

THE QUESTION OF CAREGIVER IDENTITY IN DISABILITY STUDIES
A STUDY OF THE NOVEL *MY FATHER'S NOTEBOOK*



Project submitted to St. Teresa's College (Autonomous) in partial fulfilment of the requirement for the degree of BACHELOR OF ARTS in English Language and Literature

BY

ANNA JOSEPH

Register No. AB22ENG008

III B. A. English Literature

St. Teresa's College

Ernakulam

Cochin - 682 011

Kerala

Supervisor

MRS. LISSY JOSE

Assistant Professor

Department of English

St. Teresa's College

Ernakulam



[Handwritten signature]

[Handwritten signature]

[Handwritten signature]

[Handwritten signature]



ST. TERESA'S COLLEGE (AUTONOMOUS)
ERNAKULAM

Certificate of Plagiarism Check for Dissertation

Author Name ANNA JOSEPH

Course of Study English Language & Literature

Name of Guide MRS LISSY JOSE

Department English & Centre for Research

Acceptable Maximum Limit 20

Submitted By library@teresas.ac.in

Paper Title THE QUESTION OF CAREGIVER IDENTITY IN
DISABILITY STUDIES A STUDY OF THE NOVEL
MY FATHER'S NOTEBOOK

Similarity 8% AI-19%

Paper ID 3394538

Total Pages 36

Submission Date 2025-03-11 15:58:52

Signature of Student

Signature of Guide

Checked By
College Librarian



* This report has been generated by DrillBit Anti-Plagiarism Software



Scanned with OKEN Scanner

DECLARATION

I hereby declare that this project titled “The Question of Caregiver Identity in Disability Studies: A Study of the novel *My Father's Notebook*” is the record of bona fide work done by me under the guidance and supervision of Mrs. Lissy Jose, Assistant Professor, Department of English.



Anna Joseph

Register No. AB22ENG008

III B.A. English Literature

St. Teresa's College

Ernakulam

Ernakulam

March 2025

CERTIFICATE

I hereby certify that this project entitled "The Question of Caregiver Identity in
Disability Studies: A Study of the Novel *My Father's Notebook*" by ~~Salma Saheer~~ ^{Mrs. Lissy Anna Joseph} is a
record of bona fide work carried out by her under my supervision and guidance.



Mrs. Lissy Jose

Professor

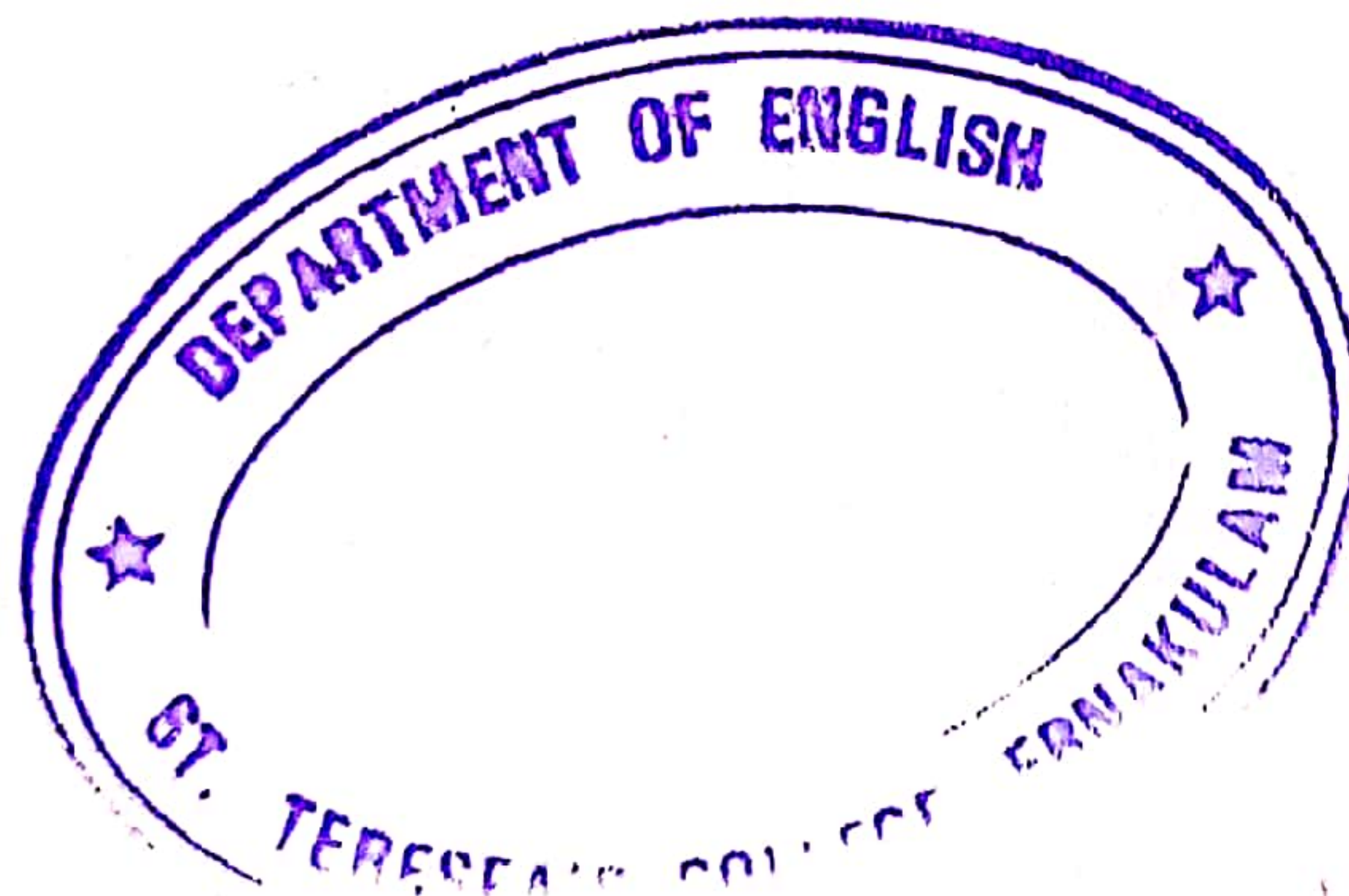
Department of English

St. Teresa's College (Autonomous)

Ernakulam

Ernakulam

March 2025



Acknowledgement

I take this opportunity to thank God Almighty for showering his abundant blessings and grace upon me during the course of my project.

