TURKISH REPUBLIC OF NORTHERN CYPRUS

# UNDERSTANDING THE LIVED EXPERIENCE OF FAMILY CAREGIVER'S IN NORTHERN CYPRUS: CAREGIVER'S BURDEN

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HEALTH INSTITUTE DEPARTMENT OF NURSING, NEAR EAST UNIVERSITY

MASTER'S THESIS: PUBLIC HEALTH NURSING

ADVISOR NAME

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## NEAR EAST UNIVERSITY

## GRADUATE INSTITUTE OF HEALTH SCIENCES

## THESIS APPROVAL CERTIFICATE

The thesis study of Nursing Department graduate student **Uduak Rosemary Imaukoh** title **Understanding The Lived Experience Of Family Caregiver's In Northern Cyprus: Caregiver's Burden** has been approved unanimity/majority of votes by the jury and has been accepted as a Master of Nursing Education Department Thesis.

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## STATEMENT DECLARATION

I hereby declare that this thesis study is my own study. I hereby declare that all information in this thesis has been obtained and presented in accordance with academic rules and ethical conduct. I also declare that, as required by these rules and conduct, I have fully cited and referenced all material and results that are not original to this thesis.

I hereby declare that the Near East University, are allowed to store and make available electronically the present Dissertation.

**Uduak Rosemary Imaukoh**

Date: 15-03-2021
Signature: ...............

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**ENCLOSURES**

**CURRICULUM VITAE**

# ABBREVIATIONS AND ACRONYMS

| | |
|---|---|
| ZBIs | Zarit Burden Interview Scale |
| APRNs | Advanced Practice Registered Nurses |
| AARP | American Association of Retired Persons |
| ADL | Activity of Daily Living |
| ACE | Advancing Care Excellence |
| WHO | World Health Organization |
| TRNC | Turkish Republic of Northern Cyprus |
| NAC | National Alliance for Caregiving |
| IT | Information technology |
| IAHC | International Association for Human Caring |
| IADL | Instrumental activity of daily living |
| COPE | Creativity Optimism Planning and Expert Information |
| CARE | Caregiver Advise Record Enable |
| PC | Personal Computer |
| VAS | Visual Analog Scale |

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## ENGLISH SUMMARY

### Introduction

For informal or family caregivers, understanding the meaning of care and the concept of care is important to know about their experiences. Care is an action taken forsomeone in time of need. For centuries, family members had to care for their relatives, especially when a relative is sick or wounded and they fulfilled various care responsibilities during the care process by starting care at their own homes. In addition, religious centers were used to heal/cure the sick and injured. All these acts of care have formed the basis of compassion and caring has been accepted as a human trait, caring is also inherent in human nature.

Many family caregivers feel overwhelmed and burdened with care during the time they give care to their relatives. Caregiver by definition is someone who provides care to a person who is wholly or partially dependent duean illness or injury. Care can be given formally or informally by caregivers. Maintenance burden; it can be called the burden that the caregivers feels burdened with due to the care provided. Introducing the care concept has enabled nurses and health professionals to understand different care and caregiving processes. There are many nursing theories that explain nurse's basic knowledge of care, and these theories help nurses to best serve in a professional manner.

**Aim of studies**: The aim of this research is to determine the burden the burden of care felt by informal caregivers in their daily lives in Northern Cyprus.

**Material and Methods:**This study is a mixed type study. The first part is descriptive and the second part is qualitative study. Population and sample size: this study was conducted with =17 people who cared for their relatives, by using snowball data collection technique until reaching repeated data.

**Data Collection Tools:**The questionnaire form includes socio-demographic questions and open ended questions (19). In addition, the ZBI burden scale (Turkish Version) consisting of 22 questions was applied. The dependency perceived by the caregivers and the satisfaction of the individuals they care for were evaluated using the Visual Analogue Scale (VAS).

**Result and Discussion:** The education level of 52.9% of this study was at the level of higher education. The mean age of the caregivers was 52.65±12.17 and the average caregiving time was 10.12±11.36. The caregivers of this research gave care for an average of 10 years.

82.4% of the participants have children and stated that they receive support from their families during their care duties. In this study, the dependency level of the care recipient when measured with the VAS scale is on average 8.00±2.06. In addition, the addiction level of five participants in this is 10 when measured on the scale of (0-10).As reported by the caregivers, the care recipient’s satisfaction level was 9.06±1.47. Caregivers’ response to caregiving was generally found to be good.

In this study, the caregivers’ care burden was determined to be 40.47±12.24 on average. This maintenance burden; It was evaluated as a moderate to severe care burden. There was no significant difference between the caregiver’s care burden score from the scale and their age ($p> 0.05$).

**Results and Suggestions:** Generally, family members of caregivers are voluntary caregivers without expecting money. Caregivers care for friends, spouses, relatives and aging parents or people with disabilities in the home environment.A caregiver provides assistance such as dressing, getting out of bed, feeding assistance, providing transportation and helping with bowel incontinence.If the duties of informal caregivers become a burden, community health nurses need to provide the right family counseling programs to help caregivers monitor their daily activities and manage their daily care routines.One of the primary functions of public health nurses is to improve the quality of life of both the caregivers and the care recipients and also nurses should listen to, and work with family care providers solely for health care purposes.This can be achieved by recommending courses in nursing schools that will help future nurses to be aware of the risks of care burden on families.

**Keywords:**caregiver’s burden, public health nurse, family member and informal caregiver burden.

# TÜRKÇE ÖZET

## Giriş

İnformal veya aile bakıcılarının için, bakımın anlamını ve bakım kavramını anlamak onların yaşadıkları deneyimlerini bilmek önemlidir.Bakım, ihtiyaç anında biri için veya ona karşı gerçekleştirilen bir eylemdir.Yüzyıllar boyunca Aile üyeleri özellikle bir akrabası hasta olduğunda veya yaralandığında yakınına bakım vermek zorunda kalmış, bakımı kendi evlerinde başlatarak bakım sürecinde çeşitli bakım sorumluluklarını yerine getirmişlerdir.Ayrıca bunun için dini merkezler hasta ve yaralıları iyileştirme / iyileştirmek için kullanılmıştır. Tüm bu bakım eylemleri, şefkatin temelini oluşturmuş ve bakım verme bir insan özelliği olarak kabul edilmiştir, bakım aynı zamanda insanın doğasında bulunmaktadır.

Pek çok aile bakıcısı, yakınlarına bakıma verdikleri süre boyunca bunanır, bakım yükü altında kalmış olabilirler.Bakıcı tanım olarak, bir hastalık veya yaralanma nedeniyle tamamen veya kısmen bağımlı olan bir kişiye bakım ihtiyacı sağlayan kişidir.Bakım, bakıcılar tarafından resmi veya gayri resmi olarak verilebilir.Bakım yükü; bakıcının sağladığı bakımdan dolayı yüklendiğini hissettiği yük olarak adlandırılabilir.Bakım kavramını ortaya koymak, hemşirelerin ve sağlık profesyonellerinin farklı bakım ve bakım verme sürecini anlamalarını sağlamıştır.Hemşirelerin, bakımla ilgili temel bilgilerini açıklayan birçok hemşirelik teorisi vardır ve bu teoriler, hemşirelerin en iyi profesyonel tarzda nasıl hizmet vermeleri gerektiği konusunda yardımcı olur.

Çalışmaların amacı: Bu araştırmanın amacı, Kuzey Kıbrıs'ta yük altında bulunan informal bakıcıların günlük yaşamlarında hissettikleri bakım yükünü belirlemektir.

**Gereç ve Yöntemler:**Bu çalışma karma tip çalışmadır. Birinci bölüm tanımlayıcı, ikinci bölüm nitel çalışmadır.

**Popülasyon ve örneklem büyüklüğü:** Bu araştırmada tekrarlanan verilere ulaşıncaya kadar kartopu veri toplama tekniği kullanılarak, yakınlarına bakım veren n= 17 kişi ile yütrütülmüştür.

**Veri Toplama Araçları**: Anket formu, sosyo-demografik soruları ve açık uçlu sorular (19) içermektedir. Ayrıca 22 sorudan oluşan ZBI bakım yükü ölçeği (Türkçe Versiyon) uygulanmıştır.Görsel Anolog Ölçeği (VAS) kullanılarak bakıcıların algıladığı bağımlılık ve bakım verdikleri bireylerin memnuniyet durumları değerlendiriledirilmiştir.

Bulgular ve Tartışma: Bu çalışmaya % 52.9'unun eğitim seviyesi yüksek öğrenim düzeyindeydii. Bakım verenlerin ortalama yaşı 52.65±12.17 ve ortalama bakım verme süresi 10.12±11.36 olarak belirlendi.Bu araştırmanın bakım verenlerler ortalama 10 yıl bakım vermiştir.Katılımcıların % 82.4’ü çocuk sahibidir ve bakım görevleri sırasında ailelerinde destek aldıklarını belirtmişlerdir.Bu çalışmada bakım alıcısının bağımlılık düzeyi, VAS ölçeği ile ölçüldüğünde ortalama 8.00±2.06 dir, Ayrıca 5 katılımcının bağımlılık düzeyi, 10 düzeyindedir(0-10).Bakıcılar tarafından bildirildiği göre, bakım alıcısının memnuniyet seviyesi 9.06±1.47 idi.Bakıcıların bakım verme konusunda tepkisi genellikle iyi bulunmuştur.Bu çalışmada bakım verenler bakım yükü ortalama 40.47±12.24 olarak belirlendi Bu yük orta-şiddetli bakım yüküne olarak değerlendirildi.Bakım verenin ölçekten aldığı bakım yükü puanı ile yaşı arasındaki anlamlı bir fark saptanmamıştır (p>0.05).

**Sonuç ve Öneriler**: Genel olarak, aile üyesine bakım verenler, para beklentisi olmaksızın gönüllü olarak bakım sağlayan kişilerdir. Bakıcı, ev ortamında arkadaşlara, eşlere, akrabalara ve yaşlanan ebeveynlere veya engellilere bakım verirler. Bir bakıcı, giyinme, yataktan kalkma, beslenme yardımı, ulaşım ihtiyacını sağlama ve bağırsak inkontinansına yardım gibi yardımlar sağlar.İnformal bakıcıların görevleri bir yük haline gelirse, toplum sağlığı hemşirelerinin doğru aile danışmanlığı programları sunarak bakım sağlayıcıların günlük faaliyetlerini izlemeleri ve günlük bakım rutinlerini yönetmelerine yardımcı olmaları gerekir. Hem bakıcının hem de bakım alıcısının yaşam kalitesini iyileştirmek için halk sağlığı hemşirelerinin temel işlevlerinden biri, yalnızca sağlık bakımı amacıyla aile bakımı sağlayıcılarını dinlemek ve onlarla çalışmaktır. Bu, hemşirelik okullarında gelecekteki hemşirelerin bakım yükünün aileler üzerindeki risklerinin farkında olmalarına yardımcı olacak kurslar önerilerek başarılabilir.

**Anahtar kelimeler**: bakıcının yükü, halk sağlığı hemşiresi, aile üyesi ve gayri resmi bakıcının yükü.

# CHAPTER ONE

## INTRODUCTION

The World Health Organization report on the prevalence of human diseases during the past decade has risen tremendously. The increase in population growth, especially in densely populated urban settlements has brought about some public health problems like; new strains of infectious diseases that may be caused by overcrowding, water, air or soil pollution due to human activities. Thus the need for public health studies(Pimentel et al., 2007).Until recently, only six infectious diseases (acute respiratory infections, human immunodeficiency virus/autoimmune deficiency syndrome, diarrhea, tuberculosis, malaria, and measles) are responsible for almost 90% of all deaths from infectious disease worldwide (WHO, 2005c). The world population rose from 1 billion in 1800 to 7.7 billion today, thus age specific mortality is of critical importance on population health (Roser et al, 2013). Among other public health concerns, the advancement in modern medicine has improved women health in the aspect of child bearing and its link to population growth, and this rapid growth has continued to pose a challenge in the healthcare system especially in countries that do not encourage and practice effective family planning methods. With rising mean in age; for example, diseases like dementia are a greater burden on individuals, families, and health providers (The Lancet, 2020). Currently the healthcare system depends on family caregivers due to rapid ageing in the general population, the increase in chronic health problems, and shorter hospital stays because of high cost of medicine(Roser et al 2013).

Care definitions differ according to the health situations of a care need individual. The medical-dictionary defines care as the services rendered by members of the health professional for the benefit of a patient. Watson (1988) defines care as; the moral ideal of nursing whereby the end is protection, enhancement, and preservation of human dignity.

The care theory has a different concept of care; Leininger considers caring to be in a cultural context’, that is; caring patterns are different transculturally.

Watson on the other hand concentrated more on the philosophic (existential-phenomenological) and spiritual foundation of caring, by viewing it from a morally and ethically point of view. Both Leininger and Watson argued whether there is a difference between generic caring and professional caring. Although most scholars define caring in their own context, a universal definition of care is not possible.

In the U.S., 86% of the caregivers are related to the care recipient and one third of the carer population care for at least a parent. The average age of a caregiver is 49, and 66% of this group are women, but men can also serve as caregivers.Most long term care is provided by family and friends in the home, and only 11% of the older population live in a nursing home in the United States (Hopkins medicine, 2020).In developing countries however caregiving may start earlier that 49 years of age, and this may be as a result of the socio economic status of the carer and carer family. In developing countries, the reality of caregiving in a context of "*compulsion*", is as a result of the low wages a caregiver earns. In Nigeria for instance, the ratio of the sick to professional health care providers is very disproportionate, the informal caregivers have taken up greater responsibilities in the care of their elderly, and this may lead to higher risk of deteriorating health status. These caregivers sometimes show signs of physical, social, mental, emotional problems (Buhse, 2008) and financial difficulties (Togonu-Bickersteth, 1989).

The care concept is a broad spectrum, which is categorized to fit the desired patients' care requirements. Patients care takes up several forms: Primary Care, specialty care, emergency care, urgent care, long-term care, hospice care, mental healthcare and many more (patient's navigator training, 2011). In order to understand the concept of care in nursing, it is necessary to identify the care concept in nursing. This concept involves five epistemological perspectives as; caring as a **human trait**, caring as **a moral imperative or ideal**, caring as an **affect**, caring as an **interpersonal relationship**, and caring as a **nursing intervention** (Morse et al., 1990).

- Nursing caring as a **human trait**: An example of Watson's caring theory is when a nurse springs into action by rescuing an accident victim found by the road side who might require some sort of resuscitation or first aid before the arrival of an ambulance. This is a typical example of a human trait in the form of nursing care with little medication or equipment in order to stabilize the accident victim. The nurse is connected to that person in that given moment and this moment is critical for the person's survival (The study mode, 1994).
- Caring as a **moral imperative** of nursing. In 1918, during the time of the influenza pandemic, volunteers were charged with a "moral duty to care". This made Florence

Nightingale famously declared that a moral character was essential for nurses when performing their duties. A typical example of amoral in nursing is the recent global pandemic of Covid-19 causing a public health crisis. This once more challenged the notion that nurses can carry out their moral duties freely and act in a manner that is constant with their personal and professional moral values. During Covid-19 pandemic, nurses all around the world were faced with innumerable obstacles in their capability to provide care, such as shortages of staff, equipment and beds were limited so nurses had to make excruciating choices about care rationing. Yet despite all these challenges of their own distress, nurses continued to bring the profession's caring essence into every contact with patients, while bearing witness to patients suffering, and yet providing comfort wherever possible (Bauce&Donius, 2020).

- Caring as an **Affect**. Nurse-related factors that can affect the relationship with a patient can be conditional constraints which are; emotional demands, imbalances in power, the frequency and intensity of care, the complexity of work and social norms (Lobchuk, 2006; Bahrammnezhad et al, 2014). Caring as an affect has many constraints, additional constraints can be: lack of good teaching models and curriculum on patient centered care, patient complexity, economic strain, inadequate education, no care continuity, no coordination and shortage of staff (Pelzang, 2010;Lobchuk, 2006; Quirke et al, 2011). Personality characteristics all affect the emotional adaptability and this can be dependent on the nurse's societal culture and ethical and religious beliefs (Huynh et al, 2008, Lobchuk, 2006, Bahrammnezhad et al, 2014).Nurses caring behaviors and actions, will determine patient satisfaction.
- Caring as an **interpersonal relationship**. As for interpersonal relationship and nursing, it is an interaction between two or more people who verbally communicate, and transfer values and energy from the roles they play in society (Borges et al, 2018).An example of caring as an interpersonal relationship, take for instance ***medical tourism***; this has started to become a highly sought after attraction in countries like, India, South Korea, Thailand, Mexico and The United States(Patients Beyond Borders, 2017). There are many factors as to why these destinations is popular; India for example has internationally trained and experienced medical staff, another example is cost of savings on medical procedures (as India is considered a cheap country), India is also heterogeneous country and has

different ethnicities, and economically India is booming and becoming one of largest economy in the world and also in the IT sector (Kaspar&Reddy, 2017). In (2017), Kaspar and Reddy said in order to draw patients to the trans-national hospitals in India two determinant factors played key role (1). An effort of demonstrating affordable world class care, (2). And this care understands and meets the practical and emotional needs of the patients. Many foreigners choose India because it is relatively cheap in regards to trans-national medical care, the patients also look for competence, empathy, and reliability in the caregivers (Larsen & Nilsson, 2018). Therefore interpersonal relationships between India and the rest of the world exist (Larsen&Nilsson, 2018).

