THE SOCIAL BURDEN OF THE CAREGIVERS OF ALZHEIMER'S DISEASE PATIENTS IN EGYPT

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ABSTRACT

<u>OBJECTIVES:</u> Alzheimer's Disease is a major health challenge with significant social, economic and psychological consequences. In addition to the staggering disease figures and tremendous changes in patients' life, Studies have shown that primary caregivers often become physically and emotionally overburdened and experience high rates of physical illness, social isolation, and emotional distress. This study aims to shade the light on Alzheimer's caregiver societal burden and raise more attention towards the disease in Egypt.

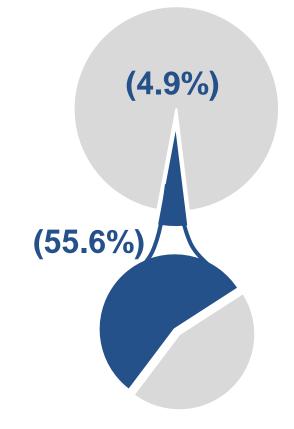
<u>METHODS:</u> A caregivers' reported outcome study was conducted with 20 caregivers in Egypt, they were responsible for closely looking after Alzheimer patients at different stages. The study spanned the care continuum from the onset of symptoms and pre-diagnosis through the late stages of the disease. Data gathering was performed through a quantitative questionnaire using face to face approach.

RESULTS: Although 90% of Caregivers are at working age, the study showed that only 20% are currently employed, and the remaining either quit their job or couldn't find a flexible opportunity accommodate caring for their Alzheimer's' patient. Moreover, the study showed that almost 90% of the caregivers are living with the patient to be able to provide the proper care and attention. 40% of caregivers sought to get home care service while 20% of caregivers hired a full-time nurse to further support in patient care. The top needs highlighted by caregiver were training on how to deal with the patient and the availability of a night care service to be consulted in case of any emergency.

<u>CONCLUSION:</u> Besides patients' deteriorated quality of life, Alzheimer's imposes a significant societal burden on their caregivers who are a fundamental stakeholder in the disease management. The study shows a need for better social and healthcare proposed solutions by healthcare systems to ease the burden on Caregivers for better care of Alzheimer's patients.

INTRODUCTION

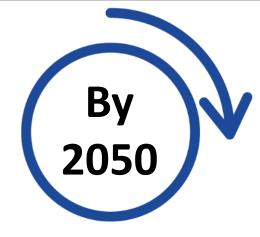
Considering the tremendous social, psychological and health consequences of Alzheimer disease, it turned to be one of the major health challenges that calls for more actions towards prevention and management. Elderly population (aged 60+ YO) represents (6.65%) population in Egypt (6,841,768) (1)



(4.9%) Is the prevalence of Dementia in Egypt out of elderly population (335,247) (2)

(55.6%) out of which are suffering from Alzheimer, accordingly Alzheimer estimated number of patients is (186,397) in 2020 in Egypt. (2) Showing the challenging situation that needs to be addressed.

OBJECTIVES



More than 150 million people will have dementia. (3)

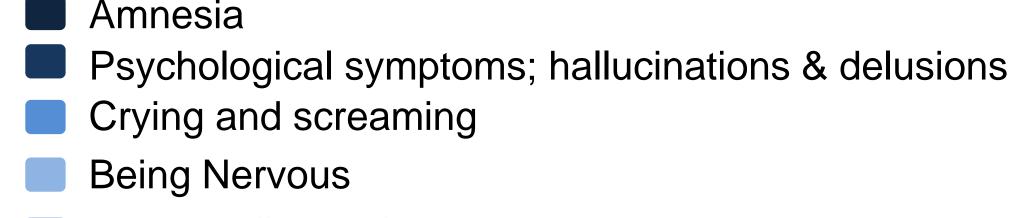
So the world desperately needs an effective treatment for Alzheimer's disease Hundreds of millions of caregivers and family members will be affected along with them, suffering emotionally, physically and financially. Accordingly this study is conducted to understand more about patient subtypes and flow, including referral pathways and time to diagnosis, also to assess the quality of life of caregivers and key challenges facing them in their journey with Alzheimer patients.