I would like to place on record my sincere gratitude to Rev. Sr. Nilima (CSST), Manager, St Teresa's College (Autonomous), Ernakulam and Dr Alphonsa Vijaya Joseph, Principal, St Teresa's College (Autonomous), Ernakulam for their continued support throughout the course of my study in this institution.

I would like to express my heartfelt gratitude and appreciation to my supervisor Mrs. Lissy Jose for guiding my thoughts in the right direction and for helping me to express them in the best possible manner.

I extend my sincere gratitude to the Head of the Department, Ms. Preeti Kumar and all the other teachers of the department without whose guidance this project could never have been completed.

The Question of Caregiver Identity in Disability Studies:

A Study of the novel *My Father's Notebook*

By

Anna Joseph

B.A. English Language and Literature

St. Teresa's College (Autonomous)

Ernakulam

Register No: AB22ENG008

2022 – 2025

Supervising Teacher: Mrs. Lissy Jose

Roughly around 650 million or 10% of the world's population live with a disability. Many of them might have paid caretakers but others especially in developing countries may be looked after by a family member. The novel *My Father's Notebook* by Kader Abdollah is the fictional tale of one such deaf-mute carpet weaver Aga Akbar and his caregiver son Ishmael who is forced to leave his home-land Iran behind and settle in the Netherlands to escape punishment for his illegal activities as a revolutionary. This project is an attempt to explore how Ishmael's experiences as a caregiver for his disabled father intersect with his complex diasporic identity, depicting how caregiving serves as a metaphorical bridge between his Iranian heritage and his new cultural context on the basis of the Caregiver Identity Theory by Rhonda J. Montgomery and Karl Kosloski along with an examination of the elements of Feminism that is found in the novel. The connection between the act of caregiving and the longing for 'home' by a refugee is studied along with the impact it has on the lives and personalities of the characters, directly and indirectly.

CONTENTS

Introduction	1
Chapter 1 The Question of Caregiver Identity in Disability Studies	5
Chapter 2 Analysis of the novel <i>My Father's Notebook</i>	13
Conclusion	27
Works Consulted`	29

Introduction

“I’d been born to serve him, so I had to save him,” says Ishmael in the work *My Father’s Notebook* (Abdollah 103).

Different cultures treated people with disability differently, in some they were outcasts while in others they were rejected. Many saw them as a financial liability and kept them alive in name while neglecting their needs and wants. The Greeks considered them as inferior Christians believed them to be possessed by evil spirits and supporters of social Darwinism were against the aid given to them. History is proof that the world has not been kind to this minority group, one example being when Adolf Hitler in 1939 began to systematically murder Germans with physical and intellectual disabilities in order to create a superior race. This was called the Nazi Euthanasia Program under which an estimated 250,000 people (who were seen as unnecessary to society) lost their lives as Nazis believed that they were undeserving of life. However, as the world progressed many people became aware of the rights of people with disabilities and believed that it was necessary to give them a voice thus creating a branch of studies and theories constructed on an interdisciplinary identity-based approach which found many lesser-known aspects of humanities which supported the rights of the differently abled.

Disability Studies first began to emerge in the west in the late twentieth century because of the work and effort of scholars like Michel Foucault and Erving Goffman who made the victory of the disability rights movement possible. It was through sit-ins, marches, protests and demonstrations that people with disability who had until then been hidden away from the world fought against discrimination and the inhuman way in which they had been treated, which resulted in improved access and inclusion

along with a feeling of pride, acceptance and community. While this was a major movement that resulted in the landmark achievement of, Americans with Disabilities Act of 1990 there is a side to it that is not very well known, the side or rather the perspective of the people who looked after the disabled, the Caregivers.

The definition of Caregivers are people who are either paid to look after someone or is a family member who does the job out of familial obligation or social expectation. The novel *My Father's Notebook* written by Kader Abdolah is the story of one such caregiver Ishmael and the person he looked after, which is his deaf and mute father Aga Akbar. The novel is told through the point of view of a third person narrator and Ishmael and is about the lives of these two characters which are intertwined with each other as Ishmael was the son who was deeply desired by all so that he could be Aga Akbar's guide and his voice to communicate with the world. The novel is set in Iran spanning the rise and fall of the Shah and his son, who were the last two rulers of the country, an era which was filled with political turmoil and revolution, in which Ishmael becomes a part of by becoming part of an underground movement whose aim was to overthrow the tyrannical rule of the Shah. His actions eventually result in him having to flee his country in secret and take refuge in the Netherlands where he receives a notebook that belonged to Aga Akbar written in a cuneiform script which Ishmael attempts to decipher in order to truly understand who his father was. It is seen throughout the novel that Aga Akbar is fully dependent on Ishmael and along with him every other disabled man in their village Jirya was dependent on their sons who became their father's caretakers from a young age. This responsibility shapes Ishmael's personality and his life, with him always knowing that he was the man of the house who had to look after his family.

This project's aim is to study this novel on the basis of the Caregiver Identity Theory (CIT) a study that was introduced by theorists Kosloski and Montgomery, which explores concepts such as identity discrepancy, caregiver burden and care receiver stressors. It is also an attempt to understand how political events which are orchestrated by the government can inadvertently affect the lives of those who live thousands of miles away and how different sections of society are affected by it differently.

The novel also contains elements from the theory of Feminism which is subtly portrayed by the characters of Hajar, Tina and Golden Bell who are respectively Aga Akbar's mother, second wife and youngest daughter. Unlike Aga Akbar's son and his uncle these three characters do not play any special role in his education, interests or creativity, nevertheless they are important in their own right as all three of them are unconventional women, who in a male dominated society lived their lives by their own terms. These three female characters were also the most affected by Aga Akbar's disability apart from Ishmael as seen in different instances in the story, where they also had to be Aga Akbar's caregivers at different points in their lives. Their identities were also intertwined with Aga Akbar's, which affected them in divergent ways and caused them to make decisions they otherwise would not have made.

