GERIATRIC CARE AND RESEARCH



Journal of Geriatric Care and Research

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Editorial

Indirect victims of catastrophic events: the case of Odisha train accident

Nilamadhab Kar

Abstract

The Odisha train accident in Balasore is a catastrophic disaster affecting a large number of people. The family members of the passengers are the indirect victims of this disaster; among them, the dependent elderly relatives of the deceased or injured passengers are most affected. In the context of the massive stress on the family, the concerns of the elderly do not get adequate attention. In most instances, their care and support get destabilized, due to the economic hardships following either the loss of an earning family member, or injury and consequent disability affecting the income of the family. Besides, there are massive psychological impacts which are often not recognized nor addressed. It is common to observe depression and anxiety disorders in the elderly relatives of affected people. It is important that the need of the families of the affected victims is assessed holistically and supported appropriately.

Keywords

Accident, Aged, Care, Disaster, India, Psychological Stress, Psychotherapy

Introduction

On 2 June 2023, three trains collided near Bahanaga Bazar railway station in Balasore district, in the state of Odisha in eastern India. It was reported that a total of 296 people were killed in the crash and more than 1,200 were injured. It is one of the most catastrophic rail accidents in India.

There was a massive response from the local people who rescued the victims; along with the personnel from the national disaster response force and fire teams. Local hospitals provided immediate medical care for the victims, and the authorities compensated the families of the deceased and the injured passengers. Despite financial compensation, it is understandable many would have economic hardships. This accident would probably have long-term consequences for many affected families.

Secondary trauma and psychological impact

The catastrophic nature of the train accident is expected to have a massive psychological impact on the affected people and their families. Besides the loss of family members, many had the added stress of difficulty in identifying the deceased. Many surviving victims had life-changing injuries; long-term disability, and probably loss of job as a consequence. These are the secondary stresses which are experienced by the affected people and their families. Indirect exposure to trauma can also occur by learning that a relative or friend has been a victim.

Impact on families

The impact of losing a family member in an accident, or injury and consequent disability of an earning family member is devastating. It is particularly a concern for the elderly people in the family. Often, as they may not be able to do anything about it, this increases the feelings of helplessness and hopelessness. Understandably many suffer from anxiety and depressive disorders, complicated grief reactions, and other stress disorders as a consequence.

It is known that the elderly are more vulnerable to the stress of catastrophic events and suffer from various categories of mental illnesses.² Even indirect exposure to traumatic events can lead to depression, anxiety, and post-traumatic stress disorder.³

However, often the distress of the relatives of the victims especially those of the elderly persons is not adequately realised and addressed. They suffer in silence, mostly psychologically; but the economic difficulties affect the family in multiple ways.

Approaches for supportive interventions

Based on the understanding of catastrophic events and their impact, few generalizations can be made regarding both direct and indirect victims.

Assess the whole family

While assessing the individual victims for physical and psychological impacts, it is essential to assess the consequences on the family and how individual members have been affected. Both practical, economic, and psychological needs are to be assessed. This is especially so as the needs could be different, so supportive requirements could be varied. In this context, the needs of the more vulnerable members of the family, especially the

elderly should be specifically looked into. They usually do not volunteer their concerns and issues in the face of a huge family problem. It is common to see that their care and support systems get destabilized, during these stressful periods which can get prolonged without adequate financial or psychosocial support.

Need-appropriate, continued, and consistent support

Following the comprehensive assessment of the victims and their families, need-appropriate support should be provided; which should not only be limited to the initial financial support. It is expected that they may require multidisciplinary support. Besides the rehabilitation-related support for the victims, the families including the elderly would need psychological support. Understandably, this support needs to continue long-term, so it needs to be consistent over some time. This needs to be emphasized as often after the initial support, the needs of the affected families are forgotten, even those of the victims.

Having a case worker or a social worker who can longitudinally follow up about how the family is coping would be helpful. This support can come from governmental or non-governmental organizations.

Addressing the needs of the vulnerable members

It is important to specifically check if the care and support of the vulnerable members of the family, especially the elderly, have been adversely affected. Often their needs are not recognized; and even if they are, there may not be adequate resources available with the family to address those. Not only replenishing the lost resources, additional needs identified following the disaster, such as this train accident, should also the met. In addition, most elderly people do not feel comfortable opening up about their needs, when the family is going through a tough time. It would need a sensitive approach and dedicated resources to address their needs and concerns.

Psychological support

Usual supportive psychological methods of stress management, enhancing resilience, relaxation techniques, and practical help might suffice; unless there are psychiatric disorders requiring specific psychological interventions. Assessing the coping strategies and supporting healthy coping are essential methods of intervention. Encouraging cultural methods of coping, religious and other activities, may be helpful. There is a role of mindfulness in stress management in the elderly. They can be provided with supportive literature, as bibliotherapy for some of the people can be helpful. These should be available in the local language at a level that can be easily understood by the general public.

Social support is a key element; maintaining and improving social connections through specific activities and avoiding isolation are important measures. Developing a network of affected families, sharing the experiences, and peer support would help manage the

challenges the victims and their families might experience as the short and long-term consequences of the train accident.

There are feasibility issues regarding the availability of appropriate psychological interventions, and the accessibility of care and support. The victims and their families of the train disaster are in a widespread area, which might make it difficult for them to travel to distant areas to receive support, attending different supportive authorities and organizations. It is essential to use technology for online support, local volunteers, and organizations to provide care.

Conclusion

Besides catastrophic natural events, traumatic events affecting the masses are not uncommon. Although train collisions are relatively infrequent, road accidents, industrial disasters, communal riots, and various other stressful events are rather frequent leading to ever-increasing numbers of direct and indirect victims, who would need long-term support. This would involve psycho-socio-economic rehabilitation and need-based care. There are challenges in providing psychological support, such as a lack of holistic assessment of the victim and their family members, inadequate knowledgebase about the culturally validated and effective measures, scant resources, and feasibility issues.