- Caring as a **nursing intervention**. A nursing intervention is any task a nurse does towards a patient or for a patient (in-home care, 2019). Intervention is done to improve comfort and overall health of their patients. Nursing intervention falls into three parts: (i). Independent intervention e.g. a nurse performs these tasks on his or her own; like educating a patient on the importance of taking their medication as prescribed. (ii). Dependent intervention: instructions are given directly to the nurse from a physician e.g. prescription of a new medication to a patient. (iii). Interdependent intervention: this intervention process require multiple members of the medical care team in order for smooth outcome e.g. a patient recovery from ankle surgery, then prescription medication order comes from the doctor, and then administered by a nurse, and involves routine physical therapy by a specialist (in-home care, 2019).

This research study will focus oncaring as an interpersonal relationship by relating it with the stress and burden on caregivers when rendering caregiving services both in a hospital setting, community, and home setting.When discussing caring as a whole, three major theories serve as a guide in the nursing care act.

**Orem** theory on self-care deficit, self-care, and nursing systems. Orem’s theory emphasizes the continuous need of self-maintenance and self-regulation. The main caring function of Orem’s theory is the “helping system”. This means doing for another, and to support another physically and psychologically. Orem’s theory can be applicable to western cultures and societies, and may not be applicable in other multicultural societies(Benston, 2001).

**Watson** the theory of human caring. This theory promotes and explicates a transactional type of relationship between a caregiver and care receiver. Watson emphasized on the spiritual, emotional, and psychological dimensions of care(Benston, 2001).

**Leininger**theory of transcultural care diversity and universality. This type of theory depicts a culturally nursing care action that inclines with a patient's expectations and beliefs. Researchers have observed the increase in intergenerational support and its importance in modern society (Benston, 2001).

Understandably there are two main forms of care action in nursing which are formal and informal caregiving. A formal care is a transactional care service rendered to a care recipient (Nursing Centered, 2020). A formalcaregiver is trained to provide care for the elderly, disabled, or the sick, of which an informal caregiver cannot give (The Stano Law, 2015).Home care can also be called a formal care, this type of professional support services allows an individual to live safely in their homes while receiving professional care. These home care services assist people live independently, while still managing chronic health issues; or an individual who has special needs or living with a disability. Nurses, aides, and therapists may provide long or short term care in the home depending on the patient's needs (Bayada home care, 2020). These professionals provide assistance such as, dressing and bathing, managing tasks around the house, provide companionship, therapy and rehabilitative service. This type of care requires a professional nurse or aid worker and such services are expensive, so in order to save the cost of hospitalization many families choose a less expensive form of caregiving and assumed informal caregiving roles.

Informal caregiving takes different forms and this type of care service can be delivered by friends, relatives, children, and spouses. Informal care is provided to the elderly, sick and disabled in a non-professional way (Wanless, 2006).According to the French Handicap-Sante survey on disability and health (INSEE-DREES, 2008-2009), of the 3.9 million people aged 60 or over receiving regular care at home, 80% are helped by a close relation while 50% receive professional help (Soullier and Weber, 2011). The average time of care provided by informal caregivers amounts to 1h 40minutes per day compared to 0h 35 minutes from paid carers. On average informal caregivers help with four practical daily life tasks; professional carers with two (Fontaine, 2011). The care support network where the carers are unpaid plays an important role in the community, especially when caring for a dependent frail elderly person and people with disabilities within the community (Australian Institute of health and Welfare).

The educational level of family carers has some impact on how to care. The more educated an informal carer is, the probability of caring for a sick, elderly or disabled individual decreases (especially those that do not live with the care recipient) Machin&McShane (2001).

The advantage of being a family carer is that the safety of the care recipient is guaranteed; the quality of care will be high, and both caregiver and care recipient will share a unique bond (care.com, 2017).

One of the many care problems an informal caregiver may face is resentment or friction especially when caregivers do not get the necessary support from other family members. Carers UK (2017) reported that more than 600,000 people suffer from mental and physical ill health as a direct consequence of the stresses and physical demands of caring. A caregiver is a family member or any significant person who assists with most; if not all of the patients, daily care needs (Agrawal, 2013). Caregivers are faced with many daily problems. Studies have discovered the effects of caregiving burden on caregivers of the elderly. Ay et al., study found that anxiety and depression levels of caregivers of the elderly were significantly high. Kalınkara and Kalaycı found that caregivers experienced 50% burnout, which increased as the maintenance load increased. Njoku's study on the effects of caregiving on caregivers' stress levels discovered that they are faced with not only stress but also depression, anxiety, anger, despair, and hopelessness. Similarly, Kim et al., study on caregivers' of individuals with dementia found that caregiving burden led to depression and deterioration of their physical, emotional, psychological, and functional status. Many families are faced with the decisions of how best they can deliver care to a dependent relative, an elderly who is care dependent, or a sick family member in a home setting. Nonetheless, each family has their unique struggles when giving care to a dependent family member.

The community health workers, nurses, or nurse's aide should be able to provide the right support to the carers. On the primary level, public health nurses should create support groups and also educate family caregivers on how best to de-stress in order to reduce burden (Acton&Kang, 2001).Counseling sessions should be encouraged by the health provider. Counseling gives opportunity for improved quality of life for caregivers of stroke survivors (Visser-Meily et al, 2005). A simple telephone call helps reduce burden on the caregivers. Houts and colleagues

(1996) describes a prescriptive program that is based on problem-solving training and therapy, by using COPE (Creativity, Optimism, Planning, and Expert information), caregivers are able to plan better and manage psychosocial problems. COPE educates family caregivers on how to develop and carry out plans orderly which address medical and psychosocial problems, and this model also helps health professionals coordinate care plan. One goal health providers should aim to achieve is, the relaying of information in a clear, understandable way via verbal, written, and electronic methods. Providingthis kind of information can relieve caregiver’s distress, and clear any uncertainty about their family members’ illness, treatment and the type of care they may need (Given B&Given C, 1996). Many caregivers have no formal education or training on how to give the proper care to their loved ones, and this in turn may lead to misinformation about the right type of care to give and when to give such care.

In (2008), Pamela Wilson pinned caregiver’s education and training to its value in the health care system. The illiteracy of a caregiver on caregiving has tremendous effects on carers, which cause a great burden of stress on caregivers and the type of care they render. Despite the lack of education of most family caregivers, there is no special school of care for caregivers. There is no specific way for caregivers to prepare for the challenges ahead when giving care and its risk on family relationships, the stress it puts on individual and the individual health. A naive caregiver can make a costly mistake due to lack of the basic knowledge on informal care. Many caregivers experience very high levels of stress, and are unaware of its impact on their health, and the relationship problems that may arise between caregiver and care recipient.Studies have evidently shown that carers are more at risk of mental health problems, especially stress and depression(Shajiet al, 2010). American Psychological Association (2020) listed some common caregiving problems such as; conflict about care, balancing need for a healthy and sick family member, behavioral issues, interpersonal conflicts, lack of cooperation by care recipients, high level of stress of caregivers, relationship stress and burden.

Caregivers’burden has been described as a “state, impact or persistent difficulty resulting from the action of taking care of a dependent, elderly person, relative with a disability or some type of deterioration which threatens the physical and mental health of the caregiver, other family relations, the job, and the financial status of the caregiver” (Gaugler et al, 2000 and Pearlin et al, 1990 and Zarit, Reever, & Bach-Peterson, 1980).Studies have shown that caregiver’s burden correlates with negative attitudes towards the elderly (Morimoto, et al, 2003 and Zarit et al, 1980).Waking up every day and feeling dreadful and reluctant about caregiving is not uncommon for family carers, but this does not mean they do not love the person for whom they care for. One sign a caregiver should look out for is the tendency to yell or frequent emotional outbursts. Many caregivers feel guilt and are often too afraid to ask for help from health professionals. When caregivers lose control of their emotions, it is important for them to change their care plan to help reduce their burden and get rid of toxic work space by seeking the counsel of a health professional (Bursack, 2020). In 2020, the U.S report published by The National Alliance for Caregiving (NAC) and AARP, on caregiving said 36% of family caregivers consider their situation to be highly stressful. Also 49% provides more than 20 hours of care each week. It is important for caregivers from time to time to take a look at their circumstances to avoid going over the limit with their care duties. It is crucial for them to ask if they are rendering the best possible care, and at what cost. These steps will help ease the burnout or burden they constantly experience.

## 1.2. Aim of the study

The objective of this study will describe the level of burden caregivers experience when giving care to care need people, who requires physical, emotional, social, and economic support and also to determine caregiver experience .

**The purpose of this study will focus on:**

1. What is the level of burden exerted on family caregivers when dealing with care recipient individuals?
2. To determine and measure the level of burden amongst caregivers in North Cyprus?
3. To understand the relationship between caregivers and care recipients in North Cyprus?
4. What is the concept of care in North Cyprus?Do Northern Cyprus caregivers experience more positive impact than negative when giving care, and vice-versa?

# CHAPTER TWO

## GENERAL INFORMATION

### 2.1. The Care Concept

In the past, nurse theorists identified caring as a paradigm unique to nursing, and this makes caring the "core concept" of nursing. The care concept has no doubt great influence; on nursing philosophy, education, and research. Despite the complexity and significance ofthe caring concept, it remains elusive (Morse et al, 1990). In 1978, Madeleine Leninger, Jean Watson, and a group of doctoral students came together for the first conference to present research and philosophical ideas related to caring and nursing. These groups of people formalized the International Association for Human Caring (IAHC) in 1988, and they continue to meet every year to share research ideas, to reflect, and discuss advanced philosophical,ontological, and epistemological assumptions about caring.The yearly IAHC conferences provided opportunities to scholars around the caring discourse, the definition of caring, the meaning of caring, and the various caring theories. The IAHC members did not advocate for one specific caring theory but understood that nursing theories frameadvancedisciplinary knowledge, and the caring theories contain underlying ontological, philosophical, and epistemological assumptions about the nature of human caring (Marian et al, 2018). In the epistemological perspective of care, caring involves five levels:

1. **Caring as a human trait:** in this aspect caring is an innate human trait, the "human mode of being," (Roach, 1987) as part of human nature, and importance to human existence (Leininger, 1985&1984). All humans have the ability to give care, although this ability is not uniform. According to Leininger'scarative factors, the definition of caring as a human trait motivates nursing actions. Benner and Wrubel(1989) concur that caring is the basic way of being in the world from which all nursing practice evolves. However Orem(1985) views caring as actions by others that may become necessary when self-care requirements cannot be met. This theory emphasizes on the continuous need of self-preservation and self-regulation. Orem's caring theory functions as a***"help system".***Simply put; to do for another, and to support another physically and psychologically.

2. **Caring as a moral imperative or ideal:** This level explains caring as a fundamental moral in nursing (Brody 1988, Watson 1985). For instance Gadow (1985) and Watson (1988) stressed on the fact that nursing care action is about preserving a patient's dignity. It means, caring is adherence to commitment to maintaining a patient's integrity. Watson explains that caring actions of nurses with patients encountered are merely "approximations of caring" and not a pure form of caring (Watson, 1985 p34). She believes that the act of caring is an unattainable ideal. Nonetheless, theorist who support the human-trait perspective, describe caring as a moral imperative that provides the basis for all nursing actions.

3. **Caring as an affect:**Authors in this category define caring as an affect that the caring nature goes beyond emotional involvement with an empathetic feeling for the patient experience (Forrest 1989: Fanslow 1987: Bevis 1978: McFarlane 1976). Bevis considers caring as a feeling of dedication in which nursing actions are motivated. It focuses on the shared intimacy between a nurse and a patient (Bevis, 1978). Unfortunately caring as an affect may be jeopardized or devalued if nursing time with patients is limited by distractions of monitors, demand for technical skills, rejection and unresponsive behaviors from patients, all these and more may inhibit the development of a caring feeling towards the patient. It is advisable for nurses to refrain from being too attached or too emotionally invested in a patient as this may devalue the importance of caring as 'an affect' in nursing (Morse et al, 1990).

4. **Caring as the nurse-patient interpersonal relationship:** on this level of caring, authors believe that interpersonal relationship between nurse-patient is the essence of caring (Weiss, 1988). They believe that caring encompasses both the feelings and the behaviors occurring within the relationship (Horner, 1988). It means showing concern and giving the necessary support in the nurse-patient relationship (Morse et al, 1990).

5. **Caring as a therapeutic intervention:** in this category theorists have directly linked caring to the work of nurses more than any other theorist. The caring actions are specific on this level such as; attentive listening, patient teaching, patient's advocacy, touch, physical presence and technical competence (Wolf, 1986). It is important to acquire adequate knowledge and skill as the fundamentals for these caring actions as well as attaining congruence between nursing actions and the patient's perception of need (Morse et al, 1990). This caring action requires an

intervention method in order to access the patient’s needs. The implementation of this intervention includes open-ended questions (asking patients to describe how they feel) by the application of a questionnaire (Morse et al, 1990). In this stage of intervention, it is the patient who defines caring and its components. Thus researchers are able to delineate the concept of care (Swanson, 1988).

There are two main conceptualizations of caring which are; Watson theory of human care, and Leninger theory of transcultural care diversity and universality.

**Watson theory of caring:** the human caring includes values, a will and a commitment to care, knowledge, caring actions, and consequences. Watson further explained that, ‘the essence of the value of human care and caring may be futile unless it contributes to a philosophy of action, this action can transcend the value’. She believes that human to human caring interactions of nursing cannot be validated or understood using a positivistic, deterministic, materialistic mindset’ (Blasdell, 2017).Watson was able to acknowledge the difference between traditional science and nursing human science for caring.

In the traditional science context, caring is: Normative, Reductionistic, Mechanistic, Method centered, disease centered (pathology-physiology of the physical body), ethics of science, quantitative, nomothetic, concrete-observable, objective experience, bound by laws, givens, facts, human as object. While nursing human science for caring is:Ipsative, transactional, metaphysical-humanistic contextual, phenomena centered, person-experience centered, human responses to illness and personal meanings of human condition, human-social ethics-morality, is it more qualitative, relativism, probabilism, human as subject, subjective-intersubjective experiences, experience (meaning). Watson believes a nurse has to perform certain acts for her patients which are legally and ethically binding (Watson, 1988). Also she viewed caring action as a pure sense of dedication and commitment to the patient. To understand nursing as the science of caring, Watson formulated 10 carative factors. These are as follows;

1. The organization of a humanistic-altruistic system of values

2. The installation of faith/hope

3. The cultivation of sensitivity to one’s self and to others

4. The development of a helping-trust relationship

5. The promotion and acceptance of the expression of positive and negative feelings

6. The systematic use of the scientific problem solving methods for decision making

7. The promotion of interpersonal teaching-learning

8. The provision for a supportive, protective, and or corrective mental, physical, sociocultural, and spiritual environment

9. Support with the gratification of human needs

10. The allowance for existential-phenomenological forces.

These carative factors are linked to the basic human needs, human relationships, and health maintenance (Watson, 1979).

Watson's theory of human care involves three main characters:

1. Nursing within the context of human science and art;

2. Mutuality of person/self of both nurse and patients with mind body-soul gestalt, within a context of inter-subjectivity;

3. The moral ideal of the human care relationship in nursing which includes concepts such as phenomenal field, actual caring occasion, and transpersonal caring (Watson, 1985). The main aim of the theory is linked to the mental and spiritual growth for oneself and others, to find meaning in one's own existence and experiences, to discover one's inner strength and control, and to enhance occurrences as a way of transcendence and self-healing (Watson, 1985).While the Watson theory focus more of the interpersonal, and spiritual growth of self-health;Leininger explains that humans are caring beings and caring is a universal trait which is important to human survival. Leininger attributes caring as a human trait.From Leininger experiences as the founder of transcultural nursing, it enabled her to understand a culturally diverse setting and this led her to develop strategies on how to handle individuals who require care, but are from a differentrace, spoke different language, and practice different religions (Cohen, 1991). Leininger

garnered vital information, developed specific concepts and themes from anthropology in other proceedings to transcultural care theory (Cohen, 1991). She saw caring as an act that is to support, assist, or facilitate actions of care towards an individual or group of people to improve human lifeway (Cohen, 1991, p900). Leininger distinguished the generic care from professional care. She considered professional care to be cognitive and a culturally learned behavior, a process, techniques, or pattern that help improve an individual, family, or community health condition (Leininger, 1985). Leininger formulated the following assumptions about human caring, these are;

1. Human caring is a universal phenomenon, but expressions, processes and patterns vary among cultures
2. Every nursing care situation has transcultural caring behaviors, needs and implications
3. Caring acts and processes are essential for human development, growth and survival
4. Caring should be considered the essence and unifying intellectual and practice dimension of professional nursing
5. Caring has biophysical, psychological, cultural, social and environmental dimensions which can be studied and practiced to provide holistic care to people
6. Transcultural caring behaviors, forms and processes have yet to be verified from diverse cultures; when this body of knowledge is procured, it has the potential to revolutionize present-day nursing practices
7. To provide therapeutic nursing care, the nurse should have the knowledge of caring values, beliefs and practices of the clients
8. Caring behaviors and functions vary with social structure features of any designed culture
9.The identification of universal and non-universal folk and professional caring behaviors, beliefs and practices will be important to advance the body of nursing knowledge.
10. Difference exist between the essence and essential features of caring and curing behaviors and processes
11. There can be no curing without caring but there may be caring without curing (p.901).