Chapter 1 is the analysis of the Caregiver Identity Theory to answer the question of caregiver identity in disability studies and investigate the metaphorical connection between caregiving and diasporic longing, that is the connections between Ishmael, Aga Akbar and their home-land of Iran. The role of memory and storytelling in constructing caregiver and diasporic identity will also be examined as the novel engages with key themes and motifs of diasporic literature such as displacement, alienation, and the search for belonging through the specific lens of caregiving.

Chapter 2 will explore the development of Ishmael and Golden Bell's caregiver identity and the interplay between personal and cultural identity along with the comparison and contrast between their experiences. It also contains the summary, setting, symbolism and structure of the novel and the real-life events which happened during the time-frame the book is set in. By applying the Caregiver Identity Theory, the distinct phases of Ishmael and Golden Bell's progression as caregivers, focusing on how their roles shape their sense of self and their interactions with the world will be studied along with how the act of caring for his father impacts Ishmael's understanding of what 'home' means.

Chapter 1

The Question of Caregiver Identity in Disability Studies

Disability Studies examines the nature, meaning and consequences of disability in social, cultural, ethical and political contexts and is mainly about the perspective of those with intellectual or physical difficulties, but there is a side to it that is not very well-explored or studied, that is the perspective or side of the Caregiver. In many under-developed countries people with disabilities are often abandoned as they are considered a burden by their families who do not want the additional responsibility and who often don't have the resources needed to take care of the special needs of differently abled people. In other instances, people who cannot afford to pay a professional caretaker (who is equipped and prepared for such a role) chooses to take on the responsibility themselves as no other alternative is available to them. Officially there are 53 million caregivers in the world who assist adults or children with special-needs. Unofficially there are many people who become unpaid caretakers for a sick or disabled family member due to reasons such as familial obligation, lack of economic resources etc. Caregiving for a family member is seen as a noble responsibility that an individual is supposed to do out of love and is a matter of pride and duty. However, their contribution or labour often goes unnoticed, and in many cases taken for granted, which at times makes it not only a difficult job but also one that is devoid of gratitude.

The Caregiver Identity Theory that was introduced in the year 2000, deals with the point of view of such caregivers who are not professionally trained or paid but who take care of a disabled family member on a full-time basis while also fulfilling their other duties such as studying, working, completing house-work etc. According to this theory family members from an existing relationship like a spouse, sibling, offspring etc face a shift in identity when they become a caretaker to their family

member in addition with their already existing relationship. This has often been normalised by society who internalises the belief into every individual that blood is thicker than water, that is no matter what, family should come above all. While this is a noble idea it is also idealistic and at times unreasonable as it burdens individuals with duties and responsibilities that should not be theirs to fulfil. In many places it is taken for granted that the role of the caregiver will be fulfilled by a family member which is how it is portrayed in certain movies and books. For example, in the novel *The Oxford Murders* written by Argentine writer Guillermo Martinez (published in 2003 and made into a movie of the same name in 2008 by director Alex de la Iglesia) the character of Beth is a full-time caretaker for her mother Mrs Eagleton, a role which she bitterly resented as it stopped her from living her own life. While the story does not pay a lot of attention to her character it is revealed in the climax that she is the one who killed her mother in a moment of desperation so as to be relieved from her responsibility. While this is a fictional novel that portrays a more drastic chain of events it cannot be denied that characters like Beth are present all around the world, some willingly in such positions while others are forced into it by family and society. Another example would be the movie *My Sister's Keeper* directed by Nick Cassavetes (released in 2009 and based on the book of the same name published in 2004 by Jodi Picoult) in which the character of Anna was born as a saviour baby to donate organs and cells to her sister Kate who is leukemic (blood cancer) while their mother Sara resigns from her job as an attorney to be Kate's primary caregiver. These two works of fiction show two contrasting portrayals of caregivers where in the former the caregiver character of Beth is deeply unhappy and tired of her existence that is tied to that of her mother's while in the latter both Sara and Anna's characters want Kate to live and are willing to do anything for her regardless of their own wishes or desires.

While these two works are a rather extreme depiction of what a caregiver will do to either protect the person they are looking after or to get rid of them in order to live their own lives, the novel *My Father's Notebook* has a more realistic take on this topic. In certain situations, a family member chooses to be the caregiver of the disabled individual and receives the support and resources needed to fulfil the demanding role, an example of which can be seen in the book in the case of Golden Bell, Ishmael's youngest sister who willingly takes her brother's place as their father's caregiver after his departure to the city of Tehran. Despite not having an opportunity to be Aga Akbar's caregiver for long she does her job well and is shown to be more patient than Ishmael as described in the quote said "Golden Bell was more patient than Ishmael. She explained things to him with endless patience" (Abdollah 208). This could be because by the time Golden Bell took her brother's position the family had prospered financially which along with her watching and learning from Ishmael's experience made things easier for Golden Bell, which showcase the contrasting behaviour and methods of the two siblings in regard to looking after their father.

This project problematizes how Kader Abdollah's *My Father's Notebook* intricately weaves the protagonist Ishmael's evolution as a caregiver for his disabled father with his complex negotiation of diasporic identity, demonstrating how the act of caregiving becomes a metaphorical conduit for reconnecting with his Iranian heritage while simultaneously shaping his understanding of self and belonging in a new cultural landscape.

Moving ahead on the theory, researcher Helene Ebenstein identified five markers which are relevant to caregiver support groups, self-definition as a caretaker, performing personal care, seeking assistance and formal service use, consideration of

nursing home placement, and termination of the caregiving role. Caregiver Identity Theory is an extension of this framework and builds upon the research of other theorists. It was introduced by Dr Rhonda Montgomery and Karl Kosloski with the main idea being that caregiving is a process that goes through constant change, and which affects relationships, activities and identities as it can be considered both an opportunity and a challenge. This is because on one hand, being someone's caretaker can help a person achieve discipline, strength and a sense of responsibility, but on the other hand it can also result in having no personal life along with a feeling of bitterness and disappointment for having to live a life that is for others. When studying about identity the perspective of the caregiver is often ignored because society conditioned many to believe that if you are a blood relative or a spouse it is your job to look after a sick family member. The idea as such is not wrong but over the years a pattern can be seen in many fictional and non-fictional works where in most cases it is the elder child or spouse who is a caregiver to the other members of the family. One dire fictional example of this can be seen in the American television series *Shameless* (adaptation of Paul Abbott's British series of the same name) developed by John Wells in the character of Fiona Gallagher who being the eldest had to raise her six siblings as her father Frank Gallagher was a neglectful alcoholic who took no responsibility and provided zero support and aid. While not disabled in the strict sense of the word Fiona's mother who abandoned her family struggled with bipolar disorder. This was passed on to her son Ian Gallagher and caused him and his family a considerable amount of distress due to difficulty in accessing his medications, their lack of security and finances etc. Fiona was thus his caretaker and the rest of her family's as well which caused her to have impulsive and self-destructive tendencies. While personas such as Fiona, Beth etc are fictional characters

they are the way Caregivers are represented in films and literature, as the unseen heroes who take on additional responsibilities and who carry an invisible weight on their shoulders.