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Insight

Functional improvement support in day services in Japan

Yohko Maki, Takeshi Yamane, Yoichi Yamane

Abstract

Healthy ageing is defined as the process of developing and maintaining the functional ability for well-being in old age based on a holistic perspective throughout the life course, including the ageing timeline, rather than on the disease at a given point in time. Integrated care in the context of healthy ageing is based on the concept of person-centred care, which emphasises the individual's values and encourages the implementation of care by a multidisciplinary healthcare team that centres on the individual and family to optimise functional ability and improve well-being. Such individualised holistic support is expected to be a complementary alternative to medical care and is expected to contribute to reducing medical and social security costs for older people. Evaluating the effectiveness of geriatric care from multiple perspectives, including cost considerations, is a future challenge.

Key words

Empowerment Approach, Functional Ability, Healthy Ageing, Integrated Care, Long-Term Care, Person-Centred Care, Social Participation, Well-Being

Optimizing functional ability for healthy ageing

Healthy ageing

The United Nations Decade of Healthy Ageing (2021-2030) is a global collaboration to improve the lives of older people, their families, and the communities where they live in line with the Sustainable Development Goals.¹⁻³ The term healthy ageing is used in various definitions, some of which distinguish between healthy and unhealthy states and define healthy ageing as the absence of disease. However, many older people have one or more chronic diseases which, when well-controlled, may have little influence on the person's functioning. Prior to the implementation of the decade, the World Health Organization (WHO) published the World Report on Ageing and Health in 2015. In this report, the WHO considers healthy ageing in a more holistic sense, from a functional perspective based on the life course, rather than based on diseases and complications at a given point in time, as 'the process of developing and maintaining the functional ability that enables well-being in older age'.4 This report defines functional ability for individual wellbeing as the 'the health-related attributes that enable people to be and to do what they have reason to value; it is made up of the intrinsic capacity of the individual, relevant environmental characteristics and the interactions between the individual and these characteristics'. Intrinsic capacity is defined as 'the composite of all the physical and mental capacities that an individual can draw on'. Well-being is considered in the broadest sense, as a general term encompassing the total universe of human life domains, including physical, mental and social aspects, that make up what can be called a "good life".

An integrated holistic perspective of older people's health

This integrated holistic perspective is evident in the field of geriatrics, as multimorbidity associated with ageing causes interactions among diseases, between a disease and its treatment, and between medications prescribed for different diseases, which cannot be resolved by a reductive approach to the causes of individual diseases. In addition, as the health status of older people can be affected by the multifaceted dynamics of underlying physiological changes and chronic multiple diseases, the synergistic effects of multimorbidity on function, quality of life (QOL), and mortality may be much greater than the effects of individual diseases and disorders.⁵ Furthermore, older ages are often associated with health conditions that may not be captured by traditional disease classifications and are therefore overlooked in disease-based assessments of health.6 Individuality must also be taken into consideration as the prognosis for the same medical condition varies from person to person and is further influenced by the person's environment. Therefore, older adults require a holistic and integrated approach in addition to mitigating the direct effects of medical conditions.6,7

Creating the environments that enable people to be and do what they value

The environment here refers to all external factors, from micro to macro, that shape the context of an individual's life, including relationships with family members and those close to them, the community and broader society, health and social policies, support systems, and services implemented. Since the surrounding environment and interaction with the environment are considered as the determinants of one's function⁴, the emphasis is on creating environments and opportunities that optimise the functional abilities of older people so that they can live according to their personal values throughout their lives.⁸

The support of and collaboration with family members and care professionals in daily living can also be considered a manifestation of a person's functional ability.

Integrated care for healthy ageing

The framework of integrated approach for older people

For the implementation of the decade of Healthy Ageing, the WHO addressed four areas for action: age-friendly environments, combatting ageism, integrated care, and long-term care.² The Integrated Care for Older People (ICOPE) approaches, which embodies the support for optimizing functional ability according to each one's continuously changing capacities throughout the life course focusing on the values of each individual and aims to improve well-being in old age.^{9, 10}

Long-term care based on integrated care concept

Based on the ICOPE concept, which supports each individual with consistent care from the high-functioning stage to the end of life, the axis of goals in care gradually shifts from maintenance of functional abilities to respect for dignity and management of advanced chronic diseases, aiming for well-being according to the stages of old age.⁴ Therefore, personalised care planning moves away from the traditional disease-oriented methods and instead sets person-centred care goals that focus on older people's needs, values, and preferences. Care plans should be developed by a multidisciplinary team that includes both the individual and their families so that the plan reflects the individual's daily life context, the person's life, values, priorities, and preferences.¹¹ The steps recommended are as follows;^{9,11}

- 1: Person-centred assessment of older person's needs and their physical and mental capacities
- 2: Shared decision-making for goal-setting. To embody the person-centred approach, the older person must be involved with decision-making and goal-setting from the outset so that their needs and preferences are reflected.
- 3: Developing and implementing a care plan through self-management support. Self-management support is provided according to each person's ability. Empowering self-management, rather than using paternalistic approaches, could improve adherence.
- 4: Monitoring and follow-up.

Examples of support for the older people in Japan that support the ICOPE concept

Long-term care insurance system in Japan

In Japan, a long-term care insurance system was launched in 2000. Those 40 years old or older are obligated to pay long-term care insurance premiums, while those aged 65 years and over and those under 65 years old who have specified diseases and disabilities have the right to receive long-term care services if they are certified as requiring

long-term care. Each municipality operates as an insurer of long-term care insurance, and premiums are standardised in each municipality. The co-payment for using long-term care insurance services ranges from 10–30%, depending on income.