In general, Watson and Leininger have different points of view of caring, they view nursing as a humanistic science, with the core concept of caring being the central field of nursing (Blasdell, 2017). Since both theorists share different ideologies, Watson focused more on the Philosophic (existential-phenomenological) and spiritual foundation of caring and emphasizes caring to be ‘the ethical and moral ideal of nursing’ (Cohen, 1991). Whereas Leininger pinned caring to a cultural context due to the fact that caring patterns can be different transculturally (Cohen, 1991). It is necessarily important to know that Watson and Leiningers’ educational background played a big part in how their theories were developed. While Watson bagged a doctoral degree in educational psychology in 1973,Leininger completed her doctoral study in which she focused on cultural anthropology. Each theorist has a different idea on generic caring and professional caring. For Watson (1988), she believes that caring is an interpersonal process between two people with transpersonal dimensions. “Transpersonal caring is when the nurse detects the subjective world of the patient, experiences union with it and expresses the union in such a way that both experience a freeing from isolation. This also implies that transpersonal caring is a spiritual space, by understanding each other’s life history. This simply means, both nurse and patient allows each other to enter a phenomenal field by a means of transcendence” (Cohen, 1991). In Leiningers’ view on generic and professional caring she views professional caring as a behavior that is learned cognitively and culturally, as a technique, or a process which assists an individual, family or a community by improving or by maintaining a healthy living condition (Cohen, 1991). For Leininger, the key element is that“human caring is a universal phenomenon, but the expressions, processes, and patterns differ among cultures... She placed caring in a biophysical, psychological, cultural, social and environmental dimension which can be studied and practiced in order to provide care holistically to people” (Cohen, 1991). Leininger strongly believes that human beings cannot exist without their cultural foundation and social structures. One important element of Leininger’s theory is the wide applicability due to the fact that ‘*theory generation’* may occur at multiple levels, be it at a macro range, middle range, and micro range. This means a researcher may enter and leave the model whenever they decide. Leininger categorized many of her constructs into taxonomy (Leininger, 1985). The purpose of this classification was to help nurses inconceptualizing, ordering, and studying different types of caring methods. For now the Leininger’s theory is the only theory that combines both theory and method and still defines different levels of abstraction and methodological approaches (Blasdell, 2017). The act of caring isn’t unique to the nursing discipline, but the specificity, and nursing goals focused on caring for people in a way that is congruent with the peoples culture, values, lifeway's, and patterns (Blasdell, 2017). Leininger defines nursing as a learned humanistic art and science that focuses upon personalized care behaviors, functions and processes directed towards promoting and maintaining healthy behaviors or recovery from illness (Cohen 1991). She emphasizes that the focus of nursing could be families, culture, individuals or society. On the other hand, Watson ideal definition of nursing which is both a human science and an art activity was derived from;

1. A philosophy of human freedom, choice and responsibility
2. from a biology and psychology of holism
3. An epistemology which accept not only empirics, but for advancement of aesthetics, ethical values, from one's intuition and process discovery
4. from an ontology of time and space
5. from the context of inter-human events, process and relationships
6. An open scientific view of the world (Cohen, 1991).

Swanson (1991), concur with Watson ideas regarding nursing and its role with client care. When defining nursing roles, Swanson included the environment as a key component by relating it with nursing, person, and wellbeing as the goals of nursing care (Blasdell, 2017). She stressed on the individual's life experience which is influenced by the genetic makeup, spiritual enrichment, and the capacity to practice free will (Swanson, 1993). Swanson sees humans as not stagnant in regards to their wholeness, but the ability for humans to continuously grow in self, ability to self-reflect, and sought to connect with others. Environment described in this context is according to specific situations (Swanson, 1993). In nursing, the environment isn't just the topography or climate, but a patient's environment, it could also be as a result of biophysical, psychological, cultural, political, economic, social, and spiritual influence. Most importantly a patient's environment may be considered the organs, or body tissues (Swanson, 1993). Swanson believes that nursing is a blend of information and knowledge and that, differentiate nursing from other professions whose practices includes caregiving (Swanson 1993, p.354). She posits five caring processes which are interconnected:

- Maintaining belief
- Knowing
- Being with

- Doing for
- Enabling

By maintaining a person’s belief; is the ability for one to progress through transitions and life events and look forward to a meaningful future (Swanson, 1993). An instance is when a nurse approach the patients with the idea that the developmental challenges of the patient has a personal meaning. Maintaining belief is the core foundation of nursing practice. This is to exercise faith through life’s obstacles, life’s transitions, and give hope when caring (Blasdell, 2017). Maintaining belief on an interpersonal level, nurses provides patients or patient’s family with physical and emotional safety by supporting them through tough life’s events. On Societal level of maintaining belief, nurses help patients get through experiences and focus on the future regardless of political occurrences in areas of care, and to facilitate the need for health care reform (Swanson, 1993). Swanson believes that “knowing is the boat that drives the beliefs of nursing/nurses to the lived experiences of those served” (p.355). Knowing gives justification for occurring events and it life’smeanings. Nurses must ‘know thyself’ in other to truly understand another person’s reality and to fully appreciate the capacity one may focus on the patients’ lived experience (Swanson, 1993). The term “being with” means to be connected emotionally to a patient. Being with is about been physically present, and also to be able to comfort and endure with patient. This is accomplished by spending reasonable time with patients, been attentive to patients need and gives reflective responses (Swanson, 1993). Argyris, Putnam, and Smith (1974) in agreement explained that, “action science is an inquiry into how human beings implement their doings’ in relation to one another. They see action science as basic research and theory building which is related to social intervention”.

**Dorothea E Orem self-care deficit nursing theory**: developed three concepts of care. They are interrelated, and by doing so created a different view forthe nursing care phenomenon.This theory is simple and easy to apply to a wide variety of patient daily care needs.

Orem’s assumption theories are;

1. People should be self-reliant and responsible for their care, as well as others in their family who need care
2. People are different from one another

3. Nursing is a form of action, and it is an interaction between two or more people.
4. Successfully meeting universal and development self-care requisites is an important component of primary care prevention and ill health
5. A Person’s knowledge of potential health problems is needed for promoting self-care behaviors
6. Self-care and dependent care are behavior learned within a socio-cultural context.

These three related parts are; **theory of self-care, theory of self-care deficit; and theory of nursing system.**The self-care theory is when an individual performs on his or her own behalf to preserve life, health and maintain wellbeing, having socio-cultural orientation, and to meet self-care requisites. A self-care requisites are associated with life procedures, to maintain integrity of human structure and function. These requisites are also called activities of daily living (ADLs). Human self-care requisites are as follows:

1. Maintenance of sufficient food, air, and water intake
2. The provision of care associated with elimination process
3. Finding a balance between activities and rest, also between solitude and social interaction
4. The prevention of hazards to human life and well being
5. To promote human functioning.

Self-care deficit, according to Orem nursing is required when an adult is limited or incapable to provide for themselves in their day-to-day life’s activities. This theory identifies five methods of helping; doing for others, acting for, guiding others, supporting another: providing an environment to improve personal development in other to meet future demands, and teaching another.

For Orem’s theory of the nursing system, it explains how the patient’s self-care needs will be fulfilled by the nurse, the patient, or by both. Under the nursing system three classifications were created to meet the self-care requisites. They are; wholly compensatory systems, partly compensatory systems, and supportive-educative systems. The systems are explained below.

- Wholly Compensatory Nursing System: this includes a complete care given to the patient by the nurse because the patient is unable to perform any of their self-care duties. Neonates, infants, and patients in coma belong to this nursing system (Burke, 2020).

- The Partly Compensatory Nursing System: in this strata, a patient can perform some but not all of their daily needs. An acutely ill patient who can still bathe their genital area and young child who can brush their teeth but not bathe properly fall in this category (Burke, 2020).
- Orem's Supportive-Educative Nursing System can also be called developmental nursing system. In this system the nurse only gives assistance and education to support the patient's self-care abilities (Burke, 2020). By doing this, the nurses separate the ADLs from *Instrumental* activities of daily living. Examples of ADLs are bathing, mobility, ambulation, toileting, personal care and hygiene, grooming, dressing and eating. While the *Instrumental activities of daily living* are more advanced than the basic activities; this includes…..grocery shopping, housework, meal preparation, and the communication with others using telephone, and a means of transportation(Burke, 2020).

Orem's approach to the nursing process, provides a manner to verify the self-care deficits and to define the roles of patient or nurse to meet self-care demands. The nursing process in this model has three parts. The first part is the assessment phase, by collecting data to determine the problems which need solving. Second part is the diagnosis phase, in this stage nurses create a nursing care plan. Lastly in this model the nursing process is implementation and evaluation. The nurse sets the health care plan into motion in order to meet the goals set by the patient and his or her health care team, and after that, evaluate the nursing care by interpreting the results of the implementation of the plan (Orem, 1985).

Leininger, Watson and Orem, main focus was on the formal/professional method of paid care actions by linking nursing care actions with persons, culture, and environment which professional health workers provide in a professional manner to patient and patient family. For the healthcare system to understand care as a whole, informal caregivers' actions and problems should be discussed, understood and analyzed correctly in order to effect positive change in the society. Informal caregiving families and friends are the backbone of the care system and has been so for a long period of time. Many of us think of "health care" as services provided only by medical professionals. However, for individuals who are suffering from chronic illness or disability, they depend on family members, friends or sometimes neighbors to assist with, toileting, shopping, eating, bathing and many more (DHHS, 1998). According to the US department of health and human service, 52 million Americans are informal caregivers. With this number of caregivers, it is important for policy makers, educators, clergy, and also the media to acknowledge informal caregivers role in the society.

Who is an informal caregiver? Despite the fact that informal caregivers are the backbone of the society, the exact numbers of informal caregiving are not available because two key elements that should play a vital role is missing:

1. An official definition of informal care
2. Official statistics on household production.

Nonetheless a report by the European Commission (Triantafillou et al, 2010) did identify the following criteria as a typical informal caregiver: having a close relationship with the care recipient, no professional training, no working contract, no equivalent pay, different caregiving duties, no official hours (working overtime with no pay), and no entitlement to social rights (Bauer & Sousa-Poza, 2016).

## 2.2. Gender Differences

Caregiving on employment, work time, and wages differs between men and women in the workforce. Carmichael & Charles (2003) explained that even though all caregivers are faced with low wages (Heitmueller&Inglis, 2007), which reduce the chances of them working paid jobs, only women in turn substitute their paid work with informal caregiving duties. Further research has shown that women tend to have weaker attachment to employment than their male counterparts (Bolin et al, 2008a). Van Houtven et al, (2013) however, contrary to these findings showed that only men providing personal care are 2.4% less likely to work, and more so women suffer a wage penalty and reduced working hours. Nguyen & Connelly (2014), in contrast found no gender differences. Carmichael & Charles (2003), said that, women are frequent caregivers, they provide care at higher intensity, and they experience higher social pressure to give care.

## 2.3. Importance of Informal Care

There is no exact price tag on being an informal caregiver, so it is difficult to compare a formal caregiving with an informal caregiving. Nevertheless many studies have tried to compare and valuate informal care monetarily using different methods to estimate an average price for care hours (Berecki-Gisolf et al, 2008). In the United Stated for example, Arno et al, (1999) investigated the prevalence of informal care and the amount of money needed to substitute all informal care with formal alternatives. In their approximation, they applied two sets of data from the mid-1980s and assumed constant caregiving ratios for the same cohorts until 1997. Hours of care was taken from the National Family Caregiving Survey, which assumes that, an average of 17.9 hours per week was spent on care. This set the valuing wage at $8.18, the mean of the minimum and average wages of a home health aide, and this means a total of $198 billion, which is equal to 18% of the total U.S health care expenditures as at that time. In a 2006 survey in Germany it was revealed that an estimated 7% (4.8 million) of the German population are informal care providers, this amounted to 4.9 billion hours of informal caregiving. For Dutch caregivers, Van den Berg and Ferrer-i-Carbonell (2007) totaled the monetary compensation of 1 additional hour would keep caregivers wellbeing constant.

### 2.3.1. Family Implication

Caregiving competes with relaxation time that is supposed to be spent with family members. The time for leisure is shortened because caregiving can last for hours or must be combined with a regular workday. Caring for a live-in elderly, not only influences family daily life but reduces the wellbeing of both caregivers and their family members (Amirkhanyan&Wolf, 2006). For example, few studies researched on the effect of caregiving on married couples. Bookwala (2009), discovers that adult caring daughters and sons, experienced less happiness in their marriage than those who take up the caregiving role. Also former experienced caregivers feel different than recent caregivers, and long-term caregivers experience more than non-caregivers, and this creates gender inequality for females in both categories. Meanwhile, Litvin et al (1995) stressed that, when care provision is exogenous, the double burden married caregivers feel can be counterbalanced if they show immense spousal support during the caregiving process. Brody et al (1995) found that the wellbeing among married caregivers is highest, while never married caregivers are less likely to co-reside with parents than their married counterparts.

### 2.3.2. Caregivers Implication

Informal caregivers are faced with burden and stress at different stages of caregiving. Many factors must be taken into considerations (Bauer & Sousa-Poza, 2016). It is important to know that care recipients usually prefer to live in their own homes, and this may require a willing family member to provide informal care or formal care support that is accessible, reliable, and affordable. It is important for aspiring caregivers to know that caregiving is a huge responsibility that is time consuming and stressful at the same time. Caring for a dependent person usually occurs at an older age, spouses are likely to be older themselves, and this will likely reduce their capabilities to care (Bauer&Sousa-Poza, 2016).

### 2.3.3. Caregivers in Employment

Some caregivers are employed in the job market while rendering informal care services to their loved ones, and this may affect their paid work. It means, opportunity costs of informal care are often linked with paid employment (Becker, 1965). In many parts of the world, caregiving is still seen as "women's work," this mean political efforts to increase female labor force participation will fail because women are tied to a caregiver role (European Commission (Eds.), 2011), and there are concerns that female labor force participation may likely reduce the willingness for informal care supply.

### 2.3.4. Caregivers Health

Most times informal care includes both the physical burden and psychological stress. Some researchers were able to distinguish between the psychological aspect of caregiving problems and the physical health outcomes of caregiving. Many studies focus more on the psychological outcomes. Some of these studies were able to measure and link caregiving and depression symptoms. Informal caregiving and psychological health are related because caring for a close family member may likely induce negative emotions linked to fear of loss and sympathy. Caregiving is a stressful job that requires huge physical effort, especially when dealing with mentally impaired relatives, who overtime has developed aggressive behavior. In order to ease physical and psychological burden, policy makers must be concerned for the individuals involved. Therefore is it important to promote, support informal care by increasing health expenditures. If these needs are unmet, caregiver's capacity will continue to yield low quality of care, or a reduced informal care supply and there may be a need for formal care demands (Bauer&Sousa-Poza, 2016).

### 2.3.5. Caregivers Physical Health

Many problems can arise when physically carrying out strenuous tasks to support a dependent family member. Informal caregiver's physical health outcomes has been linked to informal caregiving problems as follows:

- Caregiving often need physically demanding work over a long time period, and this can lead to musculoskeletal injuries, or aggravation of arthritis
- Most times caregivers do not take proper care of themselves, and by doing so ignore leading a healthy lifestyle
- Caregiving increases stress and also lowers psychological health, which will likely manifest as hypertension and cardiovascular disease (pinquart&Sorensen, 2007).

### 2.3.6. Caregivers Factors

There are different factors that influence the caregiving perception. A caregiver's socio-demographics (gender, age, education, and relationship with the care recipient), other factors are, quality of life, depression, stress, and perceived health. Marco et al, 2010; Mehta, (2005) found that female caregivers are generally more depressed, more stressed and with a lower mastery than men. Kuuppelomaky et al, (2004) and Ekwall et al, (2007) discovered also that female unprofessional carers are more unsatisfied than male. Many studies have considered caregiver's age as a determinant factor for positive or negative outcome of elder caregiving. Kim et al, (2006) and Mafullul&Morris et al, (2000) found a high level of burden in elderly caregivers, but this variable was highest in younger people. Another determinant factor is the level of education and its influence on caregivers, Kim et al, (2007) showed that perceived benefits of caregiving were higher in less educated caregivers. An educated caregiver displayed a more positive impact (Bien et al, 2007). The relationship caregivers and care recipient share is a factor that can either improve or worsen caregiving impact. Koerner et al, (2009) noticed that spouses of older adults received more benefits from caregiving than other caregivers. As for (Bein et al, 2007; Savard et al, 2006) they reported satisfaction (more positive) in spouse caregivers than adult children caregivers. Sewitch et al, (2004) found that spouses and the adult children caregivers of older adults were most vulnerable to the negative impact of caregiving and they are less satisfied by caregiving. Many research findings have pinned depression, stress, quality of life, and health of caregivers. The negative impact of caregiving is related to poor health, and depression (Kim et al, 2006; Lai, 2009). All of the above problems are also linked to cognitive, functional, and behavioral problems in caregivers (Kim et al, 2006; Tibaldi et al, 2007).

Positive and negative impact in caregiving can be affected by factors such as time of care, time from caregiving, social restriction, living space and environment, and expenses due to giving care (Vellone et al, 2011). Some authors found that overtime, the negative impact of caregiving is stable and does not change (Levesque et al, 2008: Martinez-Martin et al, 2008a). Other studies found that the more time caregivers spent in caregiving, the less they experience a negative impact (Nir et al, 2009). For caregiver's restriction and social isolation, Smith et al, (2009) reported that people who are not spouses of the care recipient suffer more from social restrictions. In perception of the living place of caregivers, some studies found that rural caregivers of older adults are more burdened, they find it difficult to access formal support services, and have poor health conditions than those carers in urban areas (Bedard et al, 2004; Bien et al, 2007). While some authors suggest living place does not affect the way caregiving is perceived by the care recipient (McKenzie et al, 2010). Many studies have shown that the living expenses of caregivers increases, while their income decreases. Especially when the care receiver has low ADL abilities (Kang et al, 2007; van den Berg et al, 2008). Although different studies have demonstrated variables that can have a positive or negative impact on caregiving of older adults, their result findings are not consistent (Vallone et al, 2011).

