontation and repeated inquiry into what happened to her and her legs (P2, 27).

The study showed that patients' inability to their social engagement partially also relates to societal perceptions towards patients with chronic illness. This was also indicated from a male participant's account:

> Neighbors' awareness of the infection was minimal and explaining her condition seemed dreadful. Also, their skeptical approach made me reduce my societal engagement. Sadly most of them were also distant even to inquiry about her illness which caused bitterness in my side towards the community I belong to (P2, 27).

The long-held society's strong tendency to see individuals with chronic illness as defective and lacking the ability to function in society does not only make patients' social engagement minimal but it further causes the development of negative attitudes, bitterness towards their community. Nevertheless, as per the participants' description, societal attitude towards chronic ill-health

conditions is often the result of lack of awareness about the nature of the problem as well as its further treatments, which is usually seen as a curse or God's punishment. This finding is confirmed by many other studies (Dowling & Dolan, 2001; Morgan, 2001; Russell, 1998) that showed societal and cultural prejudices and stigma towards individuals living with chronic illness participation and interactions in their social ecology. Therefore, the study would say that cultural perceptions and societal reactions towards chronic ill-health conditions and experiences were a significant factor that hugely determined the social engagement of the patient and the healthy family members with others. In other words, social isolation occurs when society avoids the family with chronic illness participation due to the belief and misconception about the illness.

However, in contrast to culture brought dares, the study showed that positive social interactions and reactions that family living with a person with chronic illness had with close friends. For instance, a participant elaborated "I had a best friend, the one whom I often used to talk and share my feelings, challenges, and everyday encounters" (P5, 25). Similarly, a male participant indicated "My friends are very caring and considerate. My mom's illness has affected much of my interaction with them. They were concerned and used to pray for her which made me feel loved and not left out" (P1, 25). The study indicated that, notwithstanding the reduction in lengths of time, families with chronic illness maintained friendships with close friends, which is often supportive. "…My friends were very supportive" (P2, 27).

The study showed that social interaction between any family with chronic illness and their close friends was not only positive but also had a lot of support. The study showed that close friends were the ones who were always there to share the emotions, challenges, and other everyday encounters of family's living with a person with chronic illness. The study's finding further showed how close friends were more caring for families with chronic illness. Furthermore, the

religious services delivered by visiting fellows to families with chronic illness were not only an area that kept their social interactions but also served as a key strategy to cope with the health problem they faced.

In general, as this study showed, in any family with chronic illness the social interactions the family had with others, outside their family ecology, have shown the reduction in lengths of time they spend. This could be directly related to the amount of time required to care for the patients and other home chores and errands. Furthermore, the kind of social interactions that family's with chronic illness had two features, as per the study found. The first was supportive. This was often provided by close friends. As per participants' descriptions above, close friends were often around for families with chronic illness showing their care, consideration, sharing healthy family members' feelings, challenges, and other everyday encounters. Likewise, people from the same religion had also revealed a close and positive social interaction with families with chronic illness. The second was society's attitude towards chronic illness as a barrier. As the study's finding, due to culture brought negative attitude significantly contributed to the reduction of family's outside interaction. This could be often partially associated with the long-held views of patients with chronic illness as lacking abilities to participate and function in society and related stigmas and prejudices against healthy family members.

In this chapter, in general, the study analyzed the huge challenges and changes chronic illness brought on the family's system of function and their system of interaction. The study has been shown throughout the chapter chronic illness significantly alters many aspects of the family system that is the family system of functions and interactions. However, despite the challenges and changes faced, any family living with a person diagnosed with chronic illness frequently involves different coping strategies to keep the family system functional. In the following

chapter, the study focuses on coping strategies of any family living with chronic illness used to mitigate the challenges and changes brought by the illness experiences.

Chapter Six

Relational Coping Resources

6.1. Introduction

In the previous two chapters, the altering effects of chronic illness on the overall aspects of family life have been discussed. It is clear from the study that the presence of chronic illness had huge impacts on altering the physical, emotional, and behavior of patients and healthy family members as well. Family as a system can experience many challenges by the presence of illness, patients' illness experiences, and related other turmoil. The huge altering effects chronic illness brought on the family system of function and systems of inside-out interaction were also revealed. Families with chronic illness experienced huge role shifts. It means that the presence of chronic conditions alters the roles each family member plays inside the family and their outside activities and leads to assuming more responsibilities. This showed the significant burden of chronic illness on healthy family members. Furthermore, chronic illness produced toll, in terms of family social inside-out interactions were revealed. As the study's finding showed while the social interactions within the family show improvements, creating a sense of We-nesses, interaction with others outside the family ecology, have shown the reduction in lengths of time. This was related to the reduced amount of time required to caregiving roles and other home chores and errands.

However, despite the challenges and changes, any family living with a person diagnosed with chronic illness frequently involves different relational coping strategies to keep the family system functional. In this study, families living with and caring for family members suffering from chronic illness, that is, cancer, diabetes, and hypertension were involved. Even though some features of specific illness may differ, there were several commonalities among families

caring for patients with chronic illnesses. Similar factors were found to influence the resilience of families living with chronic patients. In this chapter, the study gives a detailed description focusing on the relational coping resources that families living with a person diagnosed with chronic illness used to mitigate the challenges and changes brought by the illness experiences.

