COPING MECHANISMS, SOCIOECONOMIC AND PSYCHOLOGICAL BURDEN OF CAREGIVERS OF CHILDREN WITH BRONCHOASTHMA IN KAKAMEGA COUNTY GENERAL HOSPITAL, KENYA

BY

LUCY RUTH W. MWANGI

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF THE DEGREE OF MASTER OF PUBLIC HEALTH

EPIDEMIOLOGY AND POPULATION HEALTH

SCHOOL OF PUBLIC HEALTH AND COMMUNITY DEVELOPMENT

DEPARTMENT OF PUBLIC HEALTH

MASENO UNIVERSITY

DECLARATION

This research is my original work and has not been presented for any degree in any other University.

Signature …… Date ….……

Lucy Ruth W. Mwangi

EL/ESM/01005/2015

This research has been submitted for review with our approval as University Supervisors:

Signature …… Date …….

Dr. Dickens Omondi (PhD)

School of Health Sciences / Directorate of Research, Innovation and Partnerships

Jaramogi Oginga Odinga University of Science and Technology

Signature …… Date ……

Dr. Catherine Mbagaya (PhD)

Department of Educational Psychology

Maseno University

ACKNOWLEDGEMENT

First of all, I am eternally grateful to the Almighty God for showing me His favour from the beginning up to the successful completion of my work.

I would like to express my deepest appreciation and heartfelt gratitude to my supervisors Dr. Dickens Omondi and Dr. Catherine Mbagaya for their invaluable comments, patience and constructive criticism throughout working on this thesis, which has improved the content of my thesis. Their involvement right from planning, implementation and correction of the entire thesis has been tremendous and I could never thank them enough for their guidance. I am highly grateful to Mr. Geoffrey Olado, Dr. Betty Ogange, Ms. Millicent Atieno School of Public Health, Dr. Misiani, the Director of Health, Officer, Kakamega County and to the Administration of Kakamega County Hospital for their permission and support, and for providing me with the necessary information to carry out this study. My special thanks go to the Community Health Volunteers stationed in Kakamega County Hospital for their support and cooperation during training and data collection.

I also appreciate Mr. Kevin Wanyonyi, Ms. Jackline Makokha, Mr. Albert Murambi, all the study participants, research assistants, interviewers and transcriptionists for their commitment and full cooperation during data collection.

DEDICATION

I wish to dedicate this piece of work to my loving mother, Mrs. Margaret Mwangi, my loving husband Johnson and son Darryl, my siblings Rispah and Jonathan for their continuous support and encouragement throughout the journey of attaining this award.

ABSTRACT

Bronchoasthma is a heterogeneous chronic inflammatory non-communicable disease of lower respiratory airways characterized by spontaneous episodes. It is a life-course condition common among children, with variable intensities, frequencies and progression across population-groups. Worldwide, about 47.5 million children have bronchoasthma. Prevalence of bronchoasthma among children in Kakamega is about 4.2% out of 15.8% in Kenya. Caregivers are integral to ensuring continuity of long-term care of these children for better health outcomes, yet little is known about their mental health experiences. Stable psycho-emotional health and coping among caregivers of these children is critical for improved home care context. Understanding coping, psychological and socioeconomic experiences of caregivers is desirable to enable development of mitigation strategies thus enhancing quality of home-care. The current study was conducted among caregivers of children with bronchoasthma attending Kakamega County Referral Hospital. It sought to determine the coping mechanism, socioeconomic and psychological burden among caregivers of bronchoasthma children attending Kakamega County General Hospital, Kenya. Using cross sectional study, data was collected through structured questionnaires from 408 caregivers of children with bronchoasthma in Kakamega County. Data was analyzed descriptively. The mean age of caregivers was 33 years (SD. 9.86). Majority (78.7%) were actual parents, of whom 73.5% were married. At least, 64% had primary-level education. Caregivers earning <10,000KES per month were 76%, majority of them being self-employed. Sleep disturbance on the night previous to the interview (χ^2=65.7, df=3 p<0.001); caregivers' concern about the child's asthma medication and side effects (χ^2 =132.2, df=3, p<0.001); feeling helpless (χ^2=85.8,df=3, p<0.001) and; feeling frustrated or impatient ($\chi^{2=}$71.1, df=3, p<0.001) were statistically significant psychological concerns. Significant social and economic burdens included absenteeism from work (75.2|%), reduced total annual income (59.3%); lost job (60.8%) and; delayed family investment/cut budgets (95.1%). Most of caregivers (73.5%) were using escape-avoidance coping mechanisms (not taking any constructive interventions) among whom 79.7% simply hoped for a full recovery of the child; 72.3% were involved in substance abuse, while 68.6% downplayed the severity of symptoms because of myths and stigma. This study has demonstrated considerable psychological burden with adversarial coping particularly among economically disadvantaged caregivers. Targeted care including psychological and socio-structural support among this group is needful. Findings of this study will be to inform intervention measures to improve the quality of care for bronchoasthma children and their caregivers in Kakamega County. The study findings are expected to inform planning of improvement interventions, guide development and/or review of policies / strategic guidelines and inform practice by the health care workers and the hospital admin, on development of hospital-based training programs.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABBREVIATIONS/ ACRONYMS

AIDS	**Acquired Immune Deficiency Syndrome**
BPSD	Behavioral-psychological symptoms of dementia
CBT	Cognitive Behavioural Therapy
CCM	Chronic Care Model
CGH	County General Hospital
CHVs	**Community Health Volunteers**
COPD	Chronic Obstructive Pulmonary Disease
CSI	**Caregiver Strain Index**
DALYS	**D**isability **A**djusted **L**ife **Y**ears
ED	Emergency Department
FBO	Faith-Based Organization
GINA	Global Initiative for Asthma
HRQOL	Health Related Quality of Life
ICS	Inhaled Corticosteroids
IMCI	Integrated Management of Childhood Infections
ISAAC	International Study of Asthma and Allergies in Childhood
KCGTRH	Kakamega County General Teaching and Referral Hospital
MCH	Maternal Child Health
MOH	Ministry of Health
MOPC	Medical outpatient Clinic
MTRH	Moi Teaching and Referral Hospital
MUERC	Maseno University Ethics and Review Committee

NAC	National Asthma Campaign
NACOSTI	**National Commission for Science Technology and Innovation**
NAEPP	National Asthma Education and Prevention Program
NCD	Non-Communicable Diseases
NGO	Non-Governmental Organization
NHIF	National Health Insurance Fund
OR	**Odds Ratio**
PACQLQ	Paediatric Asthma Caregiver Quality of Life Questionnaire
PAL	Practical Approach to Lung health
POPC	Paediatric Outpatient Clinic
QOL	Quality of Life
SPSS	**Statistical Package for the Social Sciences**
US	**United States of America**
WHO	World Health Organization

OPERATIONAL DEFINITION OF TERMS

Bronchoasthma: Asthma is a chronic condition affecting the lungs for which no cure is available. However, highly effective management interventions are available for this disease. For the purpose of this study, asthma is defined as the presentation of such symptoms as unrelenting cough, chest tightness, wheezing, and breathing difficulties for at least 3 months. In this study, the terms asthma and bronchoasthma were used interchangeably.

Burden of care: The experience of physical, emotional, social and economic stress and exhaustion triggered by the frustrating and often overwhelming demands of providing care to patients with chronic conditions or ailments that require special attention and care.

Caregiver: This may be any individual who addresses the physical as well as emotional needs of a child while ensuring that the child is provided with a loving environment and access to such services as proper treatment. Within the context of the study, caregivers refer to the adults involved in undertaking these tasks and providing children with medications needed for the management of bronchoasthma.

Childhood: In this study, it is the period between the age of 7 months up to and including 14 years of age.

Chronic Care Model: This model outlines the various components that constitute the health care system and the role that it plays in bolstering the delivery of high-quality care for chronic diseases. These components include the community to which patients and their families belong, the institutions comprising the health system, self-management solutions, and the systems through which healthcare providers obtain clinical information and decision support.

Coping: Refers to the deliberate effort that individuals dedicate in a bid to alleviate personal and interpersonal hardships and minimize such adverse outcomes as stress and conflict.

Coping mechanisms: Refers to the tendencies and actions that individuals adopt as part of their efforts to manage the external stresses and the personal crises that they encounter.

Direct cost of asthma: include the direct costs that patients and their families incur while seeking treatment. Some of these costs are the emergency visit expenses, hospital admission costs, the prices of medications, and the charges levied for outpatient visits. Other costs are the personnel expenses that healthcare institutions incur and the costs of performing specific procedures such as imaging, blood tests, and pulmonary rehabilitation, among others. The patients receiving treatment also sustain transportation costs, home-care expenses, and domestic support overheads.

Indirect costs: Refers to productivity loss, worktime or opportunity costs incurred due to an illness, hospital visits or caregiving.

Intangible costs: Refer to the costs incurred in acquiring the social, human, and social supports necessary for treatment. While they are non-monetary and immeasurable, these costs are essential for the management of asthma. They play a crucial role in reinforcing the esteem of the patient while establishing a warm and loving environment that fosters recovery. The main purpose of these costs is to guarantee quality of life for the patient.

Psychosocial Burden: The social and emotional turmoil that individuals experience as they struggle to cope with the demands that they face. This concept examines the impact that psychological factors as well as one's social environment have on their capacity to withstand and thrive in the face of hardship.

Socio-demographic Factors: These are the various identifiers that place individuals in specific social and demographic populations. Some of these factors include one's education level, their economic status as measured by their annual income, marital status, race, and age, among others.

Socioeconomic status: Is the position that an individual occupies within a class or social group. The status is usually determined by considering factors like the individual's occupation, income level, and their educational attainment. The socioeconomic status heavily influences one's capacity to cope with the demands and burdens associated with asthma caregiving.

Wheeze: A high-pitched sound that resembles whistling that often occurs while breathing out.

CHAPTER 1: INTRODUCTION

1.1 Background of the study

Bronchoasthma is multi-etiologic non-communicable disorder of the lower respiratory system. It is characterized by persistent inflammation of the airway epithelium and episodic exercabations leading to episodic airway obstruction (Global Asthma Network, 2018). It is ranked as the 14th most common disorder globally as it has been linked to multiple burdens to the patients and their care givers (McCormick, 2019). By 2018, approximately 339 million people were estimated to be suffering from asthma, with figures expected to rise to 400 million by 2025, 14% of these being children (WHO, 2019). Developing countries account for more than 80% of the asthma-associated mortality (Eassey *et al.*, 2019; Global Asthma Network, 2018). About 50 million cases occur in Africa, with the prevalence of this disease in South Africa estimated at 8.1% and Kenya accounting for approximately 4 million Sub-Saharan Africa (SSA) has a fast-growing asthma burden, with an estimated 50 million asthmatic children under 15 years, and Kenya accounts for 10% (**Simba *et al.,* 2018**), out of which, Kakamega accounts for 4.2% of cases. However, prevalence data is scarce and variable due to differences in disease classification, diagnostic challenges, varied distribution of etiologic factors and geographical contexts. **(**Global Asthma Network, 2018**)**. According to Kiilu *et al.,* (2019), uncontrolled bronchoasthma was said to have serious complications with consequences of loss of quality of life, low self-esteem resulting in reduced time for social interaction, increased psychosocial trauma, reduced exercise tolerance and which occasionally leads to death. **Kenya is reported to have no population-based studies on asthma prevalence in children aged below 10 years. A recent report shows that 1 in 10 children aged between 10-14 years are asthmatic (Kiilu *et al.*, 2019).** Childhood bronchoasthma remains under-diagnosed and under-treated in Kenya, thus exacerbating risks for complications and related burdens including, cost of management, stigma as well as physical

and psychological stress. Uncontrolled bronchoasthma can be fatal or progressively lead to significant and debilitating clinical limitations with associated physical, cost, social and professional/ learning constraints (MoH, 2019). The frequent hospitalizations, expenditures on acute care at out-patient hospitalizations, prescription medication and medical consultations can be overwhelming for caregivers and other stressful factors often lead to caregivers being unusually stressed and fatigued (Waters *et al.*, 2017; Dowell., 2016).

The stress, fatigue, and depression that the caregivers face when taking care of the children with bronchoasthma influences in diverse ways their psycho-emotional status when compared to those without (Clark, 2018). **Foronda *et al.*, (2021)** reported that parents of children with bronchoasthma experienced depression. When combined with factors like child anxiety, smoking, and a home environment that undermines wellbeing, caregiver stress may compound asthma comorbidity. Furthermore, caregiver stress could also erode the child's self-efficacy and capacity to self-manage the condition while eroding the problem-solving competencies of the child's family. The ultimate outcome is poor medication adherence (Ekim & Ocakci, 2017). The interplay of these intermediaries and relationships with care-giver psychological burden is still poorly understood.

Understanding ~~correlates~~ factors of psychological burden is necessary to tailor essential social support to mitigate caregiver stress, thus enabling them to adopt effective coping solutions that allow them to confront the emotional and behavioral challenges that asthmatic children exhibit (Chalise *et al.,* 2016 and Kosisochi *et al.,* 2020). Studies have shown that caregivers vary widely in how they cope. Coping mechanisms adopted may include Problem-Focused which is concerned with alleviating or at least minimizing the stressors that caregivers face; Emotion-Focused, involving helping caregivers to adopt healthier emotional responses to stressors, or; Escape-Avoidance- Focused, involving flight from the stressors by relying on such strategies as humor and a refusal to acknowledge the difficult reality that

the caregiver faces **(Waters *et al.,* 2017)**. The coping mechanisms adopted by caregivers of bronchoasthmatic children when stressed include, strategies focused on the problem, on the emotion, on the search for support in religion, while others focus on social support (Waters *et al*., 2017). However, the individual strategies are not constant in time, subject to other overlapping mechanisms in the care context. For example, a stressful environment influences coping response, controlled in part by personality and habitual tendencies as well as costs involved (Kopel *et al*., 2017). However, in Kakamega County, usually there are no formal structures to routinely monitor these experiences nor are there necessary support measures to enhance adaptive coping strategies for caregivers.

Whereas the African region shoulders a heavy burden of communicable diseases, non-communicable diseases such as bronchoasthma in children are becoming increasingly prevalent and compounding the public health challenges that the African nations face (Juma *et al.,* 2017). Collaboration between lay-caregivers and professionals for chronic diseases care is limited across the region, while caregiver well-being is not usually integrated within the chronic care process **(Simba *et al.,* 2018; Mayo *et al.,* 2020)**. Caregivers provide essential long-term continuity of care for children with bronchoasthma through which to improve care outcomes, yet the impact of this on their well-being is unclear. Understanding the prevalence of typical stressors, how caregivers cope with them and what coping mechanisms are often adopted, is desirable to enable development of appropriate interventions to improve quality of the post-diagnosis long-term homecare-giving in an ideal chronic care model for children with bronchoasthma **(Pranther *et al.,* 2020).** Given the critical role of caregivers in the post-diagnosis long-term care, there is need to determine their lived experiences and ways of coping with stressful demands of care giving. There is still dearth of information in this regard in Kenya. The intent of this research therefore is to inquire the physiologic and socioeconomic burdens faced by the caregivers and the coping mechanisms that they adopt to mitigate the burdens.

1.2 Statement of the problem

Bronchoasthma caregivers who attend Kakamega General Hospital majorly come from the low to the middle social class group. There lacks information about their quality of life and the challenges they undergo while treating their children. One significant trend that has been emerging and is evident from the hospital is that the caregivers rarely receive any form of training and empowerment on how to cope and adapt with the socioeconomic and psychological burdens of bronchoasthma **(Simba *et al.,* 2018)**. Caregiver psychological burdens are usually hidden and of varied characteristics yet are not routinely assessed or diagnosed early. Also, majority of service providers lack appropriate skills to diagnose and monitor cases during patient follow-up care, with increasingly poorer outcomes as a result.

There has been an increase in the incidences of bronchoasthma cases registered in the paediatric and medical outpatient clinic at the Kakamega County General Hospital. Despite the government's effort to ensure universal healthcare is accessible to all at affordable costs, least about bronchoasthma caregivers in Kakamega County, coping mechanism and the burdens associated with their children condition remains undocumented.

If the business remains and works as usual in Kakamega County, bronchoasthma poverty trap will be evident in the society with caregivers giving in to the disease through spending off all the available resource to restore the wellbeing of their beloved one. The conditions surrounding the poor qualities of life are highly attributable to bronchoasthma caregiving.

One mystery surrounding bronchoasthma caregiving in Kakamega County which calls for divine intervention from the academia world to unravel the situation is how these caregivers have been coping up with the situation. Hitherto, studies on caregiving have been biased toward that of the elderly and those who are less ambulant, and largely in developed countries **(Wu *et al.,* 2019)**. It's debatable and interesting to explore what could be the driving force behind their survival mechanism and how such

could even be replicated nationwide. This small group could provide a resourceful platform for the government to introduce a national and even international standard operating practices for the Paediatric Outpatient Clinic (POPC) and Medical Outpatient Clinic (MOPC) on how coping guidelines should be established.

Childhood bronchoasthma is one of the causes of morbidity and mortality in Kakamega County, and ranks at the 5th position in diseases at the Kakamega County General Teaching and Referral Hospital. In spite of the Ministry of Public Health together with the other stakeholders in the public health sector developing health education and awareness and other environmental health programs to avert the situation, the disease continues to affect many children below the age of 14. Indeed, many childhood illnesses in Kenya are airborne. However, there has been no documented research on its burden to caregivers and how they cope up with the situation. The present research hypothesizes that most of the caregivers of children with bronchoasthma attending Kakamega County Hospital, do not have satisfactory coping skills and resilience. However, there has been no documented research on its burden to caregivers and how they cope up with the situation. Hence, there was need to understand their level of caregiving burden and methods of coping and relationships of this with the psychological status. Whereas caregivers form a crucial part of the chronic care of bronchoasthma, it remains unclear what dimensions of the chronic care continuum are associated with increased distress. It was critical to identify potential sources of increased risk for caregiver distress and how they cope with their lived experiences.