Individualized functional training under the long-term care insurance system

Since long-term care insurance aims to provide necessary services so that older adults can maintain their dignity and lead independent daily lives according to their abilities, various services are provided to improve functional abilities relevant to daily living. The individualised functional training program aimed at improving functional abilities for daily living is consistent with the ICOPE concept. The requirements of the program under the long-term care insurance system correspond with the recommended ICOPE care plans as follows:

- 1: Person-centred assessment of the older person's needs and declining physical and mental capacities; individualised assessments include personal values, preferences, life histories, and lifestyle information.
- 2: Shared decision-making for person-centred goal setting; the goals are discussed by a multidisciplinary team that includes older people and their family members. Since individualised functional training aims to improve daily living functions rather than train intrinsic capacities, the goals and training items are flexibly set according to each individual's needs, wishes, and preferences, as well as their living situation.
- 3: Developing and implementing the care plan through self-management support; individualised functional training necessarily consists of the proactive engagement of older people in their daily lives and incorporates the support of care professionals. As a shared decision-making method, multiple training items are provided to meet the individual's goals and allow them to choose the items that best suit their needs, thus contributing to improving their motivation for daily living.
- 4: Monitoring and follow-up. The plan is required to be reviewed every three months as necessary.

Introduction of a practice under the long-term care system in Japan

Prosocial Eudaimonic Activity-based CarE: PEACE

One of the practices under the long-term care insurance system is presented below (Fig. 1). Prosocial Eudaimonic Activity-based CarE: PEACE, which is provided as individualised functional training in daycare services, is conceptualised in the International Classification of Functioning, Disability, and Health (ICF), the World Health Organization framework for measuring health and disability at both individual and population levels. ¹² ICF identifies the three levels of human functioning, body functions, and structure, activity, and participation; the model also includes contextual environmental and personal factors.

The PEACE focuses primarily on proactive participation in social roles (participation level of the ICF). In daycare services, participants and care staff collaborate to create social roles according to individuals' wishes and needs, and tailor-made support is provided to enable individuals to carry out their roles according to their own functional abilities. In the ICF, it is assumed that an improvement in participation level will lead to an improvement in activity level. By willingly carrying out these roles, older people are expected to improve their motivation for life in general, and this effect will extend to all aspects of daily living, thereby realising functional improvements.

To address functional decline, having social roles and improving function through one's own creativity, rather than passive training, have the potential to improve not only function but also well-being. Purposeful activity interventions, especially those involving social roles, are reported to improve the well-being of older people. ¹³ Also, individualised and goal-oriented activities have been reported to improve functioning in people with dementia, ¹⁴ and this can also be true for those without dementia. Furthermore, taking on social roles has altruistic implications, which would benefit both providers and recipients in improving wellbeing ¹⁵ and health, ¹⁶⁻¹⁸ and could even reduce mortality rates. ¹⁹

Role-setting in care itself can be effective because of the undeniable reality that many older adults, especially those in need of care and those with cognitive decline, lose their social roles. This loss of role can lead to reduced vitality, self-confidence, and self-esteem, which can further reduce social participation and lead to serious adverse health consequences in older people, primarily those who are at risk of functional decline.²⁰

The concept of ICOPE is embodied in the following.

- 1: Person-centred assessment of the older person's needs and declining physical and mental capacities; in the intervention, assessment is conducted not only on the functional abilities but also on whether the function meets the specific role requirements and what support is needed to fulfil the role, including the environmental setting. According to the ICOPE concept, one's functional ability includes the environment and the interactions with it. Therefore, performing a role with the support of others (human environment) can also be considered as a manifestation of a person's functional abilities. 9, 10 Careful assessment is required to ensure that individuals are able to fulfil their roles and feel a sense of accomplishment since individuals' abilities may change with the progression of dementia and/or functional decline, and failure to fulfil their roles could lead to further apathy and damage to self-esteem.²¹
- 2: Shared decision-making in person-centred goal setting; as many day service users require decision support, individual roles (self-goals) are determined by shared decision-making through daily care. Since it is difficult to maintain motivation with abstract goals, such as improving cognitive function, setting personally

meaningful goals that are relevant to everyday activities is recommended;¹⁴ taking personally meaningful social roles in care settings may lead to a more fulfilling daily life.

- 3: Developing and implementing the care plan through self-management support; individualised support is provided to fulfil social roles according to the progression of dementia and/or functional decline.
- 4: Monitoring and follow-up; regular discussions with older people and care professionals are documented and activities are reviewed to ensure that the individuals can continue to fulfil their roles for as long as possible by providing support that is appropriate at the time in response to disease progression.

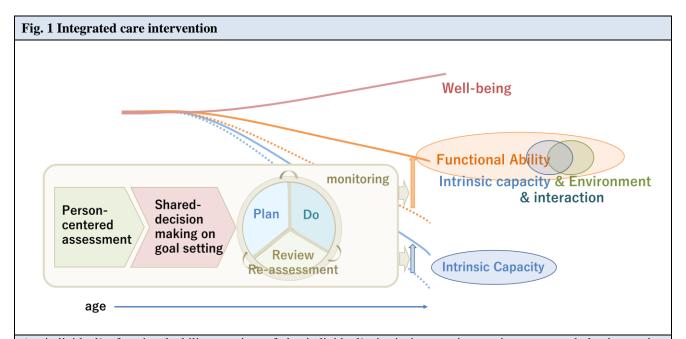
Ensuring a dignified late life

Ensuring a dignified life is emphasised in the personcentred approach of ICOPE, especially in long-term care. To support dignity, staff members are encouraged to express gratitude to individuals, thereby acknowledging their social roles. Expressing gratitude benefits both givers and recipients; for recipients, receiving gratitude is expected to have a motivational effect as a social reward, 15, 22 and the experience of receiving gratitude has been reported to have a greater impact on older people than on younger generations. For givers, especially older people, simple exercises to express gratitude have been reported to improve well-being 24 and reduce loneliness, and, consequently, improve their health. 25

Social participation for older people in need of care

The WHO identifies combating ageism, that is, stereotyping and discrimination against individuals or groups on the basis of age, as one of the four areas of action for implementation of the healthy aging decade.^{2, 4} Ideally, society as a whole would be barrier-free for those who need care to compensate for the loss of capacity, while in the real world, age discrimination is undeniable.