METHODOLOGY

A quantitative survey was conducted with (20) caregivers of Alzheimer patients using face to face approach, following a predetermined screening criteria to make sure that respondents are eligible to participate in the study, where all caregivers are responsible for closely looking after Alzheimer patients at different stages

RESULTS

The first symptom triggered Patient for medical consultation



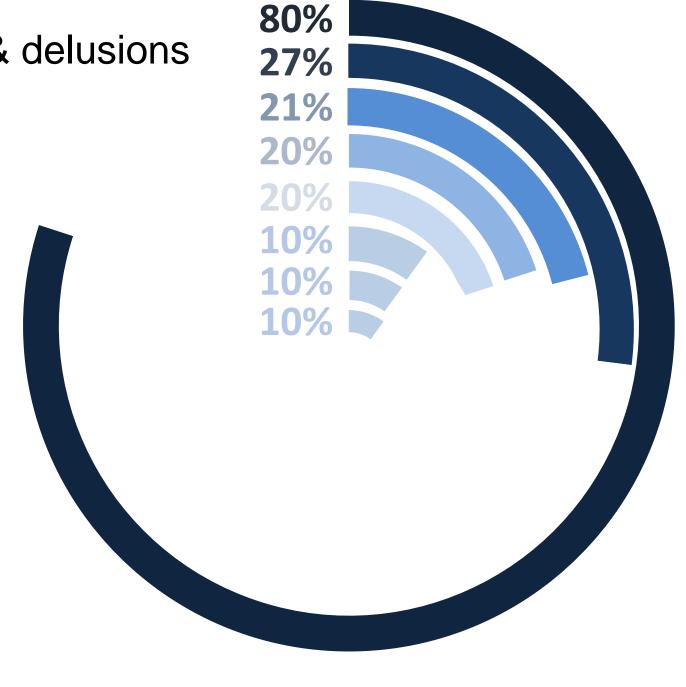
Irresponsible actions

Depression

Not knowing or distinguishing the days

Forgetting the way to home

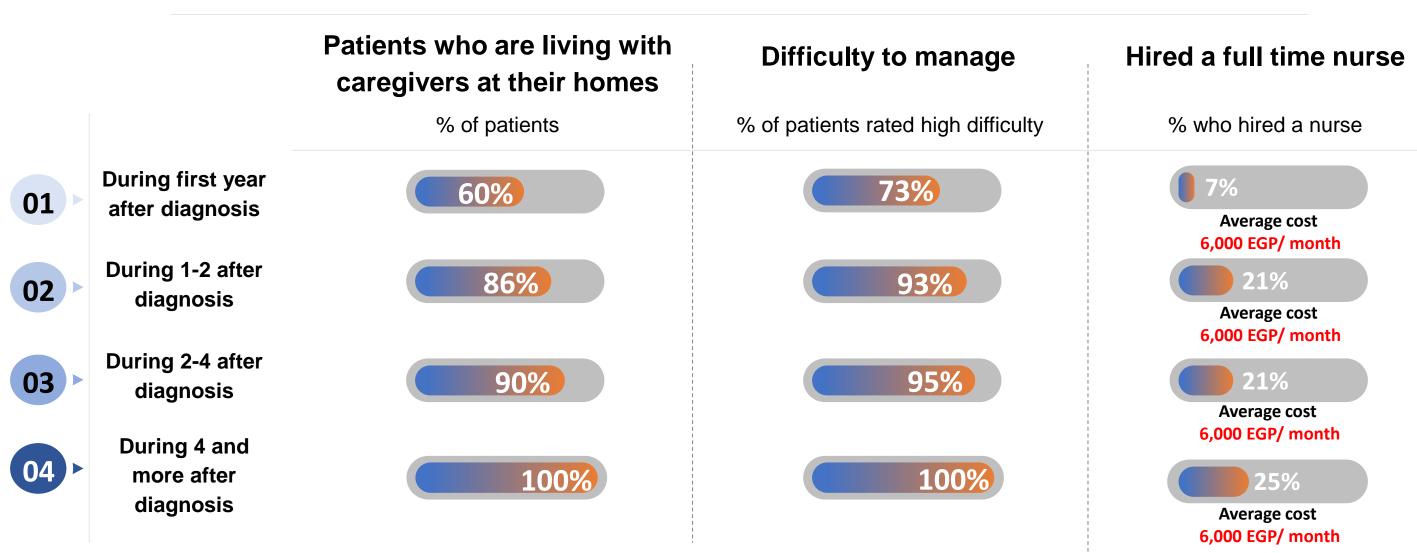
Amnesia (loss of memories, information, people, etc.) is the key trigger symptoms for Alzheimer patient to consult an HCP for 80% out of total interviewed caregivers.