1.3 Objectives

1.3.1 Broad objective

The main objective of the study will be to determine the **coping mechanisms, socioeconomic and psychological burden of caregivers of children with bronchoasthma attending Kakamega County General Hospital, Kenya.**

1.3.2 Specific Objectives

The specific objectives of this study will be to:

(i) Establish the psychological burden of bronchoasthma among caregivers of Bronchoasthmatic children in Kakamega County.

(ii) Determine the socioeconomic burdens of bronchoasthma among caregivers of Bronchoasthmatic children in Kakamega County.

(iii) Determine the coping mechanisms adopted by caregivers of bronchoasthmatic children in Kakamega County.

1.4 Research questions

(i) What are the psychological burdens of bronchoasthma among caregivers of children in Kakamega County?

(ii) What are the socioeconomic burdens of bronchoasthma among caregivers of bronchoasthmatic children in Kakamega County?

(iii) What are the coping mechanisms adopted by caregivers of bronchoasthmatic children in Kakamega County?

1.5 Justification

Bronchoasthma is a serious and debilitating disease especially if poorly managed during childhood **(Melén *et al.*, 2019; Juber *et al*., 2019)**. Based on the 2016 national MoH asthma data, Kakamega County was leading with 2834 cases recorded for children below 5 years. KCGRTH accounted for about 350 children, ranking second nationally and leading in the Western region. Nationally, it had 4.2% of the asthma reported cases out of 15.8%, for both children and adults. Caregivers' burden is still poorly understood in LMICs and largely associated with under diagnosis, under documenting, or even lack of awareness. Patients and their caregivers impact each other simultaneously (Cipolletta, *et al.,* 2020). Caregivers have no formal medical training, support structures and guidelines on appropriate care or its provision. Caregivers' psychological and mental health outcomes determine the outcome of children management, and so, warrants more research. Homecare and the caregivers' chronic care experiences is still largely unexplored in Kenya. Potential social stigma status of asthma; unpredicted timing of asthmatic attacks, cold rainy weather patterns, and severity; need for emergency care, and high costs involved, leaves caregivers anxious, financially, psychologically and socially stressed. Kakamega County has a child rich population, comprising of 47 % of the total county Population (KNBS, 2019), a high under-5 mortality rates (169/1000 live births) largely due to preventable diseases; skewed socio-economic and healthcare experiences, with potential negative health outcomes. Psychosocial Support, education and linkages by the healthcare workers on coping strategies calms and empowers the caregivers in management as well as coping in the event of stigma. Despite having regular POPC for children, caregivers are not routinely screened for or provided with psychological support. Most research studies concentrate on child health, neglecting caregivers' wellbeing. Understanding the scope and burden of psychological stress is needful for improvement of chronic care plans. Caregiver burdens and coping identified can be utilized to enhance quality of care,

potential factor interaction pathways and recommend improvement intervention points. The study findings will inform caregiver well-being interventions, policy and practice in the county.

1.6 Significance of the Study

The study reveals considerable psychological hardships and inadequate and ineffective coping strategies among caregivers of children with bronchoasthma, which indicates an ongoing adversarial microenvironment of the child, which may exacerbate the disease process leading to long-term effects. It reveals an important gap in the ongoing care of these children, because there is more focus on index patient with relative inattention to the wellbeing of their caregivers. The findings indicate need for psychosocial support for caregivers in childhood bronchoasthma management. It is expected that, active participation and professional support of the caregiver in the chronic care of the child is likely to lead to improved micro-context of informal care with improved long-term outcomes. Contextual knowledge of the inter-relationships between psychological burden of bronchoasthma and social, economic, and demographic profiles and the coping mechanisms among caregivers of children with bronchoasthma on follow up is desirable to provide evidence for decision-making on individualized medical care and planning the post-diagnosis chronic-care support. The study findings would help clarify the relationship between psychological strain and the socioeconomic situation of the caregivers and identify barriers towards good child bronchoasthma outcomes as well as proposing interventions for caregiver mental health wellness. These research findings are expected to create broad awareness on social, emotional, and economic hardships that caregivers endure as a result of bronchoasthma. Secondly, the study findings will inform planning for the integration of care-giver psychosocial support services at the Kakamega County Referral Hospital which is lacking at present. Thirdly, this study will inform the management on the essence of the establishment of a Paediatric-asthma clinic in

the facility. Lastly, this study results could be used to advocate for a combined child asthma clinic for both below 5 years and those above 5 years.

1.7 Limitations and Delimitations of the study

1.7.1 Limitations of the study

Beliefs and myths surrounding bronchoasthma, fear of stigmatization and stress observed may have clouded the caregivers' mindset from being more open about their child's bronchoasthma and personal experiences. This limitation was addressed by reassuring and empowering the caregivers with information about bronchoasthma, visiting the homes in the company of Community Health Volunteers they are familiar with and providing psychosocial help and referral as need be during the interview. However, the impact of this limitation or remedies implemented would not be known. Also, given that seasons significantly influence the manifestation of childhood bronchoasthma, the rather short period during which the study was conducted could leave out patients whose bronchoasthma is in the stable stage.

1.7.2 Delimitations of the study

The study was restricted to interviewing caregivers who had ever visited the health facility to ensure enrolling only those with objective diagnosis. There was also an age restriction of the children with bronchoasthma to those below 14 years of age, who routinely would be attended pediatric clinic. The caregivers did not have to be strictly biological, and their age specification was not a requirement. The guardians in the study were restricted to those who had stayed for a minimum of 3 months with the child with asthma.

1.8 Assumptions of the Study

The main assumption made was that the respondents supplied accurate and true information. For a disease that is relatively stigmatized, there was an assumption of an understanding between the caregiver leading the investigator to another affected caregiver. The assumption would also be that there would not be enmity or other caregiver psychosocial harm. It was also assumed that the snowballing procedure would not produce harm in terms of breach in confidentiality. Questions were designed and framed to clarify any misunderstanding in different ways to collate the responses.

CHAPTER 2: LITERATURE REVIEW

2.0 Introduction

This chapter highlighted some of the burdens that face the caregivers of children with bronchoasthma worldwide, in Kenya, and at the Kakamega County General Hospital. It also highlighted on the socioeconomic and psychosocial burdens that need to be addressed for the holistic management of bronchoasthma in children. It also addressed some of the coping mechanisms of the caregivers towards bronchoasthma in the children.

2.1 Prevalence and etiology of childhood bronchoasthma

Globally, two challenges were understood to needlessly prolong illness, reduce the quality of life of patients, exacerbate socioeconomic hardships and sometimes, death. These problems are over-diagnosis and under-diagnosis (Yang *et al.*, 2017). Poorly controlled asthma is expensive, with the high impact being disproportionately high on the poor **(Ongarora *et al.,* 2019)**. In a study by **Barakat *et al.,* (2018),** affordability and availability of medicines for asthma remains a challenge, especially in the public health facilities in Kenya. Estimates show that across the globe, asthma afflicts as many as 339 million people who were drawn from diverse demographic backgrounds. About 14% of the world's children experience asthma symptoms **(Network, 2018.)**. According to **WHO (2019)**, Asthma is a major cause of non-communicable chronic respiratory disease in childhood and is ranked 14th with regard to the duration and scale of disability that it inflicts upon patients. Projections indicate that by 2025, the number of individuals living with asthma will have risen to 400 million **(Network, 2018)**. If this expected figure is actually realized, the cost and burden of delivering care will certainly increase. **In a systematic analysis in 204 countries and territories, bronchoasthma was demonstrated to have affected about 262 million people in 2019 and caused a mortality of about 455 000 people**

(**Chen *et al*., 2022**). Compared to bronchoasthma, malaria caused 409,000 deaths (**WHO, 2019**). The disability adjusted life years (DALYS) attributable to asthma was 23.7 million in 2016. These asthma effects were also deemed to be worse in low- and middle-income countries (**Network, 2018**).

In Africa, asthma affects 50 million with majority of the victims from South Africa with intercountry prevalence data remaining scanty. It was well established that when exposed to air pollutants while engaged in such activities as play outdoors, children faced a greater risk of developing asthma and a range of other respiratory symptoms (**GINA, 2020).** However, it should be understood that much of the existing evidence was gathered in areas other than Sub-Saharan African. Moreover, the existing evidence regarding the implications that exposure to ambient air pollution presented an increase for asthma incidence and manifestation among children was inconclusive **(GINA, 2020)**.

According to **Adeloye *et al.,* (2013)**, it was estimated that children below the age of 15 years had asthma. The most recent ISAAC studies on the prevalence of asthma in Kenya, were done only in Nairobi and Eldoret towns, among children of age groups of 6-7 years and 13-14 years, with prevalence of 18% and 13.8%, respectively (**Simba, J. M. 2021**). There are no recent updates on the prevalence of asthma in Kenya, with the latest study having been done 20 years ago (**Network, 2018).** Data in Kenya and a systematic analysis from Africa shows that urban areas account for a bulk of asthma cases with increasing prevalence **(Ntubiri *et al.,* 2018)**. At present, the main factors behind the high burden that bronchoasthma imposes in Kenya are not well understood. Furthermore, the role that genetic factors as well as environmental influences play in the prevalence of this condition in the country is also unclear, but breastfeeding has been attributed to protectiveness against severe asthma **(Ntubiri *et al.,* 2018)**. However, for Kenya to succeed in delivering appropriate health solutions, it must overhaul its primary health care system by bolstering community resources and structures. Nationally, a lot of emphasis has been laid on infectious diseases, as the major causes of morbidity

and mortality **(Kisiangani *et al.,* 2018)**. However, with changing lifestyle trends and other factors, diseases like bronchoasthma are emerging as among the main forces behind poor health and alarming increases in mortality. The consequences of chronic diseases like bronchoasthma include higher healthcare costs and the straining of limited healthcare resources (**Kenya Asthma Management Guidelines, 2021**). While most of the lifestyle diseases can be prevented through healthier lifestyles, currently, there are no clear interventions that have demonstrated effectiveness in reducing the risk of developing bronchoasthma **(GINA, 2020)**.

Within the public health sphere, immense attention is being committed to minimize disease burden through early case detection and referral, provision of prompt appropriate treatment and the administration of rehabilitative and long-term care interventions **(GINA, 2020)**. Given the current situation, there is a need for the introduction of standardized and clearly defined solutions that are also cost-effective. When such programs are well implemented, Kenya can expect to adopt a more accessible healthcare regime that is particularly designed to alleviate the suffering that conditions like bronchoasthma impose on patients and their caregivers. It is indeed encouraging that as part of its national asthma guidelines, Kenya is placing emphasis on Practical Approach to Lung (PAL) Health **(Kenya Asthma Management Guidelines, 2021)**. Through this approach, the country outlines specific tools and strategies that primary care practitioners and providers should adopt in the management of various respiratory conditions and symptoms. To enhance the impact of the PAL strategy, Kenya should consider instituting desperately needed communication protocols while undertaking public mobilization in order to sensitize communities to become involved in efforts to confront asthma and promote effective coping solutions. To accomplish its public health aspirations, Kenya should invest in collaborative partnerships with stakeholders who are also keen on reducing the burden that asthma inflicts on the country (**Kenya Asthma Management Guidelines, 2011**). In Kenya, there are no customized public supported asthma – care programs to address the issues of

asthma patients. Findings on coping mechanisms provided information for designing contextual communication intervention messaging.

2.2 The Psychological burden of bronchoasthma among caregivers

Bronchoasthma has a significant and far-reaching impact on the emotional health of the caregivers. Families of children with bronchoasthma consistently experience considerable burden of psychological challenges such as stress, anxiety and depression (**Addo *et al.*, 2018)**. The current study assessed the occurrence of stress and depression that the caregivers endure when taking care of the children with asthma. A systematic review by Addo *et al.,* (2018) showed that majority of the caregivers were unemployed females. There is still no consensus on how to assess psychological burden. Dharmage *et al*., (2019) in a systematic review of the epidemiology of asthma in children and adults, observed a high prevalence of both depression and anxiety, however, some studies did not differentiate between the two. In fact, evidence indicates that within families, having children with bronchoasthma, parents report suffering from depression as well as anxiety (Clark, 2018). **Susceptibility to other infections and non-communicable diseases is increased in people or children with bronchoasthma.** In a study by Juber *et al.,* (2021), bronchoasthma in children was found to greatly increase the risks of diabetes, hypertension and stomach problems when diagnosis was made from the age of 20 years old. Studies indicate that mothers of children with chronic conditions suffer from psychological distress and burnout to a greater extent than fathers (Anclair *et al.,* 2017). In the study, the target sample consisted of 28 caregivers of children with chronic conditions, below 18 years of age, who had stress and burnout, and cognitive behavioural therapy (CBT) and mindfulness were respectively administered to two groups examine their outcome. The outcome was reduced burnout and stress levels.

In addition to leaving individuals feeling overwhelmed and powerless, caregiving has also been linked to such secondary adverse outcomes as productivity challenges in the workplace as well as strained interpersonal relationships **(Nunes *et al.,* 2017)**. However, in a contrast hospital based study in Qatar, the caregivers quality of life was found to be good. This was despite of worse psychological burdens (QoL) in mothers in lower socioeconomic groups, poor access to health care services, low quality education level, fewer employment opportunities, poor social life and were more exposed to mental and physical health problems. Therefore, higher income was associated with higher QoL **(Shaikhan & Makhlouf., 2020).**

Theories like the Social Cognitive Theory by Bandura focuses on learning experience and holds that the behaviors that individuals exhibit are influenced by a combination of **environmental, personal,** and **behavioral factors** which act upon each other to generate specific behavioral outcomes **(Rhee *et al.,* 2018)**. Behavior and environmental factors constantly influence each other, reciprocally determining each other. It is useful in identifying variables that more likely predict or motivate individuals to adapt health promoting behaviors or risky ones by identifying the psychological factors of a caregiver's responses. In the current study personal-related variables included; emotional (anxiety and stress), knowledge, attitudes, personality, demographic aspects (age, gender, marital status) or social-economic (employment, income, education level) characterizing an individual. Environmental factors are those that are physically or socially external to the person and create chances through which situational characteristics and psychosocial pressures manifest. psychosocial pressure or situational characteristics. The environmental factors may interfere with caregivers' wellness positively or negatively and include sociocultural factors, social norms as well as healthcare beliefs of the family and friends, social groups and networks. This means that the individuals' psycho-social responses are functions of the caregiving experience within the context of his / her respective environment where

they reside. Furthermore, the specific behaviors that individual caregivers exhibit in particular situations significantly affect and are shaped by a mix of environmental (situational) and cognitive and personal influences such as emotional instability, interference with family, change of daily activity and sleeplessness. Social and physical environmental factors affect a caregiver's behavior and subsequently the health outcomes that the asthmatic child experiences. For example, caregivers' housing status, weather or availability of food. The role of community volunteers and health care workers form part of the external environment that influence the caregivers during both acute and chronic phases of the disease. They can, for example, empower and follow up caregivers to enable them subsequently develop self-efficacy in coping with the care-giving tasks. This may be through health education, psychosocial and spiritual counselling as well as support groups, which are all included in the learning process to improve the outcome of the affected child. This may improve their quality of life, social economic status and coping.

Neighborhood disadvantage is among the factors related to chronic stress that has been shown to undermine development among children. Essentially, neighborhood disadvantage is a phenomenon that is defined by such community-level adverse realities as high levels of poverty, joblessness, and inadequate social capital **(Foronda *et al.,* 2021; Aryee *et al.,* 2022)**. Inadequate and poor housing, violence, and lacking social cohesion are other features that characterize neighborhood disadvantage. According to **Bellin *et al.* (2018),** in inner cities, the rate of clinical depression among mothers whose children are suffering from bronchoasthma in the US was made worse by poor housing conditions, collaborations or lack of it in School-Based bronchoasthma management, health service providers collaboration and prevalent psychological distress. Left unmitigated caregiver stress may trigger or occur alongside such other conditions as tobacco smoking, anxiety among children, and the loss of organization within the home environment. Similar to this study, a study at Moi Teaching and Referral Hospital (MTRH) by **Simba *et al,* (2018),** noted that patient education of bronchoasthma is done at

the discretion of the attending clinician, as there were no asthma educators available. In the study conducted among 2 categories of children aged between 6-7 years and 13-14 years of age respectively, lung function tests were also not performed on children who were on management for bronchoasthma at the hospital. In contrast to this study, the gap presented was that there was more focus on patient instead of health workers (**Simba *et al,* 2018**). This study focused more on the psychological status of the caregivers of the children with bronchoasthma. Similar studies in Kenya revealed that caregivers with higher mental depression had depressed children, and experienced financial, social and physical constraints (**Laurenzi *et al.,* 2021; Kuerten *et al, 2020***).

Additionally, among children, the stress could distort the child's view about their self-efficacy and their competency to self-manage the asthma and solve the problems that their family grapples with **(Foronda *et al.,* 2021)**. Eventually, these challenges could result in reduced medication adherence (Ekim & Ocakci, 2017).

Research suggests that compared to non-caregivers, caregivers tend to report higher prevalence of depressive symptoms. The results of one study show that 49.1% of parents of children with severe chronic depression are depressed and 31.8% have moderate depression (Everhart *et al*., 2015). Depressed caregivers also have lower self-efficacy **(González-Conde *et al.,* 2019).** The Spanish study among caregivers of children between 6 and 14 years, proposed that the measurement of self-efficacy be incorporated in the assessment of educational interventions in self-management targeted at the quality of life of the child with bronchoasthma and the caregivers. Not only parents but sisters and brothers of children with chronic diseases are at increased risk of psychological negative effects **(Kwena F.T. 2021).** In the Kenyan study by Kwena, the attention to the child with sickle cell disease triggered sibling rivalry and resentment towards the affected child as well as the parents. It was deemed that the child over utilized the available resources which should ideally be shared equally. If parents

are not provided with the support that they desperately need, their children could exhibit a variety of mental health issues and become exposed to a higher risk of stigma, abuse, and neglect **(Pranther *et al.,* 2020).**

Caregiver burden contributes to poorer social well-being and patient outcomes. **Kosisochi *et al*., 2020,** found that that they obtained is that social support is the major factor relieving the caregiver burden and may act as a mediator on indicators of psychological well-being. The caregivers record higher quality of life if they share a house with another adult to whom they can turn for support. A contrast systemic study by **Cipolletta *et al.,* (2020),** concluded that social support did not predict the patients' & caregivers' psychological symptoms. It stated that most research was biased toward caregiving of the elderly patients or those with mental illnesses, & cancer care, and were mostly conducted in Western cultures (**Wu *et al.,* 2019)**.

