Early Onset Dementia (EOD) and its Impact on Employment of Young Adults

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Abstract

Dementia is a collective term for diseases related to receding memory, recalling problem, analysis and decisive incapability with reference to remembrance. A progressing stage of Alzheimer’s disease is diagnosed as dementia, a brain functioning issue commonly described as memory loss. This happens mostly in people over 65 years of age. However, in recent times, dementia is observed in adults below the age of 65 too. Those showing signs of memory dysfunction between ages 40 and 60 are believed to have Early Onset Dementia or EOD. The major impacts of EOD are seen in their work-life balance, social and professional stigma, loss of employment and difficulty in getting new employment. This research focuses on the reasons of EOD, how it affects the lives of the adults suffering through it in middle age and how it can be properly diagnosed and treated. For this objective, the research surveys and analyses different social reports, statistical studies and medical factors; also, the research performs a real-life quantitative survey on a population 100 individuals suffering from EOD, and records their responses regarding effect on employment, personal life and overall life skills, due to dementia.

Introduction

What is dementia?

Dementia is an umbrella term for group of brain disorders that impacts a person’s memory, his ability to communicate, understand, learn, analyze and take decision on a particular subject. This badly hampers his work productivity and consequentially not only tampers his reputation but also affects the goodwill of the company he is working for. As a result, organizations cannot afford to support and sustain employees with signs of dementia. Dementia usually occurs in people after the age of 65. Organizations do have workers of this age due to lack of mandatory retirement age, especially in countries like Canada and USA. But, surprisingly, in recent years, probability of dementia is seen increasing among younger population too, those between the ages 40 and 60. Middle-aged individuals having a proactive professional life are drastically suffering when signs of Early onset dementia are found in their behavior [1-5].

What causes young onset dementia?

The common causes of EOD are same as those progressive diseases which cause dementia in older people, but the symptoms can be varied. It is said that Early onset dementia progresses more rapidly in younger adults than it does in older men, though the evidences are not conclusive. Dementia develops when proteins build up in the brain to form structures called ‘plaques’ and ‘tangles’. In some cases, the inheritance of this disease is purely genetic, which gets passed on through generations. This genetic form of dementia – familial Alzheimer’s disease – is caused by rare mutations (defects) in three genes. These mutations are found in between 7 and 12% of all people with young-onset Alzheimer’s. The familial Alzheimer’s disease can affect a person between his 30s or 40s or 50s. But this kind is very rare and affects about 500 families in the whole world which is less than 1% of cases suffering from Alzheimer’s disease, dementia and early onset dementia.

People with Down’s syndrome and other learning disabilities are more prone to Alzheimer’s or dementia. The extra copy of chromosome 21 present in patients with Down’s syndrome is believed to be the responsible factor triggering dementia in such individuals. Chromosome 21 carries the gene for amyloid which forms the plaques in Alzheimer’s disease. Vascular dementia occurs when flow of blood to the brain is hindered due to certain
cardiovascular problems, diabetes, stroke or heart disease. Around 15% of people get affected with this form in different age groups [6-10].

Frontotemporal dementia is caused by damage to the lobes at the front and/or sides of the brain. Around 10 to 15% of younger people with dementia may have this form – much higher than in older people.

About 5% of the younger population suffer from dementia caused due to formation of unique proteins in the brain called Lewy bodies. Parkinson's generally develop from this form of dementia. Brain damage due to alcohol related issues can cause dementia in younger crowds. There can be many other factors which lead to memory problems for younger people like liver and intestinal problems. Some can be caused from digestive disorders like Gaucher’s disease, Tay Sach’s disease and Niemann-Pick’s disease. These develop more often in childhood or adolescence and so their development in someone's 30s or 40s is much later than usual. Younger people may be affected with dementia due to hormonal disorders, inflammatory situations in body, lack of certain vitamins or even HIV issues.

Memory problems can also be caused by sleep apnea, where breathing stops for a few seconds or minutes during sleep.

The risks of having employees with dementia in an organization are numerous.

