

Dementia Care

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ABSTRACT

This report describes the research method tailored for people who take care of people with Dementia. It also talks about how Globalisation has affected our Health Care system, and how everyone can get affected by it. This project includes research insights from interviews with various caretaker from the Alzheimer's Society, UK from both Swansea and London, and focuses on trying to achieve an effective way to help people supporting initial stages of Dementia without interfering the patient's everyday routine.

INTRODUCTION

Over population is common in this 21st century, while there are increasing digital-driven health care solutions and cures, there is also no increase in new diseases being identified. Dementia is rather common these days among older people, though there is currently no cure to Dementia as such, Researchers have aimed to find cures for dementia causing diseases like Alzheimer's disease and vascular dementia. It is syndrome during which there's deterioration of memory, thinking, behaviour and therefore the ability to perform everyday activities. Rise in deaths due to dementia rises each and every year. Reports by The Office for National

Statistics (ONS) show that a total of 67,641 deaths were attributed to dementia and Alzheimer's in the year 2017 - up from 62,948 the year before. With people living longer and surviving other illnesses, the number developing dementia and Alzheimer's disease is increasing. This being the case only for The United Kingdom, Worldwide, there are around 50 million people who suffer from dementia and every year it increasingly adds 10 million new cases. There are a wide range of dementia care centres, hospitals and particularly in this digital-driven generation there are lots of mobile based and web based applications to support and create awareness about Dementia.

Helping someone with Dementia could be an emotional rollercoaster where you juggle between having them live their daily routines and fear of any danger that could possibly arise. In the early stages of dementia, many of us are ready to enjoy life within the same way as before their diagnosis. But as symptoms worsen, the person may feel anxious, stressed and scared at not having the ability to recollect things, follow conversations or concentrate. It's important to support the person to maintain skills, abilities and a lively social life. This can also help how they feel about themselves. Common practises followed today can include helping them with everyday tasks and not interfere with their everyday routine and make

them feel dependent. Studies show that when a person who is diagnosed with Dementia, they do not respond well when they are being treated as a patient. As a person who has spent their whole life working and taking care of their loved ones, they tend to get affected when they become dependent on others. Our goal here is to help them lead a normal life without interfering in their daily routine. Sometimes, memory aids used around the home can help the person remember where things are. For example, we could put labels and signs on cupboards, drawers and doors. The way your house is designed and laid out can have an enormous impact on someone with dementia. Symptoms of amnesia, confusion and difficulty learning new things means someone with dementia may forget where they're, where things are and the way things work. There are few cases where their compulsive nature affects the household and the people. For example, when a person has always been someone who keeps things safe, they tend to take things which are kept near them and hide them for safekeeping and takes a turn for the worse when they lose memory of the safe place.

There are many different technologies that can help you in your everyday life. This includes assistive technology designed to assist with problems associated with dementia also as general technology which will be useful, like apps for smartphones and tablet devices. There are applications to help with memory problems and daily activities, keeping safe, socialising and doing things that they enjoy and safer walking.

GLOBALISATION AND HEALTH

According to an article by Nils Dauilaire, MD, MPH on 'Globalisation and health', globalisation is the flow of information, goods, capital and people across political and geographical boundaries.¹ Globalisation has had both positive and negative impact on this world. It has also ensured the socio-economic difference in spite of the notion that all populations deserve good health care and support. In many ways, global transportation and communication has helped control global health crisis and epidemics saving millions of people, but at the same time, this example also provides a negative viewpoint, due to the rapid spread of communication and access to population across borders, the spread is not contained within an area, but has a threat of exposure to all over the world, especially the Poor, who majorly does not receive any awareness about a Bio threat. In the article mentioned above, Nils Dauilaire wrote, "Today, no microbe in the world is more than 24 hours away from the gateways of every industrialised country, and what incubates today in the tropical rain forest can emerge tomorrow in a temperate suburb."

