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RESEARCH ARTICLE

REVIEW ON DEMENTIA: A PLEOMORPHIC ICEBERG

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ABSTRACT

Population ageing, urbanization and migration are our time's greatest demographic definers. In the global background of ascending life expectancy, around 10 to 20% of geriatric population experiences mild cognitive impairment. The worldwide incidence is about 10 million, which rationales to one new case every 3 seconds. This unprecedented wave would endanger 82 million by 2030 and 152 million by 2050 (WHO - Global Dementia Observatory). The onus of enhancing cognitive reserve is borne by, one and all of us. With increasing age and lesser involuntary cognitive exercises we undergo day after day, be it from learning routes to GPS or from memorizing numbers to speed dials, the peril of sliding along the slippery slope of degenerative darkness looms at us, silently galloping behind veils of our sedentary, stressful, under stimulating choices in life. This article is a review on the current conditions surrounding dementia, from a public health risk perspective.

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INTRODUCTION

Population ageing, urbanization and migration are our time's greatest demographic definers.In the global background of ascending life expectancy, around 10 to 20% of geriatric population experiences mild cognitive impairment. (World Health Organization Factsheet (WHO), 2020). The worldwide incidence is about 10 million, which rationales to one new case every 3 seconds. This unprecedented wave would endanger 82 million by 2030 and 152 million by 2050 (WHO - Global Dementia Observatory)..

Healthy Ageing: Healthy ageing, being the aspirational goal of the World Health Organization (WHO) is defined as "The process of developing and maintaining functional ability that enables older people to do what they value"(2020). A longitudinal study, in 2019, on ageing, conducted by the Director of Ageing and Life, (WHO) Dr Beard and colleagues on 2560 participants in United Kingdom, deemed five sub-factors; cognitive, loco motor, psychological, sensory and vitality components crucial for healthy ageing. Cognitive abilities, as defined by Dr Blazer, an Emeritus Professor of Psychiatry,refers to the fundamental aspect of an individual's ability to engage in activities, accomplish goals, and successfully negotiate the world.

A meta-analysis by DrPrince, Principal of Global Health - King's College, London, and his colleagues in 2017 concluded; when cognition is viewed as a snapshot across varied age range, a stark picture emerges, of steady decline, year after year, across most mental abilities including memory, problem solving, attention, and focus, whilst sparing some functions such as vocabulary and speech fluency. Contrasting evidence byDr Gonzales, and colleagues, from University of Bath after tracking individualistic cognitive trends over time; concluded that cognitive decline varies from person to person, but broadly classifying these trajectories, they follow either one of the three patterns: no change, slight decline and steep drop. However, comparing both researchers, given the lack of quantitative evidence of cognitive tracking, we are more inclined towards the steady decline of cognition model, considering the research strength of meta-analysis, the timeline between studies, and number of participants in the studies. Another similar work, by Dr Mathews, translational researcher from Newcastle University, and her colleagues, in 2012, conducted a population based longitudinal study across various centres. They tested a total of 13,004 individuals, using Mini Mental State Examination (MMSE) at baseline, 2, 6 and 10 years to examine their influence of gender, education, social class, birth cohort affect and analyse cognitive change over progressive age.

Results revealed; women showed significantly steeper decline from normality in MMSE scores as compared to men; education was directly proportional to cognitive reserve and was similar for males and females; manual work showed no improvement in cognitive scores as compared to their socially active counterparts; More recent birth cohorts demonstrated higher scores. Drawbacks were, lack of parameter quantification (example, in education, number of years the individual spend on education was not considered) and social activities involved. Analysing collaborative evidence across multiple research, we cannot dismiss varied concepts of multi staged, individual specific, declining cognitive trajectory along time. However, all studies unanimously agree on the inevitable nature of cognitive decline across time, and this by extension leads to a public health responsibility to intervene and help people move 'up' a trajectory class.

Cognitive Reserve: Cognitive Reserve (CR) is the critical lifeline that potentiates people to decouple cognitive abilities from accumulation of brain pathology which is a hallmark feature of increasing age. Reserves of cognitive function can be enhanced by voluntary and involuntary exposure to stimulatory environments throughout lifespan (Meng *et al*, 2012).For further clarity,let's compare a few prominent researches on this. Quantitative study carried out in 2015, by Dr Boots, Neuropsychiatrist from Psychiatry College of Medicine, Illinois, and her colleagues, using structural MRI, cognitive evaluation and work history assessment analysed associations of these parameters on hippocampal volume and whole brain atrophy, in 323 patients concluded; those with higher occupational complexity are able to better maintain a similar level of cognitive performance, compared with those without dementia. Furthermore, of the three occupational complexity components (data, people, and objects), complexity of work with people was significantly associated with decreased hippocampal volume and increased resilience to dementia, indicating social components of occupation have the greatest value for enhancing cognitive reserve. Another landmark study by DrAdam, researcher at memory centre, University Hospital of Leige, Belgium and colleagues in 2013 using a large database (n >25000) from Survey on Health, Ageing and Retirement in Europe (SHARE) concluded definite positive association between cognitive functioning across all domains of the brain and activities, such as “going to a social/sports club”, “taking part in a political or community-related organization”, “helping family/friends/neighbours”, and “doing charity/voluntary work”. The common feature of these activities is the notion of social interaction or affiliation in elderly people. Correlating evidence from various studies, we arrive at similar conclusions, which proved increasing social interactions, via occupational complexity or social interactions, increases cognitive reserve.