Theorists Montgomery and Kosloski identify five phases of the Caregiver Identity Theory that are connected to changes in the care recipient's need for support. Phase I is the initial period, both caregiver and recipient adjust to their roles, it is an introduction to a change in their behaviour and feelings towards each other. Caregivers barely even realise that the role has shifted from family member to something more as it is a period of transition. In Phase II there is an acceptance on the side of the caretaker that their relationship with the recipient has changed and they acknowledge the addition of the existence of the caretaker identity along with whatever their initial bond was. Friction develops in Phase III when the caregivers are torn between their identities as caregivers and family members which causes them emotional distress and confusion. This happens when the person they are looking after needs more care and attention than a family member can provide and because of the circumstances a shift in identity occurs, when the giver becomes more of a caretaker and the recipient becomes more of a patient than a family member. An example of this can be seen in the Hindi movie *Piku* made by Shoojit Sircar (released in 2015) when the character of *Piku* is more like a mother and a caretaker towards her widowed father Bhashkor who has health issues which frequently disrupts her personal and professional life. Nevertheless, she fulfils her role with utmost sincerity and efficiency, often going above and beyond to make sure that her father was comfortable in every way. Phase IV occurs when the caregiver considers moving the recipient or the patient to a professional institution, such as a nursing home with professionally trained caretakers. An example of this can be seen in the hit television

series *Grey's Anatomy* created by Shonda Rhimes (released in 2005) in the episode *If Only You Were Lonely* (Season 8, Episode 16) where the character of Dr Richard Webber decides to move his wife Adele Webber (who was diagnosed with Alzheimer's disease) into a care facility after they both realise that it was not possible for him to give her the care she requires, because of the severity of the nature of her illness which required someone to constantly watch and pay attention to her for her own and others security. This was not an easy decision for either of them to make as Richard believed that as her husband, he was the one who was supposed to look after her no matter what. Like survivor's guilt (symptoms of depression and Post Traumatic Stress Disorder also known as PTSD, which happens when one person survives a traumatic event or near-death incident that others did not) Caregivers Guilt (which is defined as an adverse manifestation of the distress experienced when caring for a loved one) occurs in many caregivers who feel anxiety, feelings of conflict, anger, sorrow etc. In Richard's case he believes that he was not able to be a good husband to Adele as he was unable to look after her himself due to his demanding career which leads to him having deep feelings of guilt and inadequacy. The fifth and final phase happens when the caregiver and recipient go back to their initial relationship which significantly lowers the caregiver's burden and returns them to their original identity. For this phase to transpire the patient must be moved somewhere else such as to a different home or assisted living facility where the family member no longer has to worry about them or provide them with assistance, as they are now being looked after in the right manner by people who are trained to do so and who have no personal relationship with them.

Unfortunately, families with low-income backgrounds who live in places that do not have such facilities don't have a choice but to look after their disabled or ill

family members by themselves because they do not have the finances to hire an outsider to do a job which in their eyes is something that they can do by themselves. They fail to realize that the consequences of such an additional task that is time consuming has a negative effect on both physical and mental health which leads to a rise in medical expenses as the caretaker also becomes sick due to the added turmoil on their body and mind. Other changes include a lack of social life and declining performance in places of education or work because of an increase in stress levels as the caretaker has to look after themselves and a whole other person similar to how a new parent has to look after their newborn baby who constantly needs them. Since, caregiving is a challenging and difficult process it influences the manner in which a caregiver behaves in general with such people having a strong and determined personality with a set of characteristics and ideals that they believe they must follow. These can be expectations, rules, regulations etc which they hold themselves to and which defines appropriate behaviour. This is called Identity Standards and can cause emotions of envy, resentment, anger etc in individuals who had to become caretakers, because when the rest of the world does not follow such strict standards the unfairness of the situation that they were in will finally be revealed to them.

Each caretaker and recipient will go through these five phases in their own way based on factors such as gender, economic and social circumstances, need for family approval etc. In the next chapter we will see how Ishmael goes through these phases along with his sister Golden Bell who is Aga Akbar's secondary caretaker. The dependence their father had on them from childhood (particularly on Ishmael) formed these two siblings into the people they became, revolutionaries whose actions affected not just themselves but their whole family in ways that fundamentally changed them for better and for worse.

Chapter 2 will contain the analysis of how gender and individual experiences within the diaspora influences the development of caregiver identity, highlighting the unique challenges and perspectives faced by each sibling. This will be studied by employing the Caregiver Identity Theory and how Golden Bell and Ishmael go through the five phases mentioned in Chapter 1. How Ishmael's caregiver role intersects with his evolving understanding of his Iranian identity which demonstrates how the personal and cultural dimensions of identity are mutually constitutive will also be explored in this chapter.

Chapter 2

Analysis of the novel *My Father's Notebook*

The Dutch novel *My Father's Notebook* was published in the year 2000 in the Netherlands and is set in 20th-century Iran with the protagonist being the deaf and mute Aga Akbar. The author of this work is Hossein Sadjadi Ghaemmaghami Farahani an Iranian writer who goes by the pen name Kader Abdolah (in honour of his late friends and comrades who died under the persecution of the current Iranian regime) for reasons of his own safety and security and whose works have been translated into thirty languages. This book is translated from Dutch to English by Susan Massotty. Abdolah's father was also a deaf and mute carpet weaver with Abdolah being his helper, which indicates that although the genre of the novel is fiction, it contains elements of auto-biography. Due to his father's disability Abdolah did not have a proper childhood as he had to become a man at an early age to prove himself and look after his family of four sisters and a brother causing him to always remain in a state of alertness. He always knew he wanted to become a writer but faced a number of difficulties on his journey. During his college years he joined the left-wing student underground movement which first fought against the authoritarian rule of the Shah and later against the fundamentalist regime of Khomeini. In 1988 he migrated to the Netherlands as a political refugee after which he fell into a state of depression. He then learned the Dutch language and wrote three novels in it. Award-winning novels *The Messenger* and *The Qur'an* are works of Abdolah who is also the recipient of the Order of Orange-Nassau to recognize his contributions to society and the world of literature, and the Mundial Award for his accomplishments in the area of international cooperation, peace, and security. The prominent themes that can be seen in his works are Freedom, Religion, Exile and Politics with his novels containing the

influences of his father and uncle who both played a major role in Abdollah's childhood. He has published in over twenty countries and has written a number of columns, short stories, novels, translations and adaptations of Persian literature.