According to Richard G A Feachem, author of Globalisation is Good for your health, Mostly, argues that Globalisation has mostly had a positive effect on the health, especially for the population in a developing country. He states that "Globalisation, economic growth, and improvements in health go hand in hand. Economic growth is good for the incomes of the poor, and what is good for the incomes of the poor is good for the health of the poor." He also concurred that the gross national per capita correlates strongly with the national health status, thus openness to trade improves national health status.²

The World Health Organisation also focusses on Globalisation and its impact on health care. Though their primary focus lies of assessing acting on cross-border risks to public health security. They concurred that domestic action alone will not be sufficient to ensure health locally but also trying to take collective actions to address health risks such a cross-border risks and how to improve health outcomes significantly. ³

We are currently living in a major transition in terms of health populations. There have been an overall broad gains in life expectancy and the fertility rates are declining rapidly as well. Major causes of death and diseases is changing rapidly and the infectious diseases which are much more common than expected has a tendency to change or alter rapidly. This is formed by the opportunity produced by rising toll of population and the rise of antimicrobial resistance. Future health care depends on the change in global environment and the substantial effect of rising globalisation.

Globalisation though has its fruitful impact where, the advanced economic growth and technological advances has helped in enhancing the health and life expectancy but contradicting this, it also poses a jeopardy when it helps in the erosion of social and environmental conditions also supporting the global division of labour and rising the poor-rich gap between and within many countries accelerating the spread of consumerism. ⁴

Though only the poor, unhealthy and more prone to diseases, cannot only be targeted when it comes to migrating from the developed world, leading to more infections and threat to the safe environment. The richer population also proposes a threat with its consumer goods

such as tobacco and fast food products, while looking at the economic sector of this globalisation process, it affects the foreign direct investments and debt burdens.

Globalisation also poses the question of patients choosing their medical examiner. The migration of health professionals from poorer countries often benefit the people in the high-income societies/ countries, but this also poses the threat of population increase in a certain area. The rise of medical advances also brings out the question that new diseases and infections can be spread quicker and finding the right cure and giving it to the people across the world, can become a threat. While even if there are many cures and medications available for almost all diseases, they are often afforded only by the high-income societies. This brings us to the situation where, unless the disease is a widespread epidemic leading to thousands or millions death, healthcare does not come cheap and not everyone can afford it. This can be backed up by the example of the recent epidemics like the Nipah virus or the Corona Virus, where health care aid was provided and sponsored by the government to the victims from low socio-economic society, in order to prevent it from spreading much farther.

ASSISTIVE TECHNOLOGY

Assistive technology refers to devices or systems that help maintain or improve a person's ability to try to to things in lifestyle . These can assist with a variety of difficulties, including problems with memory and mobility. Assistive technology ranges widely from items like electronic pill boxes (that remind you to require medication) to 'smart home' systems (that you'll instruct to show up the heating or switch off the lights). There is also a lot of new technology on smartphones and tablets, which

includes applications that have been developed for general use, as well as applications specifically developed for people with dementia or other health care needs. Over time the applications for general use may replace some products that were originally developed for people with dementia. For example, electronic medication alarms could be replaced by smartphone calendar apps. You can use technology during a sort of ways, like helping with everyday tasks and activities, improving your safety and monitoring your health.

RESEARCH

Everyone must feel safe and ready to live independently in their house . This may be especially true if you live on your own. While assistive technology is useful for reducing risks, it'll never make an environment completely risk-free. Technology that supports you to feel safe can be a great help and an important part of living well with dementia. There are lots of existing products which help with everyday living, which includes:

Automatic lights, that come on once they sense movement, and explode again when the space has been empty for a group time. These are often very useful if you rise up in the dark , for instance , because the light will come on automatically without you having to seek out the switch. You can also set how long they stay for;

Automated shut-off devices that can stop the gas supply or turn off a cooker if the gas has been left on;