A Bird's eye-view on Dementia: A bird's eye-view of impact on enhancing cognitive reserve of population health cannot be overvalued. Considering social determinants of health, across under developed and developing nations, where sharper inequalities of health and healthcare systems are obvious, looms the 'double burden' possibility (Lk et at; 2019) - the iceberg phenomenon in dementia , and newly arising health threats which are more tangible and tends to toll heavily on overburdened healthcare systems. Secular equalizers to combat stigma, differences and uplift neglected population segments via schooling, higher education, occupational complexity patterns, health awareness, access to healthcare and other factors are the 'need of the hour' as the greatest impact of dementia burden is still submerged and this iceberg is bound to surface primarily in lower and middle-income countries (Livingston *et al*; 2020).

Addressing the Iceberg: Realizing this hiatus, nations of all stature, have globally coalesced, to arrest progression of dementia, with emphatic emphasis on middle- and low-income nations (Decadal evidence from World Dementia Summits (2010 - 2020. Case in point example is India. With a prevalence of 5.3 million affected, one in every 27 people , India singularly accounts for 10% of the total global incidence. In the absence of structured care homes, the families involved in informal care, 'often called the invisible second patients' (Dr.Henry *et al*; 2009) bear the greatest brunt and are the most vulnerable for newly developing emotional exhaustion (EE), depersonalization (DP) and reduced personal accomplishment (RPA) (Truzzi *et al*; 2012). Informal care is defined as the unpaid voluntary care extended to disabled people and families (Shaji *et al*; 2012), which forms the backbone of chronic care. Until recently, nobody considered caregiving as a public health matter (Brason *et al*; 2007). Stress, depression (Martensson *et al*; 2020), behavioural changes, mental and physical ailments, neurological disturbances and biomarkers of inflammation (David *et al*; 2020) are more profound in caregivers (Caregivers Burnout Syndrome, Truzzi *et al*;2012) as compared to non caregivers of similar age. The triadic model(Talley *et al*;2006), conceptualize caregiving as an emerging public health issue, with equal importance distributed amongst people, families and professional care providers.

Correlating to this, the bio ecological model by Bronfenbrenner, in 2004, equated these systems as exosystem, microsystem and mesosystem respectively. His macrosystem for gerontological dementia care corresponds to epidemiological trends in ageing and socio-political ideas that shapes policies and attitudes. Dynamic interactions between systems are mandatory to maximize human potential, and mitigate action focus from medical management model to one that seeks wellbeing, pleasure and quality of life of older people and families living with dementia (lliffe *et al*;2006). A qualitative study by lliffe and colleges from England, in 2006, investigated the roles of specialist and generalists regarding shared care for dementia patients. Results further emphasis much required focal shift and more resource allocation for 'shared partnership of care'. Within this framework, research urges us to mobilize focus from professional potential to prevention of distress and disability (Cantegreil *et al*; 2006). The reverse impact, would help medical professionals divert their frustration of 'inadequate cure' to interventional potential via psychosocial interventions and non pharmacological interventions that maximises quality of life (Adams *et al*; 2005) Shared partnership of care, refers to the human interactive behaviour where outcomes can be understood and utilized by all tiers of the bio ecological model(Harris *et al*; 2008).

Considering that some resources might be required for an individual and family at a particular time, and not another, thus partnership of care, ensures a limited resource distribution towards a larger population availability (Olivia *et al*; 2015). For example, in India, in view of limited health care resources and low awareness regarding dementia, more 'home based interventions' are directed towards achieving better quality of life for care givers and patients as compared to a developed nation. United Kingdom, for example,has four care models; case management, integrated care, consumer directed care and restorative care (Lee *et al*, 2015) to choose from, depending on the stage of the disease. Briefly describing the outlines of a home based approach, from a developing nation's viewpoint, a Randomized Control Trial, of 80 families, undertaken by Dr. Amit Dias and colleges from India, in 2008, by development of the "The Goa Home Care Programme". This alternate approach, involved training health workers to provide home care for dementia patients under psychiatrist supervision. They created 2 teams, each of which had 2 fulltime Home Care Advisors (HCA), a psychiatrist from the local public health sector and a shared counsellor. They underwent intensive training in key skills including stress management, bereavement, counselling, and health advice on common health problems. Home visits were every fortnightlyor more as per HCA assessment.