My Father's Notebook is divided into three parts (BOOK I: The Cave, BOOK II: New Ground, BOOK III: The Cave) with the story being narrated by an omniscient narrator in Book I and Book III and Akbar's son Ishmael narrating it in Book II, with the novel being written in a non-linear format. At first glance the novel can be seen as a work that describes a bond between father and son with its main topic being Ishmael's quest to discover who his father was, which he attempts to do so with the help of a notebook in which Akbar's thoughts and feelings were written in a Cuneiform (a system of writing that was developed by the ancient Sumerians of Mesopotamia) script that only he could understand along with elements of Diaspora and Feminism. The Cuneiform script was developed by Aga based on an undeciphered cuneiform inscribed in a sacred cave on Saffron Mountain (located near his village Jirya) 3,000 years ago on the orders of a Persian king, after being motivated by his uncle a poet named Kazem Khan who also played the role of a father figure in Aga Akbar's life.

To understand any literary work (particularly novels) it is necessary to understand the place and time that they are set in. *My Father's Notebook* is primarily set in Iran in the village of Jirya (known for its carpets and rugs) and the city of Tehran along with the country of Netherlands which is the home of Ishmael who had become a political recusant and who in the present day lived with his wife and daughter far away from his homeland and the family he had been born into. The time frame the book is set in is a tumultuous period in Iran's history with the exact years not being mentioned. However, it does talk about the military dictatorship of Reza

Khan which began in the 1920s through the war with Iraq that consumed the country for most of the 1980s while also displaying a time jump where a generation later Ishmael makes an effort to delve into the heart of his father's story.

The major themes this novel explores are Politics, Disability, Diaspora, Familial relationships, Love and the struggle for power between the government and the public who each have their own beliefs, ideals and fundamentals. Feminism is an underlying topic that can also be found within the novel. The village Jirya which was Aga Akbar and Ishmael's birthplace and home bordered the then Soviet Union and was near an important pilgrimage spot located on Saffron Mountain. During the time period the novel was set in, the country was under the rule of the father of the last shah of Iran, Reza Khan who was on a mission to westernize the country. Rumors suggested that he was a pawn of the British whose mission was to reform the country in order to give the West an advantage against the Soviet Union in the midst of the cold war. While it is uncertain whether or not he was working for the British he was a brutal dictator who wanted imminent change. Eventually Reza Shah died in Cairo where he was sent by the Allies (The Big Four-United Kingdom, United States of America, China and Soviet Union) during World War II.

Afterwards in 1951 Mohammad Mosaddegh became the Prime Minister and nationalized Iran's oil industry causing Britain to lose control of the oil industry which resulted in direct conflict between the two countries. He had a lot of support from leftist factions and was considered the joy and pride of many Iranians but was arrested when the government fell and the son of Reza Shah (Mohammad Reza Pahlavi) was restored to the throne after a CIA backed coup. His followers were arrested and executed while many fled the country. Many of these refugees were part of a left-wing Russian-oriented party who were against the Shah and the interference

of the United States. In the story this was one of the reasons for Aga Akbar to shift his family (which consisted of his wife Tina, son Ishmael and three younger daughters) to the city, the others being his desire to send his children to school and because he was in love with a woman in the city. Ishmael who was his father's mouthpiece and primary caretaker then moves away after a few years to attend university in Tehran which is where he realizes that just as much as his father was dependent on him, he was dependent on his father as somewhere along the way or perhaps right at the beginning he and his father inadvertently became one.

While this concludes the history and setting in which the novel takes place and gives a brief idea about the story and its characters the main purpose of this project is to understand how a caregiver's entire life and personality is shaped because of the person he/she looks after, in Ishmael's case his father's life and his were interwoven together, one's story was also the other's, because for him Aga Akbar's notebook contains the memories and experiences of his beloved homeland, which helps him to reduce the alienation he felt in the foreign country.

When a deeper analysis of the text is conducted, it reveals that while Disability is represented by Aga Akbar, Ishmael who grows up to be a rebel who is forced to seek refuge in a strange country is a representation of the theory of Diaspora. The story of Ishmael is the story of the millions of refugees scattered across the globe who for reasons such as war, poverty etc are unable to go back to the place where they were born. While Ishmael was born and brought up in Iran the latter half of his life is spent in the Netherlands where he adopts the language and culture of the Dutch which is a symbol of his Hybrid Identity and the cultural displacement that he faces by being part of two conflicting cultures and beliefs. In Iran Ishmael had a large family who all lived in a close and tight knit village where everyone knew everyone else while

friends and relatives could be found all over the country. Ishmael was also actively involved in politics in which Aga Akbar also became a part of as the party used him to smuggle letters and parcels across the border. After a few years Ishmael was forced to escape and start a new life completely alone as his spouse and child were only able to join him later. The journey was difficult but he managed to reach Holland where he had been living for many years when his father's notebook was delivered to him and reminded him of everything he had lost, his family, comrades and friends. He wanted to translate the book into something others could also read but was afraid that "everything in my father's notebook is old: the mountains, the well, the cave, the cuneiform relief, even the railway. That's why I don't dare put pen to paper. I can't imagine writing a novel on this new ground" (Abdollah 70). There was a clash between his old life and the new one in which he was living but he wanted to create something that had traces of both his identities.