Water isolation devices that can turn off a tap if it's left running, to prevent flooding. Some

people usually tend to keep themselves hygienic and that includes using lots and lots of water. While this may help them clean and hygienic, it almost never helps in sustainable water consumption, they tend to ignore the other aspects in order to complete their tasks; **Special plugs** that allow you to choose a certain water depth in a sink or bath. If the water goes above that level, the plug opens and the water drains. They can also include a heat sensor that changes the colour of the plug when it gets too hot. This can help prevent both floods and burns;

Fall sensors that can register if a person has fallen. These can also be linked to Telecare devices which can raise an alarm;

Telecare Systems are another way to help you stay safe. If you set up one of these systems, it can alert nominated family or friends in certain situations and will also allow you to access support if you need to. This can also prove to be an effective solution during the first few stages of Dementia where the patient tends to do their everyday routine without being disturbed by their peers or family. Telecare systems can include community alarms, sensors and movement detectors, and video calling. An alarm can be linked to a certain person or a call centre or a community centre with a hotline to help people in need. With technology being progressive in the past century, there are many measures to contact SOS or emergency contacts from our mobile phones, for example, when an accident takes place, people usually check the victims' phones or their identity cards to contact their friends or family after they call emergency services. While this is the case for any accidents for every age, the products to help people with Dementia can be more advanced and this

project aims to design a safe and an advanced telecare system to help people in need. These systems makes sure that their peers will be alerted either when a sensor detects a problem or when the person themselves presses a panic button or community alarm. The aim of these systems is to allow you to live independently and comfortably, knowing that your family or friends will be alerted if you have a problem. You can also set up a system to assist you to do things, for example, phoning you when it's time to take medication or having a virtual assistant to remind you in times of unfavourable circumstances. Telecare systems often need a telephone line or the internet to operate. However some use mobile data in the same way that mobile phones do. You can get more information on what is available in your local area from social services or your local independent living centre, or by searching online.

There are different types of telecare and it can be used for a range of situations:

Community alarm are wearable alarms that you can press if you become worried about your safety, for instance if you were to fall and be unable to reach the telephone;

Monitored medication reminders are similar to automatic pill dispensers but are linked to a call centre. If your medication isn't taken at a set time, an alert is raised and you'll be phoned with a short reminder;

Floods sensors can be fitted on skirting boards or floors in the kitchen or bathroom. If taps have been left running and cause a flood, the system will shut off the water and raise the alarm;

Extreme temperature sensors will send a warning if the temperature is very low, very high or changes suddenly. This can be especially useful in the kitchen where it can help prevent a fire or contact the emergency services if there is one. It can also detect if the temperature in a room is low enough for there to be a risk of hypothermia;

Bed or chair absence sensors can be put on your bed or chair so that if you get up and don't return by a certain time, or don't get up in the morning, an alarm is raised;

Getting up in the night – sensors by the bed can activate an alarm when you get up in the night – for example, to alert someone to help you get to the bathroom.

Door sensors can let your family or friends know if the front door is opened – for example during the night, or if you were due to be out until a certain time but haven't returned.

While some of these technologies might be extreme cases, it also helps in protecting the patients. Independent lives are the key to live peaceful. Sometimes, in order to protect them, we take away their individuality which leads to aggressive behaviours and quickly worsens the case of Dementia.

The KITE project design work examined the potential for designing a digital intervention to promote safe walking for people with dementia i.e. walking outdoors unaccompanied by a caregiver with minimal risk of becoming lost or experiences of anxiety. Being able to walk safely has many benefits including reduced reliance upon caregivers, exercise and helping to promote a sense of personhood. However,

safe walking activity is threatened by wandering behaviour. Wandering behaviour is difficult to define but can generally be characterised as occasions when a person with dementia walks somewhere but is not motivated by a specific goal, or is motivated by one that is not rational. A precise definition of wandering is problematic because it has to take into account a wide variety of causes and resultant behaviours ranging from rational movement in the service of non-rational goals, to non-rational movement in pursuit of rational goals.

