

## EMPOWERING FUTURES

Shaping a Dignified Long-Term Care Ecosystem for Healthy Ageing and Well-being of Carers and Older Persons in the Middle East and North Africa

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# DAUGHTERS' CARE BURDEN FOR OLDER MOTHERS WITH ALZHEIMER

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# OUTLINE

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## **Introduction**

Why women and their daughters?

02

## **The qualitative study**

Objective of the current study

Methodology

Case studies

03

## **Conclusion and recommendations**



# WHY WOMEN AND THEIR DAUGHTERS?

**The reasons for this focus can be trace to three groups of reasons**

- Demographic-based Reasons
- Dementia and Alzheimer-based Reasons
- Caregiving based Reasons





# DEMETIA AND ALZHEIMER- BASED



**Globally**  
**55 million people worldwide are affected by dementia.**

**Over 60%** of these individuals reside in low- and middle-income countries.

**Annually**, there are nearly 10 million new cases of dementia.

**Dementia** arises from various diseases and injuries that impact the brain.

**Alzheimer's** disease is the most common form of dementia, contributing to **60–70%** of cases.

**Dementia** ranks as the seventh leading cause of death globally and significantly contributes to disability and dependency among older individuals.

# DEMETIA AND ALZHEIMER- BASED



## In Egypt

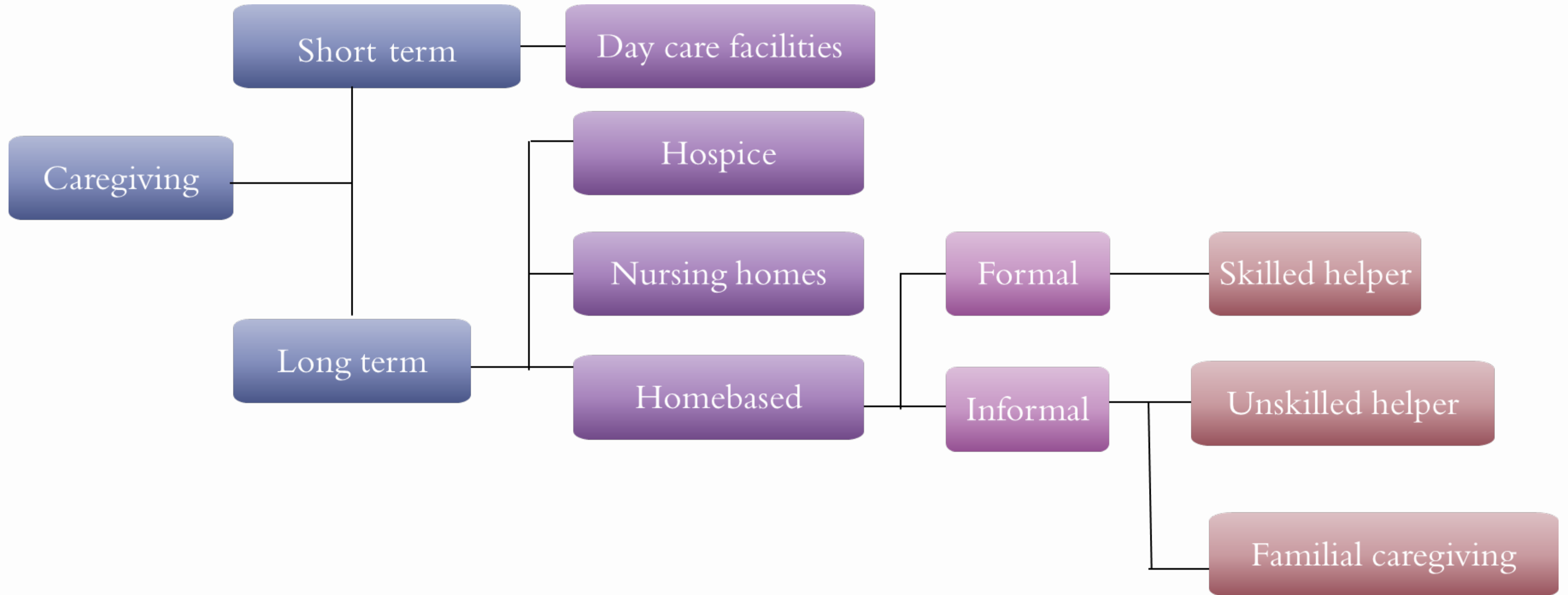
Estimates of the prevalence of dementia varies among studies, ranging from 2.01% to 5.07%.

**Dementia** increases with age, with a rapid increase among those aging 80 and above

**Dementia** prevalence is higher among women particularly those aged 80+ compared to men in particular dementia related to Alzheimer diseases.

**Dementia** prevalence is positively associated with illiteracy, suffering from chronic diseases and low socioeconomic status

# CAREGIVING-BASED





# SKILLED HELPER

## Aged Care program in Egypt

The program was launched in 2018 by the Ministry of Social Solidarity and in collaboration with the National Institute of Longevity and Elderly Studies. Beni Seuf University and some civil society organizations.