Therefore, it is desirable that there is a safe and secure place between the home and the outside world that can support those who need care. For older people in need of care, independent social participation individualised support is highly challenging. They need appropriate support and protected environments, without which they are at high risk of social maladjustment and are likely to become further isolated.²⁶ Day-care services are a pseudo-society, so to speak, where people who need care receive individualised support in a protected environment and actively enjoy social interaction until the end of life, even as their function declines. Day-care centres function as indispensable meeting places for older people who are at high risk of social isolation due to restrictions,²⁷ and day-care service use has been reported to be associated with lower mortality rates among frail older people living in the community.²⁸ As an increasing number of older people live alone or are estranged from family and relatives, safe living bases are becoming increasingly important.



An individual's functional ability consists of the individual's intrinsic capacity, environment, and the interaction between the individual and their environment. With ageing, functional ability, and intrinsic capacity inevitably decline, whereas well-being can improve until the final stage of life. The interventions aim to improve well-being and slow the decline in functional ability and intrinsic capacity. First, a person-centred assessment is conducted on each individual's needs and their physical and mental capacities. Then, the intervention goals are determined through shared decision-making with the individual and care professionals. To achieve these goals, the cycle of planning, implementing, and reviewing intervention plans, and then improving and implementing intervention plans, is repeated. Care professionals monitor the entire process to improve effectiveness.

Practical examples

In the case of a man in his 80s with lung cancer and dementia who lived alone, after being diagnosed with lung cancer, he became withdrawn, and his dementia progressed. As gardening was his hobby, the care professionals incorporated gardening as a recreational activity in the day service setting and created opportunities for him to take the initiative in watering, replanting, etc., and to collaborate with other participants. As he was undergoing treatment for lung cancer, it was necessary to constantly monitor whether role performance was appropriate for his cognitive and physical functions, and to devise support to ensure that he could continue to perform his role over the long term. Another case involved a man in his early 70s who, due to a brain tumour, was paralysed on the right side of his body. As his physical limitations made gardening activities difficult, he participated by sharing his knowledge of gardening with other participants. Through these situations, the day service allows even those who are highly dependent on medical care to participate in social activities with individualised roles. Another example involved a man in his late 80s who had an indwelling bladder catheter and was active as a calligraphy instructor. At day services, participants share household chores such as preparing meals, cleaning and decorating rooms according to their interests and abilities, and in some cases, persons with dementia aged 90 and over also take on roles such as serving food.

In cases of cognitive decline, severe chronic illness, and the use of medical devices such as catheters, individualised and appropriate support may not be expected in the outside world. Additionally, people experiencing these conditions may also experience self-stigma. In a day-service setting, they can receive individualised support to enable social participation and engage in worthwhile activities even if they are severely compromised. Engaging in personally meaningful activities and contributing to others through social interaction is expected to improve not only their functional abilities, but also their social quality of life and well-being.

Issues to be addressed

While the sustainability of systems that support older people, as advocated by the United Nations Decade of Healthy Ageing movement, 1-3 is an urgent issue, there can be a trade-off between achieving individual well-being and system sustainability in terms of costs for all countries facing rising social security expenditure. Currently, there is insufficient evidence regarding the effectiveness of geriatric care in maintaining function in older people. If geriatric care can supplement medical care to maintain functioning in older adults, the introduction of low-cost care will be expected to both benefit older adults and reduce social security costs. Evidence of the effectiveness of geriatric care is a pressing issue in the future.

As such, the challenge is to meet both demands—individual well-being and the sustainability of the system as a whole including a cost perspective. It has been reported that, if only daily living support is provided

without social participation support with the aim to reduce costs, it may be even more costly due to the increased risk of progression of dementia and level of care for individual older people.²⁹ The report suggests that support for improving the well-being of older people may lead to a reduction in social security costs, and the possibility of achieving both should be pursued.

Limitation

This is a prospective paper and does not present evidence. Practices have been accumulated; however, it is necessary to verify their effectiveness and present evidence in the future.

Ethical Consideration

With regard to the description of care practices, the authors received confirmation from a lawyer whose scope of practice includes personal information protection and a code of ethics that the description does not contain personally identifiable information and does not violate ethical guidelines regarding the protection of personal information.

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Insight

Support for improving well-being at the end of life through geriatric care

Yohko Maki, Takeshi Yamane, Yoichi Yamane

Abstract

End-of-life care is not care that ends the biological life, but rather 'care for living' to the final stage according to individual's own values. Recently, the goals of geriatrics have shifted from curing individual diseases to holistically supporting well-being. Exploring the possibility of maintaining social interaction until the final stage may contribute to improving end-of-life well-being. In Japan, under medical and long-term care insurance, cooperation between medical treatment and geriatric care enables older individuals to continue social interaction even at the end of life. Discussions on end-of-life care have centred primarily on providing appropriate medical care; however, it is also necessary to consider how to provide care that supports an individual's life. Future verification of the possibility of achieving both a reduction in social security costs and an improvement in individual well-being by enhancing psychosocial care is desirable.