## 2.4. Description of a Caregiver

How can we identify a caregiver? What makes a family member a “family caregiver”? There are questions surrounding who really is a caregiver, and the type of care they give. How can community health nurses give the appropriate support to this population group? (Reinhard et al, 2008). Family care giving raises safety issues in two ways that should concern nurses.

- Firstly caregivers are sometimes called “secondary patients”, who need guidance and protection.
- Family caregivers are unpaid providers who most times need counsel on how to become competent, and a safe voluntary worker to help protect their family members from harm (Reinhard et al, 2008).

The term ‘family caregiver or informal caregiver’ means an unpaid family member, a friend or a neighbor who manages tasks, and provides care to an individual who is care dependent. Most caregivers are women but at least 40% of caregivers are men (DHHS, 2003), this growth demonstrated a 50 percent rise in male caregivers between 1984 and 1994 (Spillman&Pezzin, 2000). MetLife Mature Market Institute (2003) talked about male caregivers becoming ever present in different tasks such as managing finances and arranging care, as well as direct assistance with more intimate care.

### 2.4. (I) Caregiver Responsibilities

Caregiving can be short term (during acute illness) or long term (when an individual is chronically sick), especially after hospitalization, and this can go on for 40years with a chronic care need person. On average, informal caregivers devote 4.3years in caretaking of this individual (Donelan et al, 2002). Many caregivers provide 8 hours of care or more every week, and 1 in 5 provides more than 40 hours per week (AARP, 2004).

In many research studies, assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) are conceptualized terms in the research field , but this cannot equate to stressfulness and the complexity of caregiving (Reinhard, 2004). For example assisting with bathing does not capture bathing a person who is resisting bath (Sloane et al, 1995; Rader et al, 2006). Helping out with medication does not include the struggle or hassle of medication administration (Travis et al, 2000), especially with those who take multiple medications every day, be it injections, inhalers, eye drops etc. Making a decision for a care need family member is stressful. As an informal caregiver, supervising people with mental illness (dementia) and being a firsthand observer in problems, such as reaction from a medication is a serious problem and daunting task (Levine et al, 2003). As a carer playing the role of a nurse or medical examiner can be frightening. Roles like managing urinary catheters, skin care around the central line, gastrostomy tube feedings, and ventilators is anxiety provoking especially as a beginner. Many family carers are unprepared for caregiving as they have inadequate knowledge to deliver proper care, and most of the time get very little guidance from a formal nurse (Bucher et al, 2001; Schumacher et al, 2000). It is important to know that nurses and family caregivers rarely agree on a specific needs or problem during hospital administration or discharge, (Rose et al, 2000) this is because nurses are unaware of the strengths and weaknesses of both the patient and caregiver. Inadequate skills and knowledge can make caregivers unfamiliar with the type of care they must provide when needed. A family carer, if not well equipped may not know the community resources available for use and this may result in neglecting their own health care needs, and can lead to deterioration of the health and wellbeing of carers (Given et al, 1994).

When discussing caregiver's problems it is stated that caregivers get little or no help from health care professionals in tasking managements. One of the greatest challenges for family caregivers is communicating effectively with nurses and other health workers in the hospital setting, and this can be a difficult caregiver-to-care recipient transition when discharged (Levine, 1998). Naylor (2003) reviewed nearly 100 studies published between 1985 and 2001, and confirms that breakdowns in care during transition yielded negative outcomes. The effective discharge planning is hindered by gaps during communication between the hospital and community interface, and hence delays occurred in sending information back to the physician (Dunnion&Kelly, 2005). Many caregivers felt that they were not prepared upon discharge hence, they faced a lot of emotional challenges. They feel abandoned at critical times (Levine, 1998).

### 2.4. (II) Caregiver's problems

The lack of attention to caregivers is a serious bridge gap in the healthcare system, and this has led to serious underlying problems for carers. Informal carers are hidden patients themselves, with serious physical and mental health consequences, due to the demanding nature of the tasks they perform for care receivers. There have been reported cases of premature deaths among caregivers (Schulz&Beach, 1999; Schulz et al, 2001). Given and colleagues (Given B et al, 1994; Given C et al, 1993) and Kurtz and colleagues (Kurtz et al, 1994) found that family carers experience a great amount of negative physical consequences as the patient illness progresses. As for elderly spouses who experience stressful caregiving demands, they have 63percent mortality rate than non-carers within the same age group (Schulz&Beach, 1999). The deterioration of caregiver's health is associated with caregivers who perceive themselves as burdened (Schulz & Beach, 1999). The strains, and burden caregivers experience is related to caregiver’s own poor health status, unhealthy living (smoking), and high use of prescription drugs (Beach et al, 2000). Authors found that caregivers are at risk of fatigue and sleep disturbances, lower immune functioning, slow wound healing, high blood pressure, and they are at high risks of cardiovascular disease (Lee et al, 2003). All these lead to great distress and burden.

### 2.4.1. Nurses Roles

Family caregivers need awareness and preparedness to meet the demand of the new roles. They need physical, psychological, social and spiritual support (Grant&Ferell, 2012).The importance of a family caregiver can be seen at all times; an example is a patient with hematological cancer treated with hematologic cell transplant, this patient is easily susceptible to infections due to lowered immune system, and they are physically vulnerable when discharged, they loss appetite and the ability to eat decreased. This may result in dehydration, and nutritional failure. Hence the need for a family caregiver (Grant&Ferell, 2012).Studies have shown that family caregivers suffer emotionally and are exposed to different health problems. For instance, high levels of depression is seen in caregivers (Braun et al, 2007), Increased risks for coronary heart disease, or stroke have been reported in spousal caregivers of cancer patients (Ji&Zoller et al, 2012). Thus the need for nursing education and support of family caregivers. It is important for nurses to educate and guide caregivers on how to properly care for their loved ones and most importantly how to maintain their own health status.

### 2.4.2. Nurses Scope and Delegation

For nurses, it is necessary for delegations to occur between nurses and patient family after hospital discharge as this gives nurses the authority to heal while also caring for the needs of the patient family. There are two governing laws that guide nurses so they can be efficient on their delivery methods. They are:

- ✓ Increases practice scope and allows advanced practice registered nurses (APRNs) to serve as primary or acute care providers.
- ✓ It allows nurses to delegate certain tasks and transfer authority to trained home care professionals and be in direct contact with patients.

**Respite Care:** increases services which allow family caregivers to take a break when needed.

**Workplace Flexibility:** by delegating, different bills should help working caregivers find a balance and responsibilities at home and work. Flexibility should be granted from state and federal government to families. Also medical leave should be given to caregivers through employers' paid/unpaid leave policies (AARP, 2014).

### 2.4.3. Planning of Care

The decision making process for treatment of patients is important for nurses, and nurses need to think critically when assessing patients and identify potential problems so proper recommendations and actions can be taken. As the final treatment decisions are made by professionals (doctors or specialists), it is vital for nurses to communicate information regarding patients' health effectively. This is due to the fact that nurses are the most familiar with individual patient situations as they monitor their signs and symptoms regularly, so their collaboration with other team members is very important for the best patient's outcomes (Smith 2019).

### 2.4.4. Patients Education and Support

Nurse's responsibility is to help patients understand their health, illness, medications, and treatments by educating them about the essence of their health moving forward, this is to enable patients take control of their own treatment when discharged. Nurses should patiently explain to families or caregivers what to do and what to expect when they leave the hospital setting. They should be supported and shouldn't be afraid to ask questions when situations are unclear to them, and also seek additional information if needed (Smith, 2019). More than half of family caregiver's constantly perform medical/nursing tasks, such as managing medications, wound care, applying monitors, or ostomy care (Reinhard, Young, Levine et al, 2019). All of these tasks are typically performed by registered nurses in hospital settings. Over decades the healthcare system has continued to evolve, this increases family caregivers taking up more professional roles to give support to their sick and injured in the home/ community, and without the instructions or guidance from a nurse professional. While there are many challenges, nurses are leading in several initiatives intended to support families and aim to protect caregiving in communities. In 2012, the AARP public Policy Institute and the United Hospital Fund conducted the ever first nationally representative, population-based online survey of family caregivers to learn what medical/nursing tasks they perform (Reinhard, Young, Levine et al, 2019). The report was then updated in 2019 and released as, *Alone Revisited: Family Caregivers Providing Complex Care report* (Reinhard, Young, Levine et al., 2019). The report collected information about seventeen medical/nursing tasks performed by family caregivers. The report finding provided an insight into the challenges necessary to support those providing care in the home. The term "medical or nursing tasks" was picked as a border term instead of nursing tasks, because only registered nurses perform such tasks. One common response family caregivers gave was "on my own" when asked how they learned to give care, and one of the common task performed was managing incontinence with disposing briefs; preparing special diet; giving enemas; using assistive devices for mobility; use during medical equipment; and managing medication (Reinhard, Young, Levine et al, 2019). All of these tasks' complexity, and care recipient risk increased and this also increased health professional's involvement in the affairs of family style caregiving. When family caregivers were asked what would likely make their jobs easier especially when performing; suctioning, mechanical ventilation, home dialysis, and urinary catheters; their response was, more and better instruction was the most common reply. These caregivers worry about making mistakes, especially managing medications, using meters (monitors), or performing wound care. Family caregivers complained about the difficulty controlling pain and they have concerns about giving too much or too little pain medication (Reinhard, Young, Levine et al, 2019).

### 2.4.5. Patient Advocacy

Patients are nurse's first priority. The role of nurses is to advocate for the interest of patients, and to help maintain patient's dignity throughout treatment and care. One of the ways this can be done is for nurses to suggest treatment plans for patients, with collaborating with other health professionals. AARP in 2014 launched a new campaign, to support caregivers with help at home, and also at the workplace to provide protection. By working with governors, state legislators, policy makers, and community partners AARP is still fighting to advance options that will help caregivers. Here are some ways to advocate for family caregivers:

The CARE (Caregiver Advise, Record, Enable) acts supports family caregivers when their loved ones go into the hospital and during transition in the home (AARP-2014).

Financial Caregiving: This bill helps family caregivers navigate financial challenges. Under this umbrella are;

- ✓ The Uniform Adult Guardianship and Protect Proceeding Jurisdiction Act….this ensures the state honors laws regarding this individuals
- ✓ The Uniform Power of Attorney….it gives power of attorney laws protect vulnerable adult, and provide tools for caregivers to make important financial decisions
- ✓ A modest caregiver tax credit….it gives family caregivers relief when they use their own money to sponsor their loved ones
- ✓ Home and Community Based care….protect caregivers, and help adult who have access to state funded services at home, like the adult day care.

How can nurses support family caregivers? By educating current and future nurses on how to identify and support families. This should be an essential for nurses and such course should be included in the nursing curriculum. The nursing curricula should address these problems both in an emotional context and in practical skills, this will help nurses understand better and give support to caregivers and caregiver families.

Some examples of ongoing support outlets are; - **John A Hartford Foundation.**

The National League for Nursing has developed many**ACE**(Advancing Care Excellence)for Caregivers are currently identified as;

- ✓ Family Centered Communication Strategies in Family Caregiving
- ✓ Positive Aspects of Family Caregiving
- ✓ Supporting Millennial Providing Care for an Adult
- ✓ Technology Support for Caregiving of Older Adults

It is important for nurses to not only prepare family caregivers for hospital discharge, but they need to ask questions about family caregivers concerns. Now is the time nurses upgrade their methods of care by providing clear and supportive communication, by including education in “teach back and “show me” methods (Nigolian&Miller, 2011).

# CHAPTER THREE

## MATERIALS AND METHODS

### 3.1. Study Design

This study was conducted as a mixed study type (Qualitative and Quantitative), and ran through October 2020 – February 2021.

### 3.2. The Study Site

### Study Location Description

Study site was in a community in Lapta in Turkish Republic of Northern Cyprus. It is a small community of about 101 families. Each family has at least four lived-in family members, which consist of father/mother, children (daughter or son), with grandchildren, and most families live in farm houses. Many of the said families have retired parent(s) or grandparent living with some form of physical or mental disabilities. This community is situated in a mountainous region in Lapta, and it has one primary health care center, and the nearest hospital is about 1008km.

### 3.2.1. Study Population and Sampling

A potential participant was reached out to in a small community via a telephone call before a face-to-face interview meeting, during the oral interview, this participant was asked to recruit other known family caregivers who live with their care recipient (a snowball method was applied). The said participant brought in 6 potential subjects, 2 people out of this 6, further introduced 6 more potential subjects for this study. A total number of 17 people participated in this study.

### 3.2.2. Inclusive Criteria for Research Sample

1. Turkish speaking
2. Must be a family member or employee caregiver
3. Must have at least six month experience of caregiving
4. Should be a full time caregiver or part time caregiver

### 3.2.3. Exclusive Criteria for Research Sample

Any participant who has Less than 6 month experience in caregiving was not included.

## 3.3. STUDY VARIABLES

This study analysis was based on both a dependent and independent variables.

### 3.3.1. The dependent Variable

Zarit Burden scale mean point

### 3.3.2. The Independent Variable

Socio demographic characteristic (age, gender, education, etc.) and open ended questions response.

## 3.4. DATA COLLECTION

### 3.4.1. The Socio Demographic Questionnaire

The personal information form was prepared by the researcher according to literature (Turkish Journal of Geriatrics; Korkmaz&Firat, 2020). All personal information was included in the socio demographic section of the questionnaire. They are as follows; age, level of education, marital status, number of children, employed, unemployed and or a full time caregiver, how many people do you care for, do you live with your care recipient, why do you give care, what is your daily routine. The Socio-demographic questionnaire was applied, the form contains two sections (open ended part and socio demography part). Refer to appendix 1 to see enclosures.

### 3.4.2. The Zarit Burden Interview Scale (ZBI)

The ZBI scale was developed by Steven Howard Zarit in 1980 to evaluate caregiver burden, it consist of 22 items scored on a five point ordinal Likert-type scale (0: never, 1: rarely, 2: sometimes, 3: frequently, and 4: nearly always), and then, the ZBI Turkish scale section which contains 22 questions: where (0) means **no**, (1) means **rarely**, (2) means **sometimes**, (3) means **quite often**, (4) means **almost always**. Permission was granted to use the Turkish ZBI scale. It was received from Pamukkale University, Faculty of Health Sciences, Department of Public Health Nursing, Denizli, Turkey. From Dr. Öğr.Üyesi Fadime Hatice İNCİ and Asst. Prof. Fadime Hatice İNCİ.

**3.4.3. Visual Analog Scale:** The Visual Analog Scale (VAS) is used to convert some values that cannot be measured numerically into digital. To both ends of a 100 mm line.Two end definitions of the parameter to be evaluated are written and the patient is asked to indicate where his condition is appropriate on this line by drawing a line or by placing a point or pointing. The length of the distance from where there is no level of dependency or satisfaction to the point that the caregiver marks indicates the feelings or addiction level felt by the caregiver.

### 3.5. STUDY PRACTICE

At first a telephone call was placed to an informal caregiver, then a face-to-face meeting was scheduled. Meeting was carried out in a children's park and all covid-19 protocol was observed including social distancing and wearing of facial masks. An interpreter was also present on the scene to help convey messages back and forth between researcher and the caregiver. The discussion was for 15 minutes. Researcher proceeded to hand out the questionnaire form and the time spent for the caregiver to answer all questions was 30 minutes. In total 45 minutes was spent with the caregiver. After that, the caregiver volunteered to connect researchers with other family caregivers in a small community of about 101 residents who are Cypriot indigenes. Participant's cooperation was acknowledged and they were thanked for their cooperation and time.

### 3.6. EVALUATION OF RESEARCH DATA

Data analysis was conducted using SPSS (Statistical Program for Social Sciences) statistical software version 18.0 for windows was used and data was coded, edited, fed and analyzed using PC (personal computer). Descriptive statistics was applied using numbers, percentage, arithmetic means, and standard deviation for the collection, analysis organization, interpretation and presentation of data. Open ended question response was examined and classified.The data was analyzed with content analysis and written as raw data. The compatibility of the raw data with the theme was determined by the researcher. Qualitative analysis of the validity of the created themes. Opinion was received from an expert who conducted research.

### 3.7. ETHICAL CONSIDERATIONS

For research to be conducted, permissions were obtained from the Near East University Ethics Committee (YDU/2020/-ANNEX 3), App 5 and the Near East University Faculty of Nursing

(ANNEX 4), App.6. After formal introduction, the researcher explained the purpose of the study by verbal communication, and in writing in other to obtain verbal consent from participants (ANNEX 5).

## 3.8. LIMITATIONS OF THE STUDY

This study was carried out during a global pandemic (covid-19) and hence study sample was limited.

# CHAPTER FOUR

## FINDINGS

**Table 1. The Socio-demographic characteristics of a caregiver (n=17)**

| **Socio Demographic Feature** | | **n** | **%** |
|---|---|---|---|
| **Gender** | Female | 17 | 100 |
| **Education Level** | Primary and Lower | 1 | 5.9 |
| | Secondary Education | 7 | 41.2 |
| | Higher Education and above | 9 | 52.9 |
| **Marital Status** | Married | 11 | 64.7 |
| | Single | 6 | 35.3 |
| **Having Children** | Yes | 14 | 82.4 |
| | No | 3 | 17.6 |
| **Are you responsible for another job** | Yes | 7 | 41.2 |
| | No | 10 | 58.8 |
| **How many people do you care for** | 1 | 15 | 88.2 |
| | 2 | 2 | 11.8 |
| **Reason for giving care** | Volunteers expecting some compensation | 11 | 64.7 |
| | Volunteering | 4 | 23.5 |
| | Financial gain reasons | 2 | 11.8 |

**Table 1**illustrates the distribution of some of the socio demographic data of caregivers. In the marital status criteria, 64.7% (n=11) were married, while 35.3% (n=6) were single. The level of education of family caregivers shows that, the number of people that attained higher education and above were the highest in the demography at 52.9% (n=9), while the lowest number of people with only primary school education was at 5.9% (n=1), and participants with a secondary school leaving certificate is at 41.2% (n=7). 82.4% (n=14) said they have children and still give care to their loved ones, then individuals with no child are lower at 17.6% (n=3), and said they are able to care for their loved ones though it is a difficult task. In another group, when asks if participants are responsible for other jobs apart from caregiving...they responded as saying: 58.8% (n=10)said No, they do not have any other job; while 41.2% (7) claims; Yes...they are gainfully employed and still provide care for their relatives. In the cause of study participants were asked how many people they care for: 88.2% (n=15) said they care for only 1 relative, while 58.8% claimed they care for 2 persons this was rated at 11.8% (n=2). Family caregivers

during the time of interviewing were asked if they have a particular reason for giving care. Only 11.8% (n=2) said they are in it for financial gains, 23.5% (n=4) are volunteering without strings attached, while the other group 64.7% (n=11) which score the highest claims they are volunteers and also they expect some forms of payment in return.

