ISSN 2524-1478 (Online)

International Journal of Social and Development Concerns

Special Issue
Social Work During COVID-19

Special Issue | Social and development concerns in Africa (c)
Special Issue on Social Work During COVID-19: Article 9 | March 2021

(An International Publisher for Academic and Scientific Resources)

BATTLING STIGMA AND MARGINALISATION AMONG ELDERLY DURING THE PANDEMIC: NEED FOR ALTERNATIVE PATHWAYS – A KERALA EXPERIENCE

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Abstract: *Asia Pacific region is acknowledged as the most virus-affected region globally, and there has been a growing concern among the health workers, administrators of welfare services, and policymakers about the stigma and subsequent discrimination faced among the elderly population. This is true to almost all countries in this region and not much different in India and Kerala, small State. Kerala, on the southwest coast of India, holds 48 lakh elderly (those who are 60 years and above) at present out of which 15 percent of them are past 80 years, which according to the Economic Review is the fastest-growing group among the old ("Kerala Ageing Faster, 2020). The State of Kerala is badly hit by the virus attack, cutting across its geographical boundaries and population segments. However, the doom and gloom of the virus are most experienced among the elderly, the populace segment considered among the most vulnerable due to the co-morbidities associated with age and health. Disabilities, social exclusion and ageing issues add to this curse. Myths, doubts, and biases make this group highly susceptible to stigmatisation as they restructure their thoughts according to the beliefs they have to be misunderstood and misinterpret responsive behaviours of their kith and kin. The psychosocial effects of ageing, coupled with the fear and anxiety of Covid-19 and the existing morbidities, bring devastating effects to these lives. The paper analyses the extent and pattern of stigmatisation seen among the elderly during the covid-19 outbreak and the ensuing lockdown in the State of Kerala. The paper spotlights the need for psychosocial interventions among the elderly as it unravelled the manifestation of many psychological and family issues and this stigmatised experience which further impacts the wellbeing of the elderly. Considering this as the need of the hour, the authors have initiated their service individually and in association with the District Mental Health Programme (DMHP), Ernakulam in nurturing and fostering the mental health of the elderly.*

Keywords: Stigma, Covid-19, elderly, psychosocial interventions

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Introduction

Social stigma in health is the negative association between a person or group of people who share certain characteristics and a specific disease (WHO, 2020). In an epidemic outbreak, this may mean people are labelled, stereotyped, discriminated against, treated separately, and/or experience loss of status because of a perceived link with a disease. In our society, people experience stigma at various levels - micro-level (self-stigma), meso level (family, community, institutions, service providers), and macro-level (structural, cultural). The structural factors associated with stigma are similar to institutionalised racism which is impacted by unequal power as seen in policies, practices, laws, etc. that operate at a very subtle level. Social scientists have posited many approaches to tackle their dreadful prevalence. One approach would be to try changing society's views of marginalised groups. Another would be developing interventions with these groups of people to minimise the impact of these negative societal stereotypes/views so that these views will not be internalised. Internalized or self-stigma has been associated with a reduction in help-seeking and seems to have a deleterious impact on an individual's sense of self and identity. This poor self-concept will result in a diminished quality of life and a lack of hope for the future.

Although much work has been carried out on stigma and stigma reduction, far less work has been done on assessing the effectiveness of stigma-reduction strategies. The effective strategies identified mainly concentrated on the individual and the community level. To reduce health-related stigma and discrimination significantly, single-level and single-target group approaches are not enough. What is required is a patient-centred approach, which starts with interventions targeting the intrapersonal level to empower affected persons to develop and implement stigma-reduction programmers at other levels. The authors' field engagements and academic discussion about applying social work methods in the pandemic crisis led to meaningful reflections on this paper's rationale.

1. Methodology

The paper analyses the extent and pattern of stigmatisation seen among the elderly during the covid-19 outbreak and the ensuing lockdown in the State of Kerala. The paper has been formulated based on the authors' field engagements and inferences developed while integrating theory to practice. An extensive review of the extant literature has also contributed to this knowledge base. The paper spotlights the need for psychosocial interventions among the elderly

as it unravelled the manifestation of many psychological and family issues and this stigmatised experience which ultimately impacts the wellbeing of the elderly. If this segment is left unattended we are moving away from our sustainable development goals; the values underlying the social work profession; instead it is a moral and social commitment not to leave anyone behind in crisis.