Poor patient care destroys the energy of the family, increases the risk of adverse physical, emotional and isolating outcomes causing despondency, helplessness, fear, embarrassment and desire for death and therefore the families of patients "Hidden patients", as they are also called (Hoerger *et al.,*2017). In addition, various factors, including reduced family size, increased marital separation, technological innovations, and medical progress in healthcare, have elevated the perceived stress and stress experienced by parents (Ekim & Ocakci, 2017).

2.3 The Socioeconomic burden

The socioeconomic burdens faced by the caregivers are mainly in terms of tangible and intangible costs like, relationships at home, borrowing finances for medicine purchases, stigma, social support at the workplace, finances, employment, absenteeism, job threats, the caregivers' level of education. In addition there are concerns about how asthma in the children limits the caregiver productivity at work

in terms of limited time, pain, grief and stress related to caregiving, loss of quality of life and also denying them from having time for social activities. Also, expenditures on acute care out and inpatient hospitalizations, prescription medication and paediatrician consultations. Bronchoasthma remains one of the most pressing public health challenges **(Nunes *et al.,* 2017)**. In addition to demanding such forms of emergency care as hospitalization, this condition also forces children to miss school while driving absenteeism from work among caregivers. Additionally, poorly managed bronchoasthma in childhood also results in disability and death (Chalise *et al.,* 2016; **Juber *et al.,* 2021**).

Uncontrolled bronchoasthma can be fatal or quickly lead progressively to significant and debilitating clinical limitations with associated physical, cost, social and professional/ learning constraints (MoH, 2019). Data emerging recently from the US indicates that among individuals with an uncontrolled events, the healthcare expenditures are substantially higher **(Lee *et al.,* 2020)**. Furthermore, according to this data, these individuals also have a 4.6-fold higher risk of hospitalization and are 1.8 times more likely to require emergency care. Furthermore, the individuals have a higher likelihood of reduced productivity. Productivity entails such issues as absenteeism as well as active employment **(Nunes *et al.,* 2017)**. With regard to productivity, the patients ailing from uncontrolled bronchoasthma tend to have higher unemployment rates and greater absenteeism and a compromised ability to perform their duties as expected. The data also demonstrated that there was no significant difference in hospitalization rates among those with controlled asthma and healthy members of the larger population **(Koul & Dhar, 2018).** They found that if left untreated, asthma usually raises healthcare costs as the patients require medicines for symptoms relief and prevention, medical devices such as spacers, acute ambulatory care, and in patient services. Other services that these patients need include management planning and education **(Kenya Asthma Management Guidelines, 2021)**. Moreover, the patients also experience productivity losses **(Ughasoro *et al*., 2021).** However, these losses have only been observed in a handful of settings in high-Income Countries.

Banjari *et al*., (2018) established that caregivers in lower and middle-income status, borrow money to finance the purchase of medicine and also to pay for consultation of medical attention. Some had to cut down on expenses of necessities like food and house rent by relocating to cheaper houses, switch to cheaper generic drugs and avoid or cut back on emergency department visits **(Banjari *et al.,* 2018)**. A study by **Sullivan *et al*., (2018)** showed that parents of children with asthma and an exacerbation missed 1.2 times more workdays ($p < .05$), whereas those with an acute attack ED visit missed 1.8 times more workdays ($p < .01$) than parents of children without asthma.

In Australia and the United Kingdom, as compared to Africa, when they are involved in informal caregiving, individuals are more likely to give up their jobs or work part time **(Hussain & Ryan, 2018)**. Furthermore, since the caregivers are usually unpaid for the services that they provide, they often contend with low wages **(Gillaspy *et al.*, 2017).** For example, due to absence from work, an informal caregiver could be issued with a warning letter which would certainly compromise their career progression, thereby resulting in the erosion of their skills and human capital as well as limited access to career opportunities (Gillaspy *et al.*, 2017). Moreover, the informal caregivers are more likely to fall into poverty due to unemployment and reduced working hours. Consequently, these caregivers can be expected to report higher rates of psychological stress and a worsening of their physical health as they struggle to balance the demands of their jobs and the pressures of caregiving **(Kosisochi *et al*., 2020)**. Social isolation, limited financial resources, and inadequate access to social supports further exacerbate the hardships that the caregivers face (Kosisochi *et al*., 2020).

Married and single parents were more affected by anxiety than were divorced parents. In a study by Alnazly and Abojedi (2019), divorced parents, however, reported higher rates of depression compared to their married counterparts. Essentially, divorced individuals face a greater risk of psychological stress because of the emotional pain that they tend to experience, conflicts within their relationships,

and being rendered unable to function as parents. The situation is worse for divorced mothers who are usually economically disadvantaged and therefore more vulnerable to depression and psychosocial burdens.

In most societies, the female caregivers usually actively participate in caregiving than the males **(Chong *et al*., 2019)**. In contrast however, an Iranian study, there was more male caregivers involvement than female, citing the cultural perceptions of the importance attached to the male child and also a larger number of male children with bronchoasthma than female **(Adib-Hajbaghery & Ahmadi, 2019).** In a study by Minichil *et al.,* (2019) in Ethiopia, compared to males, females are 2.4 times as likely to develop depression. **Similar findings** have been obtained by researchers conducting studies in Kenya (Mbugua *et al.,* 2011) and Pakistan (Azeem *et al.,* 2013). The study by Mbugua et al., (2011), was done in Gachie, on the prevalence of depression among family caregivers of children with intellectual disability in a rural setting in Kenya. The caregiver was noted to be at a risk of depression because of financial lack, due to inability to engage in income generating activity, social isolation, friendship loss and stigma associated with caring for intellectually disabled person **(Mbugua *et al.,* 2011).** Most caregivers were female, married, of primary education level and unemployed. However, the study was conducted in a Catholic church setting. Similarly, in Pakistan (Azeem *et al.,* 2013), in an institutional based study, the female caregivers were more depressed and anxious than their male counterparts when caring for their children with intellectual disability.

Among African communities, there are strict social norms which charge women with the mandate of caregiving. In fact, several studies have determined that men in Africa are reluctant to take on the caregiving role and may only perform this function in situation where women are absent **(Asuquo & Akpan-Idiok., 2020),** as caregiving is deemed to be a feminine role, where men and boys are excluded**.** For example, a study performed in Nigeria revealed that the bulk of caregiving is undertaken

by older women. This may be because observed age range may have become grandmothers and do caregiving of children orphaned by AIDS. The perceived stain and hardship that the caregivers experience is compounded by limited financial resources. Some of the traits that significantly impact the outcomes among the caregivers include their gender, socioeconomic condition, length of period during which caregiving occurs, and the nature of the relationship between caregivers and their patients (Ochigbo *et al.,*2018). The study by Ochigbo et al., (2018), however reported caregivers' burden to range from none to minimal, with only 16.4% experiencing mild to moderate caregiving burdens.

2.4 Coping mechanisms of caregivers of children with broncho-asthma

Coping mechanisms entail the strategies and skills that individuals leverage to withstand hardship **(Antony *et al*., 2018)**. These mechanisms occur in several varieties. The main coping mechanisms that were also explored in this study are: problem-focused (adaptive behavioural), are geared toward eradicating or at least minimizing stressors; the emotion-focused strategies seek to help individuals to cope by transforming their emotional responses to crises and challenges **(Akpan-Idiok *et al.*, 2020)** and; the escape-avoidance-focused mechanisms are used when individuals wish to flee from their struggles or are unable to acknowledge the difficult reality that they face **(Ayimbire, 2020).** According to Nturibi *et al.*, (2018) seeking social support and religious affirmation, viewing a stressor more positively, results into positive coping. Compared to caregivers whose children are healthy, caregivers with asthmatic children are more likely to suffer such psychological outcomes as depression, lower quality of life, and stress **(Castillo *et al.,* 2020). Fairfax *et al* (2019)** performed a systematic review which led them to the conclusion that there is a direct relationship between coping strategies and the quality of life of parents who children are struggling with various chronic ailments.

A study by Kosisochi *et al.*, (2020) established that offering social support to parents is one of the most effective solutions for alleviating anxiety and the worry that these parents exhibit. The findings of the study indicates that when developing interventions, emphasis should be given to modifying the child's behavior. A study by **Ayimbire (2020)** on coping strategies adopted by caregivers of chronic diseases in Ghana, found that some caregivers use escape-avoidance consisting of wishful thinking, the hope for a miracle or avoidance of thoughts related to the stressor by eating, drinking, smoking or sleeping. Avoidance focused coping was defined as a strategy through which one uses tools like humor to flee from stressors and an unhealthy denial which allows one to escape from the stressors, albeit for a short amount of time. A stressful environment influences coping response is controlled by a mix of personality or habitual attributes as well as the social environment in which the stressor operates (Aryal, 2017). An investigation examining the coping approaches used in Italy and Portugal identified five coping strategies namely; social support, avoidance coping, positive attitude, religious faith and humour and active coping were studied **(Perricone *et al.*, 2013)**. On the one hand, the Portuguese mothers embraced religion and prayer as part of their efforts to confront distress. On the other hand, their counterparts in Italy relied primarily on detachment and avoiding solutions in their quest for relief from stressors (Perricone *et al.*, 2013). This study focused on the caregiver of the asthmatic child so as to improve the health outcome of the child, by investigating the various coping mechanisms used. It also projected towards involving other health workers like psychiatrists to assist the caregiver better manage to cope with asthma as a chronic condition. Caregivers attending to patients ailing from chronic conditions tend to have poor and ineffective coping mechanism. This was evident in a study involving caregivers attending to senior adults recovering from stroke in Iran, which advocated for the training of caregivers on coping skills and support to reduce the number of caregivers who utilize emotion focus and escape avoidance coping. **(Kazemi *et al.*, 2021).**

However, a cross sectional mixed method study on care burden and coping strategies among caregivers of paediatric HIV/AIDS in Northern Uganda **(Mujjuzi et al., 2021),** surprisingly, the caregivers of children were found to adopt seeking of social support, spiritual assistance as well as acceptance coping strategies. There was a high level of hope and faith in religion.

2.5 Conceptual Framework

At its core, the conceptual framework illustrates the association among various independent variables (Demographic factors and Social economic characteristics) and the dependent variable (Psychological burden) and potential intervening variables (coping mechanisms which are problem focused, emotion focused and escape avoidance). According to literature, caregivers' individual factors, coping mechanisms and psychological experiences are inter-related in complex ways (Fig. 2.1). The key variables that this study examines include such demographic factors as the gender and the age of children with bronchoasthma as well as Social economic status like employment, marital status, income and education level. Caregivers are known to respond in various ways to stress and fatigue occasioned, for example, by the frequent hospitalizations and other stressful factors. Interventions to improve coping with caregiving can modify the mental health outcomes, which may be in terms of emotional stability or scheduling family routines. The psychological status of the caregiver influences in turn, the environment where the affected children live, through the lifestyle adopted by the caregivers. Poor coping mechanism may indicate unstable psychological status and may contribute greatly to exacerbated asthmatic attacks in children, further causing a vicious cycle of stress events to the entire family. Coping can influence the demographic factors or socioeconomic burden. It can also directly affect psychological burden.

Individual factors (age, marital status) and external factors (psychological & social support) influence how a person undertakes recommended disease management interventions (including making

necessary alterations to the social and physical environments in order to safeguard health and wellbeing; attending follow up clinics) for the child in order to achieve a desired endpoint or goal. However, the caregiver responses to the demands or burden of care may have stressful impact resulting to psychological symptoms. But these responses are mediated by the coping mechanism adopted by the caregiver. Healthcare workers providing chronic and acute care may in multiple way modify capacity of caregivers to cope with stressful moments. Over time, psychological symptoms may worsen, stabilize or improve.

CONCEPTUAL FRAMEWORK

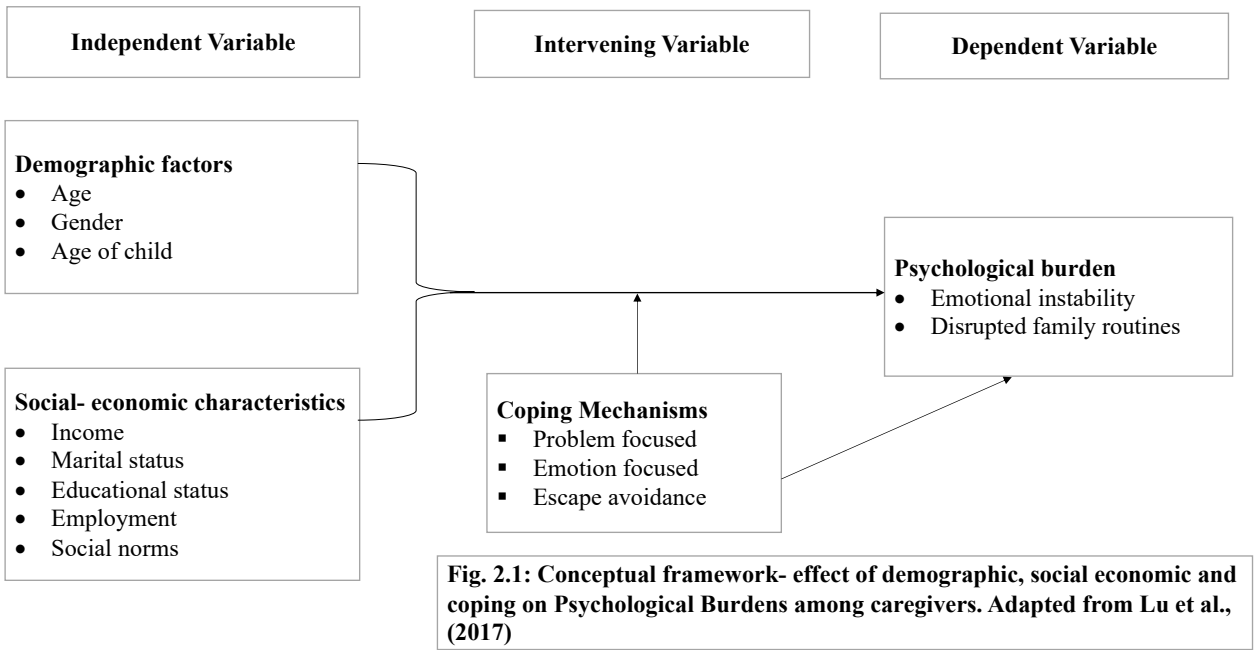


Fig. 2.1: Conceptual framework- effect of demographic, social economic and coping on Psychological Burdens among caregivers. Adapted from Lu et al., (2017)

Figure 2.1: Conceptual Framework

2.6 Summary of literature review

Current systematic studies indicate the presence of gender skewness and lack of consensus on how to assess psychological burden (Addo *et al.,* 2018; Dharmage *et al*., 2019). According to **Cipolletta *et al.*, (2020),** social support did not predict the patients' & caregivers' psychological symptoms. It also stated that the caregivers and the affected children impacted each other. Most research was biased toward caregiving of the elderly patients or those with mentally ill, & cancer care, and were mostly conducted in Western cultures (**Wu *et al.,* 2019)**. Socioeconomic burdens may result in psychological burdens, but they may be altered depending on the type of coping strategy adapted by the caregiver. Some demographic factors like female gender, marital status, as well as family income, may negatively or positively impact the psychological outcome. Further studies are recommended for interventions.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter outlines the methodology that was used in the research study. It describes the study area, research design, instruments for data collection, the study participants, inclusion and exclusion criteria, calculation of sample size, sampling procedure, data collection procedures, recruitment and training of research assistants, validity and reliability, data analysis and ethical considerations.

3.2 Study Area

The study was conducted at the Kakamega County Referral Hospital which is situated in Western Kenya, a region spanning approximately 3050 square kilometers (County Government of Kakamega, 2014). Kakamega County Referral Hospital lies at Latitude-longitude coordinates of 0°17'3.19"N, 34°45'8.24"E. The latitude position to the Equator is about 32km (20mi) from Kakamega and about 9975km (6198mi) to the North Pole **(Appendix IX)**. The hospital attends to rural and urban residents. The hospital has extended its reach to such counties as Nandi, Siaya, Bungoma, and Vihiga. The total catchment population for the hospital is estimated to stand at between 3 and 5 million, making it one of the largest in Kenya.

The county hospital was frequented by a large number of bronchoasthma patients (19,234) out of which, children < 5 years were 2675 during the year of study. It is located in an area of frequent rainy and cold seasons due to the presence of a vast forest in the county. The hospital has a bed capacity of 333 and paediatric ward bed capacity of 39.

3.3 Study Design

A descriptive cross-sectional study was employed to study caregivers of bronchoasthmatic children attending the Kakamega County General Hospital. This design was appropriate for behavioral studies. It allowed for the collection of in-depth information on the burdens of caregivers of bronchoasthmatic

children and their coping mechanisms, thus allowing for generalization of the findings to a larger population within a short period of time, and also using minimal resources. This study aimed to consider multiple variables (socioeconomic, psychological, and coping mechanisms), at a point of data snapshot in a population that is not large, therefore a cross-sectional study was best suited in identifying the relationship between the independent variables, coping and caregiving of bronchoasthmatic children. Such studies are especially vital for healthcare planning, interventions and budgeting. The volume of patients served in Kakamega County in the year of study was 19,234, with hospital in patient admissions of 266 adults and children.