- It compromises with the productivity, increases absenteeism, puts the safety of the employee, his colleagues and customers at risk.
- Dementia at workplace create interpersonal tension; divide the workforce, create stigma, biases and pollute a healthy work culture.
- Employees with dementia can affect customer relations. It impairs on-time delivery of products and services to the customer, also impacts customer trust and loyalty.
- Brand name and value is compromised with when co-workers lose trust and confidence on each other.
- Reduces profit of the organization as more expenditure has to be borne for training employees and resources. Customer loses confidence on product when worker isn't mentally perfect. Badly impacts credibility of products.
- On personal level for an employee, working with dementia gives a sense of worthlessness, being left out, being judged and overall the negative feelings reflect in his output.

**Literature Review**

The Alzheimer’s Society of Canada describes Dementia “as an overall term for a set of symptoms caused by disorders affecting the brain. Symptoms may include memory loss and difficulties with thinking, problem-solving, or language. It is usually, but not always, gradual, progressive, and incurable.” (Workplace Strategies for mental health, 2019). 747,000 Canadians were living with a cognitive impairment, including dementia. Up to 10 percent of all cases of dementia start before the age of 65. (Alzheimer’s Society of Canada, 2011). The World Health Organization, in their article, Dementia: A public Health priority reports, “the risk for dementia doubles every five years after age 65. With the absence of mandatory retirement, it is likely that workplaces will see an increase in employees who have dementia. This is a workplace issue because some employees may struggle to cope with this disease while still trying to perform their work duties. This can especially be an issue for employees who don’t understand or remember they have this disease (WHO, 2012).”

“New data from the Health and Retirement Study (HRS), a large, nationally representative survey, indicate that in 2000, 480,000 Americans age 55-64 had cognitive impairment at a level severe enough to be considered disabling. The HRS data do not specify the causes of disabling cognitive impairment, and it is not clear how many of these people had Alzheimer’s disease or other dementias” (Katie Maslow, Alzheimer’s Association, Washington DC). However, a mixed opinion on employment and employability of patients with dementia, is expressed through a research titled Job Loss After Diagnosis of Early-Onset Dementia: A Matched Cohort Study, which says, “The higher job loss rate among patients with EOD might be attributed to both inevitable and preventable factors. Past studies have shown that some patients are dismissed due to their impaired performance, whereas others impulsively left their jobs because of the shock caused by the diagnosis. Patients with EOD who cannot continue working because of their advancing symptoms might seek a substitute activity to help improve their quality of life. On the other hand, a prior study showed that more than half of patients with EOD were still in the mild stage of dementia shortly after their diagnosis, which means that some patients retain the ability to work, provided that their employers accommodate them.” (Journal of Alzheimer’s disease, 2017). “Over half a million Canadians are living with dementia, including Alzheimer’s disease, today; this figure will reach 1.1 million by 2038” (Rising Tide: The Impact of Dementia on Canadian Society, Alzheimer Society of Canada, 2010) [11-15].

**Research method**

With increase on ageing workforce in many developed countries, the risk of having employees with dementia is increasing, which as a result, is reducing employability of population, because Early Onset Dementia is being found in many younger adults. But it is necessary to understand here, whether at all, the symptoms of Early dementia can affect a person’s job, reduce his employability, and if so, then how. Only when we can understand the cause and effect with actual numbers, then can we look at approaches to solving the situation. We performed a survey over 100 individuals working for 35 large organizations, who were detected with major and minor signs of dementia or forgetfulness. To understand the impact of the disease on their regular functioning, work life and job, we recorded their responses. The sample population was divided
into groups of 25, 30, 20 and 10, based on their ages. This helped us to understand which age group is more prone to Early onset dementia. 15 out of 100 lost their jobs. Their age, employability and health impact on work were recorded separately (Table 1 & 2).