Key words

End of Life Care, Geriatric Care, Integrated Care, Person-Centred Approach, Psychosocial Care, Social Participation, Quality of Death, Well-Being

End-of-life (EOL) care to live until the final stage of one's biographical life

With the world population rapidly ageing, the United Nations has addressed a Decade of Healthy Ageing to enable older individuals to improve their well-being until death and has identified four priority areas for action: agefriendly environments, combatting ageism, integrated care, and long-term care. Integrated care aims to provide consistent person-centred care from the healthy stage to the end of life (EOL), gradually shifting the axis of goals from maintenance of function to respect for dignity and management of advanced chronic diseases associated with functional decline. EOL care, the comprehensive term referring to medical and daily care, 2 is 'care for living' to live according to their values until the final stage of their biographical lives, rather than care that ends the biological lives.3 For well-being during EOL, intensive care is required for the vulnerable individuals approaching their final stage of life, as the suffering experienced at the EOL is unique to each person related to physical, psychological, and spiritual needs, ^{4,5} and several individuals may question the self-value and purpose of their lives, especially when they can no longer fulfil the role that defines them.⁶

A systematic review of the literature of the notion of quality of death (QOD) or good death in adult individuals with life-threatening diseases has revealed that EOL and death-related preferences share some core elements: control of pain and symptoms, clear decision-making, being seen and perceived as a person, feeling of closure, preparation for death, and being still able to give something to others, although they vary widely from person to person and indeed change over the course of EOL stage.⁷ Therefore, in EOL care, in addition to medical care to control pain and symptoms, support for preparation for death and closure, respect for decisionmaking and dignity (being seen and perceived as a person), and altruistic social interaction (being still able to give something to others) are desired as support for proactive biographical lives. Furthermore, because each individual's wishes and preferences for EOL are unique and individualised, care should be provided in a personcentred manner that respects their wishes and preferences. In response to the growing discussion on QOD, Japan has been promoting a policy shift from hospital deaths, which provide intensive terminal care, to deaths at home, which emphasises living and life.

Respect for decision-making of life goals in old age leading up to the final stage

Meaningful activities for each individual as goals of care

To provide person-centred EOL care consistent with integrated care¹, it is critical to identify the goals of care that focus on the values of older individuals, beyond mitigating the direct effects of medical conditions.^{3,8,9} Prioritising and focusing on individual values is desirable for spending the rest of their time beneficially, enhancing their personal dignity, and supporting their sense of meaning in life, ¹⁰ while progressive cognitive, physical, and functional difficulties threaten self-dignity. ¹¹⁻¹³ Even for individuals receiving palliative care, they feel a loss of their roles and social participation, ¹⁴ and participating in activities in which the individuals value can improve individual outcomes and quality of life for both individuals and their caregivers. ¹⁴⁻¹⁸

Modifying the goals along with functional declines and empowerment support for engaging life goals

As cognitive and/or physical functioning declines, it often becomes difficult for individuals to engage in activities that are meaningful to them and fulfil their social roles; goal failure can lead to disappointment, unhappiness, or even depression. Having attainable goals in the face of increasing constraints may contribute to a greater sense of purpose and meaning in life, and older individuals can self-adapt to changing environments and maintain quality of life by modifying goals in response to challenges and losses. However, not everyone can cope with the reality of loss and dysfunction. Herein lies the significance of collaborative work by multiple professions to support individuals in coping with reality and living with high well-being while changing their life goals until the final stage of life.

Support for altruistic social interaction

Social participation enhances sense of dignity

Several individuals may question the self-value and purpose of their lives, especially when they can no longer fulfil the role that defines them,⁶ and a sense of contribution to others is one of the core factors for those close to their death.⁷ Furthermore, dignity, which is emphasised in the context of providing care, is not solely individualistic and personal, but rather based on social relationships and interactions, since the sense that one is valued as a person may be confirmed through interactions with others. ^{10,23}

Although the importance and need for social interaction is emphasised, older individuals tend to lose a sense of belonging, and they can experience existential loneliness, where they feel disconnected from the world, lost without a purpose, and adrift in life.²⁴ With ageing, individuals are more likely to experience a loss of a sense of belonging,²⁵ which manifests itself as loneliness and may be associated with depression.²⁶⁻³³ In Japan, the increase in the number of 'lonely deaths', in which a person dies without being cared for by anyone, has become a serious social problem.

Ageism and psychological burden of participation in the real world

Although social participation is encouraged, maintaining a high level of social participation can strain on increasingly limited resources in older individuals and thus be detrimental to their well-being, especially at EOL stages.²⁵ Furthermore, in the real world, individualized support is not always available, and participation in society without support can cause maladjustment.³⁴ Particularly, individuals with cognitive decline need appropriate support in communication, but individualized support is not readily provided because the challenges faced by each person are diverse.³⁵ In addition, there remains a prejudice against the older individuals, as the United Nations has identified combatting against ageism as one of the four priority areas for the Decade of Healthy Ageing.²³ Ageism refers to 'stereotyping discrimination against individuals or groups on the basis of their age'.1

Social participation while receiving nursing and medical care in a safe and secure environment

As mentioned above, although active participation in the real world is desirable, older individuals do not always receive the necessary support, which can cause social maladjustment. Therefore, it can be considered appropriate to provide a situation in which older individuals can continue their social lives with the necessary support until the end of their lives. What matters in the context of caregiving is not the size but the quality of social networks; older adults are more satisfied with the smaller size of their social networks than are younger adults. 31, 32, 36-40 Even if the network size is small, it is important to actively participate and have one's presence affirmed. Peer support is also important, as those who need care may find comfort in being with those who need care. With appropriate support, being with aged adults who have various challenges may lead older individuals to feel less deviant from others. 23 It may be a pseudo-society, but older individuals can select their own social roles and, with individualised support, participate in activities that are meaningful to them. Rather than the direct participation of older individuals in need of care in the community, creating groups and organisations that provide individualised support for each participant and are open to the community would protect their dignity; they are involved in the community through groups and organisations.35