3.4 Study Population

The study targeted 424 caregivers. However, only 408 caregivers' questionnaires were noted to be completely filled with the deficit accounting for those which were not completely filled. There were 8 health care workers who were at the health facility. The population of children between 0-14 years old in Kakamega County was 786,681 (KNBS, 2019). The study population was largely derived from Lurambi sub-County from Shivakala, Amalemba, Shirere, Shirakho, Matende, Shitakho villages around the hospital. In Kakamega County Referral Hospital Paediatric clinic, ordinarily there are 3 clinicians on duty per session. On average, 20,000 patients visit Kakamega County Referral Hospital for inpatient services with the hospital serving an estimated 750,000 outpatients every year (Kakamega County Report 2018). In addition to patients from local areas, the hospital also handles referrals from neighbouring counties. For example, Vihiga, Busia, and Bungoma countries are some of the areas that the hospital reaches through its referral services. The hospital also functions as a referral center for the larger Western province whose population is 4,334,282, a majority (2,242,907) of whom are females. 67.7% of the population whose needs the hospital attends to are rural residents. Thanks to the high-quality of care that it offers, the hospital has extended its reach to such counties as Nandi, Siaya,

Bungoma, and Vihiga. The total catchment population for the hospital is estimated to stand at between 3 and 5 million, making it one of the largest in Kenya.

3.5: Inclusion and Exclusion criteria

3.5.1 Inclusion criteria

Caregivers of children who were clinically diagnosed with bronchoasthma, on follow-up in the Paediatric clinic, had cared for the child with bronchoasthma for the past 3 months and consented for the study.

3.5.2 Exclusion criteria

The study excluded caregivers of children that are diagnosed to have conditions like upper and lower respiratory tract infections that mimic bronchoasthma, those who were not available for interview on the day of visit and also nonconsenting caregivers of children with bronchoasthma.

3.6 Sample Size Determination

Participants involved in the study were obtained from the larger population of Bronchoasthma caregivers registered at the POPC and also by the CHVs in KCGTRH, which was used as a recruitment site, due to the fact that a definitive diagnosis of bronchoasthma would have been made there. In order to obtain a representative sample from the target population, the sample size was computed with the standard deviation set at 0.5, the confidence level at 95%, and a margin of error of 0.05. The **Sekaran (2013)** formula shown below was used for these calculations:

$$n = \frac{\frac{z^2 x\ p(1-p)}{e^2}}{1 + \frac{z^2 x\ p(1-p)}{Ne^2}}$$

Where:

N= the population size.

Z= the Z -score which is 1.96
e= the margin of error which is 50%
p= proportion of people with the condition of interest which is 0.5

95% level of significance was adopted with 80% standard deviation and 1.96 Z score.
Thus, the sample size was
$n=1.96 \times 0.5(100-95)/0.5^2 /1+ (1.96^2 \times 0.5(100-95)/1.96^2 \times 2.2$
n= **385**
An additional 10% will be added to cater for participant attrition. The final sample size will be:

(385 x 10)/100 = 38.5 **(39)**

39+385 = **424**

3.7 Sampling procedure

Kakamega County General Teaching and Referral Hospital was identified because it serves as the main referral public health facility (Level 5) with more advanced resources: it has special paediatric outpatient clinics, where specialist doctors and clinicians conduct routine follow-up reviews for children and thus is likely to attract patients from diverse backgrounds. Since the special clinic is held twice a week, participants were recruited on those two days until the sample size was accrued. Only the patients who had had the condition for at least three months as per the records were included, given they are categorized clinically as chronic. The attending clinicians prompted the eligible caregivers about the research at the clinic and those interested in participating were given a serialized research card to present to the research assistant in an adjacent room, where the interview was conducted. For those caregivers who were unable to attend the clinic, the researcher was referred to the Community Health Volunteers (CHV) who were able to locate them at their homes using their contact details. Patients were relatively few because they mostly came in when in acute phase, then afterwards not on follow up. Because the caregivers were relatively few from the POPC contacts, the research assistants used their list to access the caregivers, who were screened for eligibility. Caregivers were given a

choice to prefer where to be interviewed from. They were interviewed in a private place. The information was also coded to ensure confidentiality.

Table 3.1 summarizes the study variables, their definitions and measures used to assess them.

Table 3.1: Variable and Variable Measure

Type of variable	Variable definition	Variable measurement
Socioeconomic status	Marital status	married; single: never married, divorced, widowed, remarried
	Education level	highest level of education level attained
	Income	based on the following categories: 1. < 10,000 2. 10,000-19,999 3.20,000-49,0000 4. >50,000
	Employment	Employed [formal; informal]; Unemployed
	Interference with the family budget	Forgone leisure activities, slashing the household budget to accommodate the affected child, reduced savings, extra source of income, loans acquisition.
	Change in daily activity routines (job, household, school, etc)	Cash reallocation (for example, rent money for hospital medication or needs), hospitalization/emergency care, house chores, household budget affected
	Caregivers' Age	based on the following categories: 19-25 26-35 36-45 46-55 56 and above
	Caregivers' Gender	Male Female
	Use of Alcohol, smoke or drug abuse	None Mother Father Both mother and father Relative
Psychological (PACQOL) Scale 1-13(≥7 indicates a high level of stress) CSI (1983; source: Robinson)	Interference with daily activities	Change plans, job/work interference, sleepless nights and night awakening.
	Emotional concern	Feel helpless, frustrated, impatient, upset, bothered, angry, worry about child's daily performance, medication and side effects, overprotectiveness and worry about child's capacity to have a normal life.
	Caregiver Stress Index	Sleep disturbance, inconveniences, physical stress, social activities limitations, change in plans/work schedule, emotional changes, financial challenges, poor concentration, satisfied by family support.
Coping mechanism questionnaire (Scale of 10 items) (source: adopted from Hastings *et al.,* 2005)	Problem-focused.	Attending training, Information gathering, taking control, Evaluating the pros and cons of the situation.
	Emotion-focused	Release of pent-up emotions, Self-distraction, Religious and social support.
	Escape-avoidance	Wishful thinking
		Substance abuse
		Downplaying severity of symptoms
Quality of life		PACQOL (source: Juniper *et al.,* 1996)

3.8 Data Collection Procedures

The data for the caregivers was gathered with the aid of a semi structured questionnaire from November 2019 to January 2019. Bronchoasthma in this case had been diagnosed by the Medical Officers and Clinical Officers who work at the hospital. The questionnaires were read out to the caregivers by section (demographic; psychological; socio-economic characteristics; coping mechanism) and responses were categorized using the *Likert* scales.

3.8.1 Recruitment and training of research assistants

Six trained Community Health Volunteers, with contacts of the caregivers, and are familiar to the community caregivers, were recruited as research assistants. **The six were selected to re-distribute the burden of data collection amongst them. Also, some areas were vast and more research assistants were needed.** The selected assistants underwent a two-day training on study process, study tool administration, ethical considerations and data entry. During the training period the assistants were subjected to tasks that required them to conduct an interview during the study. The training was done prior to pretesting of the research tools. They consented eligible participants from the clinics and administered the questionnaires.

3.8.2 Instruments for Data collection and Procedures

Questionnaires for caregivers were the main tools for data collection for this study.

Questionnaires

The three objectives of the study informed the design of the questionnaires. The questionnaire comprised of three sections. Each of these sections was made up of questions that related to the study's objectives. Section one contained questions addressing demographic variables. Section two addressed psychological factors (emotional instability and disrupted family routines) including stress and social-economic variables, while section three contained questions addressing coping mechanisms. Coping

mechanisms was stratified into 3 categories including (problem focus, emotion focus and escape avoidance). The coping mechanism questionnaire was used to assess 10 items in the coping mechanisms.

3.9 Validity and Reliability of instruments for data collection Instruments

3.9.1 Instrument Validity

After the training of data collectors, a pilot test was conducted with the goal of establishing that the questionnaire was valid and appropriate for the study. In this way, vague questions and unclear instructions were revealed for future modification to better suit the study. The researcher inquired from the respondents for suggestions that were then incorporated into the questionnaire to improve it and enhance the response rate. Face validity was used, whereby the researcher pursued feedback and input from the supervisor in order to further guarantee the validity of the instrument. The questions incomplete responses were not included in the analysis. **This did not affect my study, since my initial sample size was 385. Considering 10% attrition, I got 424. Therefore, it was adequate.**

3.9.2 Instrument Reliability

Reliability refers to the extent to which a tool produces stable and consistent results. A pre-test was conducted prior to the main study. This comprised of 10% of the study population selected from Kakamega County Teaching General and Referral Hospital **(Connelly, 2008).** The questionnaire was devised in such a way that each answer forms a 1-5-point *Likert* scale based on the attitudes of the caregivers on social economic, psychological and coping. Questionnaire on a *Likert Scale* was then administered to 42 individuals who were not part of the study sample and information received was analyzed using SPSS and Cronbach's alpha test was adopted to assess the reliability of the instruments. The findings from the study determined how to **adjust** the questionnaire so that it is better aligned

with the Cronbach's alpha coefficient. The theory posits higher scores indicate better reliability **(Taber, 2018)**. However, a score of 0.7 was accepted as it is largely in line with established convention and practice.

Confirmatory reliability was performed to establish if there was high level of internal consistency among the indicators. From the reliability analysis results, a **Cronbach's alpha of .869** was obtained indicating a reliability of 86.9%. This is well above the 70% required for sufficient internal consistency according to the rule of thumb (Cronbach, 1951).

Table 3.2: Cronbach Alpha Reliability Coefficient

Tools	**Cronbach Alpha Coefficient**
Socio-economic (15 items)	0.894
(PACQOL = 13 items; CSI = 13 items)	0.807
Coping mechanism (10 items)	0.786

3.10 Data analysis

After collecting data through the questionnaires, the researcher proceeded to undertake screening, editing, coding and analysis. Editing was prioritized to ensure that the data set was complete, and all the questionnaires were completely answered. Data coding was then considered to ensure the data was easily transformed into systematic codes that were easily detected by the computer for analyses using SPSS Version 24. The researcher also employed descriptive statistics to summarize bronchoasthma caregiver's burdens and copings strategies, in the form of means, standard deviation and percentages as appropriate.

Qualitative data from the questionnaires was coded, tabulated, entered into a computer then analyzed and interpreted with the aid of quotations and tabulations of the emerging key themes. The mean, standard deviation and percentages of the variables was calculated and used appropriately. A Chi-square test for proportions (*p* value= 0.05 level of significance) was used to evaluate if there is any significant association between caregiver burden and the coping strategies that the caregivers adopt.

A Chi-square test for proportions was used to assess the relationship between the nature burden and the coping strategies.

3.11 Ethical Consideration

Ethical and administrative Approvals

Before undertaking the study, approval to conduct the study was sought from the Maseno University School for Graduate studies **(Ref: EL/ESM/01005/2015) (**Appendix I). The researcher also sought clearance from the university's Ethics Review Committee **(REF.No. MSU/DRPI/MUERC/00768/19)** which issued the clearance for the study to proceed (Appendix II). The National Commission for Science, Technology and Innovation (NACOSTI) **(Applicant Identification Number: 885428)** (Appendix III) and the Kakamega County Government **(Ref: CGK/MOH/CDH/1/9/52)** (Appendix IV) and Kakamega County Referral Hospital **(Ref: 099/11/2019)** (Appendix V) also accorded further approvals.

To guarantee data security and privacy, the researcher stored hard copies of the questionnaires in locked units to which access was strictly limited to personnel directly involved in the project. The researcher also used strong passwords only accessible to the investigator, to secure data stored on external hard drives. Moreover, the researcher also protected confidentiality during the entire study period.

Informed Consent Process

In preparation for the study, the researcher sought and secured informed consent from all participants (Appendix VI). In particular, the consent was obtained before the administration of the questionnaires. In addition to complying with established research ethics guidelines, informed consent was also acquired with the goal of enabling the caregivers to review the information in the questionnaires and pose any questions that they may have. Each participant was issued with a consent form which outlined how the study would be undertaken, the benefits and risks, and assurance that the confidentiality and privacy of the participants would be protected. Furthermore, the forms also guaranteed that the participants could withdraw from the study at any time, without necessarily needing to provide a reason. The respondents were screened for eligibility and those who met the inclusion criteria were informed, explained to and requested to sign the consent form.

Risks

The researcher did not anticipate that the caregivers would be exposed to any risks while taking part in the study, except for potential anxieties from the burden of chronic care. However, there was a potential risk for psychological harm because of psychological distress. This was addressed during the consent process and Community Health Volunteers were available to provide support by setting the climate to make the caregivers comfortable. Explanations were made to the caregivers on the exact purpose of the study, and brochures issued from study information facts. The clients were asked which languages they were comfortable with. Those who understood English were interviewed in English. There was no instance that needed referral during the interview. However, those respondents who reported hardships in understanding the English version of the questionnaire were assisted with translations.

Benefits

The caregivers did not receive any direct or monetary benefit in exchange for their participation in the study. However, it was anticipated that information provided on bronchoasthma care heightened awareness on psychological, socioeconomic burdens of caregivers of children with bronchoasthma and their coping mechanisms.

Confidentiality

The researcher accorded utmost confidentiality to all the data and information that the caregivers supplied as part of the study. Only the researcher had access to the information gathered during the survey. All the information was anonymized by not including names and instead using specific codes for the residence, identities and even the research assistants, which was serialized. There was a master list which only the researcher carried, which included the names of the individuals for purposes of linkage to care where necessary. No personal identifiers were connected to the data for analysis. At the end of each day, the researcher collected all the filled hard copy questionnaires from the research assistants and stored under lock and key. At data entry, SPSS Version 24 was used, and the computer had a password, to be accessible to the researcher only. There was data back-up, which was secured in an external hard disk with a password to restrict access. No individual identities were used in any reports or publications that may result from this study.

3.12 Dissemination of findings

The findings and recommendations of the study were disseminated in hospital Continuous Medical Education and plenary sessions, through workshops and educational forums to the county Ministry of Health (MOH) officials. Community Health Volunteers and Community Health Extension Workers as well as MOH partners who may wish to fill any gaps detected were copied to the report. The findings, subject to journal approval, was also published in international peer- reviewed journals.

CHAPTER 4: RESULTS

4.1 Introduction

In this chapter, an overview of the findings on Sociodemographic and economic factors, Psychosocial burdens and coping mechanisms among caregivers of children with bronchoasthma in Kakamega County, Kenya, was provided.

4.2 Demographic and Socioeconomic Characteristics of Caregivers

424 participants, who were caregivers of children with bronchoasthma at Kakamega County, were interviewed. There were 16 incomplete questionnaires, making the total number of caregivers' questionnaires analyzed be 408. Of these, the youngest was 19 years old, while the oldest was 60 years old, with a mean age of 33 years (Sd. 9.86) **(Table 4.1)**. Majority of the caregivers were female 88% (n=359), while 12% (n=49) were male caregivers respectively **(Table 4.1)**. Out of the female caregivers, the parents were 67.4% (n=275), while the guardians were 20.6% (n=84) The male caregivers who were parents were 11.3% (n=46), while the guardians were 0.7% (n=3) (χ^2 = 7.7, df = 1, p = 0.006).

A slight majority of the respondents (78.7%, n= 321) were actual parents of the index child. Of actual the parents, 73.5% (n=236) were married; 11.8% (n=38) were single and never married; 7.8%, (n=25) were separated; 2.8%, (n=9) were divorced and; 4.0% (n=13) were widowed (χ^2 = 26.4, df = 16, p = <0.05).

Among the respondents who were guardians of the child, nearly half (47.1%, n=41) were married, while 14.9% (n=13) were single; 4.6% (n=4) were separated; 8.0% (n=7) were divorced, and; 25.3% (n=22) were widowed (χ^2 *=20.7*, *df*= 16, *p= <0.19*). By level of education, 64.0% (n= 261) of the respondents had primary education, 22.5% (n=92) had secondary and 8.3% (n=34) had college education respectively (χ^2 = *48.4*, *df*= 4, p=<0.001) (**Table 4.1**).

Table 4.1: Socioeconomic and demographic Characteristics of the Respondents

Characteristics		Frequency	Percent
Age bracket	19-25	101	24.8
	26-35	169	41.4
	36-45	87	21.3
	46-55	33	8.1
	56 and above	18	4.4
Gender	Female	359	88
	Male	49	12
Relationship with the child	Parent	321	78.7
	Guardian	87	21.3
Level of education	No formal education	19	4.7
	Primary	261	64
	Secondary	92	22.5
	College	34	8.3
	University	2	0.5
Employment status	Self-employed	304	74.5
	Employed	72	17.6
	Student	19	4.7
	Housewife	13	3.2
Average monthly income	Below Ksh 10000	313	76.7
	Ksh 10000-19,999	69	16.9
	Ksh 20000-49,999	25	6.1
	Ksh 50,000 and above	1	0.2
Age of the child	Below 1 year	36	8.8
	1-3 years	88	21.6
	4-7 years	117	28.7
	8-11 years	98	24.0
	12-14 years	69	16.9
Gender of the child	Male	202	49.8
	Female	206	50.2
Alcohol, smoke or drug abuse	None	261	64.0
	Mother	11	2.7
	Father	84	20.6
	Both mother and father	10	2.5
	Relative	42	10.3
Source of cooking fuel	Firewood	217	53.2
	Gas stove	29	7.1
	Kerosene stove	8	2
	Charcoal	50	12.3
	Firewood charcoal and gas	12	2.9
	Gas stove and firewood	1	.2
	Firewood and charcoal	53	13.0
	Gas stove and charcoal	13	3.2
	Firewood, kerosene stove and charcoal	12	2.9
	Firewood and gas stove	2	.5
	Gas stove, kerosene stove and charcoal	3	.7
	All	8	2.0
Housing	Stone	92	22.5
	Wooden	10	2.5
	Mud	306	75

4.3 The Psychological Burden of Bronchoasthma

The indicators were divided into domains that often interfered with caregiver's daily activities and those that caused emotional concern.

4.3.1 Interference with daily activities

When asked about interference with daily activities, significantly more participants indicated 'Never' for each dimension. Similarly, among those experiencing interference with daily activities, significantly more participants responded with 'quite often' (Table 4.2).