**The program aims to train older persons care givers with a focus on**

1. Organizing entertainment activities for older persons
2. Preparing nutritious food for older persons
3. Providing health care service including monitoring general health status in particular chronic diseases
4. Availing the medical instrument needed
5. Providing personal care and household maintenance.
6. Caring for the incapacitated and bed-ridden older adults
7. Caring for older persons with Depression, Alzheimer and other hallucination related diseases

# INFORMAL CAREGIVER

## Unskilled helper

For the helpers, they are unusually unqualified and hence unable to deal with the job requirement  
For the older persons, the high level of turn around exacerbates the insecurity feeling



## Familial caregiving

- Our collectivism culture with its familyism and filial piety has implied that this is the most common and acceptable type of caregiving in the Arab and MENA region
- This task is commonly shouldered by women as they represent the majority of the caregivers (daughters and daughters in law)
- Due to personal nature of care giving daughters are more preferred

# THE QUALITATIVE STUDY

## **Objective of the study**

Give the caregiver daughters the chance to voice their burden and support the development of recommendations to address their needs

## **Methodology**

The qualitative approach was adopted.

The identification of the caregivers was based on the personal connections of the researcher(Omnia).

**Case studies**  
(resident caregiver  
/upper middle class)

**S A E E D A**  
**( 5 7 Y E A R S )**

widow university educated, currently working, has three brothers and two daughter and one son, upper middle class. She coresides with her mother. Her relationship with her mother has been strong but became stronger after the death of her husband.

**Mother is 75 years and diagnosed with mild Alzheimer, but according to her view, her mother's condition has been progressing very rapidly**

**Case studies**  
(Non-resident caregiver  
/upper class)

**E H S S A N**  
**( 4 7 Y E A R S )**

Married with four daughters still in different educational stages , university educated, and housewife. she is the only child, upper class. She resides within the same neighborhood. Her relationship with her mother went in turbulence after the death of her father due to her mother's grief.

**Mother is 78 years and diagnosed with mild Alzheimer after the death of her husband, but things are progressing very rapidly. Mother refuses to move in with her daughter, and grandchildren were not comfortable with their grandmother taking one of their rooms.**

**Case studies**  
(Non-resident caregiver/  
lower middle class)

**S A M E H A**  
**( 5 3 Y E A R S )**

Married has coresident daughter, son and grandchildren, has one sister and one brother, university educated, her and her husband are working in the government, lower middle class. Although her father, brother and sister-in-law co-reside with the mother, she has to commute every day for 45 minutes to provide care for her mother

**Mother is 75 years and diagnosed with second stage Alzheimer, has a heavy loaded medical history including stroke, hypertension, diabetes, osteoporosis, ...etc**

# SIGNS & SYMPTOMS AS DEFINED BY THE WHO

**Changes in mood and behavior may occur even before memory problems manifest.**

Feeling anxious, sad, or angry about memory loss.

personality changes

inappropriate behavior

withdrawal from work or social activities

being less interested in other people's emotions.

**Early signs include:**

Forgetting recent events

Misplacing items

Getting lost in familiar places

Difficulty solving problems or making decisions

Trouble following conversations or finding words

Challenges performing familiar tasks

Misjudging distances visually.

# SIGNS & SYMPTOMS FROM THE PERSPECTIVE OF CAREGIVER

**The most difficult issue for the caregiver is the incomprehensible feeling of these transformations in their older familymembers and the instability and rapid progress of these transformation.**

Dementia and Alzheimer are transformative diseases that start with simple symptoms usually confused with old age (memory loss and its related feel of anger and anxiety) but progresses rapidly into incapacities in

Physical status (slow movement, inability for personal care, visual distraction...etc)

Mental Status (loss of interest, mood swings, isolation, attachment to caregiver and old things and memories)



# **MAIN DIMENSIONS OF CAREGIVER LIVES**

**Interaction with the health system**

**Physical environment at home**

**Family dynamics**

**Social network**

**Economic conditions**

**Physical conditions**

**Psychological conditions**

# MAIN DIMENSIONS OF CAREGIVER LIVES

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**Interaction with health care system has been a constant complain among caregivers. Heath system providers only focus on the disease but not the health and wellbeing and provide no supportive information to the caregiver.**

# MAIN DIMENSIONS OF CAREGIVER LIVES

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## OBSERVATIONS

*“His recommendations was to try to keep my mother condition stable and only gave us very general instructions, they were very useless”*

**Saeeda**

*“I did not find any psychological support for me or a training center on how to deal with her condition”*

**Ehssan**

*“The doctor’s manner was harsh, instilling harsh feelings of frustration within us. The only instruction the doctor gave us is not to disturb her, to act calmly in front of her, and to smile constantly.”*

**Sameha**

# MAIN DIMENSIONS OF CAREGIVER LIVES

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## OBSERVATIONS

**Formal caregivers are non existing**

*I tried to hire a nurse, but my mother fired her, because she was thought that she wanted to steal from her or worse kill her”*

*Ehssan*

*“It is so difficult to find qualified care provider”*

*Saeeda*

*“When I have to run some errands for my home or my mother’s home, I call upon my sister-in-law”*