Another way in which the novel portrays the loss of identity is when in an attempt to modernise the country, Iran under the dictatorship of the Shah was forced to give up its traditions, customs and beliefs in order to be more like the West, a movement which benefited the European countries who wanted to ensure that the oil rich country remain was under their rule so as to be ahead of the USSR in the Cold War. The measures he undertook included the imprisonment or killing of writers, intellectuals and political leaders, the banning of chadors for women who instead of the traditional Iranian clothing were supposed to wear western attire (thousands of hats were imported for this purpose), the establishment of radio stations, modern schools, parks, new businesses, printing presses, theatres, roads, buses and taxis. The Shah also wanted an obedient army and all of his subjects to carry identity cards because of which the first census of Saffron Village occurred. Under his rule all the

men of the country had to be in the military for two years which was compulsory for all except for those with intellectual or physical disability, which resulted in many pretending to be handicapped as a way to escape military service. He also ordered a railway be built from the south of the country to the northeast which would benefit Europeans the most but also be left long after they were gone. While countries like India was under the direct control of the British Iran was not formally colonised but the Shah did his best to westernize the country overnight which resulted in much of Iran's heritage and culture being considered unimportant or backward by many.

The other significant aspect of this novel is the depiction of women which is not the standard way male authors normally portray female characters in a male-centric text. The women of the village Jirya spend their whole lives weaving their dreams and longings into carpets as their lives are controlled by their fathers, brothers or husbands. They are not mistreated or oppressed in any way but they do not have the freedom to go beyond what they are allowed to do by the men in their lives. Therefore, it is surprising to see that the women in Aga Akbar's family are strong, courageous and in control of their lives with each of them being more than what people around them expected them to be. The first is Hajar, Aga Akbar's mother who chose to be the *sigeh* (temporal spouse) wife of a nobleman and who single handedly raised her seven children with-out anyone's help. Since she was a *sigeh* wife her children did not receive their father's name or any of his wealth and neither was they ever shown to him. The only exception was Aga Akbar who was Hajar's youngest child and who she showed to the noblemen and asked him to give his name to Aga Akbar, which was proof of her courageous and independent nature. Not much else is said about her as she dies a few years later but she nevertheless played a major role in helping Aga Akbar come to terms with his disability and how to live with it.

The next influential character is Aga Akbar's second wife Tina (his first wife died soon after their wedding as she had a terminal illness which was not revealed to him or his family until after her death) her surname never being mentioned in the novel which is unusual as most female characters are usually addressed by their surnames to showcase that their identity is often that of their father's or their husband's. Since Aga Akbar's physical limitations made it difficult for him to find a bride (despite him having a job as a carpet weaver and being one of the richest in their village as he received a high amount of money from the Shah for helping to build the railway around Saffron Mountain) he was in a relationship with a prostitute which was unacceptable for his family as they did not want his children to have a prostitute for a mother (topic of hypocrisy and prejudice) and particularly because they wanted a strong woman with a good head on her shoulders who would give birth to a healthy son who would bear Akbar's burden. Tina's character also has a role in Ishmael becoming who he is, because like the rest of their family she too wanted him to constantly be with his father. She criticized Ishmael often for not looking after his father properly and blamed Aga Akbar for ruining her life. After being married three times and called a man-hater she had wanted to live a quiet life, which unfortunately did not come into being and caused her to have episodes that Ishmael described as having a wolf inside of her. Ishmael had three sisters of which the first two saw him as a father figure and who were closer to Tina. He indirectly influenced them by hiding Jamileh in their house which resulted in them choosing to marry men who were arrested by the secret police of the new regime, the Islamic Republic of Iran. The youngest sister Golden Bell who was her father's and brother's favourite became a revolutionary who was eventually imprisoned for her illegal involvement in the rebel party. Tina thus blamed Jamileh for ruining her daughter's lives, especially

Golden Bell who had joined the party because she saw Jamileh as a role model after being inspired by her beliefs and ideology. In spite of her flaws and her dependence on Ishmael, Tina was a strong, independent woman who was willing to do anything for her family. This is seen when she helps Ishmael to protect Jamileh even though she very well knew the repercussions of what would happen if they were caught.

Another character that must be mentioned is Safa, Ishmael's wife who does not play a very significant role in the book, but from a feminist point of view deserves recognition and appreciation. Unlike Tina or Golden Bell Safa has no direct relationship with the Leftist party but is forced to go into hiding with her daughter because of Ishmael's involvement which leads to years of separation between them especially when Ishmael is forced to escape the country. Although a period of extreme difficulty in her life none of these events break her with Safa always choosing to believe that Ishmael was doing what he did for the greater good. She is also one of the few people in his life who never blamed him for the choices he made and who did not burden him with expectations and other constraints.

There are many quotes in the book that acknowledge the fact that Aga Akbar was the reason his children became revolutionaries. One such example would be when Ishmael said, "If I'd had any other father, I might not have felt the need to join the movement, or at any rate I wouldn't have become so involved or gone so far. Being the son of such a father brought me, led me, propelled me in this direction" (Abdollah 130). This quote is evidence to the fact that Aga Akbar who was Ishmael's strength and his weakness was the reason why he became a political revolutionary, who risked his own and his family's lives many times in order to keep the mission of overthrowing Iran's government alive. While Aga Akbar was the cause for him

participating in the movement, it was Ishmael's sister Golden Bell and his wife Safa who was his quiet strength and support.

It is essential to note here that it was Ishmael and Golden Bell who made the dangerous and risky decision to become insurgents who the country viewed as criminals while their sisters lead safer lives by being ordinary citizens who accepted the life society set for them, that of marriage and family. This is because these two siblings were their father's helpers who knew him better than they knew themselves as their lives had been about making sure that his life was comfortable and that his needs and wants were met before their own. Even when Ishmael went away to university for his higher studies, he felt incomplete and unsteady, he had been worried about how his father would be able to manage without him, but it was Ishmael who felt off-balance like a prisoner who felt strange without the chains he had been wearing for a long time. Aga Akbar was Ishmael's strength and his weakness, perhaps this was why no matter how much physical distance was between them they always had some kind of mental contact that made it difficult for them to be separated in any way. Even after Aga Akbar's death Ishmael still felt connected to him and blamed himself for not doing the task he was given properly as he felt that he had deserted his family when he was forced to leave the country.

Sometimes I think I'm writing this book out of guilt. The guilt of a son who failed his given task, who escaped halfway through the job and left his father to his fate. Maybe that's why my father comes to me so often in my dreams, why he never looks at me, but avoids my glance and averts his head.