DEMENTIA CARE IN INDIA

Dementia care in India is not as well versed as other countries. The population mostly are not aware that dementia can not be cured. And some of them are not aware of the disease in itself, but end up thinking memory loss happens with age. Dementia is mostly associated with a lot of superstitions. It includes stories like, “madness in elderly” and it happens with everyone, or its associated with normal ageing. Medicines are always a short term relief, they do not help in recovering in the long term. It’s very common that, once a patient is suffering with dementia, there’s no going back. No medicine can slow down with time, that is, no medicine can reduce or slow down brain damage. With increase in time, the patients become more and more dependent and it’s important that the family understands Dementia.

Not everyone understands the seriousness of dementia, nor do they understand how we can take care of dementia patients. It’s crucial that every family understands this and helps the patient through the last phase of their life. The

basic need of spreading awareness by health organisations and media around India.

The caregivers are often someone who has to lose a lot in order to take care of their loved ones. Due to lack of support in health care facilities and system in India, especially with minimum awareness in Dementia care, family members have to in turn take care of the patients, this ends up taking up lots of time and effort. This could then lead to family members, admitting the dementia patients in old age homes or dementia care facilities. But then, not all old age homes have enough security or manpower to take care of people with dementia who are in turn very dependant. It is a relatively unique situation in India with the family and extended family set up of supporting the people with dementia and also for many generations to live in the same house at the same time including children less than 16 years of age. Though this provides supportive care to the elderly, it also affects the carer with burden and affects the economy due to lack of income generation by that family member. Old age homes usually take in people due to various reasons. Some elders are stranded from their family due to personal issues, and some become estranged due to medical reasons. There are also multiple instances where persons with dementia are left in old-age homes which have very little infrastructure for caring for these patients and their children do not even attend the last rites. Older people with dementia in India cannot be viewed as a separate group in society and many a times the patient's and caregivers needs are unmet, which results in the psychological strain and economic disadvantage which in turn will have a negative impact on all family members leading to impoverishment and educational disadvantage.

The services provided for dementia care in India is quite fragmented and patchy depending of the geographical areas in addition to rural or urban locations. The Alzheimer's and Related disorder Society in India (ARDSI), along with other social governmental and non-governmental organisations produced a list of services available to support people with dementia. The minor number of resources in India could be seen when the facilities and services available for people with dementia are analysed. In a country of growing elderly population and straining socio-economic condition there are 6 Residential care facilities (respite facility, family support); 10 day care centres (medical attention and supervision); 6 domiciliary care services (advice and tips for caring families); 100 memory clinics (provide assessment, support, information and advice) and 10 dementia help lines.

Due to the increased level of responsibility and fear of losing their loved ones, some people can be extra cautious and ruin the patients everyday routine, which intern takes a turn for the worse. When you end up being more controlling, and having things play according to other people's schedules, it damages the patient psychologically. With the number of working women on the rise, particularly in urban areas, and breaking down of the traditional joint family system, caregivers are being stretched to their limits. Behavioural and psychological symptoms of Dementia and lack of self-restraint are the main sources of caregiver strain which is further exacerbated by lack of support by local health agencies and other family members. India has been a country predominantly of youth population, but its population is ageing rapidly. Governments are still grappling with issues of maternal and child health and immunisation, whereas

geriatric health care is in dire need for more resources. The percentage of the elderly was 8% of the total population in 2015 and is likely to be 19% by the end of 2050. Around one-fifth of the elderly are living alone or only with their spouses and they have to manage their activities of daily living alone. The ratio of working persons to dependents has increased to 100 from 15, and there is a huge variation state wise. The Dementia India Report estimated that 3.7 million people were affected by dementia in the year 2010 itself.

RESEARCH METHODOLOGY

Initial research work involved setting up interviews with the Alzheimer's society, UK including both patients and caregivers. The aim of the interviews was to understand the problems faced by them. The initial step to this primary research was to identify problems and the difficulties and methods used by health care professionals around the country.