**Table2.Caregivers socio-demographic characteristics of daily activities(n=17)**

| Social demographic feature | Min | Max | SS |
|---|---|---|---|
| **Age** | 31 | 75 | 52.65±12.17 |
| **Care period (years)** | 1 | 40 | 10.12±11.36 |
| **Daily maintenance time** | 3 | 24 | 16.82±8.57 |
| **Time spent on daily cleaning** | 0 | 5 | 2.47±1.50 |
| **Time spent on daily shopping** | 0 | 4 | 1.12±0.92 |
| **Time spent on daily physical care** | 0 | 5 | 2.35±1.41 |
| **Time spent on daily psychological need** | 1 | 12 | 4.35±3.51 |

In the socio demographic feature on care routines, the mean age that provides the most care in this study was, (ss =52.65±12.17). When comparing the number of years care has been provided by caregivers to daily maintenance time, the mean cumulating was totaled at (ss =10.12±11.36; 16.82±8.57) this goes to show that caregivers have spent more time in care than the actual care period. When caregivers explained their time of daily self-care; the time spent on daily cleaning was (ss =2.47±1.50), while time spent on physical care was (ss =2.35±1.41), this is closely related to the amount of time caregivers spent on both tasks. While the lowest amount of time spent on as tasks was spent on shopping at (ss =1.12±0.92). On the psychological need of caregivers the average time spent on self was (ss =4.35±3.51).

**Table 3. Socio demographic characteristics care recipient**

| **Socio demographic feature** | | **N** | **%** |
|---|---|---|---|
| **Gender** | Female | 11 | 64.7 |
| | Male | 6 | 35.3 |
| **Education level** | Primary and Lower | 12 | 70.6 |
| | Secondary education | 3 | 17.6 |
| | Higher Education and above | 2 | 11.8 |
| **Care share duties with who** | Yes | 9 | 52.9 |
| | No | 8 | 47.1 |
| **(n=9)** | Father /brother/son | 6 | 66.6 |
| | Professional caregiver | 3 | 33.3 |

The number of female caretakers at the time of this study was 64.7% (n=11), while the male caretakers was at 35.3% (n=6), this shows that more women were cared for. Many of the study correspondence have primary/lower certificates in the education level both gender scored at, 70.6% (n= 12), While on the secondary level both male and female participant scored 17.6% (n=3), also fewer caretakers have higher education degrees and they represent only 11.8% (n=2) of the total group. When asked if caregivers of this study share their care duties; 52.9% (n=9) said yes they get help sometimes, and 47.1% (n=8) claimed they get no assistance in providing care to their loved ones. Furthermore they were asked who they share their care duties with 47.1% (n=6) say they share responsibilities with their father/brother/sons; while 47.1% (n=3) said they share care responsibilities with a professional caregiver.

**Table 4. Comparing dependence level and satisfaction level of care recipient**

| Socio demographic feature | Min | Max | SS |
|---|---|---|---|
| **Age** | 21 | 960 | 64.41±26.80 |
| **Dependence level of the care recipient** | 4 | 10 | 8.00±2.06 |
| **Satisfaction level with regards to** | 5 | 10 | 9.06±1.47 |

The dependence level of care recipient on minimum is 4 and maximum is 10, while satisfaction level minimum is 5 and maximum is 10: for the (ss = 8.00±2.06) dependence and (ss = 9.06±1.47) on satisfaction level. This shows that there is a slight difference in both dependence and satisfaction level of the care recipient.

**Table 5.Average care burden score of participants(n=17)**

| **Care burden scale** | **Min** | **Max** | **SS** |
|---|---|---|---|
| | 0 | 88 | - |
| **During care** | 16,00 | 61,00 | 40.47±12.24 |

In this scale, the care burden at the minimum level was 0 and at maximum level was 88 (high burden on care providers), while employed caregivers at minimum showed 16.00 burden level and on maximum showed 61.00. This goes to show the level of stress exerted on individual who give care. The mean average of caregiving burden was totaled at (ss =40.47±12.24). This denotes a clear difference on caregiver burden in this study.

**Table 6.Care recipient dependence level and disruption behavior during caregiving (n=17)**

| Participants | Average score | Dependence level | Addiction cause | Caregiver | Disruption Behavior |
|---|---|---|---|---|---|
| **1** | 34.00 | 9 | 21 age physically disabled | Mother | Do not complain |
| **2** | 34.00 | 10 | 96 old elderly | Daughter | Being told |
| **3** | 36.00 | 10 | 40 physically disabled | Mother | Has a disability and cannot react |
| **4** | 40.00 | 6 | 65 aged due to surgery | Daughter | Don't get angry |
| **5** | 42.00 | 10 | 28 aged physically disabled | Mother(father helping with care) | Don't talk when angry |
| **6** | 61.00 | 10 | mother:75 father:78 maternal dementia patient | Daughter | Don't become nervous |
| **7** | 16.00 | 5 | 73 years old leaving alone | Caregiver | Warn |
| **8** | 46.00 | 10 | 72 years old Alzheimer patient | Wife (also has a caretaker) | No reaction |
| **9** | 30.00 | 10 | 82 years old Alzheimer patient | Daughter (also has a caretaker) | Don't get angry |
| **10** | 22.00 | 8 | 92 years old elderly and reduced physical activity | Daughter (also has a caretaker) | No reaction |
| **11** | 38.00 | 8 | 89 years old elderly and reduced physical activity | caregiver (daughter also help with care) | Does not complain or say negative word |
| **12** | 52.00 | 9 | Physical and mental disability | Mother (father and brother help with care) | Throwing tantrum |
| **13** | 53.00 | 8 | mother:80, father:82 with age mother has Alzheimer, father has Parkinson | daughter(other sons also help with care) | Not calm always, and sometimes cries at spouse |
| **14** | 34.00 | 5 | 85 years elderly with limited disability | Bride | warn |
| **15** | 56.00 | 10 | 96 years old Alzheimer patient | Grandson | Don't experience anger |
| **16** | 39.00 | 4 | 66 years old CA had operations +dialysis patient | Daughter | Sulk |
| **17** | 55.00 | 6 | 74 years old Alzheimer patient | Daughter | Refuse eating |

Seven participants share the same dependence level when measured on the scale of (0-10), they are participant number 2, 3, 5,6,8,9, and 15 respectively. Each of these individual scored 10 on the scale, and it is also the highest level of dependence in this study.

**Participant number 2** is a 66 year old female and a restaurant owner, who provides daily care for her very elderly father. The difficulty the caregiver experienced during time of care was measured on a scale of (0-4), and scored an average of 2. The caregiver expresses inability to make decisions sometimes, she stated that she finds it hard to care for her family and her job at the same time.

**Participant 3** is a 69 years old mother who cares for her 40 year old physically disabled child. When asked about caregiving problems she stated by saying her child is disabled and expresses no reaction when care is ongoing. When asked about her difficulty level in time of care she says she suffers from indecision on many days, she also faces economic strain, and has no time for herself care and also it was determined that the difficulty she experiences was 3 points when measured on the burden scale of (0-4).

In this category a mother and father share care responsibilities. They look after their 28 years old son who is care dependent. The mother is 56 years old and her husband is 63 years of age. Since they have very high dependence, **participant number 5**scored very high on the scale measurement of (0-4) and scored 4 points. They were asked about their difficulty level during time of care; they said although they do not need help, but they feel angry sometimes, they have no private or social life, they feel tension between them. Due to care the mother had to quit her teaching job to constantly see to her son’s need, while the father works part time on the farm. They both say they are not afraid of what the future might bring for them.

A 42 years old female banker’s care responsibilities are towards both of her parents’ father aged 78 and her dementia mother aged 75. **Participant number 6** difficulty level was measured on a scale of (0-4), she scored a 3 point. She said her private life is gone, she feels insufficient, and tense. She said she lacks the capacity to fulfill both family and job responsibilities.

**Participant 8**, is a wife and a caregiver for her 72 years old Alzheimer husband. She is 70 years old. Her difficulty level was measured on the scale of (0-4), and she scored 3 points. She and her spouse are both retired professors and currently live on their pension. She also gets support from a caregiver, who comes in 3 times every week to care for her and help her with shopping. She feels that if she can get help, she will focus more on caring for her disadvantaged husband. She alleged that she feels discomfort and anger sometimes when giving care to her spouse. She has no private or social life, and doesn’t think about her own health.

**For participant 9**, the 53 year old daughter renders care to her Alzheimer father who is 82 years old and depends heavily on his daughter. The daughter also has a caregiver who cares for her needs. When her difficulty level was measured on the scale of (0-4), she scored a point 2 on average. She said she has no constant interest to give care and also has no social life.

The dependence level in **participant number 15** is 10 on the measurement scale that is a very high dependence experienced by the caregiver. This participant is a 33 year old music teacher. He cares for his 96 year old grandfather who suffers from Alzheimer. When asked about difficulty level it was determined that; he feels insufficiency, tension, he is indecisive about care, and he may no longer continue to care for his grandfather. He has no private and social life, he is not able to care for his family as he should, and also lacks interest in caregiving.

**Participant number4** is a 35 years old lawyer. At the age of 65, she is caring for her mother who had an operation a year ago. The mother's dependence level on the caregiver (daughter) is measured on a scale of point 0-10, she scored a point 6; the difficulty the caregiver experienced during time of care between points 0-4, she scored a 2 point. It was determined that she had difficulty fulfilling her work and family responsibilities that she suffered from deterioration in her social life/relations with friends, all of these duties didn't give way for any private life. She had difficulty showing constant and she also suffered from economic strains. The caregiver stated that she stressed due to these situations and needed help while providing care.

**Participant number 11** is a 39 year old female caregiver who earns money from care, and looks after an 89 years old. The dependency level of the caregiver was scored at 8 points. Caregiver 'I cannot do activities such as eating, drinking and bathing alone, I provide support' to them. She also expresses the care she gives by saying 'I have the food, medicine and cleaning job too. She expresses that the care recipient complained at a disruption level during care with the following words: 'sometimes she curses me, I know that she curses my children too'. The caregiver stated that he felt uncomfortable in this situation and she felt tension while giving care. The elderly woman stated that the caregiver had difficulty in making out time for her and making friends is tough, she also thought that her health is deteriorating.

**Participant number 12** is a 50 years old mother who has been caring for her disabled son suffering from Joubert syndrome for 21 years. The level of dependency of the caregiver is 9 points. In the disruption level of care expresses the following words: "he had a tantrum when I left home and went to the market last year". While he was trying to take a lighter he burnt his shirt, burnt himself, and there was a fire outbreak in the house. Our neighbor heard the voices and broke the windows and entered the house. He was rushed to the intensive care unit. Three quarters of his body was burnt, and he was hospitalized for 8 months. The caregiver said that she is indecisive about his care, and expresses that she is afraid of what the future will bring and that she feels nervous in some situations.

**Participant number 1,** is a 37 year old mother and a part time child counselor. She cares for her 21 years old physically disabled daughter. Her dependence level when measured on the scale of (0-10), it was determined that she scored 9 out of 10 on the scale. She feels like sometimes she cannot fulfill her responsibilities for family, job and for herself. When caring for her child, she said during care disruption, the care recipients do not complain. When her difficulty level was measured on the scale of (0-4), she scored a 2 point. When asked about her emotional feelings she said; she rarely feels disturbed by the care she gives. Though she said sometimes her job and care duties are fulfilling, she has no time for herself, family, and her paid employment.

**Participant number 7** is a 25 year's old paid caregiver who cares for a 73 year old woman who lives alone in the home. Her dependence level when measured at (0-10), she scored an average of 5. When asked about the disruption response from her patient she said her patient 'warns' her whenever she isn't comfortable or when she is having mood swings. On the difficulty level; it was determined after measurement that she scored a 0 on the scale of (0-4). This means she is the only participant to score zero in the study. When asked about her emotion in regards to caregiving; she said she feels nothing, but she rarely has time to herself.

**Participant number 10** is a 69 years old retired police officer, who cares for her 92 years old mother with reduced physical activity. When asked about disruption during care she claims that "no reaction" from her mother. On the dependence scale of (0-10), she measured at 8 points, with difficulty level measured at 2 on the scale of (0-4). She said needs help as daily tasks are becoming more difficult. She stressed at her lack of time for self-care, and has no constant interest in care any longer.

In this group the children (daughter and sons) help out with care responsibilities of both parents mother aged 80 suffering from Alzheimer, and father aged 82 with Parkinson disease. **Participant 13** expresses their concern during disruption of care as "not calm always, sometimes they cry to each other”. On the dependence scale measurement (0-10), they scored 8 points, while during difficulty level they scored 3 out of (0-4). The children said they can no longer care due to high demand from both parents. They stated their lack of having a private life, but don’t consider much about their health.

**Participant number 14** is an 80 years old woman that cares for her 85 years old husband with limited disability. When the dependence level was measured, she scored a 5 point on a scale. During disruption, caregivers stated that care recipients “warn/scold” when uncomfortable. When asked about caregiver difficulty level, it was measured on a scale of (0-4), and she scored 1 on the scale. In response to emotional feelings; she is not afraid of what the future brings, although she cannot take family responsibilities fully. She also is strained economically.

**Participant number 16** is a 30 years old female who cares for her 66 years of father who had operation 2 years ago and also currently on dialysis. When her dependence was measured on a scale of 0-10 she scored 4 points, while her difficulty level when measured on a scale of (0-4), it was recorded at an average of 2 points. She explains that she has economic strain, difficult to make time for herself, and lacks interest in caregiving. She said she feels inadequacy, anger, discomfort due to the behavior of the care recipient, and do not need help with care. During disruption she said the care recipient sulks.

**Participant number 17**the caregiver is a female baker aged 44, and renders care to her 74 years old Alzheimer mother. When rating her dependence level on a scale of (0-10), she scored 6 points. She explains that during disruption her mother refuses to eat. While her difficulty level was measured on a scale of (0-4) at 3 points. The caregiver lacks social life, has no ability to fulfill family and work responsibilities. She emphasizes the need to get help with maintenance, she also said she isn’t afraid of the future. Although she feels discomfort with care recipient behaviors.

The Burden Interview is scored by adding the numbered responses of the individual items. Higher scores indicate greater caregiver distress. The estimates of the degree of burden can be classified into;

| | | | |
|---|---|---|---|
| 0-20 | Little or no burden | 41-60 | Moderate to severe burden |
| 21-40 | Mild to moderate burden | 61-88 | Severe burden |

**Table 7. a.Burden scale score of participant emotion and the difficulty in their daily life.**

| **Scale score range** | **Participant number** | **Dependence level** | **Difficulty situation (0-4)** | **The emotion she or he feels the most** | **Difficulty in daily lives** |
|---|---|---|---|---|---|
| **Little or no burden** (0-20 point) n=1 | 7 | 5 | 0 | No | Rarely he/she can't spare time for self |

**Table 7a.Participant number 7**, this 25 year's old paid carer, provides care for her 73 years old client. Her perception of dependence was 5 points when it was measured on a scale of (0-10), On the burden interview scale score; measuring between (0-88) it was determined that she scored 16 points. Which fell in the category of 'little or no burden' with 0 difficulty situation, and also when asked about her emotional state of mind, she said none (no feeling). Although she said she can't spare time for herself.

**Table 7b.Burden scale score of participant emotion and the difficulty in their daily life.**

| **Scale score range** | **Participant number** | **Dependence level** | **Difficulty situation (0-4)** | **The emotion she or he feels the most** | **Difficulty in daily lives** |
|---|---|---|---|---|---|
| Mild to moderate burden (21-40 point) n=9 | 1 | 9 | 2 | Rarely disturbed by the behavior of the person he/she care | Sometimes fulfilling responsibilities for him/herself, the job, and the family |
| | 2 | 10 | 2 | Indecision<br>Rarely feels nervous | can't spare time for him/herself<br>losing control of life when relative is sick |
| | 3 | 10 | 3 | Indecision<br>Tension (sometimes) | -to show constant interest<br>-can't spare time for self |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | -economic strain<br>-in relationship with friends |
| | 4 | 6 | 2 | Don’t need help<br>Tension (sometimes) | -in fulfilling work and family responsibilities<br>-in social relationship with friends<br>-living private life -to show constant interest -economic strain |
| | 9 | 10 | 2 | No | -show constant interest living social life |
| | 10 | 8 | 2 | Compliance need help | -in making time for self-to show constant interest |
| | 11 | 8 | 2 | Discomfort due to behavior<br>Tension | -can’t spare time for him/herself-do you think your health is bad- in making friends |
| | 14 | 5 | 1 | Not afraid of what the future brings<br>Indecision about care | -in fulfilling family responsibilities -economic strain |
| | 16 | 4 | 2 | Don’t need help<br>Indecision about care<br>Feeling of inadequacy<br>Anger<br>Discomfort due to behavior | -to show constant interest-economic strain -living social life-in making time for self |

**Table 7b.Participant number 1** this 37 year old mother provides her 21 year old physically disabled daughter with daily care. She scored 9 points out of (0-10) on the dependence perception. Her burden level when measured on the scale of (0-88), she scored 34 points, which means she has mild to moderate burden’ and she was rated at 2 out of (0-4) on her difficulty situation. When asked about her feelings when giving care; she said indecision and nervous feeling is what she experiences the most.