Provision of an environment that maintains social ties even during EOL care

Integrated care recommends shifting emphasis from maintaining function to preserving dignity as function declines.^{1,3} In response to functional decline, it is desirable to shift the focus of care from active participation support to care that emphasises personal dignity; a gradual shift from active to passive participation, from activity-based support to sharing and place-based care, and from verbal to sensory communication is desired. According to the functional assessment staging (FAST) tool of Alzheimer's disease, in severe stages, after speech ability is limited to using a single intelligible word on an average day (FAST stage 7b), the loss of ambulatory ability (FAST stage 7c), and loss of ability to sit up without assistance (FAST stage 7d), the ability to smile remains (FAST stage 7e) just before the loss of ability to hold the head up independently (FAST stage 7f).41 As such, prosocial communication ability remains until the final stage.

Social connections should also gradually shift from active contribution to sharing of place and mental support from raising motivation to alleviating feelings of alienation and isolation, gradually increasing feelings of security and satisfaction and achieving QOD in a natural way. As such, daycare services may serve as a place for the individual to belong if the individual fosters relationships with staff and other participants. Recently, the number of individuals living alone has increased, family relationships are becoming weaker, community ties are fading, and an increasing number of individuals are facing

their final days in solitude. In reality, it is difficult to restore family and community ties, whereas day service communities can provide a stage for QOD without feeling alienated.

Contribution of care professionals in multidisciplinary team for EOL care

Support for psychosocial aspects of EOL care

In summary, it is desirable for older individuals to gradually reach the EOL stage by repeatedly adjusting their life goals in response to the decline and loss of function associated with ageing while receiving the necessary support. To practice integrated person-centred care, healthcare professionals are expected to focus on the preferences and wishes at that point in time while maintaining a perspective of continuity as a single individual.

In reality, medical care is often prioritised over psychosocial aspects of EOL care, as many individuals require specialised medical care at the EOL stage and resources and time are limited for medical professionals, 42, 43 although psychosocial factors influence the perception of symptoms. 44 This is where collaboration between care and medical professionals becomes important. It can be feasible for care professionals to provide psychosocial support through daily life support based on care plans developed by multiple professionals, including the older individual and their families to understand and respect their needs, values, preferences, and priorities. The quality of person-centred medical care may be improved by medical—care collaboration. 44

The initiative using day service under long-term care insurance system in Japan

This section introduces EOL care using day services in Japan (Fig. 1). In Japan, individual certified as requiring long-term care can use day services through long-term care insurance. Care professionals provide psychosocial support for participants by constructing a day service setting as a community in which each individual participates proactively in one's own social role. As each participant experiences life-threatening diseases, such as advanced cancer, appropriate medical and daily life support is provided according to each participant's condition. Support is then provided to enable individuals to continue their meaningful activities.

For example, a woman in her early 70s who was told she had only a few weeks to live with rectal cancer began using day services. Both she and her family wished to spend her last days doing what she liked, such as enjoying karaoke and spending eleven and a half months at the day service, and the woman died before dawn on the day after his last day of use.

Support is also provided to add an altruistic sense of contribution to others in activities that are meaningful to the individual. For the individual, active participation with altruistic role is expected to enhance a sense of belonging, security, and dignity. ¹⁰ For example, a woman in her late 80s who was worried about the recurrence of breast cancer began to use the day service. She enjoys knitting, and when the other participants thanked her for knitting their scarves, she began to feel a sense of well-being that she could make others happy by doing something she was good at. As such, hobbies will be supported to expand involvement with others, such as gift-giving and collaborative activities. By positively valuing contributions to others and engaging in activities that are meaningful to the individual, socio-psychological support is provided to help the individual feel that his/her life has meaning until the final stage.

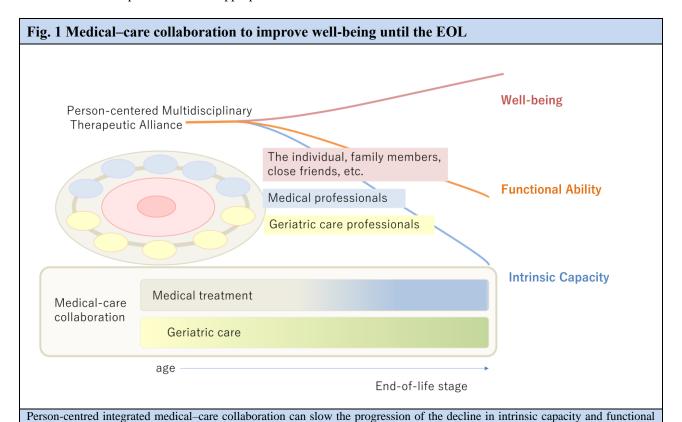
Furthermore, support is provided to enable them to continue these activities that are difficult to perform on their own due to functional decline. According to the WHO integrated care, functional ability is considered to include environments and interaction with environments, therefore, support from care professionals, considered as a human environment, can be also included in one's functional ability. In addition, psychosocial support is provided for the participants to make them feel that their lives have meaning until the final stage by positively valuing activities that are meaningful to them and their contributions to others.

Participation in the outside world can be challenging for those in need of highly specialised medical care. A man in his late 70s with prostate cancer wearing an indwelling prostate catheter and who had reduced interaction with others because of worry about his appearance has become a leader of a mahjong circle, which is his hobby, and is experiencing a sense of contribution to others in day service. A man in his early 70s with terminal colorectal cancer began using a day service after his cancer diagnosis and felt that his subjective well-being had improved as he felt more secure through daily life support, talking and interacting with other participants and discussing his concerns about treatment with care professionals. Also, a man in his late 80s who had lived alone and had been experiencing repeated loss-ofconsciousness attacks due to an abdominal aortic aneurysm moved to a senior citizen's residence with a watch-over service and began to use the day service. He enjoyed bathing, chatting, and playing Shogi (Japanese chess). He became friends with several participants in the day service and attended the day service until the day before his death. While living alone, he often withdrew, but by attending day service, he became more active in social interactions and was able to avoid dying alone.