Trial was for 6 months, with evaluation at 3 and 6 months. Each dementia patient was seen once a month, by the psychiatrist and fortnightly reports kept him updated on their status. HCA's met with the counsellor every week to problem solve. Flexible home care model helped improve knowledge of family caregivers, emotional support, improve skills and support caregivers. Beneficial outcomes were evidenced by higher scores in all outcomes measured such as caregivers mental health score (GHQ score), perceived burden (Zarit Burden score), functional ability (EASI), distress behaviours (NPI-D) and severity of behavioural problems (NPI-S). Analysis of research quality using GRADE techniques, we agree that even though Randomized Control Trial contributes a high grade of evidence; limitations were - small sample size; questionable directness - as caregivers and patients, were from varied stages of dementia. Hence disease burden and disease progress were added variables. Another limitation was the failure to blind physicians and participants.Hence we conclude our GRADE analysis by stating that more research is needed before we can upscale this model and close treatment gap on dementia in India. Interestingly Cochrane analysis on dementiasuggests, rather than more specialized care units (Cochrane analysis, Lai *et al* 2009) it would be more significant to give personally tailored activities for people with dementia in the long term (Cochrane analysis, Mohler *et al*;2018), as more community involvement, is better than residential homes. This multi -directed approach is more embraced, as we trail along contemporary research, both for developing and developed nations, by evaluating online interventions to address issues of caregivers and patients, at a familial level. For example, Dr. Upasana and her colleges, from India in 2021, conducted a Randomized Control Trial across 155 caretakers to evaluate effectiveness of training and support program via an online platform. Results showed low recruitment and retention rate of 44.67% and 36.42& respectively. Despite this, significant outcomes were seen in caregivers who adhered to the program ($t=2.228$; $p < 0.05$). Comparing to a developed nations study along similar lines, by Emeritus Professor Dr. Debbie from Mc Gill University and her colleges in 2019, across 170 caregivers also concur on improved physical health, decreased depression and improved positive emotions ($d=58, p<0.01$).

A Salutogenic Approach to Dementia: An alternate perspective by Antonovsky, a medical sociologist who viewed the world along a continuous linear dichotomy between health and disease. Cognitive, behavioural and motivational components constitute the sense of coherence. For example, when confronted by a stressor, a strong sense of coherence would be motivated to cope; behaviour and cognitive components would seek for solutions and resources for the same. Along these lines, Dr. Golembiewski, the Director and Architect of Psychological Designhave helped create Australia's Dementia Training Centre since 2012, which has been using salutogenic approach to dementia. Valid research outcomes are awaited. On the strength of eight studies, one quantitative and seven cross sectionals (Tan *et al*, 2014) salutogenesis in dementia has mainly been restricted to residents in care homes with little or no cognitive impairment, and research on community dwellers tends to exclude large segments of cognitively impaired individuals

Patient Public Involvement in Dementia: Patient Public Involvement (PPI) is defined as research being carried out 'with; or 'by' members of the public, rather than 'about', 'to' or 'for' them (National Institute of Heath Research). Review of 20 researches, studies conducted between 2005 and 2018, recommends PPI as the quality standard for clinical trials (Miah *et al*, 2019). This review evaluates how PPI distributes its effectiveness across participants with dementia, caregivers, the research process and the research itself. Of the 20 models, 14 included involvement from patients, care givers and public, 5 included only patients and 1 involved only care givers and public. Methodology of intervention and feedback analysis showed, (Stevenson *et al*, 2019) used questionnaire to assess perspectives and benefits in being a co researcher, while another research group (Littlechild *et al*, 2015) used semi structured interviews and focus groups to assess the involvement in all stages including formulations of research questions, study designs, recruitment, data analysis and interpretation of results. They also analysed the perspectives of co-researchers, voluntary organizations and academic researchers. Another study (Morgan *et al*, 2012), used online surveys with semi structured interviews to understand the impact of volunteers who provide PPI input in research projects. Furthermore 3 studies (Flaherty *et al*, 2014; Schipper *et al*, 2014; Brown *et al*, 2013) used PPI in identifying and prioritizing research questions. The synopsis, of 20 research papers reviewed, revealed a multi tangential role of PPI. Overall PPI participants benefited from all studies, in terms of new skill and knowledge, personal development, support and friendship, better understanding of the community, financial rewards, enjoyment and satisfaction. On research platforms, they contributed towards development of drafts, activity workbooks, intervention manual, language clarity and materials used in intervention. They addressed practical issues with interventions, including prioritizing time thereby increasing participation in interventions. At a co researcher platform, PPI gave feedback that helped researchers understand reasons for non-adherence to the interventions, PPI helped in shaping research agenda, bought about improvements in research tools, awareness of support that care partners may need in carrying out the intervention, renamed interventions to appeal more participation from participants, modified consents to a language that can be understood by participants. Their greatest contribution of PPI was clinically significant positive changes during non-pharmacological interventional methods (Cochrane; Dementia and Cognitive Improvement guidelines) for patients with dementia. As there is no treatment for dementia to date, this interventional methodology has the greatest impact on patients with dementia.