2. The Concept of Social Stigma

The most established definition regarding stigma is written by Erving Goffman (1963) in his seminal work: Stigma: Notes on the Management of Spoiled Identity. Goffman (1963) states that stigma is "an attribute that is deeply discrediting" that reduces someone "from a whole and usual person to a tainted, discounted one" (p. 3). The stigmatised, thus, are perceived as having a "spoiled identity" (Goffman, 1963, p. 3). In the social work literature, Dudley (2000), working from Goffman's initial conceptualisation, defined stigma as stereotypes or negative views attributed to a person or groups of people when their characteristics or behaviours are viewed as different from or inferior to societal norms. Due to its use in social work literature, Dudley's (2000) definition provides an excellent understanding of the stigma. Social stigma in the context of health is the negative association between a person or group of people who share certain characteristics and a specific disease.

People with mental health problems say that the social stigma attached to mental ill-health and their discrimination can make their difficulties worse and make it harder to recover. Mental health problems are common. They affect thousands of people and their friends, families, work colleagues, and society in general. It is estimated that 1 in 6 people in the past week experienced a common mental health problem. 10% of children and young people (aged 5-16 years) have a clinically diagnosable mental problem. Depression is the predominant mental health problem worldwide. Most people who experience mental health problems recover fully or can live with and manage them, especially if they get help early (Armitage & Nellums 2020).

Covid-19 and its impact on individuals and groups' mental wellbeing have been widely discussed during the pandemic period. Still, it requires special attention as it forms the base of wellbeing at the micro-level of the individual. As the virus wrecked human lives across the globe, it triggered off many problems at the individual, group, and community level imposing differential impact on different segments – the most vulnerable being the elderly. Among the psychosocial factors affecting the mental health of the elderly during the pandemic, stigma and marginalisation deserve special mention. Though the stigma experience is unique and cannot be generalised,

certain common causal factors are social context-specific (Kerala). Other factors in the larger context include culture, governance, and other social indices that make this experience of stigma differ among populations.

3. Stigma, Elderly and Covid-19

Stigma is an annoying social force associated with a multitude of traits, conditions, and social groups. Mental health stigmatisation includes analysing the social context to a much greater extent, which explains the situation so that people become classified as undesirable due to possessing a specific attribute or showing certain behaviours. This attitude, in turn, leads to generalised stigma toward this subsection – the people afflicted with this disease. The level of stigma associated with COVID-19 is based on three main factors: 1) it is a disease that is new and for which there are still many unknowns; 2) we are often afraid of the unknown, and 3) it is easy to associate that fear with 'others'. Understandably, there is confusion, anxiety, and fear among the public. Unfortunately, these factors are also fueling harmful stereotypes.

The elderly also suffer due to the prevalent stigma of ageism. The innate fear of 'ageing', 'losing vitality' and death has made 'ageism' a prevalent 'social evil'. India's rich culture and tradition are interwoven with a strong religious and philosophical base respecting and revered the older generation. Albeit these values to which we adhere to fulfilling our lives' purposes, elderly in the contemporary society are often neglected and ignored of this mere fact of 'ageism'. Society equates ageing with loss of 'charm and beauty' of youth that often becomes advantageous for old-age abuse. Such stigma and abuse can flare up during an outbreak with an age-specific vulnerability (Amering et al., 2005.

Stigma can undermine social cohesion and prompt possible social isolation of groups, which might contribute to a situation where the virus is more, not less, likely to spread. This can result in more severe health problems and difficulties controlling a disease outbreak. Stigma can drive people to hide the illness to avoid discrimination, prevent people from seeking health care immediately, discourage them from adopting healthy behaviours stigma hurts everyone by creating fear or anger towards other people. Stigmatised groups may be subjected to social avoidance or rejection, denials of healthcare, education, housing or employment, physical violence. (Watson, P. W. (n.d.)

In the eastern cultures like India and especially concerning the cultural attributes and attitudes among Kerala people, stigmatising involves labelling, discriminating, plunging them in fear and anxiety through misappropriate and misleading information and language that makes them anxious and guilty. Older people with COVID-19 experience three types of stigma: (i) self-stigma in that they feel deficient and devalued; (ii) stigma from significant others, those who reject them; and (iii) stigma from society who discriminate against older adults and prevent their full integration into society. Self-stigma reduces self-esteem and leads to feelings of shame and not wanting to ask for help from others. Stigma from family and society leads to more social isolation, and not using social opportunities. Generally, COVID-19-related mental health stigma among older adults is associated with several factors such as a high prevalence and mortality from COVID-19, lack of awareness of COVID-19, and consequently the general public's fear of the illness, and attributing this fear to older adults, and the prevalence and spread of inaccurate and false information. This incorrect information, rumours, and social media, play a pertinent role in the adverse effects of COVID-19, including stigma and discrimination among older adults.