6.2. Relational Coping Resources

It is clear from this study that chronic illness is burdensome, and hugely alters the family system as a whole. It often changes the family system in terms of roles, social interactions, lifestyle, and value priorities. A family under chronic illness often experiences imbalances that disturb the function of the family. Thus, it makes families resilient to cope with illness causing-situations and mobilizing family's relational resources and being able to adapt and make an adjustment to chronic situations. Understanding the relational coping strategies of families living with a person with chronic illness would help to clarify how family and individuals maintain the balance and functioning when confronted with chronic health situations.

This study identified some of the coping strategies for families with chronic illness used to maintain the family system when encountered with chronic health situations. In the following sections, the study analyzes each.

6.2.1. Religious Support

This study reflected the positive outcome religious support could bring for families living with chronic illness in building their adaptation and resilience capacity. The study findings revealed that religious support was mentioned as one of the major relational coping resources often used to get out of and adopt the chronic health condition. As the participants' account shown, in some belief system visiting and staying at different religious places gives hopes to get out of the health

problem faced. Concurring with the finding of Walsh's (1996) religious affiliation, faith, and spirituality, religious support plays a significant role in family adaptation when dealing with illness-causing situations. One major behavioral change experienced was patients' unceasing complaints about everything, including the purpose of life, looking for answers for things happening, blaming God or gods, and about fate. For instance, an excerpt from a male participant reads "Aha, mom always complains. She complains about life, about God, about fate, about medication, and almost everything" (P1, 25). Similarly, a male participant elaborated "The disease particularly mutilated mom's spiritual understanding and devotion. She was the one who introduced our family to faith. But, the pain produced her trembling faith and unceasing complaints have left deep bruises in our lives" (P2, 27).

Often the onset crisis leaves any family living with confirmed diagnoses to chronic illness to fall into hopelessness affecting the spirituality and faith to which they have long been committed and followed. This was marked by one of the basic questions they repeatedly raise: why does it have to be this way? However, notwithstanding the illness-causing trouble on their faith, soon families with chronic illness bounce back to and pursue meanings for the chronic health problems they faced pursuing religious supports and expecting to get religious answers. Here participants' descriptions talk:

> Faith in God alone is the only solution we have. Our comfort comes from God's providence alone. That is why, we often visit our pastors looking at their prayers, comforting words, and hoping God's instant healings. I believe we would get out of this problem anytime soon. We depend on our faith in God (P2, Male, 27).

> We believe in our St. Virgin Merry and her son, they can to get us out of this problem. That is why we often visit holy places, to get and drink holy water (P5, Female, 25).

Since the onset and over the course of illness, most families with chronic illness put their eyes towards the relational coping resource from religious institutions aspiring to get relief from the health problems they faced. This often happens, as per this study, as an immediate response to the problem faced. As the study's finding indicates visiting pastors looking for their prayer and hoping to get instant healing, visiting holy places to take and drink holy water, and visiting religious fathers to get their comforting words were some of the religious services used as coping strategies hoping and believing to bounce back and get the cure for the problem faced. There was also a belief that God is ultimately in control. Thus, families often find answers and comforts in their beliefs. Similar to this finding, Walsh (2003) revealed that spiritual practices, like prayer, strengthen families, and gives them guidance and comfort. Studies have also shown that families with a strong sense of religious wellness, whether formal religion or other shared beliefs and purposes, enable them to stay strong when facing and dealing with problems like chronic illness (Estess, 2004; Steinnett & DeFrain, 1985). After the initial shocking feelings, and other related dares, therefore, this study indicated, often there was a higher tendency among families with chronic illness to rely on their religion even more than modern medical treatments. Religion support, as per participants' accounts, helps to come to terms with the life they were undergoing. Often, there was a religious perspective that urges accepting challenges, for instance, chronic ill-health experiences, indicating God's good purpose or developing a belief that God would not allow without reason, and showing that the illness is a part of life. Therefore, this kind of religious explanations gives families some kind of comfort. Similarly, Walsh (2003) showed that

religious support empowers families by providing meaning and purposes beyond themselves and their current problems.

Apart from the above mentioned emotional supports, religious affiliations provided families living with chronic illness the opportunity to get different support from their fellow friends. The study showed that families living with chronic illness received social support, like care for the patient and other home-based activities, from close friends. A male participant elaborated:

> When you see your church friends around even providing help in your home chores, it makes you feel loved and not left out. Oh, my friends are very caring, considerate, and supportive (P2, 27).

The study indicated that religious affiliation and fellow friends were important and supportive in the ill-health caused strain situations. The study indicates religious-based friendships not only helped non-patient family members not to feel lonely rather it had further importance in getting support in home-based activities, such as preparing food and other home chores and errands.

In general, the study indicates that religious support obtained by being part of some religious activities, on one hand, used as a social avenue through which family members of the chronic patients could take a break from illness-causing situations strains and stress at home and feel related. Furthermore, religious services were used as a buffer against illness-causing troubles at home.