In some cases, the behavioural and psychological symptoms of dementia (BPSD) are alleviated by the use of day services. For example, a woman in her early 90s had BPSD, such as refusal of care, verbal abuse, violence, and biting, but her symptoms disappeared after the use of day services. She proactively participated in daily services until the day before admission to the hospital and died 1 week after the admission. In addition, in the case of dementia, day services may provide protection from the society. In the case of a man in his early 80s in the terminal stage of oesophageal cancer, his family was

concerned that he might be deceived by scams, sales, or other forms of solicitation, as he was frequently invited to a neighbourhood karaoke snack bar and even made to pay for the accompanying persons' fees. Using the day service, he was able to enjoy his hobby of karaoke and was simultaneously protected from scams.

Even when residents are highly dependent on medical care, as in the above example, through collaboration between care and medical professionals, safe and secure environments are provided with appropriate medical support, and the continuation of meaningful activities, social participation, and social contributions for the individual are realised mainly through professional care support. They can continue to engage in activities that they value until EOL by providing enhanced medical care and life support for the functional decline associated with disease progression. Toward the EOL, function gradually declines, and support shifts from active to passive and sensory-oriented participation. This seamless continuum of care is expected to facilitate natural EOL experiences.



ability and simultaneously support to maintain or even improve well-being at EOL stages. To this end, it is critical to create a person-centred interdisciplinary team that includes the person, family members, and close friends at the centre of the team to

Future Issues

By strengthening the provision of medical care as the disease progresses and by strengthening geriatric care support as function declines, even when individuals are highly dependent on medical care, as in the above examples, medical and geriatric care can collaborate to support the continuation of activities and social participation. In EOL care, discussions have prioritised providing appropriate medical care. The importance of appropriate medical care goes without saying, but simultaneously, emphasis should be placed on 'care for living', which helps each individual to live better until the final stage of life according to his or her own values. Recently, there has been a growing debate regarding excessive medical care, including life-prolonging treatment, from the perspective of both the quality of life at EOL and the reduction of social security costs. By emphasising geriatric care rather than medical care, it may be possible to achieve well-being during the EOL

provide care according to the values and preferences of the individual.

period and reduce social security costs. The challenge is to consider measures that simultaneously improve an individual's well-being at EOL and reduce social security costs.

Limitation

This perspective manuscript does not provide evidence of its effectiveness. Since EOL care is highly individualised and it is difficult to show quantitative effects, it can be necessary to verify its efficacy based on detailed case studies.

Ethical Consideration

With regard to the description of care practices, the authors have received confirmation from a lawyer whose scope of practice includes personal information protection and code of ethics that the description does not contain personally identifiable information and does not violate ethical guidelines regarding the protection of personal information.

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Insight

Ageing in place and social participation in Japan

Yohko Maki, Takeshi Yamane, Yoichi Yamane

Abstract

To promote aging in place, rental housing with care for older people is being developed in Japan. Residents are able to live as freely as at home, while also receiving safety confirmation and lifestyle consultation services from staff; geriatric care services that use Japan's longterm care insurance is also available at their discretion. Moving into a serviced senior residence in a familiar neighbourhood support the societal changes where family members may no longer be expected to provide care. To further promote the concept of aging in place, providing opportunities for social participation while receiving appropriate support through day services and other services open to the community is beneficial as individuals requiring geriatric care face various barriers to social participation. Future challenges will be comprehensively examining measures to simultaneously improve the wellbeing of older people and curb growing social security costs.

Key words

Aging in Place, Business Carer, Housing with Care, Integrated Care, Person-Centred Care, Social Participation, Well-Being, Young Carer

Environments as determinants of human functional ability

well-being Maintaining function and improving throughout the life course is emphasized in the World Health Organization (WHO) Healthy Aging goals, and human function is considered to be holistic, encompassing not only individual's capabilities, but also the relevant environments, and the interaction between the individual and these environments. 1,2 This concept of human function implies that healthcare should be based not only on a biomedical model that focuses on disease, but also include on a person-centred social model, whereby human functional capacity is considered to encompass the environments, including the living environment and interaction with others.³

Living and housing environments

Aging in place

Housing policy is critically linked to health policy due to the impacts of housing on health and well-being, especially for older people, 5,6 and aging in place is defined basically as "the ability to live in one's own home and community safely, independently and comfortably, regardless of age, income or level of capacity". The concept of aging in place is supported by residents' wishes and cost considerations. The 2021 Home and Community Preferences survey by American Association of Retired People found that over three-quarters (77%) of adults age 50 and older want to remain in their homes as they age; that figure has remained relatively stable for more than a decade, even after the COVID-19 pandemic. Aging in place is also generally viewed as having significant financial advantages in terms of health-care expenditure.