Table 4.2: Interference with Daily Activities (N= 408)

Dimensions	**Always n=**	**Quite often n=**	**Once in a while n=**	**Never n=**	χ^2	**df**	**p**
	%	**%**	**%**	**%**			
Need to change plans because of the child's condition	58(14.2)	110(27)	82(20.1)	158(38.7)	54.3	3	<0.001
Child's condition interferes with your job or work	58(14.2)	118(28.9)	86(21.1)	146(35.8)	43.0	3	<0.001
Have sleepless nights because of the child's condition	52(12.7)	126(30.9)	86(21.1)	144(35.3)	50.0	3	<0.001
Awakened during the night because of the child's condition	52(12.7)	135(33.1)	72(17.6)	149(36.5)	65.7	3	<0.001

Table legend: chi square was goodness of fit test.

4.3.2 Emotional Concern

Based on table (4.3) participants who felt 'bothered because of the child's condition' (38.7%) and 'angry that the child has the condition' (33.1%) and; 'were concerned about the child's asthma medication and side effects' (48.5%); were more. About half (48.3% of the participants were never 'worried / concerned about the child being able to lead a normal life' **(Table 4.3)**.

Table 4.3: Emotional concern

Dimensions	Always-n%	Quite often-n%=	Once in a while- % n%	Never-n%	χ^2	df	p
Feel helpless frightened of child condition	102(25)	77(18.9)	52(12.7)	177(43.4)	85.8	3	<0.001
Feel frustrated or impatient because of the child's condition	60(14.7)	102(25)	75(18.4)	171(41.9)	71.1	3	<0.001
Feel upset because of the child's condition	99(24.3)	99(24.3)	80(19.6)	130(31.9)	12.6	3	<0.001
Feeling bothered because of the child's condition	158(38.7)	101(24.8)	54(13.2)	95(23.3)	53.8	3	<0.001
Feel angry that the child has the condition	135(33.1)	100(24.5)	49(12.0)	124(30.4)	43.0	3	<0.001
Worried or concerned were you about the child's performance of normal daily activities	105(25.7)	179(9.4)	68(16.7)	156(38.2)	45.2	3	<0.001
Worried or concerned were you about the child's asthma medication and side effects	198(48.5)	81(19.9)	42(10.3)	87(21.3)	132.2	3	<0.001
Worried or concerned were you about being overprotective of your child	93(22.8)	120(29.4)	54(13.2)	141(34.6)	41.5	3	<0.001
Worried or concerned were you about your child being able to lead a normal life.	81(19.9)	74(18.1)	56(13.7)	197(48.3)	121.2	3	<0.001

Table legend: chi square was goodness of fit test.

4.3.1 Caregiver Strain Index

The majority of respondents (82.9%, n=345) (**Table 4.4**) had high level of stress. The mean care strain index was found to be 9.3 with a standard deviation of 2.8 (compared to a normal of 7).

Table 4.4: CSI Stress Level

Level	Frequency	Percent
Low	6	1.5
Moderate	65	15.9
High	337	82.6
Total	408	100.0

Majority of the caregivers were disturbed from sleep in the previous nights by the child's condition (90.4%, n=369); experienced financial challenges (84.6%, n=345) and experienced emotional changes (84.1%, n=343); Female caregivers (59.8%, n=244) and males (10.8%, n=44) were inconvenienced by caregiving; felt physically constrained; changed plans because of caregiving; experienced emotional changes ;experienced financial challenges; had difficulty in decision making; and felt affected by their relative's situation **(Table 4.5)**. However, almost half of the caregivers were not greatly disturbed by the limitation of social activities participation (46.6%, n=190) and inability to leave the relative alone (48%. n=196) (**Table 4.5**).

Table 4.5: Caregiver Strain Index

Characteristic		Frequency	%
1. Disturbed by sleep on previous night	No	39	9.6
	Yes	369	90.4
2. Does caregiving inconvenience you?	No	120	29.4
	Yes	288	70.6
3. Feel physically constrained by caregiving	No	109	26.7
	Yes	299	73.3
4. Caregiving limits social activities participation	No	190	46.6
	Yes	218	53.4
5. Change in plans due to caregiving	No	108	26.5
	Yes	300	73.5
6. Emotional changes due to caregiving	No	65	15.9
	Yes	343	84.1
7. Change / adjust work schedule	No	140	34.3
	Yes	268	65.7
8. Experience financial challenges	No	63	15.4
	Yes	345	84.6
9. Experiencing trouble focusing on tasks	No	116	28.4
	Yes	292	71.6
10. Feel like you couldn't leave relative alone	No	196	48
	Yes	212	52
11. Experience difficulty in decision making	No	116	28.4
	Yes	292	71.6
12. Feel affected by relative's situation	No	153	37.5
	Yes	255	62.5
13. Feel satisfied by support accorded by family members	No	110	27
	Yes	298	73

4.4 Socioeconomic burden of Caregiving

Socioeconomic questionnaire addressed financial strain and adjustments, social life deprivation and lifestyle changes associated with the caregiving.

Almost three-quarter of caregivers (72.8%, n=297) had made several emergency departments visits in last 12 months preceding the study and; (86.3%, n=352) agreed to have had hospitalization (**Table 4.6**). Significantly more participants experienced being absent from work (75.2%; p= 0.015); reduced total annual income (59.3%; p= 0.045); job loss (60.8%; p= 0.037); poor quality of life (83.6%; p< 0.001); child discontinued schooling (82.1%; p= 0.011) and; Delay investment / cut budgets (95%; p= 0.015) (**Table 4.6**). The majority of participant disagreed with the statement that caregiving had 'Impaired daily activities' (81.4%; p< 0.001) (Table 4.4).

A great majority (92.2%, n=376) of respondents had some form of income generating activities. At least three quarters (76.7%, n=313) were earning less than Ksh 10,000 per month (χ^2 = *110.1; df. 1;* p *<0.001)*. Of these, 74.5% (n=304) were self-employed while only 17.6% (n=72) were in formal employment (χ^2 *=11.7*, *df=3*, *p < 0.008*). Majority of the caregivers lived in mud houses (75%, n=306) compared to others who lived in stone houses (22.5%, n=92) and 2.5% (n=10) who lived in wooden houses (χ^2 = 343.5, df=2, p *<0.001*) (**Table 4.1**).

Table 4.6: Socioeconomic Burdens of Caregiving

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	χ^2	df	p
	Row N	Row N	Row N	Row N	Row N			
ED visits in last 12 months	2(0.5)	83(20.3)	26(6.4)	96(23.5)	201(49.3)	292.8	4	<0.001
Absent from work	6(1.5)	62(15.2)	33(8.1)	145(35.5)	162(39.7)	232.2	4	<0.001
Hospitalization	1(0.2)	21(5.1)	34(8.3)	167(40.9)	185(45.3)	372.8	4	<0.001
Borrow finances for medication	2(0.5)	29(7.1)	38(9.3)	217(53.2)	122(29.9)	379.5	4	<0.001
Negatively affect relationship	4(1)	61(15)	49(12.0)	162(39.7)	132(32.4)	202.4	4	<0.001
Lack time for social activities	6(1.5)	89(21.8)	55(13.5)	152(37.3)	106(26)	147.5	4	<0.001
Loss of opportunities for career advancement	8(2)	85(20.8)	54(13.2)	176(43.1)	85(20.8)	185.2	4	<0.001
Reduced productivity at work	9(2.2)	77(18.9)	52(12.7)	195(47.8)	75(18.4)	233.7	4	<0.001
Reduced total annual income	7(1.7)	93(22.8)	66(16.2)	170(41.7)	72(17.6)	169.7	4	<0.001
Lost job	8(2)	102(25)	50(12.3)	179(43.9)	69(16.9)	202	4	<0.001
Face neglect from there family	7(1.7)	68(16.7)	84(20.6)	155(38)	94(23)	138.4	4	<0.001
Poor quality of life	3(0.7)	38(9.3)	26(6.4)	183(44.9)	158(36.5)	334.4	4	<0.001
Impaired daily activities	4(1)	51(12.5)	21(5.1)	183(44.9)	149(36.5)	311.9	4	<0.001
Discontinued schooling	2(0.5)	31(7.6)	40(9.8)	144(35.3)	191(46.8)	324.6	4	<0.001
Delay investment/ cut budgets	2(0.5)	12(2.9)	6(1.5)	170(41.7)	218(53.4)	530.8	4	<0.001

4.5 Caregivers Coping Strategies

Problem focused

From table 4.7, caregivers who were using problem-focused coping mechanisms were unsure about attending trainings, (33.3%, n=136). Of these, some did not see the need to attend trainings (44.1%, n=180). Others sought health information (58.8%, n=240), evaluated pros and cons (43.6, n=178),

while only (47.1%, n= 192) focused on the intervention on improvement in the behaviour of the child and effectively in reducing anxiety and worry *(*χ^2 = 102.1; df=4; p= <0.001).

Emotion focused

For the caregivers who utilized emotion focused coping mechanism, a majority sought spiritual help (61.3%, n=250), while (37%, n=151) had withdrawn the child from school as a result of his/her condition *(*χ^2 =119.97; df=4; p=<0.001*)* (**Table 4.7***)*.

Isolation of the child from the public was rarely done by (59.5%, n=243) caregivers taking care of the children with bronchoasthma **(Table 4.7)**.

Escape avoidance

The commonly adopted coping mechanism was escape avoidance, utilized by 72.9% of the divorced people, followed closely by the widowed at 72.4% (**Table 4.7**).

Most of the participants, hoped and prayed for the betterment of their children (79.7%, n=325), while those who were involved in substance abuse were (72.3%, n=295) *(*χ^2=181.6; df=4; p<0.001) **(Table 4.7)**. Some of the drugs of abuse used included the locally brewed illicit alcohol.

More than a half of the caregivers who adopted escape avoidance, downplayed the severity of the symptoms because of the myths and stigma surrounding bronchoasthma, (68.6%, n=280) *(*χ^2 =141.9; df=4; p<0.001) **(Table 4.7)**.

Table 4.7: Caregivers Coping Strategies N= 408

			Frequency (n)	Percent%	χ^2	df	P value
Problem focused	Attend training	Strongly disagree	72	17.6%	102.1	4	<0.001
		Disagree	**108**	26.5%			
		Neutral	136	33.3%			
		Agree	78	19.1%			
		Strongly agree	14	3.4%			
	Seeking health information	Strongly disagree	29	7.1%	151.8	4	<0.001
		Disagree	50	12.3%			
		Neutral	89	21.8%			
		Agree	**173**	42.4%			
		Strongly agree	67	16.4%			
	Evaluating the pros and cons of the situation	Strongly disagree	53	13.0%	98.7		<0.001
		Disagree	108	26.5%			
		Neutral	69	16.9%			
		Agree	**145**	35.5%			
		Strongly agree	33	8.1%			
	Focus on intervention on improvement	Strongly disagree	28	6.9%	110.4	4	<0.001
		Disagree	93	22.8%			
		Neutral	95	23.3%			
		Agree	**148**	36.3%			
		Strongly agree	44	10.8%			
Emotion focused	Seek consolation from a spiritual leader	Strongly disagree	32	7.8%	88.6	4	<0.001
		Disagree	74	18.1%			
		Neutral	52	12.7%			
		Agree	131	32.1%			
		Strongly agree	119	29.2%			
	Withdraw the child from school	Strongly disagree	34	8.3%	119.97	4	<0.001
		Disagree	117	28.7%			
		Neutral	75	18.4%			
		Agree	**146**	35.8%			
		Strongly agree	36	8.8%			
	Isolate the child from the public for fear of being stigmatized	Strongly disagree	**103**	25.2%	84.4	4	<0.001
		Disagree	**140**	34.3%			
		Neutral	63	15.4%			
		Agree	71	17.4%			
		Strongly agree	31	7.6%			
Escape avoidance	Wish hope and pray that the child will get better	Strongly disagree	6	1.5%	348.9	4	<0.001
		Disagree	41	10.0%			
		Neutral	36	8.8%			
		Agree	217	53.2%			
		Strongly agree	108	26.5%			
	Involved in substance abuse	Strongly disagree	37	9.1%	181.6	4	<0.001
		Disagree	51	12.5%			
		Neutral	25	6.1%			
		Agree	148	36.3%			
		Strongly agree	147	36.0%			
	Downplaying the severity of symptoms	Strongly disagree	52	12.7%	141.9	4	<.0001
		Disagree	42	10.3%			
		Neutral	34	8.3%			
		Agree	145	35.5%			
		Strongly agree	135	33.1%			

CHAPTER 5: DISCUSSION

5.1 Introduction

Presented in this chapter are the key findings that the study generated. To set the stage, the section begins with a discussion of the psychological burden of bronchoasthma. The next sub-section discusses socioeconomic burdens of bronchoasthma. The last part of this chapter discusses the coping mechanisms adopted by caregivers of children with bronchoasthma in Kakamega County.

5.2 Psychological Burden of Bronchoasthma

In the current study, at least 2 of every 5 parents/guardians always experienced a sense of helplessness, frustration or concern related to the child's asthmatic condition, 43.3% of respondents a feeling of helplessness and immense concern when their child exhibited such symptoms as wheezing, coughing or difficulty breathing. Researchers have observed that the mental health issues that caregivers endure are shaped by factors like the severity, duration, and the extent of their involvement in caring (Cipolletta *et al.,* 2020). This indicates that asthma symptoms negatively impacted caregivers' physical, psychological, emotional, financial and social aspects of well-being. A Kenyan study by Laurenzi *et al.,* (2021), showed that caregivers struggling with mental health challenges placed the child at a risk of developing mental health conditions. Mental health is a subtle disease that may not be easily diagnosed but yet is a common problem (Laurenzi *et al.,* 2021). In the study done in Western Kenya in Kisumu, Laurenzi *et al* purported that, caregiver mental health problems had a negative outcome to the behaviour of the sick children that they were caring for.

The mean of psychological index of this study ranged from 2.10 to 2.80. This narrow mean implies that caregivers' daily activities were quite often interfered with by the condition of the child. This was consistent with the observed stress index which showed that majority (82.9%) of the participants experienced high level of stress including anxiety and sleepless nights. Studies by Waters *et al.*, (2017) found that families with children ailing from bronchoasthma encounter significant challenges and are

more prone to such poor outcomes as high stress levels and impaired psychological functioning. In a study that explored the experiences and the psychological burden shouldered by caregivers of children with childhood sickle cell disease in Homa Bay Kenya, it was noted that caregivers of children between the ages of 1-10 years experienced psychological stress because of the condition of the child's ill health, as well as financial, social and physical constraints (Kuerten *et al.,*2020). This calls for a more comprehensive chronic care approach and mechanisms which also integrate psychosocial support for caregivers of pediatric patients with asthma (Margolis, 2020). In a study by Minichil *et al.,* (2019) in Ethiopia, similar to this study where caregivers are given little attention, compared to males, females are 2.4 times as likely to develop depression. Similar findings have been obtained by researchers conducting studies in Kenya (Mbugua *et al.,* 2011) and Pakistan (Azeem *et al.,* 2013). The study by Mbugua et al., (2011), was done in Gachie, on the prevalence of depression among family caregivers of children with intellectual disability in a rural setting in Kenya. The caregiver was noted to be at a risk of depression because of financial lack, due to inability to engage in income generating activity, social isolation, friendship loss and stigma associated with caring for intellectually disabled person (Mbugua *et al.,* 2011). Most caregivers were female, married, of primary education level and unemployed. However, the study was conducted in a Catholic church setting. Similarly, in Pakistan (Azeem et al., 2013), in an institutional based study, the female caregivers were more depressed and anxious than their male counterparts when caring for their children with intellectual disability. In contrast, a study in Iran showed more male involvement than female in addressing the needs of the asthmatic child (Adib- Hajbaghery & Ahmadi, 2019). This finding was attributed to the higher number of the male child with asthma than female and also cultural perception of the importance attached to the male child.

The caregivers in this study are within a low socioeconomic status, cannot focus on work routine because of the frequent disruptions because of the additional stressor which is bronchoasthma from their child. They are emotionally distressed, and their work output is low. The stressors may lead to loss of income, thereby worsening socioeconomic status which then brings about the cycle of disease occurrence. Caregiving leaves individuals feeling overwhelmed and powerless, and has also been linked to such secondary adverse outcomes as productivity challenges in the workplace as well as strained interpersonal relationships **(Nunes *et al.,* 2017)**. However, contrary to expectation, in a Qatar hospital based study, the caregiver's quality of life was found to be good. This was despite of worse psychological burdens (QoL) in mothers in lower socioeconomic groups, poor access to health care services, low quality education level, fewer employment opportunities, poor social life and were more exposed to mental and physical health problems. Therefore, higher income was associated with higher QoL (**Shaikhan & Makhlouf., 2020).**

5.3 Socioeconomic Burdens of Bronchoasthma

Significant majority of caregivers were found to be of low socioeconomic status. Poverty is among the most potent drivers of poor health and chronic disease. It is a risk factor which creates other pathways of perpetuation, thus, is a vicious cycle. The microenvironment of the child with bronchoasthma plays a critical role in the clinical progression and management outcomes. Interventions to improve a child's microenvironment as well as of the caregiver are part of the Chronic Care Model. However, its implementation remains problematic within resource limited regions (**Ross *et al*., 2019**).

A large majority of the caregivers enrolled in the current study were actual parents, married and largely of primary level education with only modest income levels. This indicates they were largely of low socio-economic status, a recipe for additional stress. The caregivers stress index was high (86.2%)

among the respondents with primary or lower education levels and concurrently lower earnings of less than Ksh 10,000, with a slight majority living in mud houses with thatched or iron sheet roofs. This could be a major contributor to increased asthma attacks due to exposure to dust mites. Further, the study found that the respondent's occupation was significantly affected by the caregiver stress index (p=0.001). Bellin *et al,* (2017) had found that low income combined with such stressors as exposure to community violence, joblessness, unsafe neighbourhoods exacerbate caregiver stress and reduce quality of life. Borrowing of money, cost cutting, job absenteeism and job threats lower the caregivers' quality of life (Banjari *et al*., 2018). Financial burden was a factor that also caused stress because some could not afford to take their children to hospital for emergency treatment, follow up clinic visits, purchase of medication and also payment of hospital admission fees. In Kenya, government hospital medical attention is affordable for children below 5 years but not applicable to those above. National Hospital Insurance Fund (NHIF) is not affordable to most of the caregivers. The caregiver is also more likely to develop psychological issues due to the development of inhibitors on her or his career development, welfare of the child, personal life and financial status.