6.2.2. Understanding about the Illness

One of the major onset crises, especially for healthy family members, was lack of a knowledge and information about the illness that caused pains that patients undergo. It means that because

of a lack of knowledge and information about the symptoms, pains, and treatments of the illness, family members of the chronic patient often experienced resentment and further tense relationships within the family, usually between the patient and other family members. The study's finding revealed that most family members with chronic patients did not know the symptoms, the pains the patient was undergoing, and also about the treatment. For most families living a person diagnosed with chronic illness, it was often the onset experience.

> When mom's diagnoses were confirmed, Cancer, I did not know anything about the disease, the illness, its symptom, and I have never heard of it. So, I didn't even know how to take care of her. …It's full of confusion (P8, Male, 28).

Lack of knowledge about the illness had its effect not only on the kind of treatments the patient needed but also the care supposed to be given by the healthy family members. The family members included in this study, who have patients with diabetes and hypertension, revealed that both types of chronic illness need special care, for instance in terms of food choices, because often they have higher rates of unhealthy eating practices. Most patients with diabetes and hypertension, as per the study, expected to follow a specific diet required to manage their health condition. For instance, dietary restriction, such as following a gluten-free diet and monitoring insulin and blood sugar levels and making the dietary choices based on those levels poses a need for a lifestyle change. Besides, especially patients, with diabetes and hypertension, did not need stress-causing situations rather cheering social environments were considered as potential illness controlling strategies. Therefore, the course of illness urges non-patient family members to know about the illness better.

The study indicated that families have learned about the illness and its treatment as time went by. The study revealed three major sources through knowledge or information obtained and used to get to know about the illness and its treatment. So that, through which they used to manage and mitigate the impacts chronic illness could have created.

One rarely mentioned source of information or knowledge was scientific articles. This could be linked to society's poor reading culture. In this study, only two participants cited scientific articles as sources that gave them more information about the illness. For instance, an excerpt from a male participant reads "I have read scientific articles about her [mom] illness from reliable sources so that I could feel her pain and understand her struggle" (P2, 27).

The other most essential information source the participants cited were people who had prior exposure to the same chronic experiences and close friends. It means that as per study finding, information collected or heard from other people with a similar health condition were shared and used as an important source of knowledge to mitigate the ill-health condition faced. The study described how the information received from supportive friends gave non-patient family members more knowledge and understanding about the illness and the changes it had caused. Two examples included:

> I am very pleased about the friends I have and you know, we can talk, share, and they are always around for us. We even managed to handle some of the chronic health situations following the information and advice they gave (P5, Female, 25).

> Whenever we get depressed, our friends are the ones who were always around and gave us advice. They tell us what they heard about the illness from people with the same experiences. To be honest, it was their advice that helped a lot (P7, Female, 24).

The other most essential source of information that gave improved knowledge about the illness was professional support rendered by health professionals, usually doctors. For instance, an excerpt from a female participant reads "They [doctors] are the ones who told us what kind of food we should prepare for patients, with diabetes, which helped the family to control the progress of their illness" (P15, 24). The study indicated professional support as the most common approach that doctors usually used to inform non-patient family members of patients about the illness, its pains, treatments, and things that healthy family members should and should not do, to mitigate the impacts of chronic illness could create on their family. A participant elaborated "It was doctors' advice that helped us a lot. They often call us to their office and tell things that we should and shouldn't do to control the illness" (P18, 21). Similarly, an excerpt from a participant reads "They [doctors] tell us not to do things that can particularly hurt mom's emotions" (P7, 24).

As the study showed understanding the illness was essential not only to understand the patients' painful experiences but also to provide the care supposed to be provided. Understanding the illness also gives ways to learn and practice a doctor's role at home, for instance, how to give injections. A family member of the diabetic patient put "…You know, I had to get learned how to give the injection" ((P15, 24)).

In general, the participants' description revealed that family resilience gets easy if members of the family understand certain characteristics of chronic patients, including pain, anger, aggressiveness,…etc. which are part of the illness. They further indicated that by understanding the nature and symptoms of the illness, they were better able to cognize the patient's experiences, thus making it easier to adopt and make an adjustment to the illness-causing situations. Concurring with this finding, studies also showed that understanding illness is a key

element in the process that could help family members of the chronic patients to normalize and contextualize their situations (McCubbin and McCubbin, 1996; Walsh, 2002). Besides, these studies indicated that by understanding the crisis, family members of the chronic patient could be able to maintain a sense of control over illness-causing situations, which fosters confidence that their circumstances will ultimately work out positively.