The stigma related to Covid-19 among the older persons in Kerala has manifested in the following behaviour responses regarding not attending to the health care measures and not following the norms and rules and not disclosing the experienced symptoms. The behaviour responses were extremely frightening and very inducing severe anxiety, stress, or injury. Its impact seems to be even impending for older people who are experiencing social isolation and cognitive decline. It is evident from the field experiences that those older adults who experience symptoms similar to Covid-19 symptoms, but not tested positive also have stigmatised in the name of the disease. Their experiences have been reported as traumatic; the vulnerability is more experienced for the mere fact that they are ‘aged’. The physical and emotional disposition a person is in, being in this age group, having or not having attacked by the virus is beyond generalisation.

4. An Invisible Human Rights Crisis

We all have equal rights, regardless of age. However, the COVID-19 pandemic has posed distinct yet differential threats to older persons' equal enjoyment of human rights. Because older persons are at higher risk of severe complications due to COVID-19, looking at this issue as a human rights violation helps understand its complexities. The mental health stigma of having COVID-19 causes older adults to endure the pain and stress of illness and fear of death and suffer

the negative attitudes and feelings of society, such as rejection, humiliation, and other kinds of discrimination. Therefore, it appears that the consequences and problems of COVID-19-related mental health stigma are more painful for older adults than the disease itself. Therefore, our shared responsibility is to help contain the spread of COVID-19 and ensure that care is delivered to those who most need it. Solidarity between and within generations and family and societal cohesion is the best answer to the pandemic. Stigmatisation due to fear of contracting the virus weakens social cohesion and leads to social isolation. It is double discrimination and neglect the older adults face just being aged- an entrenched vulnerability that affects their wellbeing. Stigmatising them as frail, passive, or a burden during this pandemic is a breach of their inherent dignity and worth as a human being.

Elderly are at a higher risk of COVID-19 infection due to their decreased immunity and body reserves and multiple associated co-morbidities like diabetes, hypertension, chronic kidney disease, and chronic obstructive pulmonary disease. The health risks and support need particular to that age group must be considered in policy planning and operational strategies. Some older persons – alongside other people in vulnerable situations– will need additional support to access essential goods (e.g. food), and services (e.g. social or health care). The need for psychological support could never be disregarded. Most of them long for a compassionate heart and empathetic ear to anchor their emotional needs. Failure to deliver essential support during the crisis amounts to a breach of human rights.

5. Social Isolation and Its Vandalising Effect

Social isolation is the objective lack of social engagements and social contacts. It has got its subjective perception and understanding termed as ‘loneliness’. In 2017, this phenomenon was declared a global epidemic in older adults (Lambrini, 2016). Before the outbreak of Covid-19 itself, a study conducted in December 2019 portrayed that nearly one-third of India's older people experienced varying degrees of social isolation and loneliness (Panwar et al., 2019). The State’s strategies to contain the virus focused on the primary measure – social distancing or social isolation. Social isolation has hit the elderly differently. In Kerala, the majority of the elderly live alone far from their children. As families had undergone structural and functional changes due to urbanisation and migration, the joint family system was dissolved, leaving the old parents in their

ancestral home and children visiting them occasionally. These old couples found solace and entertainment in social groups, clubs, daycare centres, associations like pensioners' clubs, and places of worship. They look forward to such weekly gatherings where they met their fellow mates, mutually sharing their joys and woes, thus leading a contented life. Studies among the elderly in Kerala found this as one of the significant determinants of their wellbeing. When COVID-19 slammed into their lives, their lives upended. All these sharing and gatherings which integrated them into their communities have been suspended. On top of it, the worry of being away from their children and the anxiety developed not knowing what is happening at their end fatigued them. Social distancing and social isolation have deleteriously affected their psychological wellbeing. Those elderly who live with their children experienced strained relationships with their children as all of them stayed at home, working from home. The days which were blissful at the beginning of the lockdown changed to days with stress and strain. The family dynamics changed. India has 85.8% of the elderly population being digitally illiterate (Agewell, 2020), virtual platforms were found to be less interesting for them, and a shift to the new normal was less welcomed. The information being bombarded by the print/visual media also has negatively contributed to their mental wellbeing.