The caregivers with the lowest education level earned below Ksh. 10,000, and were mostly self-employed. The caregivers who were more educated were more likely to be employed and the burden of the illness of the child might interfere with their daily work. It was also noted that the family that had a lower average monthly income had more stress, anxiety, worries, frustrations, fatigue, and constant concerns. They frequently needed to change their plans, had sleepless nights and the unexpected attacks interfered with their job. This caused mental strain, anger, fear for the child's safety and worry most of the time. The finances that had been allocated for various roles at home had to be re allocated towards transportation to the hospital, buying of medicine, medical consultation as well as admissions when necessary. This made the caregivers feel helpless and subsequently, some ended up looking for alternative means of treatment which included herbal medication. This was consistent

with a study in Kilifi Kenya, whereby, it was determined that among caregivers who reported being economically overwhelmed by the demands of caregiving, the rates of depressive symptoms were significantly higher (Katana *et al.,* 2020).

Most caregivers were not involved by the health care workers in the education on the prevention, early detection and management or referral of the child with bronchoasthma. The health care workers mostly concentrated on relieving the episodic bronchoasthma attacks and did not address the caregivers' psychological needs. Just like in this study, a systematic review conducted in sub-Saharan Africa countries, Addo *et al.,* (2018), most of the caregivers are female and not formally employed with the highest level of educational attainment being primary school. The few who were employed were involved in such pursuits as farming and petty trading. A majority of caregivers reported inability to work due to their caregiving responsibilities. The caregivers who worked lamented that they were often forced to reduce their working hours in order to fulfill their caregiving obligations. In yet another study that sought to highlight the struggles of Ghanaian caregivers, it was determined that some of these caregivers were compelled to resort to selling personal belongings and properties to raise the finances that caring for mentally ill relatives demands. This study demonstrated that the economic burdens that the caregivers carry is grossly under-estimated. Subsequently, policy makers are unable to fully understand these burdens and the damaging impact that they have. The policies that they formulate tend to be inadequate and ineffective since they do not fully reflect the struggles of caregiving in sub-Saharan Africa.

Married caregivers were more likely to endure more psychological burden than caregivers who are either divorced, separated, single or widows. They may have had other factors like having more children to care of or lack of employment or low-incomes that are unable to cater for the needs of their family members. This is consistent with a study by Alnazly and Abojedi (2019) which posits that

married caregivers had more anxiety levels than divorced caregivers, and the reverse was the case in terms of depression.

Older caregivers were predicted to be more likely to develop more psychological burden than the young ones. As age increased, caregivers were more likely to be faced with other responsibilities of the growing child and their needs might escalate. This confirms the findings from a study by Ochigbo *et al.,* (2018), which suggests that older women caregivers taking care of AIDS children were more depressed, as compared with the younger age groups.

The study predicted that psychological problems associated with caregiving were more prevalent among female caregivers. Assumptions that were emerging were that the children were left with mothers or female guardians considering the high percentage of female respondents who were not single.

Batulla et al. (2020) conducted a prospective cohort study within a hospital in India with the goal of determining the quality-of-life implications of caregiving. They determine that in situations involving uncontrolled asthma, the quality-of-life outcomes were worse than those among caregivers of children with controlled asthma. (Batulla *et al.,* 2020). A study set in Western Kenya revealed that, **similar to some of the findings of the current study**, some of the key problems that the caregivers grapple with include inadequate finances for treatment, limited access to care due to high cost, emotional distress, and feeling overwhelmed by the many responsibilities of caring. Furthermore, the caregivers complained that they often feel unable to provide adequate support to their children and that they need to make immense personal sacrifices while dealing with stigma and negative attitudes within their communities (Johnston, 2017).

In a study by Saijo *et al.,* (2021) in Japan, childhood asthma and symptoms like wheezing were more common among children whose parents had low educational attainment. However, after accounting for pre-and post-natal influences, the same study also determined that in some cases, the risk of

wheezing and asthma is high despite a parent's high educational attainment. Another study examining the encounters of asthmatic children and their parents suggested that asthma diagnosing is challenging and scares the caregivers due to the fear to continuing symptoms and repeated hospitalizations. It recommends supportive relationships, partnerships and comprehensive caregiver education by the healthcare professionals right from diagnosis to demystify cultural myths, ensure adequate follow up, address psychosocial and cultural concerns and offer relevant information for good child outcomes. Training for education staff and support groups for caregivers ensures caregivers' support, create environments that safeguard the health of asthma patients and ensure swift emergency response (Fawcett *et al.,*2019).

Due to unpredicted nature of the bronchoasthmatic attacks among the children, most caregivers made several emergency departments visits in last 12 months preceding the study, agreed to have had hospitalization and had experienced reduced annual income. Majority of the caregivers had impaired daily activities and had discontinued schooling. Almost all the respondents had had to delay investment/ cut budgets in order to afford care for the child. Others had to borrow money to facilitate the medical attention of the child. This gave them stress and some felt frustrated, worried and concerned about their child. Some also reported that to cut down on costs, they purchased a reliever syrup for the child since the inhaler was expensive and brought about an aspect of stigma to the child and the family. This is largely in line with a study by Simba *et al.,* (2018), conducted in Eldoret among caregivers.

Bronchoasthma was reported to be a burden to the caregivers as some of them had not gone to work during the time of the child's illness and this also reduced productivity. Those caregivers who had income generating activities reported losses in income and their farm produce gone bad because of the distraction caused by caring for their loved one. The caregivers in formal employment were stressed

because some of them had received warning letters at work and some even lost their jobs because of frequent absenteeism caused by caregiving.

In a South African study conducted among caregivers of school going children with visual disability, elevated caregiver strain was found to be associated with financial difficulty, diminished independent living skills, and an unwillingness to be separated from the visually impaired child (St Jerry, 2021). Married and single parents were more affected by anxiety than were divorced parents. In a study by Alnazly and Abojedi (2019), divorced parents, however, reported higher rates of depression compared to their married counterparts. Essentially, divorced individuals face a greater risk of psychological stress because of the emotional pain that they tend to experience, conflicts within their relationships, and being rendered unable to function as parents. The situation is worse for divorced mothers who are usually economically disadvantaged and therefore more vulnerable to depression and psychosocial burdens.

In the current study, it was demonstrated that absenteeism from work, asthmatic child hospitalization in the preceding 12 months, borrowing of finances for medication, and loss of opportunities for career advancement significantly independently associated with caregivers' higher stress index. A study by Ciccarelli & Van Soest (2018) and Fujihara *et al,* (2018) showed that for the employed caregivers, the nature of caregiving competed with their employment, reducing their man hours and subsequently their income, which indicates that all caregivers get socioeconomic challenges regardless of the condition. A study in Kilifi Kenya revealed that among caregivers attending to HIV positive adolescents, the rate of poverty and adverse mental outcomes was worryingly high. This may indicate that such trends occur at different levels and health conditions (Katana *et al,* 2020). However, whether this condition was unique to different conditions was not examined in this study. A study in Nigeria among grandmothers caregiving orphaned AIDS children by Ochigbo *et al*., (2018), in contrast to this

study, reported caregivers burden to range from none to minimal, with only 16.4% experiencing mild to moderate caregiving burdens.

In most societies, the female caregivers actively participate in caregiving than the males **(Chong *et al*., 2019)**. In contrast to the present study, however, an Iranian study, there was more male caregivers involvement than female, citing the cultural perceptions of the importance attached to the male child and also a larger number of male child with bronchoasthma than female **(Adib-Hajbaghery & Ahmadi, 2019).** In a study by Minichil *et al.,* (2019) in Ethiopia, compared to males, females are 2.4 times as likely to develop depression. A study in Japan suggested that the outcome of caregiving would be improved when the caregivers got a paid family leave, when they had to be away from work taking care of their sick relative (Feinberg, 2019). However, this is a concept that is yet to be applicable in the Kenyan context.

5.4 Coping Mechanisms adopted by Caregivers of children with Bronchoasthma.

In this current study, slightly over half the participants coped by "Down-playing the severity of symptoms" while considerable proportion abused drugs. Other methods used but comparatively less frequently in coping included attending health-related training, seeking health information and evaluating the pros and cons of their situation. This indicates that the problem focused coping mechanism was under-utilized by the caregivers.

However, only few of the caregivers adopted the emotion focused components (Seek consolation from a spiritual leader; withdrew the child from school and isolated the child from the public for fear of being stigmatized). Based on the caregiver feedback, the majority did not have access to a formally structured psychosocial and emotional support system. These observations indicate considerable unmet intervention needs to enhance caregiver resilience in this region.

In this study, some caregivers especially mothers blamed themselves for the outcome of their child's illness. This concurs with a study by Zhang *et al,* 2018 in Singapore, whereby self-blame was as a result of stigma following the feeling of internalizing others' accusations. This made them prefer to utilize emotional focus coping whereby they sought religious and herbal medication for relief of their child with bronchoasthma. In contrast, a study on the coping strategies used in sub-Saharan Africa by caregivers to alleviate the stresses and burdens of caregiving include appreciation, support from family, adopting a more positive view of themselves, empathy, and reprioritization (Akpan-Idiok *et al,* 2020).

As with caregivers of other chronic conditions, caregivers of children with asthma experience psychological burdens which affect their quality of life (Fairfax *et al.,*2019). The outcome of psychological burdens is dependent on the mediation of coping strategies adapted by the caregivers. This means that, with problem solving coping mechanisms for instance, caregivers can reduce the chances of being mentally affected by the process of caregiving. To reduce their risk of stress and to guarantee positive mental health outcomes, caregivers need to adopt appropriate and effective coping solutions (Lu *et al.,* 2017). The study by Lu *et al* (2017) undertook an investigation to determine how coping strategies modulate the association between the burdens that caregivers shoulder and the depressive symptoms exhibited by families of children living with musculoskeletal conditions in Shanghai, China.

Other studies have also confirmed that the specific coping mechanisms that caregivers adopt heavily influence their wellbeing. For example, Yu *et al* (2013) found that when they embraced the active coping approach, caregivers were less likely to report depressive symptoms. On the other hand, the prevalence of these symptoms increases when the caregivers use the avoidance strategy.

A study in Malaysia by Baharudin *et al* (2019) sought to establish the link between caregiver burden and behavioral as well as psychological outcomes among caregivers of patients living with dementia.

The study also sought to explore the mediating impact that the specific coping strategies and the personalities of the caregivers had on the relationship among these variables. As with this study, distress is most common among caregivers who adopted the emotion-focused coping measures. Other caregivers turned to alcohol and drug abuse, to spiritualists while others just wished hoped and prayed for a miracle to occur. Furthermore, when they adopted the emotion-focused coping solutions instead of problem-focused coping, the caregivers were more prone to such issues as burnout and depression. A recent study among caregivers of sickle cell disease in Kenya (Kuerten *et al*., 2020) also showed considerable experience of coping challenges by caregivers of children with chronic illness across various spheres of health and functioning. Recent systematic studies have shown that Individual and household level psychosocial support can enhance not only caregiver resilience in chronic illness situations, financial stability and quality of life across other multiple functional domains (Kuerten *et al.,* 2020; Fairfax *et al*., 2019) but also the quality of disease management (Puffer, *et al*., 2019) and support for other household members (Patel *et al*., 2020).

Training, motivation and emotional stability of caregivers helps them to focus on the problem and act positively towards the process of adaptation to the child's chronic disease (Hassan, Esmat & Mohamed, 2018). In the study set in Egypt and performed by Hassan *et al,* (2018), the outcomes of the children with bronchoasthma and their mothers coping strategies improved when the mothers of the children were trained and given a discharge plan in emergency department, inpatient and outpatient clinics.

In a cross-sectional mixed method study on care burden and coping strategies among caregivers of paediatric HIV/AIDS in Northern Uganda **(Mujjuzi *et al.,* 2021),** surprisingly, the caregivers of children were found to adopt seeking of social support, spiritual assistance as well as acceptance coping strategies. There was a high level of hope and faith in religion. This indicates the positive use of problem focused as well as emotion focused coping mechanisms which were poorly utilized by the caregivers in the present study.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1: Conclusions

1) Majority of the participants felt psychologically inconvenienced by caregiving. Sleep disturbance, financial challenges and life uncertainties were prevalent. The caregivers also had a high strain index consistent with high burden of caregiving to their child with BA.
2) Majority of caregivers were experiencing considerable financial strain, significantly associated with adverse stress index. Female participants who were the majority, were largely characterized by social deprivation, low productivity and lifestyle changes associated with the caregiving to their children with bronchoasthma.
3) Most of caregivers were using escape avoidance coping mechanisms. Most of them abused drugs and largely expressed a sense of desperate disposition, wishing, hoping and praying for the full recovery of the child.

6.3 Recommendations

The following recommendations are being made for consideration:

1: Interventions to improve psychological support care are needed. The County Ministry of Health and health teams, require appropriate strategies to implement caregiver support.

2: There is need for strategies to empower caregivers as well as reduce social economic and financial burdens they face.

3: County health teams to provide multi-disciplinary multi-level care using person centered strategies, for example, interventions to enhance information seeking, promoting psychosocial motivation and emotion stability and, mitigating drug abuse.

6.4 Suggestions for Future Research

1. There is a need for further research to evaluate the quality of life among asthmatic children residing in Kakamega County, in terms of number of missed school days, mental and emotional health assessment.
2. A study should be performed in order to assess the impact of males caregiving on the outcome of asthma.
3. Further research involving health workers is needed to shed light on their beliefs and attitudes as well as the best possible interventions applicable to facilitate caregivers' adherence for follow up clinic visits.

REFERENCES

Addo, R., Agyemang, S. A., Tozan, Y., & Nonvignon, J. (2018). Economic burden of caregiving for persons with severe mental illness in sub-Saharan Africa: A systematic review. *PloS one*, *13*(8), e0199830.

Adeloye, D., Chan, K. Y., Rudan, I., & Campbell, H. (2013). An estimate of asthma prevalence in Africa: A systematic analysis. Croatian Medical Journal, 54(6), 519–531.

Adib-Hajbaghery, M., & Ahmadi, B. (2019). Caregiver Burden and Its Associated Factors in Caregivers of Children and Adolescents with Chronic Conditions. IJCBNM.;7(4):258-269. doi: 10.30476/ IJCBNM.2019.73893.0.

Akpan-Idiok, P. A., Ehiemere, I. O., Asuquo, E. F., Chabo, J., & Osuchukwu, E. C. (2020). Assessment of burden and coping strategies among caregivers of cancer patients in sub-Saharan Africa. *World journal of clinical oncology*, *11*(12), 1045–1063. https://doi.org/10.5306/wjco.v11.i12.1045

Alnazly, E. K., & Abojedi, A. (2019). Psychological distress and perceived burden in caregivers of persons with autism spectrum disorder. *Perspectives in psychiatric care*, *55*(3), 501-508.

Anclair, M., Lappalainen, R., Muotka, J., & Hiltunen, A. J. (2018). Cognitive behavioural therapy and mindfulness for stress and burnout: a waiting list controlled pilot study comparing treatments for parents of children with chronic conditions. *Scandinavian Journal of Caring Sciences*, *32*(1), 389-396.

Antony, L., George, L. S., & Jose, T. T. (2018). Stress, coping, and lived experiences among caregivers of cancer patients on palliative care: A mixed method research. *Indian Journal of Palliative Care*, *24*(3), 313.

Aryal, B. P. (2017). Psychological Effects on Children with Asthma A Literature Review the Family Having. *Journal of Asthma*, *45*(6), 465–472.

Aryee, E., Perrin, J. M., Iannuzzi, D., Kuhlthau, K. A., & Oreskovic, N. M. (2022). Association of neighborhood characteristics with pediatric asthma. *Academic Pediatrics*.

Asuquo, E. F., & Akpan-Idiok, P. A. (2020). The exceptional role of women as primary caregivers for people living with HIV/AIDS in Nigeria, West Africa. In *Suggestions for Addressing Clinical and Non-Clinical Issues in Palliative Care*. intechopen.

Ayimbire, B. A. (2020). *Psychological Distress and Coping Strategies of Caregivers of Children with Chronic Conditions in the Ashanti Region of Ghana* (Doctoral dissertation, University of Cape Coast).

Azeem, M. W., Dogar, I. A., Shah, S., Cheema, M. A., Asmat,… A., Akbar, M. (2013). Anxiety and depression among parents of children with intellectual disability in Pakistan. J Can Acad Child Adolesc Psychiatry. ;22(4):290.

Baharudin, A.D., Din, N.C., Subramaniam, P. & Razali P. (2019). The associations between behavioral-psychological symptoms of dementia (BPSD) and coping strategy, burden of care and personality style among low-income caregivers of patients with dementia. *BMC Public Health* **19,** 447 (2019). https://doi.org/10.1186/s12889-019-6868-0

Banjari, M., Kano, Y., Almadani, S., Basakran, A., & Alahmadi, T. (2018). The Relation between Asthma Control and Quality of Life in Children. *International Journal of Pediatrics*, *77*(10), 1–8.

Barakat, D., Rockers, P. C., Vian, T., Onyango, M. A., Laing, R. O., & Wirtz, V. J. (2018). Access to asthma medicines at the household level in eight counties of Kenya. *The International Journal of Tuberculosis and Lung Disease*, *22*(5), 585-590

Battula, M., Arunashekar, P., & Nagarajan, V. P. (2020). A Prospective Study to Assess the Quality of Life in Children with Newly Diagnosed Asthma and Their Caregivers using the Pediatric Asthma Quality of Life Questionnaire. *Journal of Primary Care & Community Health*, *11*, 2150132720961272.

Bellin, M. H., Collins, K. S., Osteen, P., Kub, J., Bollinger, M. E., Newsome, A., Cassie Lewis-Land, C., & Butz, M. A. (2017). Characterization of Stress in Low-Income, Inner-City Mothers of Children with Poorly Controlled Asthma. *J Urban Health* **94,** 814–823. https://doi.org/10.1007/s11524-017-0162-1

Castillo, J. M., Browne, C., Perez-Algorta, G., & Runcorn, W. A. (2020). Examining the Association Between Mentalizing and Parental Mental Health in a Sample of Caregivers of Children with Asthma.