6.2.3. A Strong Sense of We-ness

As it was discussed in chapter five, one major positive outcome of chronic illness was the increased sense of unity or we-ness inside the family despite illness caused challenges and changes. It was also used as an important source of the family's resilience when faced with challenges, as a chronic illness. It is clear from this study that chronic illness causes strain within the family. The strain starts often since the onset of the chronic illness. During those times, family members of the chronic patient, as the study indicated, experience confusion, depression, hopelessness, shock, fear, and many more illness produced negative experiences. Three examples included:

> "Mom diagnosed with cancer and we didn't see any hope; so we thought that our mom was going to die anytime sooner" (P1, Male, 25)
>
> "…we fall into anxiety anticipating the future hassle…" (P12, Male, 28)
>
> "…we were shocked…" (P5, Female, 25)

However, despite illness-causing situations within the family, a strong sense of unity, we-nesses, or in other words, family support contributes a lot to make a family resilient or cope in the face of illness-causing situations. The study revealed how illness caused open communications within

the family was essential not only to admit the reality but also to reorganize the family structure in the face of chronic illness causing situations. This finding also is consistent with a study by Walsh (1996) who found that family's level of communication could determine the process of family resilience or coping despite all the illness-causing situations a family is undergoing.

The study further described how the familial relationships have improved because of the time spend together and the communication developed about the illness-caused situations at home. For example, a female participant said, "We were so happy to see and get quality time to communicate with each other about illness caused the situations at home" (P20, 21). Participant 17 also said, "Now, we understood each other…I think communication was the most essential thing that binds our family together" (26). Similarly, an excerpt from a female participant reads "Oh, it was too good to be together, if not I don't know how we could manage to cope with the illness-causing situations we were experienced at first" (P5, 25).

Consistent with this study's finding, some studies indicate how families can mitigate illness caused by challenges and changes faced as they communicate effectively with each other (Donoghue & Siegel, 2000; Leone, 2010). Concurring to this study's finding, preceding studies further indicated that communication barrier often occurs in between the patients and healthy family members, and also among healthy family members due to lack of understanding about the illness-causing situations.

However, chronic illness greatly impacted the pattern of communication as families role shifting. It is clear from the study that the presence of ill-health conditions alters the role each family member supposed to play. It means it was expected for family members of chronic patients to assume more responsibilities to compensate for the roles left unfilled by the chronic patient. In

other words, role shifts often increase the burden that each family member supposed to play. Therefore, the study identified the supportive family relationships as essential to ease the burdens that each health family member could assume. The excerpts of two participants have shown how improved family support eased the burden placed on the individual family member. Two examples included:

> I think things are getting better and better than before because there is understanding within the family, and each family member is playing an essential role compared to the experiences we had when we first heard mom's diagnoses. Despite illness caused strains and stresses, we often share responsibilities, especially in matters related to mom's care. Because of that, now the burden that placed on the individual family member, often females, significantly decreased. Now, there is a strong sense of unity, especially since mom's diagnoses with diabetes (P15, Female, 24).

> In the beginning, there was confusion. Because of that, we didn't even know what to do. Later on, things started to improve as we began to support each other. As a result, the pressure on one person significantly reduced (P14, Female, 23).

As the above participants' description, the resilience of the chronic patients' family could not only be determined by their supportive familial relationships but also family members' will to assume more roles and responsibilities. It means that stepping out of the enclosure of own identity in the face of something that is not once due but that you consider being your due (Öhman & Söderberg, 2004) was necessary to maintain the family system in the face of illness caused family crumbling and confusions.

A strong sense of unity, we-ness, or family strength within a family was revealed as the most essential relational coping resources in the face of illness caused stress and stains. The presence of chronic illness provided an opportunity for family members to get united and move forward together despite the experiences the illness caused situations experienced. They also expressed the joy they felt because of the good relationships they had at home, even though the stress and strains were still there. Participants further indicated the essence of talking to each other and staying together sharing everything happening. The study's finding showed that a sense of togetherness gave family members with chronic illness strength and a feeling of pleasure for being together. As per the above participants' account, having a unified understanding of the way they thought about the illness, its impact on the family as a whole, its treatment, and readiness to assume more roles and responsibilities were essentially created a strong sense of unity, we-ness. This study's finding strongly indicated that a strong sense of unity within the family helped to cope with the crisis caused by chronic illness. Therefore, the study affirms that the relational resources that family members had done not only help adapt to challenges and changes the illness caused but also to make adjustments to mitigate the stress and stains that can be brought on the family system of function and social inside-out interaction.

Apart from the above revealed relational (inside-out) coping resources used by family members of the patient, organizational support, especially from employers, was also essential to keep the economy of the family from crumbling due to chronic illness. An excerpt from a male participant reads how the family gets relief when they heard the employer's readiness to keep paying the salary of the patient who got a chronic illness.

> Mom's staff and administration of the hospital where she worked over the years showed readiness to pay her salary throughout the treatment period while she in the hospital

> taking her treatment has boosted our confidence and relieved our financial stress somehow (P2, Male, 27).

One major toll that chronic illness could create was the potential impact it could have on the family's income sources because the illness possibly made the patient dysfunctional. It means that when the individual became ill, the person could not be able to work. An excerpt from a male reads "When mom became diagnosed with chronic illness, she couldn't work anymore" (P8, 28).