(Abdollah 95)

Ishmael was a man of experience and wisdom yet he felt guilty for many things, for not being there for his family, for abandoning his father and for his sister's imprisonment. One of the reasons why he joined the party and progressed quickly through its ranks was because he was used to taking responsibility and risks that most people his age would not have had to take. It can even be argued that the reason why they chose such a perilous and fear filled life was because in some way or the other they were seeking an escape from their identity of that of a caretaker, by undertaking missions that had the power to change their country's very foundation, but at the same time not wanting to leave behind the lives that they had led until then.

To conclude it can be derived that Ishmael and his sister went through the five phases of Caregiver Identity Theory, from the time of their childhood to adulthood which is explained below in further detail.

Phase I began for Ishmael right from his birth, he was taught and trained to become his father's mouthpiece which meant wherever his father went he also had to go. He was not alone in this, along with him there were also the children (sons) of the other disabled people of the village.

The families and the other villagers did their best to teach these boys the language of adults. The imams even taught them how to read the Holy Book at a very young age. They had little contact with other children, since they were always with the men. They were expected to fulfil family obligations and to be present at both feasts and funerals. (Abdollah 74)

Golden Bell's case was similar as she too had been born to reduce Aga Akbar's hardship except that because her big brother was there as the primary caretaker, she only had to take on a secondary role which made her childhood comparatively easier

and better than his. There is no particular adjustment in either case, Ishmael was born for the purpose of being both a son and a caretaker, neither the father nor the son know another reality. Of-course this also gave them some privileges, Ishmael and Golden Bell from the time of their birth were their father's favourites and were deeply loved by all "For example in the beginning I was called Mine. When he put his right hand to the left side of his chest, everyone knew he was referring to Ishmael" (Abdollah 108). They were a team, the three of them, and their relationship was that of friends and companions.

In Phase II Ishmael understood the extent of the role he had to play in his family and what made him different from other children of his age which is seen when he says, "I had been appointed by family, friends, neighbours and even nature to be my father's guide, so I had to lead him as I saw fit" (Abdollah 130). This shows how his first priority had always been his father, how he puts his responsibilities first even before his own needs and wants. Golden Bell on the other hand adapts to her position slowly, she is more patient than Ishmael when dealing with Aga Akbar because unlike Ishmael her duties only started once she reached adulthood or rather after Ishmael left home for college.

Ishmael unconsciously resented his father and the circumstances to which he was thrust into when everyone appointed him as his father's caregiver (something that was collectively decided upon even before his birth). Apart from short bursts of anger he never conveyed his feelings to anyone (except for writing about them in his book), rather he continually blamed himself for not being there for his father when he was for the first time in his life forced to choose himself instead of choosing his father's needs or what his family desired. However, he also knew that despite the unusual nature of their relationship Aga Akbar had always been there for him and was a good

father. One instance was when the principal of Ishmael's school made him perform a humiliating dance in front of the whole school and Aga Akbar despite being restrained by many people came to protect his son. Another example would be Aga Akbar buying Ishmael books after noticing his love of reading, which showed his kind and caring nature even though the books he bought were not ones Ishmael wanted to read, but was proof of his desire for his son to do what he loved and achieve knowledge. The father and son also had other shared interests such as going to the rooftop to view the full moon while Ishmael told stories and poems in sign language for his father to understand. All of these events are proof of the deep connection and understanding between the two individuals who were two bodies but one soul, which could be why for Ishmael the idea of 'home' was directly linked to his father, that is if was able to bring the presence of his father to the place he was living through acts of service and care to others, he would be able to feel more at home. To elaborate on this point Ishmael's mind must be studied. From a young age he had learnt to communicate not just his thoughts and feelings but also that of his father's. Taking care of others from such a young age gave him a personality that was dedicated to helping others which is why his determination and dedication never wavered during his years as a revolutionary whose main aim was make to Iran a free country, even though he knew that if he was ever caught it would have been immensely dangerous for him and his family and which could have resulted in him being tortured and killed.

Phase III is what occurs throughout the latter half of the novel, Ishmael is torn between the loyalty he has towards his party's cause and his family's wishes. He faced fear, guilt, loss of self-confidence etc, but in spite of his confusion and the troubles he faced, Ishmael never regretted the choices he made, as seen in the quote: "These were difficult years, but he wasn't sorry he'd escaped or made the political

choices he had. He'd learned a lot, he'd had all kinds of experiences and he'd even enjoyed life" (Abdollah 206). Sub-consciously Ishmael decided to let go of being his father's caretaker and for the rest of his life he felt guilty about it because he believed he had abandoned his father halfway through the journey that they were supposed to undertake together. Ishmael had done his job faithfully for years, when he left it was passed on to Golden Bell who also looked after Aga Akbar with dedication and sincerity. Since Golden Bell was arrested before she reached that stage of friction she never went through Phase III and it is not certain whether or not she would have reached that point where she would have felt a crisis in her identity as her father's caregiver and as his daughter.

For Ishmael Phase IV occurs when instead of his father being moved away to a professional care facility (which was something their family would never agree to) he goes to Tehran for higher education, so as to lead a better life with a higher standard of living. This is where he deals with Caregivers Guilt, the belief that he had failed at his task and that he had abandoned the people who needed him. While Ishmael's departure to Tehran was voluntary, his shift to the Netherlands was a desperate move to avoid capture and to save his life. After he reached Holland Golden Bell was also compelled to leave her home and her family as she was taken to jail from which she at the end of the book escapes from. In this phase both of Aga Akbar's children who are also his caregivers are the ones who left with Aga Akbar remaining where he was.

Ishmael never sees his father again because after finding out that Golden Bell had escaped from prison Aga Akbar goes to look for her in the mountains where he dies. At this point the fifth and final phase occurs, Ishmael becomes a grieving son far from home who mourns his late father and worries about his sister's fate as nothing is ever found out about her and the rest of the escaped prisoners. It is not certain whether

or not Golden Bell found out about her father's death or what happened to her, but Ishmael lives the rest of his life in the hope that his father forgave him because he knew that he had served his father faithfully despite at times using him for his own purposes. He moves on in life but never forgets his father, his family and his life in Iran and thinks about the happy memories they had together and how in the face of adversity they all stood together, such as when Tina got hit by a bomb and was shifted to another village for recuperation where the whole family joined her and lived together for a few days in peace and harmony.