Bellin, M. H., Newsome, A., Lewis-Land, C., Kub, J., Mudd, S. S., Margolis, R., & Butz, A. M. (2018). Improving care of inner-city children with poorly controlled asthma: what mothers want you to know. *Journal of Pediatric Health Care*, *32*(4), 387-398.

Chalise, S. P., Bhatta, N. K., & Singh, R. R. (2016). Global Initiative for Asthma: Pocket Guide for Asthma Management and Prevention. *Thorax*, *46*(1), 1–8. https://doi.org/10.1016/j.rppneu.2014.08.003

Chen, S., Liu, M., & Xie, F. (2022). Global and national burden and trends of mortality and disability-adjusted life years for silicosis, from 1990 to 2019: results from the Global Burden of Disease study 2019. *BMC pulmonary medicine*, *22*(1), 1-10.

Chong, Y., Mak, Y., Leung, S., Lam, S., & Loke, A. Y. (2019). Acceptance and Commitment Therapy for parental management of childhood asthma: An RCT. Paediatrics. ;143(2): e20181723. DOI: https://doi.org/10.1542/peds.2018-1723

Ciccarelli, N., Van Soest, A. (2018). Informal Caregiving, Employment Status and Work Hours of the 50+ Population in Europe. *De Economist* **166,** 363–396. https://doi.org/10.1007/s10645-018-9323-1

Cipolletta, S., Morrison, V., & Vilchinsky, N. (2020). Editorial: Caregiving and Social Support in the Context of Health and Illness. *Frontiers in psychology*, *11*, 620357. https://doi.org/10.3389/fpsyg.2020.620357

Clark, R. D. (2018). Emotional aspects in the etiology of bronchial asthma. *Clinical and Experimental Allergy*, *330*(43), 1058- 1066.

Connelly, L. M. (2008). Pilot Studies. *Medsurg Nursing : Official Journal of the Academy of Medical-Surgical Nurses*, *17*(6), 411–412.

County Government of Kakamega. (2014). *Kakamega County Integrated Development Plan*.

Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. Psychometrika. 16, 297-334.

Dharmage, S. C., Perret, J. L., & Custovic, A. (2019). Epidemiology of Asthma in Children and Adults. *Journal of Allergy and Clinical Immunology*, *7*(6), 1–15. https://doi.org/10.3389/fped.2019.00246

Dowell, J. A. (2016). Social interactions and children with asthma. *Journal of Child Health Care*, *20*(4), 512–520. https://doi.org/10.1177/1367493516643419

Eassey, D., Reddel, H. K., Ryan, K., & Smith, L. (2019). The impact of severe asthma on patients ' autonomy : A qualitative study. *Health Expectations*, *222*(11), 528–536. https://doi.org/10.1111/hex.12879

Ekim, A., & Ocakci, A. F. (2017). Caregiver Burden in Pediatric Asthma: A Systematic Review. *Health Science Journal*, *10*(6), 1–7. https://doi.org/10.21767/1791-809x.1000476

Everhart, R. S., Fedele, D. A., Miadich, S. A., & Koinis-Mitchell, D. (2015). Caregiver quality of life in pediatric asthma: associations with beliefs and concerns about medications and emergency department use. *Clinical Pediatrics*, *54*(3), 249—256. https://doi.org/10.1177/0009922814551134

Fairfax, A., Brehaut, J., Colman, I., Sikora, L., Kazakova, A., Chakraborty, P., & Potter, B. K. (2019). A systematic review of the association between coping strategies and quality of life among caregivers of children with chronic illness and/or disability. *BMC pediatrics*, *19*(1), 215.

Fawcett, R., Porritt, K., Stern, C., & Carson-Chahhoud, K. (2019). Experiences of parents and carers in managing asthma in children: a qualitative systematic review. *JBI Evidence Synthesis*, *17*(5), 793-984.

Feinberg, L. F. (2019). Paid Family Leave: An Emerging Benefit for Employed Family Caregivers of Older Adults. *Journal of the American Geriatrics Society.* doi:10.1111/jgs.15869

Foronda, C., Gonzalez, J. M., Snowden, K., Prather, S., Majilton, C., Weisman, A., ... & Cardenas, M. (2021). Improving knowledge and decreasing depressive symptoms in caregivers of children with asthma through the Asthma Academy: A randomized controlled trial. *International Journal of Nursing Studies Advances*, *3*, 100047.

Fujihara, S., Inoue, A., Kubota, K., Yong, K. F. R., & Kondo, K. (2018). Caregiver Burden and Work Productivity Among Japanese Working Family Caregivers of People with Dementia. International Journal of Behavioral Medicine. doi:10.1007/s12529-018-9753-9 https://link.springer.com/article/10.1007/s12529-018-9753-9

Fujihara, S., Inoue, A., Kubota, K., Yong, K. F. R., & Kondo, K. (2019). Caregiver burden and work productivity among Japanese working family caregivers of people with dementia. *International journal of behavioral medicine*, *26*(2), 125-135.

Gillaspy, S. R., Hoff, A. L., Mullins, L. L., Pelt, J. C. Van, & Chaney, J. M. (2017). Psychological Distress in High-Risk Youth With Asthma. *Journal OfPediatric Psychology*, *27*(4), 363–371.

Global Asthma Network. (2018). The Global Asthma Report Asthma affects. *World Allergy Organization Journal*, *64*(6), 476–483.

González-Conde, V. M., Pérez-Fernández, V., Ruiz-Esteban, C., & Valverde-Molina, J. (2019). Impact of self-efficacy on the quality of life of children with asthma and their caregivers. *Archivos de Bronconeumología (English Edition)*, *55*(4), 189-194.

Hassan, S. E.S., Esmat, O. M., & Mohamed, H. M. (2018). Discharge Plan for Mothers to Cope with their children suffering from Bronchial Asthma. IOSR Journal of Nursing and Health Science (IOSR-JNHS), vol. 7, no.2, pp. 24-37.

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). *Coping strategies in mothers and fathers of preschool and school-age children with autism. Autism, 9(4), 377–391.* doi:10.1177/1362361305056078

Hoerger, M., & Cullen, B. D. (2017). Early integrated palliative care and reduced emotional distress in cancer caregivers: reaching the “hidden patients”. *The oncologist*, *22*(12), 1419.

Hussain, R., Wark, S., & Ryan, P. (2018). Caregiving, employment and social isolation: challenges for rural carers in Australia. *International journal of environmental research and public health*, *15*(10), 2267.

Johnston, H. (2017). Caring for caregivers: challenges facing informal palliative caregivers in Western Kenya.

Juber, N. F., Lee, C. C., Pan, W. C., & Liu, J. J. (2021). Associations between pediatric asthma and adult non-communicable diseases. *Pediatric Allergy and Immunology*, *32*(2), 314-321.

Juma, K., Juma, P. A., Mohamed, S. F., Owuor, J., Wanyoike, A., Mulabi, D., ... & Yonga, G. (2019). First Africa non-communicable disease research conference 2017: sharing evidence and identifying research priorities. *Journal of global health*, *8*(2).

Juniper, E. F., Guyatt, G. H., Ferrie, D. H., Ferrie, P. J., Griffith, L. E., Townsed, M. (1996). Measuring quality of life in the parents of children with asthma. Quality of Life Research. 5(1):27–34. doi: 10.1007/BF00435966.

Kakamega County Integrated Development Plan 2018-2022 (2018)

Katana, P. V., Abubakar, A., Nyongesa, M. K., Ssewanyana, D., Mwangi, P., Newton, C. R., and Jemutai, J. (2020). Economic burden and mental health of primary caregivers of perinatally HIV infected adolescents from Kilifi, Kenya, BioMed Central Public Health, 20:504 https://doi.org/10.1186/s12889-020-8435-0

Kazemi, A., Azimian, J., Mafi, M., Allen, K. A., & Motalebi, S. A. (2021). Caregiver burden and coping strategies in caregivers of older patients with stroke. *BMC psychology*, *9*(1), 1-9.

Kenya Asthma Management Guidelines (2021).

Kenya National Bureau of Statistics web (2019).

Kiilu, C., Jefferys, S., Aiello, A., Were, C., Sifuma, B., Kimathi, G., & Kimeu, A. (2019). Effectiveness of innovative training models in building capacity of frontline health workers to manage Non-communicable diseases. A cross-sectional study in four counties in Kenya.

Kirenga, B. (2019). Asthma prevalence and mortality in sub Saharan Africa: the case of Uganda. University of Groningen. https://doi.org/10.33612/diss.102038349

Kopel, L. S., Petty, C. R., Gaffin, J. M., Sheehan, W. J., Baxi, S. N., Kanchongkittiphon, W., … Phipatanakul, W. (2017). Caregiver stress among inner-city school children with asthma. *The Journal of Allergy and Clinical Immunology: In Practice*, *5*(4), 1132-1134.e3. https://doi.org/10.1016/j.jaip.2017.02.026

Kosisochi, C. A., Ayogu, E. E., Ngwoke, B. A., & Okonta, E. O. (2020). Knowledge, attitudes and quality of life of caregivers towards asthma in their children: a Nigerian perspective. *Journal of Health Sciences*, *10*(1), 47–57. https://doi.org/10.17532/jhsci.2020.860

Koul, P. A., & Dhar, R. (2018). Economic burden of asthma in India. *Lung India: official organ of Indian Chest Society*, *35*(4), 281.

Kuerten, B. G., Brotkin, S., Bonner, M. J., Ayuku, D. O., Njuguna, F., Taylor, S. M., & Puffer, E. S. (2020). Psychosocial Burden of Childhood Sickle Cell Disease on Caregivers in Kenya. *Journal of Pediatric Psychology*, *45*(5), 561-572.;

Kwena, F. T. (2021). Psychosocial and economic vulnerability of informal women caregivers of sickle cell disease in Nairobi, Kenya.

Laurenzi, C. A., Hunt, X., Skeen, S., Sundin, P., Weiss, R. E., Kosi, V., Rotheram-Borus, M.J., & Tomlinson M. (2021). Associations between caregiver mental health and young children's

behaviour in a rural Kenyan sample, Global Health
Action, 14:1, DOI: 10.1080/16549716.2020.1861909

Lee, L. K., Ramakrishnan, K., Safioti, G., Ariely, R., & Schatz, M. (2020). Asthma control is associated with economic outcomes, work productivity and health-related quality of life in patients with asthma. *BMJ open respiratory research*, *7*(1), e000534.

Lu, Nan, Liu, Jinyu, Wang, Fei, Lou, Vivian W.Q., Caring for disabled older adults with musculoskeletal conditions. (2017). A transactional model of caregiver burden, coping strategies, and depressive symptoms. Archives of Gerontology and Geriatrics http://dx.doi.org/10.1016/j.archger.2016.11.001

Margolis, R. (2020). Relationship between caregiver social support, depressive symptoms, and child asthma outcomes in Low- income, urban, African American Families. umaryland.edu

Mayo, A. M., Siegle, K., Savell, E., Bullock, B., Preston, G. J., & Peavy, G. M. (2020). Lay caregivers' experiences with caring for persons with dementia: A phenomenological study. *Journal of gerontological nursing*, *46*(8), 17-27.

Mbugua, M. N., Kuria, M. W., Ndetei, D. M. (2011). The prevalence of depression among family caregivers of children with intellectual disability in a rural setting in Kenya. Int J Fam Med.

McCormick, S. (2019). Life Stress, Social Problem-Solving and Asthma. *Journal of Consulting and Clinical Psychology*, *458*(61), 932–946.

Melén, E., Guerra, S., Hallberg, J., Jarvis, D., & Stanojevic, S. (2019). Linking COPD epidemiology with pediatric asthma care: implications for the patient and the physician. *Pediatric Allergy and Immunology*, *30*(6), 589-597.

Minichil, W., Getinet, W., Derajew, H., & Seid, S. (2019). Depression and associated factors among primary caregivers of children and adolescents with mental illness in Addis Ababa, Ethiopia. *BMC psychiatry*, *19*(1), 1-9.

MoH. (2019). Guidelines for Asthma Management in Kenya. *Ministry of Health, Kenya*, *64*(15), 769–874.

Mujjuzi, I., Mutegeki, P., Nabuwufu, S., Wosukira, A., Namata, F., Alayo, P., ... & Nyeko, R. (2021). Care Burden and Coping Strategies among Caregivers of Paediatric HIV/AIDS in Northern Uganda: A Cross-Sectional Mixed-Method Study. *AIDS Research and Treatment*, *2021*.

Nturibi, E., Mecha, J., & Kamau, E. (2018). Epidemiology and Risk Factors for Asthma in Kenya. *Journal of Kenya Association of Physicians*, *1*(2), 66–72.

Nunes, C., Pereira, A. M., & Morais-Almeida, M. (2017). *Asthma costs and social impact. Asthma Research and Practice, 3(1).* doi:10.1186/s40733-016-0029-3

Ochigbo, S. O., Oparah, S. K., & Torty, C. (2018). Burden of care on caregivers of children infected with human immunodeficiency virus in Calabar, Nigeria. *Int J AIDS Res*, *5*(3), 177-180.

Opoku-Boateng, Y. N., Kretchy, I. A., Aryeetey, G. C., Dwomoh, D., Decker, S., Agyemang, S.A., Tozan, Y., Aikins, M. and Nonvignon, J. (2017). Economic cost and quality of life of family caregivers of schizophrenic patients attending psychiatric hospitals in Ghana. BMC Health Services Research. 17(Suppl 2):697 DOI 10.1186/s12913-017-2642-0

Patel, P., Kaiser, B. N., Meade, C. S., Giusto, A., Ayuku, D., & Puffer, E. (2020). Problematic alcohol use among fathers in Kenya: Poverty, people, and practices as barriers and facilitators to help acceptance. *International Journal of Drug Policy*, *75*, 102576.

Perricone, G., Prista Guerra, M., Cruz, O., Polizzi, C., Lima, L., Morales, M. R., ... & Fontana, V. (2013). Maternal coping strategies in response to a child's chronic and oncological disease: a cross-cultural study in Italy and Portugal. *Pediatric reports*, *5*(2), 43-47.

Prather, S. L., Foronda, C. L., Kelley, C. N., Nadeau, C., & Prather, K. (2020). Barriers and facilitators of asthma management as experienced by African American caregivers of children with asthma: an integrative review. *Journal of pediatric nursing*, *55*, 40-74.

Puffer, E. S., Friis-Healy, E. A., Giusto, A., Stafford, S., & Ayuku, D. (2019). Development and implementation of a family therapy intervention in Kenya: a community-embedded lay provider model. *Global Social Welfare*, 1-18.

Rhee, H., Wicks, M. N., Dolgoff, J. S., Love, T. M., & Harrington, D. (2018). Cognitive factors predict medication adherence and asthma control in urban adolescents with asthma. *Patient preference and adherence*, *12*, 929.

Robinson, B. (1983). Validation of a Caregiver Strain Index. Journal of Gerontology. 38:344-348.The Hartford Institute for Geriatric Nursing, Division of Nursing, New York University.

Ross, M. K., Okelo, S. O., & Bui, A. A. (2019). Towards Personalized and Comprehensive Pediatric Asthma Management: Understanding the Role of Social Determinants and Environmental Factors. *Academic pediatrics*, *19*(6), 599-601.

Saijo, Y., Yoshioka, E., Sato, Y., Miyamoto, T., Azuma, H., Tanahashi, Y., ... & Japan Environment and Children's Study (JECS) Group. (2021). Parental educational level and childhood wheezing and asthma: A prospective cohort study from the Japan Environment and Children's Study. *PloS one*, *16*(4), e0250255).

Shaikhan, F. M., & Makhlouf, M. M. (2020). Quality of life among caregivers of asthmatic children attending pulmonology clinics at Hamad General Hospital, Qatar. *SAGE open medicine*, *8*, 2050312120973500.

Simba, J. M. (2021). *Effectiveness of Parent-Targeted Health Education on Control of Asthma among Children attending Clinics at Moi Teaching and Referral Hospital, Kenya* (Doctoral dissertation, JKUAT-COHES).

Simba, J., Marete, I., Waihenya, R., Kombe, Y., Mwangi, A., Mburugu, P., & Ogaro, F. (2018). Knowledge and perceptions on childhood asthma among care-takers of children with asthma at a National Referral Hospital in Western Kenya: a descriptive study. Afri Health Sci. 2018;18(4): 965-971. https://dx.doi.org/10.4314/ahs.v18i4.16

St Jerry, M. (2021). The impact of caring for a school-going visually impaired child in Cape Town, Western Cape on the home caregiver and the rest of the family- the health, socio-economic and psychological health burdens (Doctoral dissertation).

Sullivan, P. W., Ghushchyan, V., Navaratnam, P., Friedman, H. S., Kavati, A., Ortiz, B., & Lanier, B. (2018). The national burden of poorly controlled asthma, school absence and parental work loss among school-aged children in the United States. *Journal of Asthma*, *55*(6), 659-667.

Taber, K. S. (2018). The use of Cronbach's alpha when developing and reporting research instruments in science education. Research in Science Education, 48(6), 1273-1296.

Waters, D. M., Olson, A. M., Fousheé, N., Shelef, D. Q., Stewart, L., Yadav, K., … Teach, S. J. (2017). Perceptions of stress, coping, and intervention preferences among caregivers of disadvantaged children with asthma. *Journal of Child and Family Studies*, Vol. 26, pp. 1622–1634. https://doi.org/10.1007/s10826-017-0670-3

WHO. (2019). Global asthma prevalence in adults: Findings from the cross-sectional world health survey. *World Health Organisation Library*, *12*(1), 204. https://doi.org/10.1186/1471-2458-12-204

Wu, B., Petrovsky, D. V., Wang, J., Xu, H., Zhu, Z., McConnell, E. S., & Corrazzini, K. N. (2019). Dementia caregiver interventions in Chinese people: a systematic review. *Journal of Advanced Nursing*, *75*(3), 528-542.