Employers could terminate job agreements with chronic patients. This causes unemployment for the patients and financial problems for the family. The problem gets worse for single-parent families if the patient was the sole breadwinner of the family. In addition to the presence of illness, issues of job loss were the other worrisome experiences of many families with chronic illness. Any employer's kind support to keep the patients' finance, as per the above participant's description, was a big relief. The organizational support obtained from employers helped families a lot since it keeps not only the financial sources they rely on to cover so many expenses but also the anxiety that could follow the loss of jobs. Thus, this study suggests that the presence or absence of organizational support as one of the basic elements that challenge or supports the mitigation processes of illness-causing challenges and changes.

As discussed in the previous sections, any family with chronic illness involves various inside-out relational resources to bounce back from illness-causing situations or mitigate effects that illness could create and maintain the family system with its function. The study showed that religious support, family's illness understanding, and family members inside a sense of unity, we-nesses, played essential roles in mitigating the altering effects of chronic illness causing situations. The

study also revealed how professional support, especially by doctors, played an important role in creating awareness about the illness, its pain, and treatments for families living with a person diagnosed with chronic illness. Furthermore, the participants' description also revealed the social support obtained from close friends, both as a source of information about the illness, treatment, and also friendship supports, including sharing the emotional burden of healthy family members.

6.3. Resilience Challenges

Despite the above mentioned relational coping resources that any family with chronic illness could use to bounce back from or mitigate illness-causing situations, the study also revealed the challenges that kept the family still to experience the effects of chronic illness. In the following sections, the study presents two of the major challenges that stand against the family's resilience capabilities.

6.3.1. Illness Character

Taking care of people with chronic illness lasts long enough to become the life of the family. So, in the process of caring and the family's attempt to bounce back and mitigate the effects that illness could cause, an unexpected and traumatic character of chronic illness could disrupt the family in its functioning threatening the stability of the family.

> …dad sometime experience anxiety following the bad things that happen at the workplace, and as a result, his blood pressure rises. So, when things like this happen, it's common to visit hospital for days until his blood level gets normal. We wish if he could stop his work. But, it's our only source of income. Aha…it's hard to continue living like this (P19, Female, 24).

> Sometimes we receive phone calls and hear dad's hospitalization after falling down somewhere on the street, following losing the needed level of sugar from his body. It really hurts your emotions. It makes you unstable (P16, Male, 19).

The above two participants' descriptions showed how difficult it was to control chronic illness fully despite all the relational inside-out resources used to mitigate the effects it had. This was partly because of the nature of the illness. Despite the care given at home, such as lowering the amount of salt intake and improving the anxiety-causing environment, the study found that often unpleasant work environments cause anxiety, which could be a contributing factor to get tension at work, depression, and end up, finally, with higher blood pressure. Similarly, despite all the care taken, diabetic patients often experience a low level of sugar in their blood if the patient gets thirst, hunger, fatigue, etc. These symptoms may occur suddenly. As a result, chronic patients often experience sudden hospitalizations. As the participants' account reveals, such experiences do not only create an emotional toll on the healthy family members but also disrupt the family functioning and threaten the stability of the family. However, as discussed above, the level of understanding of the unexpected and traumatic character of the illness could mitigate the impacts of such sudden illness experiences. In other words, families are expected to make sense of such unexpected and traumatic character of the illness before the reaction they could respond to the illness-causing situations.

6.3.2. Socio-cultural Perceptions

> Neighbors' awareness of the chronic illness was minimal and explaining her [mom] condition seemed dreadful (P4, Male, 31).

One of the major challenges for individuals living with chronic illness and their families was negatively attached to socio-cultural perception to their chronic illness caused situations. For example, an excerpt from a male participant reads "Our societal perception of chronic illness is poor" (P1, 25). Often the perceptions consider individuals living with chronic illness as defective and lacking abilities to participate and function in their social roles and responsibilities. Often a family's response even to their chronic ill-health experiences also largely depends on the meanings, which is influenced by the broader socio-cultural perceptions which they are part of. As a result, to avoid prejudiced and stigmatizing meanings attached to the ill-health experiences families with chronic illness often prefer to stay at home.

The study shows how societal awareness of chronic illness was minimal or poor. This is further revealed by their skeptical approach to the patients and their healthy family members. As a result, families with chronic illness often have reduced social engagement. For instance, a male participant elaborated "…their skeptical approach made me reduce my societal engagement. Sadly most of them were also distant even to inquiry her illness which caused bitterness in my side towards the community I belong to" (P2, 27). In other words, the relational resource that can be accessed from the social engagements, and which is necessary to adapt and mitigate the effects of illness-causing situations, becomes more inaccessible. This could have further consequences by reducing the resilience capacities of any family living with chronic illness.

Apart from their reduced social engagements, societal and cultural prejudices and stigma towards individuals living with a chronic illness and their families further contributed, as the participants' account indicated, for the development of bitterness towards the society they belong to. In other words, any family with chronic illness could develop and experience hostile relationships against society. Thus, out of frustration and desire to compensate for the conventional methods of

accessing social resources, sometimes families with chronic illness get involved in different deviant or unconventional activities. Even though, participants' were refrained from mentioning those activities. However, some studies mention deviant activities, including bagging, stealing or robbery, and prostitution often used to keep the family's resilience process. Often these activities focused on meeting some of the expenses of the family, including patients' medical costs.