This research focuses on trying to understand how we can help solve wandering and other issues occurred due to dementia. It also discusses products which help people with Dementia, and ideate into a more advanced, user- centric product. Research techniques were used to generate large amounts of raw data from the primary research and dig into secondary research. Secondary research concluded that, in fact there are many existing products to help with dementia wandering.

Wandering, in people with dementia, is a common behaviour that can cause great risk for the person, and is often the major priority for caregivers. It is estimated to be the most common form of disruption from people with dementia within institutions. Although it occurs

in several types of dementia, wandering is especially common in people with Alzheimer's disease. This can be due to forgetfulness, and also to a frequent need for stimulation.

Wandering also leads to a behaviour known as **Elopement**. Any changes in routine can trigger wandering. Disaster scenarios are an example of a drastic change in routine that can lead to wandering and other catastrophic reactions. The overstimulation of activities, individuals and/or noise such as thunder and other stimuli such as lightning can trigger wandering behaviour.

There are various ideas that could be used as a solution scope for Dementia, like a GPS based device which helps prevent wandering. Device which enables discretion and reliability without tampering the freedom of the patient. GPS tracking watches might be the go-to solution but they have their own downfall. Though smartwatches are liked by many people, it might not always be a hit with the elderly, especially in the Indian context, where they prefer 'Old school' watches. One of the wandering technology includes GPS insole tracking, which alerts the caregivers with location details, while this tops the scope with discretion and location tracking, it does not help in emergency aid and preventing accidents. These wandering technologies uses 'Geozone' technology, where one can easily and precisely draw out areas on the integrated Google maps where the individual would be safe within, meaning you'll only be notified via text or email when they leave a certain area e.g. their home or garden, street or village. This technology can also help us narrow some danger zones like busy roads, lake or railway crossings, and notify the caregiver about the unfavourable circumstance.

The KITE project's design approach engages people with dementia in participatory design. Specifically, the process aims to foster an empathic relationship between designers and people with dementia by demanding close, respectful contact. The approach focuses on trying to develop a holistic understanding of people with dementia's day-to-day lives and acknowledges that there is likely to be a wide gulf between designers' and people with dementia's life experiences. To address this, the initial stages of the process included participant's accounts of experiences relevant to the issue and allow a shared understanding of the issue to develop connection and a level of understanding the process. This design approach works with individuals to produce personally tailored prototypes or in this case, research insights that reduce the need for abstract thinking (which can be challenging for people with dementia) and allow an in- depth exploration of individual's thoughts and experiences.

The main tenet of the approach used in the KITE project is creating an empathic relationship between the designers, people with dementia and caregivers. Fostering a sympathetic, empathic disposition on the part of the designers will develop an environment in which people with dementia can speak openly. The attitude of the designer towards the participants is central to creating this relationship.

CONCLUSION

This paper presents my attempt to understand Dementia care, the patient's struggles, the coping of their caretakers and how they try to handle the very common issue, Wandering. It also tries to explain the different situation in two countries, India and the United Kingdom.

Globally, there is rise in the population of the elderly people with the generation of baby boomers having entered the age of 60 years. Old age is commonly associated with disorders such as high blood pressure and heart diseases. Along with this problem, it also leads to slowing of the brain functions. Memory lapse is the most common brain dysfunction that people notice and are aware of. However, the attribution of memory lapse to old age commonly masks the onset of a disease called dementia. Globally, India houses the second most number of individuals suffering from dementia with an estimated 4.1 million people suffering from it as per the 'Dementia India' report published by the Alzheimer's and Related Disorders Society of India. This is expected to double by 2035. Maharashtra and Uttar Pradesh alone are expected to house more than 5,00,000 patients by 2026. The research concludes that expensive medical treatments and facilities cannot alone save them from having a difficult time. Personal care and attention by caregivers without affecting the patient's routine and their mental peace. It also includes some devices that is used in other countries other than India, and suggests how effective each can be and how it can help the caregivers and patients have a non-stressful time.

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