*Sameha*

# MAIN DIMENSIONS OF CAREGIVER LIVES

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**Home physical environment had to be altered to accommodate the mother's health condition and facilitate caregiving tasks**

# MAIN DIMENSIONS OF CAREGIVER LIVES

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## OBSERVATIONS

### **Challenges & alterations needed for the Home**

*“I put locks on all doors and windows so mother would not wander in the street without knowing or fall looking out of the window.”*

*Saeeda*

*We had to put iron bars on all windows and balconies.”*

*Sameha*

*“I installed surveillance cameras in my mother’s house so that I could follow her”*

*Ehssan*

# MAIN DIMENSIONS OF CAREGIVER LIVES

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**While family begins with supporting the caregivers, conflict appears as the caregivers become more occupied with the caregiving activities**

# MAIN DIMENSIONS OF CAREGIVER LIVES

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## OBSERVATIONS

**Conflicts emerges as caregiving continues  
and requires more time**

*“ I have not been able to see my  
grandchildren for long and can not have a full  
phone call with my daughter.”*

*Saeeda*

*“When I go home everybody is frustrated  
with my absence and feel neglected .”*

*Ehssan*

*“”My husband is always complaining from my  
absence and threatens that I might lose him  
and he will marry someone to take care of him*

*Sameha*



# MAIN DIMENSIONS OF CAREGIVER LIVES

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**Social network is a double-edged issue. To some extent supportive ones are very helpful but usually does not last, while unsupportive ones are harmful and have many negative consequences for both the mother and caregivers**

# MAIN DIMENSIONS OF CAREGIVER LIVES

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## OBSERVATIONS

*"I would hear harsh words like "When your mother is in such a condition, don't show her off better keep her home and no need for scandals"*

**Saeeda**

*"When we visit our village and relatives and neighbors come to visit my mother, her condition becomes stable"*

**Ehssan**

*"All my friends and colleagues have forgotten about me. I learn about their news from the social media."*

**Sameha**

# MAIN DIMENSIONS OF CAREGIVER LIVES

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**Caring for a person with dementia entails many economic costs not only the labor & medication**

- **Large amount of unneeded purchases**
- **Home alteration cost**
- **Destructive costs and home maintenance cost**

# MAIN DIMENSIONS OF CAREGIVER LIVES

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## OBSERVATIONS

*“She began to buy many things from street vendors, sales representatives and electronic sales sites or using the phone, which initially exposed me to financial crises”*

**Saeeda**

*“Sometimes, she feels angry with the food I serve her, she throws it on the floor and walk all over it. It is not only money waste, but also extra cleaning effort.”*

**Sameha**

# MAIN DIMENSIONS OF CAREGIVER LIVES

Interaction with the health system

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**Physical conditions**

Psychological conditions

**Physical strain comes with the daily activities of personal care for the mother and maintaining the household(s)**

# MAIN DIMENSIONS OF CAREGIVER LIVES

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## OBSERVATIONS

**Physical strain comes with the daily activities of personal care for the mother and the maintaining the household(s)**

*“She throws her entire weight on my back, causing tears in the ligaments in my shoulders and at least hand or arms twist or a muscle strain in my back”*

**Saeeda**

*“I sleep with my eyes opened like a beast... I am too scared to fall asleep and some thing happened.”*

**Ehssan**

*“She would say “ do not go to sleep and leave me alone”*

**Sameha**

# MAIN DIMENSIONS OF CAREGIVER LIVES

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**Psychological conditions**

**With these ongoing daily experiences of the caregiver, they end up under substantial mental and psychological pressure, feeling lost, frustrated, over exhausted, filled with guilt and totally socially isolated**

# MAIN DIMENSIONS OF CAREGIVER LIVES

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**Psychological conditions**

## OBSERVATIONS

*“I am almost clinically dead,” “Everyone is upset with me... I am living dead person”*

**Saeeda**

*“My children and the marriage are on one hand, my mother is on the other hand,” “I am in major turbulence”*

**Ehssan**

*“I am the one who is sick, not my mother.” “When does this day end.. so I can get some sleep.”*

**Sameha**



# CONCLUSIO

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**Substantial lack of information about the disease and its progress**

**Substantial lack of qualified physicians, skilled caregivers and support groups**

**Caregivers learn from experience**

**Caregiving has significant implication the caregiver's social, practical, physical and mental wellbeing**

**The cost of caregiving needs to be more comprehensive and exceeds the current approach of labor and medication costs**

# RECOMMENDATIONS

## **01 Caregivers need to receive comprehensive:**

Education about dementia, including its progress overtime and different stages.

Training on managing all care dimensions to the person with dementia.

Information on managing stress during caregiving and preventing burnout.

Mapping of any support groups that exist within their community.

## **02 General public should receive information on the disease, its risk factors and prevention and early signs**

# RECOMMENDATIONS

- 03 Increase the health care labor force in geriatric and dementia care with culturally sensitive training**
- 04 Create a cadre of skilled caregivers**
- 05 Develop initiatives and interventions supporting caregiving that are culturally sensitive**
- 06 Support research and studies on the social aspects of Alzheimer, Dementia and caregiving burden to set recommendations for the wellbeing of the patients and their caregivers**



**THANK YOU !**

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