Chapter Seven

Summary and Conclusion

7.1. Summary

This qualitative research study attempted to reveal the family experiences of living with a family member diagnosed with chronic illness from the non-patient family members' perspectives. The study applied a phenomenological approach to reveal the lived experiences of family's living with a chronic patient and explore the challenges and changes chronic illness brought on the overall family system.

The study revealed how the presence and experiences of chronic illness were challenging and altering for both the patient and other family members since the onset of the illness. Specifically, the study revealed how the onset experiences were chaotic leaving the family in general for more negative experiences, such as shock, hopelessness, anxiety, and depression. The study revealed the factors that can significantly influence the onset and later family's illness experiences. These includes first, the types of the disease diagnosed, for instance in cases like cancer the feelings and experiences were significantly tense. Secondly, family's prior knowledge about the disease, pain, symptoms, and treatments of the illness were identified as significant in determining the family's illness experiences. The study revealed that lacking (having) prior knowledge about the illness was significant to intensify or mitigate the effects of chronic illness on the families living with chronic illness. Furthermore, the study revealed how the patients' reaction to the illness and other related changes on their physical, emotional, and behavior as a significant factor to determine the family members' illness onset and later experience. Often, the changes were apparent, especially during the first few days or weeks, following the diagnoses.

The study also revealed how the presence of chronic illness was a serious upheaval for the family as a whole often changing the physical, emotional, and behavior of each family member. Changes in patient's overall physical appearances (extreme weight losses) were related to the chronic nature of the illness itself and related changes in lifestyle, in terms of diet. Likewise, healthy family members also experience huge physical changes: such as fatigue, headache, weight loss, and sleeping-sickness. These changes often associated with the attentions paid for the patient or the caregiving burden, and the overloaded responsibilities at home but also in outside activities. The study also revealed illness brought emotional tolls, such as anger, grief, depression, hopelessness, anxiety, worries, and fears anticipating the future hassles. Besides, the study revealed the dramatic behavioral changes, for instance easily getting angry, isolation or loneliness, being complainant of every little thing, and so on.

Apart from the changes in the physical, emotion, and behavior that chronic illness could bring, the study revealed the altering effects of chronic illness on the family system, mainly on the family function and inside-out interactions. The study revealed the role shifts that family's with chronic illness experience. This implies that the presence of ill-health conditions alters the roles each family member expected to play. Each family member expected to assume more responsibilities to compensate for the roles left unfilled by the chronic patient to keep the function of the system. Role shift often occurs due to the caregiving roles supposed to be provided to the patients. These role shifts often force non-patient family members to miss work or other activities to help the patient attend, for instance, medical appointments or accompany patients to procedures. This often limits non-patient family members' career advancement and takes a financial toll.

Furthermore, chronic illness produces a mix of experiences for the whole family as a unit on their inside-out social interactions. The study revealed that, on one hand, the presence of chronic illness contributes to the rebirth of the family's strength. This means, despite the challenge and changes, family's illness experiences produce a strong sense of We-ness that holds all together. On the other hand, the presence of chronic illness produces much turmoil that could negatively affect family interaction. Since the onset and throughout the illness, family experiences tensions on their inside social interactions created by role disruptions. Similarly, chronic illness produces a blend of experiences on families outside interaction. The social interaction the family had with others, outside their family ecology, showed a reduction in lengths of time spent. This directly related to the amount of time required to care for the patients and other home chores and errands. However, families outside interactions had two features. The first was supportive. This was often provided by close friends and religious groups. Close friends were often around for families with chronic illness showing their care and consideration. Likewise, people from the same religion had also revealed a close and positive social interaction with families with chronic illness. On the other hand, the study revealed society's attitude towards chronic disease, chronic illness, chronic patients, and their family as a barrier to the outside interaction. This was often partially associated with the long-held views of patients with chronic illness as lacking abilities to participation and function in society and related stigmas and prejudices against healthy family members.

Finally, the study revealed the various relational coping resources used to mitigate the altering effects of chronic illness despite the challenges and changes. The study revealed that religious group supports; knowledge or information about the illness; and family's strong sense of unity, we-ness as essentials to mitigate the altering effects of chronic illness. The study further revealed

how professional support, especially by doctors, played an important role in creating awareness about the illness, its pain, and treatments for families living with a person diagnosed with chronic illness. However, despite the relational coping resources used to bounce back or mitigate from illness-causing situations, the study revealed the two major challenges: i.e. the illness character and socio-cultural perception that kept the family still to experience the effects of chronic illness.