In providing care, **participant number 2** is a 66 year old female that cares for her 96 year old father. Her burden interview level was recorded at 34.00 on the scale of (0-88), this mean she belonged in the category of mild to moderate burden and also her dependence level was scored at 9 on a scale of (0-10) with her difficulty level at an average of 2 when measured on the scale of (0-4). She claims she is not bothered by the caregiver behavior, and sometimes it is hard fulfilling family, job or self-care duties.

**Participant number 3**, this 69 years old mother gives care to her physically disabled 40 years old child. The dependence level was marked at 10 points on a scale of (0-10), while the difficulty to activity was 3 on a scale of (0-4). The burden level of this individual was recorded at 36.00 when measured on the Burden Interview scale of (0-88), this means she experiences ‘little or no burden’. She complained about the tension and indecision she experiences while on care duty and also hoped she can help so she shows constant interest. When asked about her self-care time, she replied saying there is no time for self-care.

**Number 4 participant** is a 35 year old lawyer that cares for her mother who had surgery one year ago. Her dependence on a scale of (0-10) was marked at 6 points and on a scale of (0-88) her Burden Interview score was 40.00, which means she suffers from ‘mild to moderate burden’. When asked about how she feels during time of care, she said do not need help with tasks but feels tense sometimes due to difficulty level which is 2 when measured on a scale of 0-4. She said she cannot fulfill work and family responsibilities, experiences economic strain, lacks interest in care duties but is lucky to have social relationships with friends.

**Number 9 correspondence** has a difficulty level measured at 2 when scored on the scale of (0-4). This 53 year old daughter provides care for her Alzheimer father who is 82 years old. The dependence on a scale of (0-10) falls at 2. The Burden Interview score when measured on a scale of (0-88) was determined at 30.00 which means she has ‘mild to moderate’ burden. I have no social life and no emotional feelings, she said when asked about care action.

**Number 10 participant** is a 69 year old woman that cares for her 92 years old mother with reduced physical activity. Her dependence on care when measured on the scale of (0-10), she scored an 8, while her difficulty level of activity was marked at 2 on the scale of (0-4). Her burden scale point was recorded at 22.00 out of (0-88) which ismild to moderate burden. She emphasized on the need to get help, she lacks time for self-care and also shows no constant interest.

**Participant number 11** is a 39 year old female paid caregiver, she gives care to an 89 years old woman. The dependency level of this professional carer was measured on the scale of (0-10), she scored 8 points. Her difficulty level of activity was scored on a scale of (0-4) she scored an average of 2 points, while her burden score when measured on a scale of (0-88) it was recorded at 38.00 mild to moderate burden. She stressed on not having time for self-care, difficulty in making friends, and barely having the time to think about her health. Emotionally her discomfort is due to the client’s behavior and this makes her tense.

**Participant number 14** expresses inability to fulfill family responsibilities, and suffers from economic strain. This 80 year old woman cares for her 85 year old husband. On the dependence level it was measured at 5 out of (0-10), while difficulty in performing tasks when measured on a scale of (0-4) was scored at 1. In response to how she is feeling emotionally; she said she is not afraid of what the future brings, and finds it hard to take full responsibility for her family. Her burden scored when measured on a scale of (0-88), she scored 34.00 in the category of ’mild to moderate burden.

**Correspondence number 16** is a 30 year old female who provides her 66 year old father with post-surgery care for over two year. When her dependence was measured (0-10), it was scored at 4 points, while difficulty in tasks when measured (0-4) was an average of 2. “It is hard to care for myself” when asked about her emotional needs. Also she has economic strain and lacks interest in caregiving, she feels she doesn’t need help, she is also indecisive about care decisions, she also expresses anger due to care recipient behavior, she feels inadequate, lacks a social life. When her burden score was measured on a scale of (0-88), it was recorded at 39.00 point on the scale. This is categorized as ’mild to moderate burden.

**Table 7c.Burden scale score of participant emotion and the difficulty in their daily life.**

| **Scale score range** | **Participant number** | **Dependence level** | **Difficulty situation (0-4)** | **The emotion he or she feels the most** | **Difficulty in daily lives** |
|---|---|---|---|---|---|
| **Moderate to severe burden**(41-60 point) n=6 | 5 | 10 | 4 | Not afraid of what the future brings<br>Tension<br>Anger<br>Don’t need help | - to show constant interest -<br>living social life and private life |
| | 8 | 10 | 3 | Discomfort due to behavior<br>Tension<br>Anger | -to show constant interest<br>-don’t think of bad health<br>-living private and social life |
| | 12 | 9 | 3 | Indecision about care<br>Tension<br>Not afraid of what the | -in social life<br>-to show constant interest |

| | | | | | |
|---|---|---|---|---|---|
| | | | | future brings | |
| | 13 | 8 | 3 | Feeling unable to take care any longer<br>Indecision about care | -living private life -don’t think of bad health -living social life -in fulfilling family responsibilities |
| | 15 | 10 | 3 | Indecision about care<br>Tension<br>Needing help with maintenance<br>Feeling unable to care any longer<br>Insufficiency | -to show constant interest -living private life<br>-living social life -in fulfilling family responsibilities |
| | 17 | 6 | 3 | Needing help with maintenance<br>Not afraid of what the future brings<br>Discomfort due to behavior | -living social life -in fulfilling family and work responsibilities |

**Table 7c. Participant number 5,** in this phase the parent (mother and father) share the care responsibilities by looking after their 28 year old son who requires care. When measuring their dependence level the participants scored 5 points out of (0-10) on the scale. When measuring difficulty level during the task, the caregivers scored 4 out of (0-4) on the scale, while their burden interview was measured at 42.00 point out of (0-88) on the score scale, and it is classified under the ’moderate to severe burden’. When asked about their challenges, the mother said she had to quit her job in order to provide full time care for her son, while the father continued to work part time on the farm. When asked about their personal life they said they have no private or social life, there is existing tension between the parents, and there is a feeling of anger sometimes.

**Participant number 8,** is a caregiver and a wife to her husband. During the burden interview her level when measured at (0-88), and she scored 46.00 on the scale, this indicates moderate to severe burden. When measuring dependence level on a scale of (0-10), it was recorded at 10, while the difficulty level on the scale of (0-4) was 3 points. When asked about how she feels, she said that, sometimes she gets angry when giving care, she has no private or social life.

**Participant number 12,** this candidate is a mother whose disabled son has suffered from Joubert syndrome for the last 21 years. When asked about her challenges she said; her son throws a lot of tantrums due to his physical and mental disability. She also said she gets assistance from husband and second son during care. Her level of dependency when measured on a scale of (0-10) was scored at 9 point, also the difficulty she experience in care task when measured on a scale of (0-4) she scored 3 point, while her burden level when measured at (0-88) she scored 52.00 in the moderate to severe category.

**Correspondent number 13,** in this group the siblings (daughter and son) provides care responsibilities of both parents both with severe medical conditions. Both participants expressed their worries during care as “they are not calm and they cry a lot to each other”. Both participant said that they lack private life and also they do not think about their own health, also when asked about their life, they said that, they have no private life, no social life, no family obligation due to hours of spending time with their parent, they are indecisive when it comes to decision making and they feel they are unable to give care any longer. On the burden interview exam, when measured on the scale of (0-88), they scored 53.00, while their dependence level was marked at 8 point on the scale of (0-10). They scored 3 out of (0-4) on their difficulty level during task.

**Participant number 15,** cares for his grandfather who suffers from Alzheimer. The 33 years old music teacher explains that his difficulty level was set at 4 out of (0-4). And his dependence when measured on a scale of (0-10) was 10 which is the highest. While he said he feels insufficient, tensed, and indecisive about care and he fears that he may no longer be able to provide care for his grandfather. His burden score range when measured on the scale of (0-88), he scored 56.00 which is on the ‘moderate to severe’ level.

**Participant number 17,** renders care to her mother who is an Alzheimer’s patient. When asked about her life experiences in regards to caregiving she said, I have no social life, I am not able to fulfill my family and work responsibilities, and also she feels uncomfortable with care recipient behavior during care or when her needs are not met immediately. On the dependence level when measured on a scale of (0-10), it was determined that she scored 6 points, while difficulty in caregiving was measured at 3 points on a scale of (0-4). It is also determined that her burden interview scale score range was given as 55.00 out of (0-88), this shows that the patient is categorized in the ‘moderate to severe’ burden level.

**Table 7d. Burden scale score of participant emotion and the difficulty in their daily life.**

| Scale score range | Participant number | Dependence level | Difficulty situation (0-4) | The emotion he or she feels the most | Difficulty in daily life |
|---|---|---|---|---|---|
| **Severe burden** (61-88 point) n=1 | 6 | 10 | 3 | Insufficiency | -living your private life<br>-in fulfilling family and job responsibilities<br>-not to lose control of life |

**Table 7d. Participant number 6,** cares for both parent. Her mother is a dementia sufferer. Her difficulty level when measured on a scale of (0-4) it was set at 3 points, while her dependence on a scale of (0-10) was set at 10. When asked about daily challenges she said that, she has no private life, no time to fulfill family responsibilities, and she is trying not to lose control of life. Her burden interview score was given at 61.00 when measured on a scale of (0-88). This falls in the category of ‘severe burden’.

# CHAPTER FIVE

## DISCUSSION

The increase in elderly population and person's living with disabilities has seen tremendous change, this change was brought about by the advancement in technology, demographic characteristics, social and political influences, also the prolongation of human life, which brought about new health challenges, increase in chronic diseases and care problems (National Research Council, 2001).

The health care systems all around the world are striving to improve home care services by creating policies to meet the care needs both in short and long term period. To make this possible care must be comprehensive and also cost effective (Delivering Quality Health Service, 2018). Home care services have undergone many historical processes in the past but it is a known fact that home care services are more appropriate for some patient groups than hospital services and this has remained an unchanged reality (In-home care, 2019).

A person in need of care due to old age, disability or chronic illness can affect both caregiver's self, caregiver's daily routine and also life activities. This circumstance creates a burden of care on caregivers (Tayaz&Koç, 2018). In Tayaz&Koç (2018) study, the burden of caregivers of disabled people suggested that women caregivers' burden on average scored was 32.35±10.61 on the burden scale (Tayaz&Koç, 2018). A descriptive study including 242 family caregivers in a nursing home was conducted to determine the burden of family caregivers in TRNC. The score was obtained from the ZBI scale at 36.92±17.33 and ranges from a minimum 2 and maximum 81. According to the analyzed age group, the care burden of caregivers aged 30 and below is significantly higher than the other age groups ($p<0.05$). It was also revealed that low income caregivers with no children had a high burden of care (Korkmaz&FiratKiliç, 2019). In (2020) Besey and Aydin obtained a result finding mothers who care for their disabled child from the care burden scale the score was determined on average at 47.58±3.71 (Besey&Aydin, 2020). In another study conducted by Korkut and Gençtürk (2019), the average score obtained from the "care burden scale" of female caregivers who care for elderly was 60.91±17.37. The average point the caregivers scored in this study was 40.47±12.24. This average score is higher than Tayaz and Koç's score, and lower than Besey and Aydin's and also Korkut and Gençtürk, score average. There is no doubt that women regard caregiving as the natural order and see it as part our culture, but when it comes to urgency of global pandemics, HIV/AIDs and others, the impact on women and girls highlights how disastrous the disproportionate burden of caregiving can be (United Nation Report, 2009). Pamela (2008) stated the difficulties faced by untrained caregivers and the high stress level this creates on person and health. Pamela (2008) emphasized the experiences of the caregivers, the level of education and its effects on the caregiver's health. In the 1980's, 20% of 65 years and above of all people lived in multigenerational households, and 40% of them were 90 years or older (Coward&Cutler, 1991). Brody et al (1995), stated that gender and marital status play a major role on how care is provided in a society. A questionnaire was applied in the study and 70% of them (n= 364) was said to have females sharing the same household with their families. The females of the study were seen as essential caregivers, readily available to help out with shopping, transportation, as well as to give emotional support. Of the 364 women sharing their home with relatives, 5% (n= 199) were married, 19.2% (n=70) were separated/divorced, 10.1% (n= 37) were widowed and 16% (n= 58) was single. In this study, the majority of caregivers were married females 64.7% (n= 11). This means that gender and marital status played a big part in caregiving (Brody et al, 1995). One study showed that two-third (n= 227) of the participants were employed, one-third unemployed, and 11.5% (n= 227) left their job to care for their elderly. In this study when participants were asked whether they are responsible for another job or not, 41.2% (n= 7) replied YES in table 1 which is only a small group, while 58.5% (n= 10) provided full time caregiving. Brody et al (1995) found that married/remarried women, separated/divorced women have the highest rates of care support than the single women. In another study, Crown, Mutschler, Schulz, and Leow (1993) found that unmarried women (widowed, single, divorced and separated) had a much higher poverty rate than married women. The divorced and separated women were found to have the highest poverty rate. It was discovered that younger divorced women (those who have children to care for) continued to care for their parents even in their poor economic situation until their middle aged years.

In Turkish society, the responsibility of providing care is often expected from relatives and it is seen as a virtuous behavior whose caregiver roles are glorified by the society. For instance the bride/groom, who later joins the family is seen as a close family member due to his spouse status, customarily, the bride or groom has to take up primary caregiving roles. These individuals, who assume the role of caregivers, are generally not asked for their consent because of the cultural structure of the Turkish society. In a study done by Altin&Aydin (2016), 37.9% of the caregiversare the spouses of the patients, 33.9% were children, 10.7% were wives and siblings 10.2% and 7.3% were son in laws of the patient. In this study, 15 participants were family members (mother, child, sister), only two of them were paid carers. Note that, not all participants have worked in any health related job or have a certificate in care. They stated that they received advice from the doctor or nurse of the people they care for on issues such as medication time, diet, and dressing within the scope of discharge training. Many of them are first relatives of the caretakers (daughter, mother etc.).

In table 1, 82.4% (n= 14) of the women in this study stated that they had children and only 17.6% (n= 3) were caregivers without children. This result supports the hypothesis that married caregivers with children get more support from their relatives performing their caregiving duties (Thornton et al, 1993), but Barret and Lynch (1999) stated that single and widowed individuals are more involved in care. Such a discrepancy can be seen in different study results. Also in another view in literature, divorced and single women tend to live with their elderly parents as they see their parent's home as economically convenient and necessary for them, in the hope of feeling comfortable. Barret&Lynch (1999) found that it is difficult to interpret the activities of single women in time of care duties because they live in separate homes and in the hope they will return to a more independent lifestyle. In this study, 88.5% (n= 15) reported that they took care of their relatives while 11.8% (n= 2) rendered care services for financial gains. These results relate to the finding that was emphasized in the literature as; care needs are mostly met by informal caregivers, family members and women.

Caregiving is defined as a physical care task that is time and energy consuming and can place a financial strain on caregiver and caregiver family. Care services are not limited to one particular caregiving type. Assisting with health care activities like (taking medication, receiving treatment and monitoring health progress etc.), or personal care like (washing, feeding, assisting with toileting, shopping and home care etc.), and also coordinating social services like (shopping and home management) with the inclusion of financial aid assistance while still sharing the same house is considered being a caregiver. Meeting all these needs in the care process is important to maintain the caregiver's wellbeing. However, in this difficult period, family members who give care face many problems like; psychological, physical, economic and social problems. This means that they are heavily burdened in times of caregiving (Caregiver.org, 2020). According to

Stanfield et al (2017) and Greenwood&Smith (2016), being an unpaid caregiver is considered a mixture of satisfaction and this negatively affects the physical and mental health of caregivers and therefore causes financial difficulties for the caregiver (Carers UK, 2018). In this study, 64.7% of the caregivers (n= 11), performed care voluntarily, due to unemployment or been retired from their paying job, only 11.8% (n= 2) of the caregivers were caring for their families or themselves. A participant said “*I only work to provide for my father’s needs*”. Four participant with similar response said *“Everything I do is for family; because family comes first”*. Measuring the informal caregiver’s financial expenses can be difficult because each family has its own unique problems so therefore spending habit differs. Caregivers should be counseled and supported in other to encourage them; also professionals should take their socioeconomic situation into account and design solutions that suit the caregiver circumstance. In this study it is observed that, the Turkish Cypriot community is family oriented and also, they experience a more positive outcome during care actions.

In the health care process, healthcare professionals share care information with the patient’s wife, children, friends and relatives as a stakeholder who provides informal care (Soner&Aykut, 2017). This applies to caregivers who exchange care for money.The American Nurses Association developed the standard for home care nursing in 2008. They said a community skill such as, diagnostic skills, health education, planning and managing care is necessary to achieve the best results, with case management, and the nurses who give home care should apply their nursing knowledge and skills effectively when working with informal caregivers (Abele&Nies, 2010).

Home care services includes thus: examinations, analysis, treatment, medical care, follow-up and rehabilitation services which are provided by the private sector, and public sector that include nursing care service in a home setting, family environment, and also provides social and psychological counseling services to those who need home health services(In-home care, 2019). One of the reasons a home care service is appreciated is because it is effective and economical more than the hospital services. In the western world, social security organizations have made home care services as a new option for patient by insuring its coverage, and by establishing a positive balance of risk/benefit (In-home care, 2019).