PPI with Asset Based Community Development: PPI incorporating Asset Based Approaches, is defined as the paradigm shift of perspectives from deficit and disease burden to societal contribution and inclusion, along with mitigation of stigma, prejudice and discrimination (Swaffer *et al*, 2014) With insufficient research data from Indian studies, we analyse an Indian Non Government Organization model, Aarohi , with global partnerships and accreditations . On the Himalayan foothills, in 1992, Aarohi began with a vision of holistic development towards self reliant mountainous communities. Tangents of Health, Education, Livelihood Pursuits (HELP) expanded their outreach from 150 people in 1992, to 66,128 people in 2020 (Annual report 2020). Employing innovative strategies such Vocal for Local - Community skill development program; Mobile Medical Unit (supported by Swiss Himalayan Amity), to provide uninterrupted healthcare services in remote mountain areas; Uttarayan - a rural culture, cuisine and heritage show across the world, by the students of AArohi; Mother Child Health (MCH) across inaccessible areas that lack policy advocacy at state level; The Hans Foundation funded development of contextualized learning material using natural resource management methodology; Capture! Develop! - restoration initiative by students; Science on Display; Santa Claus in town; are just a few interventions to attain Sustainable Development Goals (SDGs) by 2030. Their annual reports, national level policy implementations and global accreditations are a testament to their success in Asset Based Approaches.

Alternative Approach in dementia - Theory to practice: Amalgamation of Asset Based Approaches (For example Aarohi model) with evidence based pre clinical extension of dementia(Rakesh *et al*, 2017) via antidepressants(Sheline *et al*, 2014), exercise (Morgan *et al*, 2012; De Bruijn *et al*, 2013), immuno modulators(Salloway *et al*, 2014), meditation (Quach *et al*, 2016), Mediterranean diet (Canevelli *et al*, 2016; Hardman et, 2016), lowering psychological stress (Peavy *et al*, 2012), cognitive retraining (Cheng *et al*, 2016), assisted animal therapy (Cochrane analysis, lai *et al*;2019) and others (Bruce *et al*, 2014).Additionally policy changes, across all dementia summits, were abolishing mandated cognitive limitations, obstacles for volunteerism, counteracting social isolations, old age loneliness, alongside igniting cognitive sparks via support for lifelong learning, plans of retirement for the brain before the physical retirement, so as to partake in development of hobbies with significant conversion ratio into societal development. These capacity buildings, when employed by the vast majority of people within and across groups of a community, are the stepping stones of sustainability, and as we multiply such intercalated programs, across various tiers of bio ecological framework we escalate our societies, towards social enterprise and propel us towards manifesting our utopian dream.

Public health in the 21st century: Public health, the quintessential yardstick that translates and transfers scientific advancements till the last societal mile, underwent seismic shifts from medicine led approaches to community participation, precipitated by enhanced collaborations between research initiatives and public health partnerships.For example, the Human Brain Initiative (HBI) and local public health partnership have identified 25 actions that will be implemented in the communities between 2018-2023 (Benjamin *et al*, 2020). Caregiving, as well, have transformed from short term in the 19th century, prolonged in 20th century, and in 21st century, we have more people with chronic disabling conditions than ever before, who needs care cover for longer periods of time. Hence additional frameworks for caregiving must be moulded such that individuals and organization can fully explore and exploit resources, needed to address their functional undertaking competently.

Conclusion

As specific treatment for dementia remains elusive, evidence based anti-dementia strategies,are our best steps forward. The onus of enhancing cognitive reserve is borne by, one and all of us. With increasing age and lesser involuntary cognitive exercises we undergo day after day, be it from learning routes to GPS or from memorizing numbers to speed dials, the peril of sliding along the slippery slope of degenerative darkness looms at us, silently galloping behind veils of our sedentary, stressful, under stimulating choices in life. "Today I pledge, to be More Cognitive Conscious, than Yesterday.

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