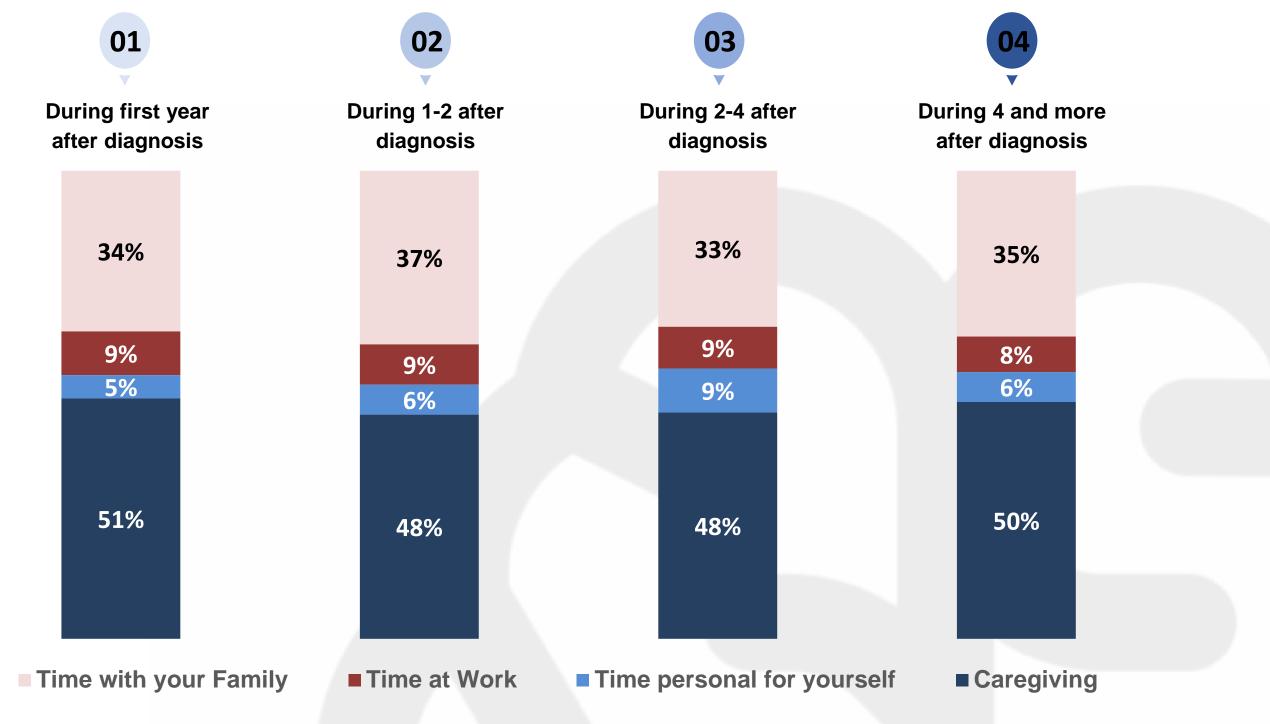
Although, 90% of Caregivers are at working age

Only 20% are currently employed as caregiving consumes a lot of time from their daily activities.

Majority of caregivers are females (87%), where most of them are patients' daughter (47% out of total caregivers) and daughter in law (20% out of total caregivers). 93% are married.



Caregiving tasks reach to occupy 50% of caregiver's time across different years after diagnosis with Alzheimer, decreasing the dedicated time for work, family or even personal time



CONCLUSION

Besides patients' deteriorated quality of life, Alzheimer's imposes a significant societal burden on their caregivers who are a fundamental stakeholder in the disease management. This study explored different ideas to facilitate caregiver's daily life like training on how to deal with the patient, night care service and rehabilitations centers beside addressing the psychological aspect of caregiver through support groups either physically or virtually. The study also showed a need for better healthcare proposed solutions by healthcare systems to ease the burden on Caregivers for better care of Alzheimer's patients.