In societies where there are no home care services: how and where people live, their income level, the role women play, the participation of informal caregivers in home care services, the patient’s home (permanent or temporary or homeless), the house whether in urban or rural area, the climate and geography, infrastructure of local communities, all of these affect the content and scope of home care (Report of a WHO Study Group, 2020). In order to ensure the quality and continuity of home care services (which is becoming more popular), effective interaction and cooperation should be established between healthcare personnel, patients and their families(Report of a W.H.O study group, 2020).A major challenge a family caregiver might encounter is the inability to communicate effectively and accurately with nurses and other health professionals in the hospital setting, and this might lead to a caregiver-to-care recipient difficulty upon discharge from the hospital (Levine, 1998). Naylor (2003) reviewed 100 studies published between 1985 and 2001 and discovered the breakdown of care during the transition phase and this problem had negative consequences. Effective discharge planning is hindered by gaps during communication between the hospital and families, and this may delay families in getting the right amount of support (Dunnion&Kelly, 2005). Many nurses should be prepared to engage families and communities in discussing how to properly care the right way in the home environment.

In the study conducted in this literature, there are results about the effect of socio-demographic characteristics of caregivers on care burden (Cook, Snellings & Cohen, 2018). The care recipient may feel more uncomfortable in the family due to different reasons; loss of function, old age, mental deficit, illness etc. In the study conducted by Kekeç (2011), no significant relationship was found between the care burden and the caregiver’s gender, marital status, working style and profession, while a relationship was found between age, educational level and income level (kekeç, 2011). Çelik (2014) study, found that the care burden of caregivers with secondary education and above is higher than those with primary education and below. Kahriman (2014) stated that age has an effect on caregiving; gender, employment status and income level. In Bugge et al study, it was found that gender has an effect on caregiving and male caregivers have less care burden. (Bugge et al, 1990).In the study it is said that, the average a family caregiver would spend on care provision is more than 24 hours each week, but many studies have shown that caregivers spend more than 40 hours each week on care duties. AARP and NAC (2015) said that, longer hours caregivers means that they are 51.8 years old, while the lesser hours care recipient which was 47% when measured were 75 years and above. In table 2, caregivers spent the minimum average of 10.12±11.36, while the maximum (n= 40) and minimum (n= 1). The mean age of caregivers in this study was 52.65±12.17 (min = 31 yrs. and maximum= 75yrs). A). A demographic study data done in the U.S by family caregiving alliance (2019), gave the average age of caregivers as 49.2 years., and said 48% of that group age range from (18-49 yrs.), whereas 34% of caregivers were 65 years and above (National Alliance for Care and AARP, 2015). On the average, caregivers spent 13 days each month on tasks such as shopping, food prepping, house cleaning, laundry, and medication, while 6 days in a month was spent on grooming, walking, bath, and giving toilet assistance (Gallup-Healthways, 2011). In (2015) AARP suggested that 4.2 of the 7IADLs were carried out by caregivers; that are 78% in transport, 76% in shopping and 72% in housework. Although the data statistics in this study vary at min (n= 3), max (n = 24), the average mean for daily care is 16.82±8.57. For daily cleaning average mean was 2.47±1.50 (min= 0, max= 5). Time spent on shopping min average was 1.12±0.92 (min= 0, max= 5). The average for physical care was 2.35±1.41 (min= 0, max= 5). For daily psychological need average mean 4.35±3.51 (min= 0, max= 12). As nurses identifying caregiver's problems on a daily basis so that caregivers can achieve the optimum psychological need. Nurses can help by introducing the COPE mechanism to educate family caregivers on how to plan and implement accurately, and this will further help caregivers address their medical and psychosocial problem (Given B&Given C).

NAC and AARP (2015) analyze the age distribution of the care recipient as follows; the average age is 64.9, at this stage they become heavily dependent on care support, which is as a result of illness or injury. In this study, 14% of care recipients were 18-49 yrs. old, and 47% of care recipients were 75 yrs. old. In table 3, the median age for women is 64.7% (n= 6). Statistically, this study shows that women were more dependent on external support than men.

The educational level of care recipient is important for understanding the level of care among care recipients. There are those with low adult education in all societies. Illiteracy is particularly common among minority groups or in rural communities (Arizona Statistical Review, 1987). One study focused on the Medicaid recipient and found that they were more likely to be hospitalized or suffer from premature death due to low literacy levels (Weiss et al, 1992). 402 people participated in the study. The age group of the subjects ranged from 18-94, the median age was 45, and the mean average age was 49.0 (± 17.9 yrs.). Participants had 9.7 (± 3.7 yrs.) of formal training, and it ranged from year 0-13 years. This result shows that the people with extremely poor reading skills have worse health status. It also means that people registered with Medicaid may not be able to use the services due to poverty and ignorance. In this study, the statistical data in table 3 revealed that the participants with only primary education level were 70.6% (n= 12), while secondary education got the lowest score with 17.6% (n= 3) and higher education level care recipient score 11.8% (n=2).

Previous studies have found a relationship between illiteracy and health status among addicted individuals. In the shared care responsibility section, it was determined that people who shared their responsibilities were, 52.9% (n= 9), and 47.1% (n= 8), undertook all care on their own. The other category where care was provided by a formal caregiver, the care task was shared amongst father, brother and siblings at 66.6% (n= 9) and 33.3% (n= 3).Caregiving can be performed either in the short or long run. Individuals who have been cared for over a long period of time are tenser than those who have been cared for less than a year. Many caregivers provide care for 8 hours or more per week, and 1 in 5 caregivers provide more than 40 hours of care weekly (AARP, 2004). It is difficult to measure the burden the caregiver feels or the amount of pain they experience daily. However, measuring IADLs during the research is important for nurses to give the best possible advice when dealing with overwhelmed caregivers (Reinhard, 2004).

Pamela (2008) stated the difficulties faced by untrained caregivers and the high stress this creates on person and health. She emphasized the educational level of caregiver’s experiences and its effects on the health of the caregiver. A study was conducted in Germany in which 966 people were identified as caregivers, and participants aged 18 and over (n= 6087). All socio demographic characteristics, caregiving burden, and subjective health were evaluated using standard questionnaires. Analysis of the study showed that 50% of caregivers reported high physical loads and 71% felt mentally burdened. Also this study showed that higher education level reduced the worries of feeling burdened. The level of education attained by the participants in Table 1 was 5.9% primary education 41.2% (n = 7) and higher education degree 52.9% (n= 9). This result finding alleged that participants with higher education experience less physical burden, but they are emotionally distressed, especially during care activities. According to Schnitzer et al, (2017), quality training of caregivers improved their subjective health and at the same time reduced the likelihood of feeling physically burdened, while caregivers with higher education level may have greater mental burden from loss of autonomy due to higher investment in education. In one study, it was shown that 31.9% of caregivers are illiterate, 52.84% are primary education graduates, and only 4.61% have undergraduate and graduate degrees. In this study the caregiving scale scores of primary school graduates were significantly lower than the caregiving burden scale score of illiterate and literate. The methods of coping with stress, attitude and awareness of the illness of educated individuals as well as financial opportunities and communication skills were found to be higher than the uneducated people. This is why the burden of care is higher in individuals with low education levels (Yavaş, 2020). Also 52.9% of the participants in this study are university graduates.

**In this study three sub-themes was determined, they are;**

1. Perception of the caregiver with dependence level of the care receiver
2. The difficulty caregivers lack of interest in grooming efficiency
3. The areas that caregivers have difficulty about their own life while giving care.

1). Perceptions of caregiver with dependence level of the caregiver explains that; in a literature, it is stated that as the level of addiction increases (especially in elderly), there is an increase in care burden (Zaybak et al: Ay et al, 2017). According to one study, there is statically significant difference between the duration of daily caregiving and the depression score, and there is significant difference against individuals who care for 8 hours or more per day (U= 179.50, p= 0.001). In addition, it was found that individuals who care for 8 hours or more daily have higher levels of depression compared to other individuals ($p<0.05$) (Dermirlek&Ozdemir, 2015).

In this study, the average of caregiver's perception of the dependency levels of their caregivers was found to be 8.00±2.06. Caregiver's perceptions of addiction were primarily the "physical dependence" of their care recipient. Caretakers were perceived as dependent on daily living activities e.g. like; (eating, bathing, going shopping, meeting hygiene practices, etc.) due to functional deficiencies. However, in the interview conducted, it was observed that addiction was also perceived as "social dependence" and "mental dependence". For example, participant's number 11 was a 39 year old caregiver who earned money from formal caregiving. The elderly woman she cared for was 89 years old and lived in her own home 24 hours every day. The caregiver perceived the dependency level of the old woman as 8 (min=0-max=10). This caregiver stated that she often felt discomfort and tension during the care process. She stated that “she could not spare time for herself nor make friends because she is always working, and she thought that her health was impaired. She said “the care receiver cannot do activities such as bathing, eating, and drinking alone, I always support her”. In addition, “I take responsibility in caring for her food, administering medication on time and correctly.., I also do house cleaning...” she said. In addition, when there is a delay of care attendance, she complains about everything, she talks to me more than she would to her relatives.... she always wants me to stay in front of her and look into her eyes.... sometimes she speaks abusively, curses my children, then I don’t know what to do, I get angry and I feel sorry for this woman who is totally dependent on me..”. In addition, to physical dependence of the care recipient, social and psychological dependence can also cause an increase in the care burden of the caregivers, and mental and behavioral disorders and burnout.

Participant number 12 is a 50 year old mother who has been caring for her disabled ‘Jobert syndrome’ son for 21 years. The caregiving mother of the child perceives the addiction level as 9(min=0-max=10). The mother expressed the reaction of her son an event of a disruption in her care with the following words: “he had a tantrum when I left home and went to the market last year. While he was trying to take a lighter, he burnt his shirt and it caught fire which also affected and burnt the house. Our neighbor heard the voices and broke the windows and entered the house. They rush my son to the intensive care unit. Three quarter of his body was burnt; he had burns all over his body ‘we were hospitalized for 8 months’. “This mother, who is indecisive about care, expresses that she is afraid of what the future will bring and that she feels nervous in some situations”.

2). The challenges of caregivers are frequent, different literature studies has reported that caregiving increases when the burden of care is linked to other responsibilities in other areas of life, apart from the care recipient (Eğici et al, 2019). It is stated that individuals with more family, work and social responsibilities experience inadequacy and feel the limitations of their own lives more while assuming the role of caregivers. In this study, more than half of the participants stated the difficulty they felt while providing care, when measured on a scale between 0 and 4. These informal carers were women who have other responsibilities and generally take care of themselves alone. Participant 5 is a 62 year old woman who cares for her

28 year old son with physical disability. This carer provides care to her son, and perceives her child's dependence level as 10 (min=0-max=10). She rated the difficulty she experienced while providing care as 4point (0-4). In this study she is the only participant that indicates both the level of dependency of the caregiver and the difficulty experienced by herself at the most severe level. This caregiver is a mother with three children. She has been caring for her 28 year old child all by herself. She stated that "she had a lot of difficulty during the care processes, and that her private and social life were bad". However she said that, "My concern was about the future care of her child, I am worried for his future". This carer said, "all these years, even if you have a child, taking care of someone depended on you in every way is the hardest thing in the world...' I gave up my life, but my main fear is that, if something happens to me; like me 'dying' who will care for this child.." She cried. The limitations that occur in his life increase the psychological burden of the caregiver and cause difficulties while providing care. In a study conducted by Dağdeviren et al, (2020), a statistically significant relationship was found between feeling exhausted, weakness, helplessness, needing help, and using depression medication and sleeping medication in cases where a single person undertook care (Dağdeviren et al, 2020). In this study, participant number 6 looks after two elderly individuals. Her care burden on the scale was described as "heavily burdened" in table 6. A 54 years old woman has been caring for both of her parents alone for 15 years. She said the difficulty she felt while giving care is 3 point on the scale (0-4). Her mother is 75 years old (with dementia) and her father is 78 years old. This carer stated that her private life, family, and business life were bad, and she sometimes lost control of life. "Everything is twisted, my mother, father, and I... as my life goes, I can't do anything. Sometimes I feel like we are not family". I think I lost control of myself everyday…." The caregiver role causes changes in the daily life order of this individual and affects the family negatively by creating limitations and friction in their life activities. The caregiver reported that she felt inadequate in these situations.

3). Caregivers' difficult areas; in this aspect, studies show that caregivers face some problems and being a caregiver is a stressful role. In Aksayan and Çimene's study, it was reported that 66.2% of family members changed their family roles, while 66% experienced fatigue, anxiety, social life change and wanted health personnel to solve these problems (Aksayan&Çimene, 1998). In the study conducted by Navaine et al, it is stated that women experience care stress by trying to fulfill many roles and responsibilities at the same time and also taking care of the patient and neglect their personal needs (Navaine et al, 2020). In another study conducted by Teşdelen&Ateş (2012), it was determined that caregivers have the most ‘time burden’. In this study, almost all of the caregivers stated that “they cannot spare time for themselves” and “they cannot fulfill their responsibilities in their work/marriage/private life because they have to show constant attention and be with the person they care about”.

The participant number 4 is a 35 year old female lawyer. She is caring for her 65 year old mother who had an operation one year ago. Her mother's dependency level on scale was 6(0-10), and she said her difficulty level was 2(0-4) points during the care process. “I lost a whole year because of this operation”. “Thankfully it could have been worse, she said”. I can't help but think about the time and business opportunities I lost. If this situation gets continues…my life will become a mess.” Participant number 4 stated that her difficulties in fulfilling her family's responsibility. Participant number 4 said that her social life is on a decline and her social relations with her friends is bad, she has no private life because she commits herself to full time caregiving. Although she admitted in saying that, she lacks interest in caregiving and also, she is financially burdened. The caregiver stated that she was stressed due to these situations and needed help while providing care. This information reveals that women with higher education at a young age and higher education degree, experience difficulties, especially in social areas, although their care burden is not at a “heavy level”.

Objective care burden generally results from the difficulties experienced while providing care to the patient, lifestyle changes of the person and financial balance disorders can be shown as an example to this group. The subjective care burden is more related to the inner world of the caregiver. The characteristics of the caregiver such as age, gender, ethnic origin, educational status, health, working status, profession, economic status, cultural level, degree of relationship with the patient and the patient’s personal characteristics such as age, gender, and disease level affect the burden of providing care. It can be shown as an example of factors. In a study conducted by Soner&Aykut (2017), the difficulties experienced in the subjective care burden of caregivers of Alzheimer's patients were examined into themes such as difficulties in jobs requiring physical strength while providing care and they cannot spare time for themselves and their social environment. It was concluded that this situation creates negative psychological effects on the caregivers and they cannot live their lives as before (Soner&Aykut, 2017).

The educational level of the participant number 15 is at the higher education level, he is 33 years old. This individual cares for his 96 year old grandfather who suffers from Alzheimer's. This participant stated the dependency level to be 10 (0-10). The level of difficulty experienced while providing care was 3 (0-4). According to Turkish cultural structure, when their grandchildren grow up, they take up care responsibilities of their grandparents, and most times they all live in the same household or they live in a closely knitted community. The participant said “we had to move to my grandmother’s house with my wife and children”. Our lives is in chaos currently I do not know what to do. I cannot run away from home. My grandfather does not understand me and he is always needing something. My friends are on vacation having fun but I cannot because of my situation. I love my grandfather so much, but he suffers greatly from memory problems, some days he remembers me, and some days he does not know who I am”. This participant may have perceived the difficulty in providing care at a low level, as he felt both responsible for his grandfather’s love. In the Turkish family structure throughout life the children care for their elderly as if they were their own biological children. They also provide self-care for the elderly such as bathing, and eating, which results in caregivers sacrificing their own lives. In this study, in addition to the research findings of participant 4 Participant (number 8, 9, 15, 17) who cared for Alzheimer's patients; it is concluded that caregivers are gradually breaking away from social life. Family patterns are completely changing and they have to discard their own old habits to adapt to the new family order (Lindeza et al, 2020).In a study, it was determined that there is a statistically significant negative and moderate relationship between caregiving burden, and the social support score on average of the participants (p= 0.001). Accordingly, they stated that when the support of caregivers increases, there is a decrease in caregiving burden (r= -0.596) (Yavaş&Çamdeviren, 2020). In this study, some of the participants (number 15, 13) who had a lot of difficulties in providing care stated that “they felt that they could not maintain care any longer”. In cases where there is no one from other family members to share the burden of care, or if they do not voluntarily take responsibility, people who think they cannot continue to care more feel more burdened. In many cities, although there is institutional care especially for the elderly or disabled people, they do not want to give their beloved family members (parents and children) to such institutions due to cultural characteristics and social pressure. In one study, participants said, ‘I don't think of a nursing home at this stage’. A retirement home can be considered as a last resort. I feel very sorry for the old people in the nursing home. I recommend home maintenance.

Home care is good for the patients, it does not go away. I also care for my neighbor downstairs sometimes. He says he goes to the nursing home to stay with an old friend for a while. He feels his friend is neglected by health staff. After I saw how he lacked affection, I felt empathy and so sad when I came home and this made me cry. Choosing institutional care is more difficult for both the elderly and the caregivers than home care". (Hindawi, 2013).

They also found the reason why nursing homes and elderly care centers are not preferred as the first choice in the care of Alzheimer's patients is due to the social perception about these institutions as well as cultural characteristics. On the other hand, participant number 7, who stated that he did not have any difficulties with care, also said that he did not have a negative emotion during the care process.