7.2. Conclusion

This study aimed to reveal and gain insight and understanding into the experiences that families have when living with a family member that has been diagnosed with chronic illness. This study aimed to take a phenomenological approach to add to the previous studies in the area of chronic illness, which were medically oriented or patient-centered. Concurring with family system theory, the results of this study suggested that the family living with a person diagnosed with a chronic illness is greatly affected in many ways. These include changes in their physical, emotional, and behavior; limitations being put in place for family activities and outings; and the family's inside-out social interaction. It means that the relationship processes within families, which hold the experience (chronic health) of one family member significantly affect the experiences of other family members. It is clear from this study that the family members living with a person with chronic illness were affected by many factors that occurred throughout their daily lives. These include all the ecology or contextual factors associated with chronic illness. For instance, families' interpersonal factors or family relationships produced both opportunities (i.e. a sense of We-ness) and risks (i.e. role-related strains). It is also clear from this study that the factors external to the family unit are just significantly altering and influence family illness experiences. Concurring with the ecological model, this study makes it clear that families illness experiences can be affected by social support, organizational support, and the societal perception

towards chronic illness. These ecological factors significantly influence the families coping strategies by providing opportunities or hindering the families' capabilities of accessing relational coping resources. These factors and situations could limit the family and cause more distress but they also provide significant opportunities that help the family to cope with the chronic health condition. Concerning these ecological factors, the study identified two major challenges that any family with chronic illness probably experiencing since the onset and in the courses of the illness. The first is a lack of knowledge and information gap about the illness, i.e. the pains that patients undergo, symptoms, and treatments. This is partly the outcome of the health system which entirely focuses on treating the patient, often physiological therapy. This means the health system does not give ample emphasis to the altering effects of chronic health condition that encompasses more than simply the physical processes of the biological body. In other words, the health system gives less emphasis to every aspect of the individual life, (i.e. emotion, behavior, and social wellbeing) that chronic illness could alter. Additionally, the health system gives also less attention to the altering impacts of chronic illness to everyone living with or around the patient, usually family members. The study found that family therapy or counseling services are lacking from the health system for families living with chronic patients. As a result, challenges and changes that can be lessened because of the knowledge or information obtained in the health system, usually from doctors create a serious upheaval for the family as a system due to the knowledge or information gap about the illness. The study revealed the importance of knowledge and information regarding chronic illness to manage the effect. Therefore, this study suggests that in the process to help the family resilience, the health system should consider including family therapy or counseling service sessions for healthy family members as well apart from the health services delivered to the chronic patient.

The second major challenge for families living with chronic illness, the study found, is pejorative societal perceptions towards chronic disease and chronic illness experiences. There is skepticism among the broader society towards the nature of chronic illness. There is also a tendency to view a chronic patient as a person lacking abilities to participate and function in societal affairs. Besides, the study revealed society's tendency to view the diagnosis of chronic illness as possession with evil spirits or as a curse or God's punishment for doing something wrong. This negative labeling towards chronic patients and their healthy family members, therefore, contributes not only to the reduction of family's outside interaction with broader society but also becomes a barrier to access the relational coping resources possessed by their associations with the broader society. The society's long-held negatively attached traditional perception towards chronic illness could be related to their lack of knowledge or adequate information about chronic disease and related illness experiences. Therefore, the study suggests the need to create awareness about chronic disease and related illness experiences to mitigate the stigma and prejudice against healthy family members.

Given the significant increase in the problem of chronic disease and the effects that this can have on many aspects of families of the chronic patient further investigations are needed to gain a multidimensional insight into the problem of chronic illness. Therefore, this study suggests that in future research, researchers should attend all the limitations mentioned in this current research to gain a better understanding of the family experiences of living with a family member diagnosed with chronic illness.

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Appendices

Appendix: 1 Information Sheet and Consent form for study participants

Kaleab Fikre is a graduate study in the department of sociology at Addis Ababa University and conducting a research study on family experiences of living with a person diagnosed with chronic illness, in partial fulfillment of the requirements for the Master of Arts Degree in Sociology. This research has an objective of revealing the family experiences of living with a person diagnosed with chronic illness.

In this study, healthy family members living with a person diagnosed with chronic illness will be asked to participate in the study. Participation is completely voluntary. As a research participant, you will be asked semi-structured interview questions consisting of open ended questions in reference to the illness, and the family experiences of living with a family member with chronic illness. The interview will last approximately 60 minutes. You will be expected to be honest and forthright with your response. The only perceived potential risks and discomforts associated with this study may be due to the emotional content of the topics to be discussed. This means, there is a possibility that you could experience discomfort from answering questions about your and families illness experiences. Thus, if you feel or experience discomfort of answering some of the interview questions, you can ask to avoid those questions. These risks, however, are considered to be minimal. All the interviews will be recorded for the research purpose only.

Participation in this study may benefit you directly by providing an opportunity to reflect upon, gain valuable insights about the family experiences of living with a person diagnosed with chronic illness. Participation in this study may benefit also other families with the same chronic health conditions because the information you provide might prove instrumental in aiding and assisting them when they are faced with the same health problem.

Your participation in this study is completely voluntary. You may refuse to participate or withdraw any time without adverse consequences. Your answers to research questions will be kept strictly confidential and your input is greatly appreciated. All data will be labeled with code numbers and stored in secure facilities to strictly maintain confidentiality. You will be asked to sign a consent form prior to your participation in the research study.

You are welcome to keep this information sheet if you wish.