Table 1:

| Group | Age       | Employment Status | Impact on work due to Dementia                                                                 | Status of diagnosis                        |
|-------|-----------|-------------------|------------------------------------------------------------------------------------------------|--------------------------------------------|
| 25    | 42-55 years | Employed          | Forgetfulness affects day to day delivery, inability to recall information details. Inability to produce details during group communication and meetings | Not diagnosed/never consulted a specialist |
| 30    | 38-51 years | Employed          | Minor forgetfulness; not recalling names, addresses etc. Forgetting deadlines. Disruptive customer communication due to frequent forgetting of information. | Not Diagnosed                              |
| 20    | 52-65 years | Employed with restrictions | Major forgetful issues; inability to recover files and important document due to forgetting their storage location. Incoherent speech structure producing irrelevant information in customer meets. Lack of assessment of serious issues. | Under therapy                              |
| 10    | 58-71 years | Soon to retire     | Forgets sometimes, lesser workload hence lesser complication | Under therapy                              |

Table 2: The 15 people in the sample who lost their jobs were surveyed separately.

| Sample | Age | Loss of employability reason | Diagnosis status |
|--------|-----|------------------------------|------------------|
| 1      | 41  | Worked on database, hence regular mistakes in updating and storing data, inability to recall data | Under treatment |
| 2      | 39  | Lack of concentration       | Not diagnosed    |
| 3      | 54  | Work culture ragging        | Under treatment  |
| 4      | 48  | Resignation due to lack of confidence | Under treatment |
| 5      | 61  | Losing control on thoughts  | Under treatment  |
| 6      | 59  | Lost hard copies frequently | Not treated      |
| 7      | 43  | Major forgetfulness and analysis issues | Not diagnosed    |
| 8      | 55  | Feeling of worthlessness    | Under diagnosis  |
| 9      | 60  | Work culture ragging        | Under diagnosis  |
| 10     | 46  | Damage customer relation    | Under diagnosis  |
| 11     | 57  | Work culture ragging        | Under treatment  |
| 12     | 60  | Major forgetfulness and heavy workload, stress | Under treatment |
| 13     | 53  | Lack of confidence          | Under treatment  |
| 14     | 65  | Brain tired                 | Not treated      |
| 15     | 44  | Forgetfulness               | Under treatment  |

Result

In the first table it is safe to say that at least 55 out of 85 suffered from Early onset dementia, which is 64.705% of the total. Those suffering from dementia at a younger age have lesser or manageable impact on work, but their forgetfulness tend to be frequent and fast progressing as we see for the second group. Also, a major problem with employed patients with dementia is that, they fear being officially diagnosed with the disease, the reason can be social stigma, fear of losing employment, hence we find that people in age groups 38 to 55 years stay away from doctors and never get their disease diagnosed. The remaining groups who are higher in age, understand their brain disorders and agree for treatment while nearing retirement.

From the second table we find that 6 out of 15 are unemployed due to non-cooperation from co-workers or lack of self-worth, i.e. 40% of the total have lost their jobs due to negative social factors prevalent in an organization.

When we compare both tables, it is evident that people between age groups 40-60 are engaged in business positions where they are involved in customer communications, and employees with dementia in these positions are not good for customer relations, customer trust and loyalty. 15 out of 100 people lost their job due to dementia which is 15% of the total, not a less number.

Limitations

In this study, it should be noted that we have selected the sample from 35 large organizations who may have funds and resources for training, support and upliftment of such special employees struggling with dementia, and keeping them employed while counselling them, still identifying their strengths and weaknesses. Perhaps that is the reason why so many with dementia remain employed here, with some social and medical support, while for medium and smaller enterprises, a major part of data is missed out, so we are unaware of the bigger picture. Also, the reasons given...
by the individuals may have their personal conflicts and biases forming the responses.

Conclusion

Early Onset Dementia can be a serious problem in the lives of middle-aged adults as it can destroy their work functioning and reduce their employability when they are still in their proactive age. Dementia in workplace can dissolve the reputation of the individual, at the same time, reduce productivity and profit of the firm, tamper brand value and credibility of the organization. It can also promote negative work culture which on personal grounds, affect the individual deeply. Employees losing job due to dementia are unlikely to find another job soon, because of their fallen confidence and their persistent disease.

• It is important to create awareness among people regarding the subject, its causes and effects.
• It is imperative that co-workers in workplaces co-operate with such employees struggling with the disorder.
• Organizations should have reserves and tools to support employees suffering from forgetfulness.
• Individuals themselves should acknowledge the problem and go for immediate diagnosis, after getting a few symptoms, before condition gets worse.

Acknowledgement

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Conflict of Interest

No conflict of interest.

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