As far as co-morbidities are concerned, social isolation among older adults is a "serious public health concern. This is due to their heightened risk of cardiovascular, autoimmune, neurocognitive, and mental health problems. People with Parkinsonism's, dementia and Alzheimer's will have negative thought patterns that would lead to misinterpretation of the actual information. The Health System and governance made it mandatory for older adults to remain home, have groceries and vital medications delivered, and avoid social contact with family and friends. Empirical evidence depicts that social isolation as a preventive measure adopted and implemented by the State is misinterpreted as marginalisation, leaving them anxious and uncertain.

Elder abuse has been reported during the pandemic in many parts of the country and the State. The recent report of a 75-year-old lady who has been stabbed to death in the northern district of Kerala deserves mention. The vulnerability of marginalisation and pandemic imposed restrictions, including social isolation, has plunged these lives into utterly pathetic situations. The saddest part of it is the perpetrators are mostly known people- either family members or neighbours. There is greater scope for empirical studies to assess elder abuse's extent during the pandemic in the State because the length and breadth of this violence cannot be ascertained from

the sporadic news reports presented in the media. Along with these struggles stigmatising and actual marginalising would have an invincible impact on them.

6. The Alternative Pathways

Kerala experience is engaging with elderly issues during pandemic has helped the authors to suggest specific measures to protect the older adults from this marginalisation and promote their wellbeing. Like other situations related to any disaster, most older adults are likely to have sub-syndrome mental health issues like anxiety and depressive symptoms related to the threat of COVID-19. This will require brief psychological and psychosocial intervention that any healthcare personnel, volunteers, etc., with some guidance and training from mental health professionals. Older adults need reassurance that most of the mental health issues experienced in these situations are normal reactions to abnormal stress. They should also get appropriate information and clarification about various myths and false messages spread through multiple unreliable sources. Guidance about maintaining a routine, physical exercise, Yoga, meditation, healthy diet, mental stimulation through home-based activities with appropriate safety precautions is essential. Brief relaxation exercises and supportive therapy can be done for those having severe psychological distress. Treatment by mental health professionals, including medications and other interventions, may be required for severe mental health disorders and emergencies.

People are advised to defer visiting hospitals/clinics for their scheduled appointment for minor issues in the current scenario. There is a need for using other modes of communication with doctors and other health care professionals in this situation. Steps can be taken to increase awareness about mental health issues among older adults and their family members via social media (Online programs, websites, online forums, group email, or messages). Employ community health workers and trained social workers to screen older adults in local communities and other rehabilitative services for mental health issues. Lessons from the District Mental Health Tele counselling program revealed a multitude of cases and problems experienced by the elderly. The evidence states the need for having someone available to listen to them for psychological comfort. The already established helpline is common to all, and in pandemic crisis, it was experienced that other than the problems of fear, anxiety, and stress on the contraction of the disease, most of the elderly were open to sharing their family problems which aggravated during this lockdown. The magnitude of the cases calls for a separate tele helpline service through which any older adult or family member can approach any mental health issue. Through this medium, a basic assessment

of problems followed by a brief psychological intervention can be facilitated. For cases that require detailed psychiatric interventions, referrals can be done with appropriate precautions related to COVID-19 (WHO, 2020).

Those who do not have close family or friends, and rely on voluntary services or social care could be placed at additional support. Online technologies could be harnessed to provide social support networks and a sense of belonging, although there might be disparities in access to or literacy in digital resources. Those interested could be enrolled in acquiring digital literacy. Interventions could involve more frequent telephonic contact with significant others, close family and friends, voluntary organisations, healthcare professionals, or community outreach projects providing peer support throughout the enforced isolation. Beyond this, cognitive-behavioural therapies could be delivered online to decrease loneliness and improve mental wellbeing.

Conclusion

Among the many concerns of the COVID 19 pandemic and the nationwide lockdown, the health and wellbeing of our elderly deserve attention. Kerala's health care system is well established and has adopted an efficient decentralised approach in addressing this issue. Material, as well as psychological needs, are addressed while flattening the curve of virus spread. These additional social protection measures are reported to be reached to those at the utmost risk of being disproportionately affected by the crisis. Developing stigma interventions should involve inter-disciplinary efforts with social work, psychology, anthropology, medicine, nursing, public health, law, public policy/administration, criminal justice, economics, business, etc. Interventions would need to target all levels—micro, meso and macro levels to address inequalities and promote holistic wellbeing. Social workers could lead the way in identifying and addressing these structural factors, advocating for these dis-empowered groups, working directly with communities and institutions to reduce this discrimination and prejudice, and partnering with people from these stigmatised groups to empower them to help them resist or reduce the impact of self-stigma.

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