I have read, understood, and received a copy of the information sheet, and willingly consent to participate in this study.

1. I confirm that I have understood the Information Sheet. □
2. I have been offered the opportunity to ask questions. □
3. I am willing to participate in this study. □

_____ _____

Signature of the participant Date

Appendix: 2 Interview Guiding Questions

Addis Ababa University
College of Social Sciences
Department of Sociology

Research Title: View from In: Family experiences of living with a person diagnosed with chronic illness

You are invited to participate in this research project being conducted by Kaleab Fikre, in partial fulfillment of the requirements for the Master of Arts Degree in Sociology. This research has an objective of revealing the family experiences of living with person diagnosed with chronic illness. As a research participant, in this study you will be asked interview questions consisting of open ended questions in reference to the chronic illness experiences and related family life. The interview will last approximately 60 minutes. You will be expected to be honest and forthright in your response. If you feel or experience discomfort of answering some of the interview questions, you can ask to avoid those questions. The entire interview will be recorded for the analysis purpose.

Your involvement in this study is completely voluntary. You may refuse to participate or withdraw any time without adverse consequences. Your participation in this interview will be confidential and your input is greatly appreciated.

Interview Guide for the Study Participants

Personal Information

1. Anonymous Name: _____
2. Your age: _____
3. Sex: _____
4. Educational Status: _____
5. Marital Status: _____
6. Your relationship to the sick person:_____
7. The age of your sick family member: _____
8. The sex of your sick family member: _____
9. How many children are in the household currently living?
10. Educational Status of the sick person: _____
11. Occupational Status of the sick person:_____
12. The position of the sick persons in the household:_____
13. What is the major income source of the families? _____
14. Who is the head or breadwinner of the family:_____

Elaborative Questions

- Questions on the major physical, emotional, and behavioral changes brought about by the chronic disease on patients and their family members from non-patient family members' perspective;
    - What can you tell me about your family member's illness?
    - What chronic illness your family member diagnosed? What led up to the diagnosis?
    - What were the symptoms before the diagnoses to the ill-health condition?
    - How did the person know about the illness? How and when did you know about the illness?
    - What paths your family has gone through to find the condition was chronic?
    - How soon after the chronic illness symptoms began was a diagnosis made?
    - How long has it been since your family member was diagnosed with chronic illness?
    - Did your family member have other ill-health conditions before the diagnosis to chronic illness?
    - What was the health status and functions of the sick family member before the diagnosis?
    - How did the family respond….in order to help the ill person get back to health?
    - Can you describe the kind of feeling you and your family had experienced when you first heard about the diagnoses of your family member's chronic ill-health condition?
    - When did the family realized that things wouldn't get back to "normal" (like before), how did the family take this situation?
    - Does the then initial feeling changed over time? If so, how? What contributed to such changes?
    - Can you briefly tell me the limitations or changes in personal as well as social behavior as a result of the ill health condition?

- Can you tell me about any ways your life has been affected or changed by your family member's ill-health condition?
- Can you tell me how living with someone with chronic ill-health condition makes you feel?
- Can you tell me what things in particular make you feel like this? Can you give examples?
- Can you tell me the behavior and activities change as a result of illness brought feelings?
- Has your family member's health condition affected your health at all? If so, how?

- Questions on changes in the family functions and family inside-out relationship due to a family members' chronic diseases;
  - Can you briefly describe the kind of familial relationship/life your family have had before the onset of the illness?
  - Can you tell me how the illness has affected your families' relationship?
  - How does your family member's ill-health condition affect your social life?
  - What effect does your family member's ill-health condition have on your friendships with others?
  - Can you tell me about activities that you used to do which you cannot now as a result of your family member's ill-health condition?
  - Can you briefly describe the changes in the family function, emanated from ill health condition, especially in terms of roles and responsibilities shifts?
  - What effect does the ill-health condition of your family member have on your day to day activities?
  - Does the ill-health condition of your family member have any effect on home chores? If so, how?
  - Does your family member's ill-health condition affect your education/job at all? If so, how?
  - Has your family member's health condition affected your mobility for different events or activities at all? If so, how?

- Have you ever changed your activities, such social activities or involvements, at all as a result of your family member's health condition? If so, how?
- Can you tell the impact of the illness on you and your family's social involvement, i.e. in idir, ikub, and mahiber?
- Can you tell me how these traditional institutions help you in your situations?

- Assess the coping strategies of family members use to deal with effects linked to chronic diseases.

  - Can you tell me briefly what do you do or you have been doing to adjust your everyday life to the ill-health condition of your family member?
  - Who do you talk or share about your feelings of living with a person diagnosed with chronic illness?
  - Do you have any support from people or groups, including friends? If yes, what kind of support you have had from others.
  - Do you use any support services e.g. websites/counseling to help you with your feelings of living with a person diagnosed with chronic illness? If so, what do you use and why?
  - Can you tell me the major challenges while trying to adjust to the illness or bounce-back to your normal everyday life despite the ill-health condition?

Closure

1. Is there anything that comes to mind that was not covered in this interview? Do you have any thoughts, comments, or stories you would like to share?