# CHAPTER SIX

## CONCLUSION AND RECOMMENDATIONS

### 6.1a. Conclusion

In this study research all participants involved were female, with a higher educational level of 52.9%, whereas secondary school educational level was 41.2%, and followed by primary school education level 5.9%. With married caregivers score at 64.7%, and single caregivers at 35.3%. 82.4% of the carers have children, while 17.6% have no none. This means the married carers with children get external support in times of care duties according to these results. When asked how many people they cared for 88.2% said they give care only to one person, this could explain why 64.7%, and 11.8% need some sort of financial compensation as moral boosters to continue their care duties because they are responsible for two care recipients. With an average mean age of 52.65±12.17 and a caregiving experience of 10.12±11.36 years. It means there is no significant difference between higher educational levels and caregivers care years. While to 41.2% are gainfully employed carers. In this study, more than half of the participants 58.8% are full time caregivers. It is said that many caregivers are retired or lost their job due to these responsibilities.Care recipients in this study had a primary educational level of 70.6 %, a secondary level education of 17.8% and a higher educational degree of 11.8%. The average mean age of care recipient was 64.41±26.80, with female recipient score at 64.7% and male at 35.3%. When asked about their dependence level caregivers said that they have a dependence of an average 8.00±2.06 when calculated using SPSS analysis, and the least score was 4 minimum and 10 maximum on the scale when the ZBI was applied. Caregiver's said the care recipients are satisfied with the level of care. When analyzed it was determined that the average means score was 9.06±1.47, where minimum 5 and maximum is 10. The level of participants burden and their score on an average mean was 40.47±12.24, when measured on the ZBI scale, their maximum score was determined at 61.00 on the scale of (0-88) which means they have 'severe burden' and their minimum score was 16.00.

The caregiver's burden is significantly linked to the number of years they have spent in caregiving, and there is no significant difference between the educational level of caregiver's and how the care recipient responds to caregiving.

### b. Sub-themes conclusions

1. Perception of the caregiver with dependency level of caregivers; in this study the average caregiver's perception of the dependency levels of the caregivers was found to be 8.00±2.06.
2. Perceived difficulty caregivers related to caregiver performance: in the study, more than half of the participants stated the difficulty they felt while providing care when measured on the scale of**(0-4),** as 3 and 4 points was the most common response provided as difficult.

3. The areas that caregivers have difficulty about their own life while giving care and their emotions:the section covers all caregiver's worries, and they all stated that "they could not spare time for themselves and they could not fulfill their job/marriage/private life responsibilities becausethey hadto show constant attention and be with the person they care for".

## 6.2. Suggestion

1. Nurses training should be planned for caregivers about the cause of the disease, treatment and the problems they will encounter in the care process. In addition to the frequency and duration of home healthcare visits, communication should be made at certain and regular intervals via telephone/internet, and the caregivers should be prevented from feeling aloneand helpless during the care process.
2. With the holistic care approach, the health problems, psychological and social needs of care recipients and caregivers should be addressed together.
3. Platforms, associations, volunteer groups can be created where caregivers of individuals with similarly or different needs can communicate with each other and share their social problems.

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# APPENDIX ONE

# QUESTIONNAIRES

## Bakım Veren Yükü- Sosyo- Demografik Soru Formu

Bu anket, yaşlı ebeveyninize / yakınınıza verdiğiniz bakım türünü değerlendirmek için kullanılacaktır.Tüm bilgiler gizli tutulacak ve başka hiçbir yerde kullanılmayacaktır.Katılımınız için teşekkürler.

***Bakım Veren Kişi;***

1. Yaşınız..........................................

2. Cinsiyetiniz nedir?
a). Kadın
b). Erkek

3.  Eğitim seviyeniz nedir?
a). İlköğretim
b). Ortaöğretim
c). Yükseköğretim ve üzeri

4. Medeni durumunuz nedir?
a).Evli
b). Bekar
5. Çocuğunuz var mı?
a). Var *kaç tane?* ........................
b). Yok
6. Yakınınıza bakım vermek dışında gelir getirecek bir işte çalışıyor musunuz?
a). Evet *nedir?* ..........................................
b).Hayır
7. Kaç kişiye bakım veriyorsunuz?............................

8. Yakınınıza
a). Bir günde kaç saat bakıyorsunuz? .......................................
b). Ne kadar sürerdir bakabilirsiniz...............

9. Yakınınıza neden siz bakım veriyorsunuz?
a).Gönüllü olarak bakım vermek istiyorum.
b).Yakınımın benden beklediği bu olduğu için gönüllü bakım veriyorum.
c).Mecbur/zorunlu kaldığım için istemeden bakım vermek durumunda kalıyorum.
d).Maddi kazancım olduğu için bakım veriyorum.

10. Günlük zaman çizelgesi;
Temizlik................................
Fiziksel Bakım...............................
Psikolojik ihtiyaç giderme.................................
Alışveriş işleri.............................

# APPENDIX TWO

## OPEN ENDED QUESTION SECTION FOR CAREGIVER’S

***Bakım Alan Kişi için;***

1. Bakım verdiğiniz kişinin yaşi...............................

2. Bakım verdiğiniz kişinin cinsiyeti nedir?
a). Kadın
b). Erkek

3. Eğitim seviyesi nedir?
a). İlköğretim
b). Ortaöğretim
c). Yükseköğretim ve üzeri

4. Bakım verdiğiniz kişi sizin dışınızda başka bir birey tarafından da bakım alıyor mu?
a). Evet *Kim/kimler?*.................................................................
b).Hayır

5. Bakım verdiğiniz kişinin, size/bakım veren kişiye bağımlılık seviyesini 0-10 puan arası nasıl tanımlarsınız? ..........................................

6. Bakım verdiğiniz kişinin bakıma neden ihtiyacı bulunmaktadır?
Düşme, Alzeimer, ekonomik
.....................................................................

7. Bakım alan kişiyle yakınlık dereceniz nedir? ..................................................

8.Bakım alan kişi, sizin bakımınızdan memnuniyet seviyesini 0-10 puan arası nasıl tanımlarsınız?
...........................................

9. Bakım alan kişi, eğer bakımında bir aksama hissederse ne yapar?......................................

## APENDIX THREE

## THE ZARIT BURDEN INTERVIEWE SCALE

**Bakım Verme Yükü Ölçeği'nin Türkçe Çevirisi**Aşağıda insanların **bir başkasına bakım verirken** hissettiklerini yansıtan ifadeler bulunmaktadır. Her bir sorudan sonra sizin bu duyguları hiçbir zaman, nadiren, bazen, oldukça sık ve hemen her zaman olmak üzere hangi sıklıkla yaşadığınızı gösteren ifadeler

**Açıklama**:

**1.** Yakınınızın ihtiyacı olduğundan daha fazla yardım istediğini düşünüyor musunuz?
0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**2.** Yakınınıza harcadığınız zamandan dolayı, kendinize yeterince zaman ayıramadığınızı düşünüyor musunuz?
0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**3.** Yakınınıza bakım verme ile aile ve iş sorumluluklarınızı yerine getirme arasında zorlandığınızı düşünüyor musunuz?
0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**4.** Yakınınızın davranışları nedeniyle rahatsızlık duyuyor musunuz?
0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**5.** Yakınınızın yanındayken kendinizi kızgın hissediyor musunuz?
0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**6.** Yakınınızın diğer aile üyeleri ya da arkadaşlarınızla ilişkilerinizi olumsuz yönde etkilediğini düşünüyor musunuz?
0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**7.** Geleceğin yakınınıza getirecebileceklerinden korkuyor musunuz?
0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**8.** Yakınınızın size bağımlı olduğunu düşünüyor musunuz?
0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**9.** Yakınınızın yanındayken kendinizi gergin hissediyor musunuz?
0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**10.** Yakınınızla ilgilenmenin sağlığınızı bozduğunu düşünüyor musunuz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**11.** Yakınınız nedeni ile özel hayatınızı yaşayamadığınızı düşünüyor musunuz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**12.** Yakınınıza bakmanın sosyal yaşamınızı etkilediğini düşünüyor musunuz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**13.** Yakınınızın bakımını üstlendiğiniz için rahatça/kolay arkadaş edinemediğinizi düşünüyor musunuz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**14.** Yakınınızın sizi tek dayanağı olarak görüp, sizden ilgi beklediğini düşünüyor musunuz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**15.** Kendi harcamalarınızdan kalan paranın yakınınızın bakımı için yeterli olmadığını düşünüyor musunuz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**16.** Yakınınıza bakmayı daha fazla sürdüremeyeceğinizi hissediyor musunuz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**17.** Yakınınız hastalandığı zaman yaşamınızın kontrolünü kaybettiğinizi düşünüyor musunuz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**18.** Yakınınızın bakımını bir başkasının üstlenmesini ister miydiniz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**19.** Yakınınız için yapılması gerekenler konusunda kararsızlık yaşıyor musunuz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**20.** Yakınınız için daha fazlasını yapmak zorunda olduğunuzu düşünüyor musunuz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**21.** Yakınınızın bakımında yapabileceğiniz işin en iyisini yaptığınızı düşünüyor musunuz?

0 Hiçbir zaman 1 Nadiren 2 Bazen 3 Oldukça sık 4 Hemen her zaman

**22.** Yakınınıza bakarken genellikle nekadar güçlük yaşıyorsunuz?

0 Hiç 1 Biraz 2 Orta 3 Oldukça 4 Aşırı

## APPENDIX FOUR

**Name: Rosemary Uduak Imaukoh**
Address: No 2. Kilicarslan sokak Lapta, Girne Northern Cyprus.
Email address: roseima4@gmail.com, +905338607092
Contributing to nation building by working with the best people in the field of public health, and be of great support to the team I am assigned to.

### Personal Data

Date of Birth: Nov 2. 1992

Sex: female

Marital Status: single

Nationality: Nigerian

State of Origin: Akwa-Ibom State

LGA: Ibesikpo Local Government Area

### Education

Near East University, Public Health Nursing (Master's Degree) 2019-2021
Faculty of Health and Sciences, Department of Nursing 2013-2017
Qualification: Bachelor of Science (hons) Nursing

Lagos State University, Jibowu Campus (part-time program) 2009-2013
Industrial Relations and Personnel Management (IRPM)

Bachel Computer Training School, Egbeda 2007-2008
Qualification: Certificate on Desktop publishing

Ajeromi Ifelodun Senior High School, Lagos 2003-2006
Lagos State Model College Kankon, Badagry West 2001-2003
Rybeka Model Primary School, Lagos 1995-2000

### Additional training

-Hygiene Training, organized by Eeva Klein Limited 2009

## Work Experience

The National Sickle Cell Center, Library Assistant 2010-2013
B Telecommunication Center, Sales Representative 2007-2008
Eeva Klein Limited Branch Supervisor & Personal Assistant 2009-2010
Near East University Grand Library (Shelving) 2019

## Events Attended

World Sickle Cell Day (annually) June 19th 2010- 2013
Free Genotype Test Screening Sickle Cell Center (data collection) 2012
(Lagos State University Teaching Hospital)
Lefkosa Turkcell Kosuyor / SOS Çocuk Köyü Marathon (4KM) 2017

## Referees

Reference: Mr. Ebenezer.A. Adeleye; Programme Co-ordinator; Sickle Cell Foundation Nigeria Tel: +23435846666 Email: eadeleye@sicklecellfoundation.com

# APPENDIX FIVE

## YAKIN DOĞU ÜNİVERSİTESİ
## BİLİMSELARAŞTIRMALARETİKKURULU

## ARAŞTIRMAPROJESİDEĞERLENDİRMERAPORU

**ToplantıTarihi** :26.11.2020
**ToplantıNo** :2020/85
**Proje No** : 1200

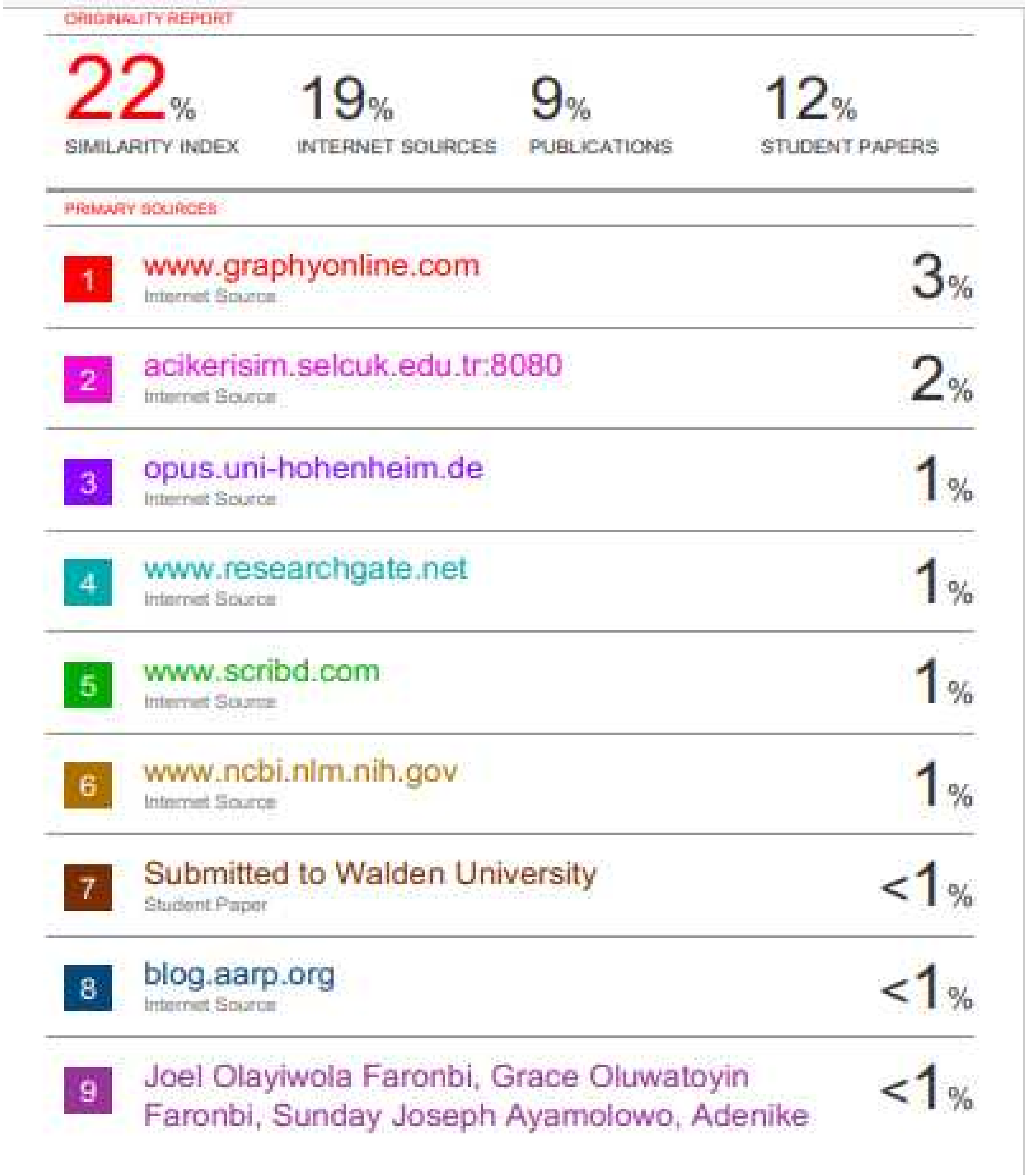
Yakın Doğu Üniversitesi Hemşirelik Fakültesi öğretim üyelerinden Doç. Dr. HaticeBebiş'insorumluaraştırmacısıolduğu,YDU/2020/85-1200projenumaralıve**"Understanding the Lived Experience of Family Caregiver's In Northern Cyprus: Caregiver's Burden**.**"** başlıklı proje önerisi kurulumuzca online toplantıdadeğerlendirilmişolup,etikolarakuygunbulunmuştur.

Prof. Dr. RüştüOnur

Yakın Doğu Üniversitesi

BilimselAraştırmalarEtikKuruluBaşkanı

## APPENDIX SIX



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# APPENDIX SEVEN

## ZARIT BURDEN INTERVIEW PERMISSION TOOL SCALE

**Pamukkale University, Faculty of Health Sciences,**
**Department of Public Health Nursing,**
**Denizli, Turkey.**

## ZARIT BURDEN INTERVIEW SCALE

Geçerlilik ve güvenilirlik çalışmasını yaptığımız “Bakım Verme Yükü Ölçeği’ni" kullanma isteğiniz bizi çok memnun etti. teşekkür eder, çalışmalarınızda başarılar dileriz. kaynak olarak aşağıdaki makaleyi gösterebilirsiniz.

Inci F H,& Erdem M. (2008). Bakim Verme YüküÖlçeğininTürkçeyeUyarlanmasıGeçerlilik ve Güvenilirliği.. AtatürkÜniversitesiHemşirelikYüksekokuluDergisi,11(4): 85-95

Dr. Öğr. Üyesi Fadime Hatice İNCİ and Dr. Öğr. Üyesi Müyesser ERDEM

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# Bakım Verme Yükü Ölçeği

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To: UD Ima <roseima4@gmail.com>

Sayın UD Ima,

Geçerlilik ve güvenilirlik çalışmasını yaptığımız “Bakım Verme YüküÖlçeği’ni" kullanma isteğiniz bizi çok memnun etti. teşekkür eder, çalışmalarınızda başarılar dileriz.
kaynak olarak aşağıdaki makaleyi gösterebilirsiniz.

İnci F.H. , & Erdem M. (2008). Bakım Verme Yükü Ölçeğinin Türkçeye Uyarlanması Geçerlilik ve Güvenilirliği. Atatürk Üniversitesi Hemşirelik Yüksekokulu Dergisi, 11(4): 85-95

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