Yang, C. L., Simons, E., Foty, R. G., Subbarao, P., To, T., & Dell, S. D. (2017). Misdiagnosis of asthma in schoolchildren. *Pediatric Pulmonology*, *52*(3), 293–302. https://doi.org/10.1002/ppul.23541

Yu, Y., Hu, J., Efird, J. T., & McCoy, T. P. (2013). Social support, coping strategies and health-related quality of life among primary caregivers of stroke survivors in China. Journal of Clinical Nursing, 22(15–16), 2160–2171. http://dx.doi.org/ 10.1111/jocn.12251.

Zhang, Y., Subramaniam, M., Lee, P. S., Abdin, E., Sagayadevan, V., Jeyagurunathan, A., Chang, S., Shafie, S. B., Fauziana, R., Vaingankar, N. A., Chong, S. A. (2018). Affiliate stigma and its association with quality of life among caregivers of relatives with mental illness in Singapore. Psychiatry Research vol 265, pp 55-61. https://doi.org/10.1016/j.psychres.2018.04.044

APPENDIX I: SCHOOL OF GRADUATE STUDIES APPROVAL

MASENO UNIVERSITY

SCHOOL OF GRADUATE STUDIES

Office of the Dean

Our Ref: EL/ESM/01005/2015

Private Bag, MASENO, KENYA
Tel:(057)351 22/351008/351011
FAX: 254-057-351153/351221
Email: sgs@maseno.ac.ke

Date: 13th August, 2019

TO WHOM IT MAY CONCERN

RE: PROPOSAL APPROVAL FOR LUCY R. W. MWANGI — EL/ESM/01005/2015

The above named is registered in the Master of Public Health in Epidemiology and Population Health, Maseno University. This is to confirm that her research proposal titled "Coping Mechanisms, Socioeconomic and Psychological Burdens of Caregivers of Children with Bronchoasthma Attending Kakamega County General Hospital, Kenya." has been approved for conduct of research subject to obtaining all other permissions/clearances that may be required beforehand.

MASENO UNIVERSITY
13 AUG 2019
DEAN SCHOOL OF GRADUATE STUDIES
P.O. BOX PRIVATE BAG, MASENO

Prof. J.O.Agure
DEAN, SCHOOL OF GRADUATE STUDIES

APPENDIX II: ETHICS REVIEW COMMITTEE APPROVAL

MASENO UNIVERSITY ETHICS REVIEW COMMITTEE

Tel: +254 057 351 622 Ext: 3050
Fax: +254 057 351 221
Private Bag – 40105, Maseno, Kenya
Email: muerc-secretariate@maseno.ac.ke

FROM: Secretary - MUERC

DATE: 26th September, 2019

TO: Lucy Ruth Wairimu Mwangi
EL/ESM/01005/2015
Department of Public Health
School of Public Health and Community Development
Maseno University
P. O. Box, Private Bag, Maseno, Kenya

REF: MSU/DRPI/MUERC/00768/19

RE: Coping Mechanisms, Socio-Economic and Psychological Burden of Caregivers of Children with Bronchoasthma attending Kakamega General Hospital, Kenya. Proposal Reference Number MSU/DRPI/MUERC/00768/19

This is to inform you that the Maseno University Ethics Review Committee (MUERC) determined that the ethics issues raised at the initial review were adequately addressed in the revised proposal. Consequently, the study is granted approval for implementation effective this 26th day of September, 2019 for a period of one (1) year. This is subject to getting approvals from NACOSTI and other relevant authorities.

Please note that authorization to conduct this study will automatically expire on 25th September, 2020. If you plan to continue with the study beyond this date, please submit an application for continuation approval to the MUERC Secretariat by 15th August, 2020.

Approval for continuation of the study will be subject to successful submission of an annual progress report that is to reach the MUERC Secretariat by 15th August, 2020.

Please note that any unanticipated problems resulting from the conduct of this study must be reported to MUERC. You are required to submit any proposed changes to this study to MUERC for review and approval prior to initiation. Please advice MUERC when the study is completed or discontinued.

Thank you.

MASENO UNIVERSITY SECRETARY 26 SEP 2019 ETHICS REVIEW COMMITTEE

Dr. Bernard Guyah
Ag. Secretary,
Maseno University Ethics Review Committee.

Cc: Chairman,
Maseno University Ethics Review Committee

MASENO UNIVERSITY IS ISO 9001:2008 CERTIFIED

APPENDIX III: NACOSTI LICENCE

REPUBLIC OF KENYA

NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Ref No: **885428**

Date of Issue: **05/November/2019**

RESEARCH LICENSE

This is to Certify that Ms.. LUCY RUTH MWANGI of Maseno University, has been licensed to conduct research in Kakamega on the topic: COPING MECHANISMS, SOCIOECONOMIC AND PSYCHOLOGICAL BURDEN OF CAREGIVERS OF CHILDREN WITH BRONCHOASTHMA ATTENDING KAKAMEGA COUNTY GENERAL HOSPITAL, KENYA for the period ending : 05/November/2020.

License No: **NACOSTI/P/19/2406**

885428

Applicant Identification Number

Director General
NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Verification QR Code

NOTE: This is a computer generated License. To verify the authenticity of this document, Scan the QR Code using QR scanner application.

APPENDIX IV: KAKAMEGA COUNTY GOVERNMENT MoH APPROVAL

REPUBLIC OF KENYA
COUNTY GOVERNMENT OF KAKAMEGA

Telephone: 056 31125
E-mail: pdmswestern@gmail.com
Website : www.kakamega.go.ke
When replying please quote
Ref : CGK/MOH/CDH/1/9/52

THE COUNTY DIRECTOR
P O BOX 2309- 50100
KAKAMEGA

DATE: 25TH October, 2019

DEPARTMENT OF HEALTH SERVICES

TO

- The Medical Superintendent, KCGH.

RESEARCH AUTHORIZATION – COPING MECHANISMS, SOCIO – ECONOMIC AND PSYCHOLOGICAL BURDEN OF CAREGIVERS OF CHILDREN WITH BRONCHOASTHMA ATTENDING KAKAMEGA GENERAL HOPSITAL, KENYA.

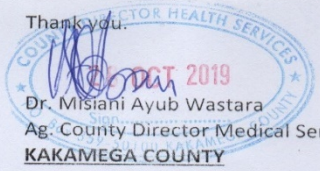
The matter refers.

Ms. Lucy Ruth W. Mwangi, a student at Maseno University is hereby approved by the County Departmnet of Health Services to carry out the aforementioned research following ethical approval by the Maseno University Ethics Review Committee vide letter ref: MSU/DRPI/MUERC/00768/19 dated 26th September 2019.

She is instructed to remain within the confines of the research protocol and the ethical approval and to submit an executive summary report within 30 days upon completion of the study to the County Research, Monitoring and Evaluation Co-ordinator, Department of Health Services.

Kindly accord her the necessary assistance as she carries out the research.

Thank you.



OCT 2019

Dr. Misiani Ayub Wastara
Ag. County Director Medical Services
KAKAMEGA COUNTY

Copy to:

- The Chief Officer Medical Services

APPENDIX V: KAKAMEGA COUNTY GENERAL HOSPITAL RESEARCH APPROVAL

COUNTY GOVERNMENT OF KAKAMEGA

E-mail: wpgh15@yahoo.com
Telephone: Kaka mega 0702930346
When replying, please quote:

REF:CGTRH/KAK/ERC/VOL.I/69

COUNTY GENERALTEACHING
&REFERRAL HOSPITAL
P.O. Box 15-G.P.O-50100
KAKAMEGA

DATE: 11TH NOVEMBER, 2019

MINISTRY OF HEALTH SERVICES

Lucy Ruth Wairimu Mwangi
EL/ESM/01005/2015

RE: RESEARCH PROPOSAL APPROVAL – 099/11/2019

This is to inform you that the Ethics and Research Committee has reviewed and approved your work titled "**COPING MECHANISMS, SOCIAL –ECONOMIC AND PSYCHOLOGICAL BURDEN OF CAREGIVERS OF CHILDREN WITH BRONCHOASTHMA ATTENDING KAKAMEGA GENERAL HOSPITAL, KENYA. PROPOSAL REFERENCE NUMBER MSU/DRPI/MUERC/00768/19**"

The approval is valid for six months from the above date and any continuation thereafter will necessitate a request for renewal.

Note that this approval is only for the work that you have submitted to us. The committee must be notified of any changes or amendments and serious or unexpected outcomes related to the study. You will be expected to submit a final report at the end of the study and may be requested to do a presentation of the same to the hospital.

This information will form part of the database that will be consulted in future when processing related research studies so as to minimize chances of study duplication.

Thank you for your interest in research in our institution.

for
DR. AUSTIN S. AJEVI
CHAIRMAN
ETHICS AND RESEARCH COMMITTEE
CGH - KAKAMEGA

CC

The Medical Superintendent
CGH - KAKAMEGA

APPENDIX VI: CONSENT FORM

Participant informed consent form

My name is Lucy Ruth Mwangi. I am a student at Maseno University. I am currently conducting a research project as a requirement for the award of Master of Public Health. The research project is entitled, **Psychosocial Burden and Coping mechanism of Caregivers of children with bronchoasthma attending Kakamega County General Hospital, Kenya.**

Dear respondent,

You have been selected to participate in this study: "Coping mechanisms, Socioeconomic and Psychological Burden of Caregivers of children with bronchoasthma attending Kakamega County General Hospital, Kenya". You will voluntarily participate and have the right to withdraw from the study at any time without being penalized. I request you to honestly respond to the questionnaire given to help me achieve the objectives of this study. All this information you give will be treated with confidentiality and only used for academic purposes. You can skip any question that you do not feel comfortable answering and in case you need any clarifications, do not hesitate to speak.

If you accept to participate, kindly sign below.

Signature..... Date……

Thank you.

APPENDIX VII: RESEARCH QUESTIONNAIRE FOR CAREGIVERS OF CHILDREN WITH BRONCHOASTHMA.

Kindly answer with a tick () in the answer box.

Part A. Personal Details

1. Age of the child
    a. Below 1☐
    b. 1-3☐
    c. 4-7☐
    d. 8-11☐
    e. 12-14☐
2. Sex of the child
    a. Male ☐
    b. Female ☐
3. How many children do you have?
    a. 1-2 ☐
    b. 3-4 ☐
    c. 5 and above ☐
4. Have you lost any child before?
    a. Yes b. No

If yes, how many _____. What was the cause of death? _____

5. What is your relationship with the child?
    a. Parent ☐
    b. Guardian ☐
6. What is your marital status?

a. Single ☐

b. Married ☐

c. Separated ☐

d. Divorced ☐

e. Widowed ☐

7. What is your age?

_____

8. What is your highest level of education?

a. No formal education ☐

b. Primary ☐

c. Secondary ☐

d. Tertiary ☐

e. Other, specify _____

9. What do you do to earn your daily food?

a. Self-employed ☐

b. Employed ☐

c. Other, specify _____

10. What is your family income monthly in Ksh?

a. Below 10,000☐

b. 11,000-20,000☐

c. 21,000-50,000☐

d. OVER 50,000☐

11. Does anyone in your household take alcohol, smoke or use drugs?

a. Mother ☐

b. Father ☐

c. Other ☐ _____

12. What source of fuel do you use for cooking at home?

a. Firewood ☐

b. Gas stove ☐

c. Kerosene stove ☐

d. Charcoal ☐

13. What type of house do you live in?

a. Stone ☐

b. Wooden ☐

c. Mud ☐

Part B

1. PACQOL Questionnaire (Psychological)

This section of the questionnaire is designed to find out how you have been during the last week. We want to know about the ways in which your child's asthma has interfered with your normal daily activities and how this has made you feel. Please answer each question by placing an x in the appropriate box. You may only mark one box per question.

Key: 1=Always, 2=Quite often, 3=Once in a while, 4=Hardly any of the time

Statement		**1**	**2**	**3**	**4**
1.	During the past week, how often did you feel helpless or frightened when your child experienced cough, wheeze, or breathlessness				
2.	During the past week, how often did your family need to change plans because of your child's asthma				
3.	During the past week, how often did you feel frustrated or impatient because your child was irritable due to asthma				

4.	During the past week, how often did your child's asthma interfere with your job or work around the house				
5.	During the past week, how often did you feel upset because of your child's cough, wheeze, or breathlessness				
6.	During the past week, how often did you have sleepless nights because of your child's asthma				
7.	During the past week, how often were you bothered because your child's asthma interfered with family relationships				
8.	During the past week, how often were you awakened during the night because of your child's asthma				
9.	During the past week, how often did you feel angry that your child has asthma				
10	During the past week, how worried or concerned were you about your child's performance of normal daily activities				
11	During the past week, how worried or concerned were you about your child's asthma medications and side effects				
12	During the past week, how worried or concerned were you about being overprotective of your child				
13	During the past week, how worried or concerned were you about your child being able to lead a normal life				

Sources: (Juniper *et al,* 1996)

Caregiver Strain Index (CSI)

I am going to read a list of things that other people have found to be difficult. Would you tell me whether any of these apply to you? (GIVE EXAMPLES)

1. Were you disturbed from sleep in the previous nights by the child condition?
    a. Yes
    b. No
2. Does Caregiving inconvenience you?
    a. Yes
    b. No
3. Do you feel physically constrained by the caregiving?

a. Yes
b. No

4. Does Caregiving limit you from social activities participation?
    a. Yes
    b. No
5. Did experience change in your plans because of caregiving?
    a. Yes
    b. No
6. Did you experience emotional changes as a result of Caregiving?
    a. Yes
    b. No
7. Did you have to change/adjust work schedule because of caregiving?
    a. Yes
    b. No
8. Did you experience financial challenges because of caregiving?
    a. Yes
    b. No
9. Did you experience trouble keeping your mind on what you were doing?
    a. Yes
    b. No
10. Did you feel like you couldn't leave your relative alone?
    a. Yes
    b. No
11. Did you experience difficulty in decision making?
    a. Yes
    b. No
12. Did you feel affected by the situation of your relative?
    a. Yes
    b. No
13. Do you feel satisfied with the support accorded to you by your family?
    a. Yes
    b. No

Total Score (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.) NB. Yes=1 &No=0

Adapted from Robinson, B. (1983). Validation of a Caregiver Strain Index. Journal of Gerontology. 38:344-348.The Hartford Institute for Geriatric Nursing, Division of Nursing, New York University.

2. Socio-economic burden

Complete the following statement. Please answer each question by placing an x in the appropriate box. You may only mark one box per question.

Key: 1= Strongly Disagree, 2=Disagree, 3= Neither, 4=Agree, 5= Strongly Agree

Statement		**1**	**2**	**3**	**4**	**5**
1.	I have several Emergency Department visit in last 12 months.					
2.	Most of days I have been absent from work due to bronchoasthma attacks					
3.	Children who have Bronchoasthma have been in hospitalization most of times					
4.	Caregivers of children who have Bronchoasthma often borrow finances for medicine purchases.					
5.	Children living with Bronchoasthma have negatively affect relationships at home.					
6.	Caregivers of children who have Bronchoasthma lack time for social activities.					
7.	Caregivers and Children with Bronchoasthma loss of opportunities for career advancement.					
8.	Caregivers have reduced productivity at work in terms of limited time, pain grief and stress related to caregiving.					
9.	Caregivers of children living with Bronchoasthma in this community face reduced total annual income.					
10.	Caregivers of children who have Bronchoasthma in this community have lost job for caregiving.					
11.	Caregivers of children living with Bronchoasthma in this community face neglect from their family.					

12.	Caregivers of children having Bronchoasthma has poor quality of life.					
13.	Caregivers of children living with Bronchoasthma in this community face impaired daily activities.					
14.	caregivers of children living with Bronchoasthma have him/her or family member discontinued schooling					
15.	Caregivers acquire loans/ delay investment/ cut budgets to medicate the child					

Sources: (Genberg *et al.*, 2009)

Part C. Caregivers coping strategies.

Problem focused.

1. I always attend training at health facility of coping with broncho-asthma?

    a. Strongly agree_____ b. Agree_____ c. Neutral_____

    a. Disagree e. Strongly disagree

3. I seek health information on home care, self-efficacy, asthma management skills, or the family's problem-solving abilities from professionals?

    a. Strongly agree_____ b. Agree_____ c. Neutral_____

    b. Disagree_____ e. Strongly disagree_____

4. I regularly evaluate the pros and cons of the situation?

    a. Strongly agree_____ b. Agree_____ c. Neutral_____

    b. Disagree e. Strongly disagree

5. I have focused on the intervention on improvement in the behaviour of the child and effectively in reducing anxiety and worry?

    a. Strongly agree_____ b. Agree_____ c. Neutral_____

    b. Disagree_____ e. Strongly disagree_____

Emotion-Focused

6. I seek consolation from a spiritual leader or an elder or an alternative medical practitioner?

    a. Strongly agree_____ b. Agree_____ c. Neutral_____

    b. Disagree_____ e. Strongly disagree_____

7. I had withdrawn the child from school as a result of his/her condition?

    a. Strongly agree_____ b. Agree_____ c. Neutral_____

    b. Disagree_____ e. Strongly disagree_____

8. Had isolated the child from the public for the fear of being stigmatized?

    a. Strongly agree_____ b. Agree_____ c. Neutral_____

    b. Disagree_____ e. Strongly disagree_____

Escape-avoidance

9. I always wish, hope and pray that the child will get better?

    a. Strongly agree_____ b. Agree_____ c. Neutral_____

    b. Disagree_____ e. Strongly disagree_____

10. The impact of broncho asthma have contributed to be involved in substance abuse?

    a. Strongly agree_____ b. Agree_____ c. Neutral_____

    b. Disagree_____ e. Strongly disagree_____

11. I have been downplaying the severity of symptoms or risk of exacerbations as it is beneficial by reducing or limiting anxiety?

    a. Strongly agree_____ b. Agree_____ c. Neutral_____

    b. Disagree_____ e. Strongly disagree_____

Sources: Hastings *et al,* (2005).

APPENDIX IX: STUDY SITE MAP