Ishmael and Golden Bell made similar choices that had different outcomes for the both of them. Their father and their country were an integral part of them which was why their lives were different from that of others, they were children who became caregivers of an adult man and rebels who fought for a larger cause rather than individuals who were seeking personal fulfilment.

In the end it can be derived that in one way or the other they achieved what they were meant to attain, an identity that was beyond the expectations and boundaries that were placed on them. Ishmael in particular truly became his father's son because even though he was a refugee in another country, he accepted it as his home and became an established writer who adapted the customs and traditions of a foreign land as his own. No matter the years and distance between Aga Akbar and Ishmael they were two people who could not function without the other, like binaries such as good and evil, light and darkness. Both of them led different lives, but at the end of the day they both needed each other to find a sense of belonging.

Conclusion

“The unforgettable story of a father, his son and the country they love” is the sentence that is on the cover page of this book. In a way this is a one-line summary of the novel which shows the key elements of this book, love and service towards one’s family and country.

In a relationship between a parent and their child, it is normally the parent who is the child’s main provider and the adult in the relationship. Children grow up watching their parents, who play an essential role in shaping them to be the people they are. Parents are their children’s first guides, teachers and friends who influence them in various ways. However, the relationship between Aga Akbar and Ishmael is more complicated as the son becomes his father’s guide and care-provider. Years later after his father’s death Ishmael, an established writer, struggles with unanswered questions which he tries to answer by using Aga Akbar’s notebook. *My Father’s Notebook*, although fictional, has similarities with its author Kader Abdolah’s life and is a story that describes the struggles and challenges faced by caregivers everywhere along with the lack of belonging felt by refugees.

As a child Ishmael had always wanted to know his father’s past which he does so by asking relatives and friends about Aga Akbar’s childhood and his life before Ishmael’s birth. When he reaches adulthood through his experiences and memories he knows and learns more about his father and thus learns about his heritage and cultural identity which helps him to understand his diasporic identity better, because for a long time he was a fragmented individual seeking acceptance in a country that was not his own. Eventually Ishmael realizes that the notion of ‘home’ is not related to geography or where he was present physically, but rather it was the feeling of safety and comfort felt with the people who become part of us internally. The notebook plays an

important role in his journey of self-discovery as it preserved the stories, history and culture of Ishmael's background and that of his family's roots which had been lost to Ishmael due to his migration to Holland. Deciphering it made him feel closer to his father and his land which led to him being able to reconnect with his Iranian Identity with a stronger sense of self. *My Father's Notebook* is a novel that unpaid caregivers and refugees around the world can relate to. Through Ishmael's eyes we see the complex emotional and psychological dynamics involved in caregiving and the displacement faced by refugees who are neither here nor there. The novel highlights the transformative power of caregiving experiences and the need for support and self-care for caregivers, which ultimately can be solved only through long-term reform and change by making people understand that caregiving should not be the job of only one person but rather a collective role that is shared by everyone. Caregivers must also be given more appreciation and recognition so as to reduce the pressure they feel which would give them the stability and validity they deserve.

Works Consulted

- Abdolah, Kader. *My Father's Notebook*. Canongate, *Book Read Free*,
<https://bookreadfree.com/book/15453>, Accessed 26 Aug. 2024.
- Abrahams, Frits. "Freedom Can Be a Nightmare: An Interview with Kader
Abdolah." *Words Without Borders*, Accessed 2 Dec. 2024.
- Broome, Adam. *The Oxford Murders*. Ostara Publishing, 2008.
- Byrne, Matt, and Shonda Rhimes. "Grey's Anatomy, If Only You Were
Lonely", *Grey's Anatomy*, season 8, episode 16, Jio Hotstar, 23 Feb. 2012.
- Cassavetes, Nick, director. *My Sister's Keeper*. 2009,
<https://www.youtube.com/watch?v=LfHUuHf1PqI>. Accessed 10 Jan. 2025.
- "Disability Statistics: Information, Charts, Graphs and Tables." *Disabled World*,
Disabled World, 12 Sept. 2024, www.disabled-world.com/disability/statistics/.
- Ebenstein, Helene. "The Relationship Between Caregiver Support Groups and
the Marker Framework of Caregiving." *Research Gate*, Disabled World,
[www.researchgate.net/publication/233273917_The_Relationship_Between_Car
egiver_Support_Groups_and_the_Marker_Framework_of_Caregiving](http://www.researchgate.net/publication/233273917_The_Relationship_Between_Caregiver_Support_Groups_and_the_Marker_Framework_of_Caregiving).
Accessed 13 Dec. 2024.
- Humblé, Philippe. "Twice a Rebel: Kader Abdolah's Conflictive Relationship
towards Iran and Islam." *Research Gate*, Aug. 2020,
[www.researchgate.net/publication/343987399_Twice_a_Rebel_Kader_Abdolah
's_conflictive_relationship_towards_Iran_and_Islam](http://www.researchgate.net/publication/343987399_Twice_a_Rebel_Kader_Abdolah's_conflictive_relationship_towards_Iran_and_Islam).

Mark, Joshua J. "Cuneiform." *World History Encyclopedia*, 17 Nov. 2022,
www.worldhistory.org/cuneiform/.

Montgomery, Rhonda J. "Caregiver Identity Theory Overview." *Research Gate*,
www.researchgate.net/publication/265260328_Caregiver_Identity_Theory_Overview. Accessed 17 Nov. 2024.

"The Murder of People with Disabilities." *United States Holocaust Memorial Museum*, United States Holocaust Memorial Museum,
encyclopedia.ushmm.org/content/en/article/the-murder-of-people-with-disabilities. Accessed 27 Feb. 2025.

Pavey, Ruth. "My Father's Notebook, by Kader Abdolah, Trans Susan Massotty." *The Independent*, Independent Digital News and Media, 15 June 2006, www.independent.co.uk/arts-entertainment/books/reviews/my-father-s-notebook-by-kader-abdolah-trans-susan-massotty-6098034.html.

Singh, N. P., et al. *Piku*. Yash Raj Films, 2015,
<https://www.sonyliv.com/search?q=piku>. Accessed 8 Sept. 2024.