Housing as a social determinant of health

On the other hand, it is undeniable that the mismatch between functional decline associated with aging and the living environment can lead to decreased activity and withdrawal, and the possibility of facing a decline in quality of life (QOL). The six challenges to aging in place were identified by thematic analyses and include: 1) memory decline, 2) emotional challenges/low mood, 3) social isolation/loneliness, 4) difficulty with mobility and physical tasks, 5) difficulties with activities of daily living/instrumental activities of daily living (ADL/IADL) and 6) lack of educational resources on cognitive change. These challenges are particularly interrelated for those affected by cognitive decline. Depressive symptom is one the prominent behavioural and psychological symptoms of dementia (BPSD), and cognitive changes could be a constraint to social participation, leading to social isolation, 10 while social connections have been highlighted as an important factor for aging in place.¹¹ Cognitive decline can affect ADLs as much as physical changes do. Furthermore, a lack of understanding about cognitive changes can isolate older people in the community.¹⁰

Changing family structure is another challenge. Families, especially women, have historically cared for the older persons in the home, but the number of employed women is increasing, and the increase in the number of older-only households and households with people living alone raised questions regarding depending on informal family carers. As of March 1, 2023, Japan's aging rate (29.1% of the population is aged 65 and over) was the highest in the world. As of June 2, 2022, households with persons aged 65 and over account for 50.6% of all households, of which 32.1% are couple-only households and 31.8% are

single-person households. ^{12,13} While Japan's total population has been in a declining phase since 2008, the number of older people, including those living alone, will continue to increase for the foreseeable future.

Here, the issue of cost requires more than just a comparison between the formal costs of institutional care and family care. The informal care costs of family care must also be included, and the feasibility of home care that relies on family care in the first place should also be considered. Indeed, aging in place should not be viewed as a policy that allows governments to simply minimize costs, and it should be noted that this requires the presence of caring family member. In the United States, according to the report issued in 2021 by Blue Cross Blue Shield Association, it is estimated that the direct economic effect from the need for caregiving is estimated at nearly US\$44 billion through the loss of more than 650,000 jobs and nearly 800,000 caregivers suffering from absenteeism issues at work, and the overall economic impact of caregiving across the direct and indirect channels is estimated at US\$264 billion. 14 In Japan, the annual social cost of dementia was estimated to be approximately 14.5 trillion yen in 2015 (medical costs: 1.9 trillion yen, long-term care costs: 6.4 trillion yen, informal care costs: 6.2 trillion yen) per year (in 2015). 15

The increase in business carers (people who are engaged in caring for family members and/or others while working), young carers, caregiver turnover, and other burdens on the next generation also lead to losses for society as a whole. A 2023 report by the Ministry of Economy, Trade and Industry estimates that economic losses in 2030 are expected to amount to approximately 9.1 trillion yen, including a decline in labour productivity due to the difficulty of balancing work and geriatric care. 16 Also, the burden on young carers who take on caregiving responsibilities and continue their academic studies must also be taken into account. Furthermore, caregiver burden goes beyond economic factors and has a negative impact on physical and psychological health, especially in the case of dementia. 17,18 The burden on society needs to be considered from a comprehensive perspective that includes the economic, health, and psychological burdens of informal care, not simply the cost of direct caregiving.

Aging in the right place: Balancing receiving care and being independent

As above, even if older people wish to remain in their homes, declines in their capacity often require older people to make changes in their living environment, either by remodelling their homes or by relocating to a more supportive environment. Here, the goal of aging in place is enabling older people to remain in or maintain connections with their community and social networks, and evidence suggests that continuity of care within the community is important to achieve integrated personcentred care for the individual who is aging in place. Therefore, aging in the *right* place extends the concept of aging in place to 'the ability to live in the place with the closest fit with the person's needs and preferences — which may or may not be one's own home'.

Barrier-free home modification is one option, but even if the home is modified to be barrier-free, lack of transportation also leads to isolation and hinders access to a variety of goods and services that are essential to everyday living. ¹⁹ In addition, many older people share that one of their greatest concerns about aging is the lack of safety checks. ²⁰ Moving into a nursing home with comprehensive care is one option, but the transition is often accompanied by a decline in physical and mental health. ²¹

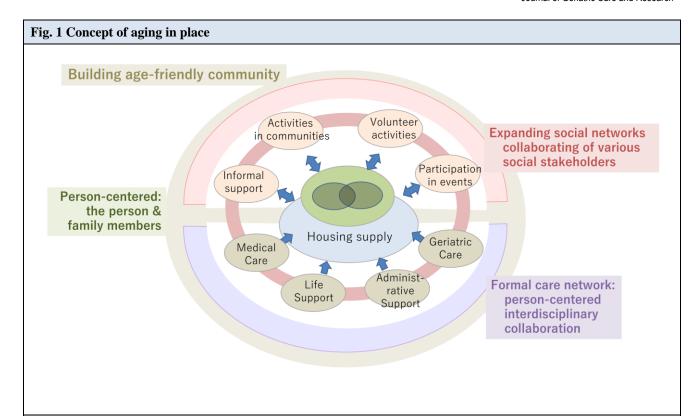
Rather than the all-or-nothing choice of staying at home or moving into a nursing home, another option is to move to a senior housing complex with safety confirmation service within the community, where older people can live safer and more adapted to their needs, while maintaining vital connections with their community, friends and family. Housing with care (HWC), a residential environment for older people that combines housing with a range of care services, is currently considered to be the optimum model.²¹ Living at HWC allows for the gradual incorporation of necessary services as one's function declines.

As part of its housing policy, Japan is promoting the supply of rental senior housing in which residents can live as freely as they do at home, while receiving safety confirmation and lifestyle consultation services from staff. When geriatric care becomes necessary due to functional declines, the residents can continue to live in the same location while incorporating the necessary geriatric care services at their discretion; recently, end-oflife care services have also become available.²² Resettlement in a serviced senior housing facility in a familiar neighbourhood is in line with the broad aging in place concept and will be low-cost for society as a whole, including informal care by families. Furthermore, in areas where residences are dispersed and on-site medical and geriatric care services are difficult to provide, resettlement can reduce social security and administrative costs.

Human environment as the entity of functional ability

Social interaction

The goal of aging in place is enabling older people to remain in or maintain connections with their community and social networks; as people age, they may give increasing priority to maintaining relationships, ²³ which can enhance older people's longevity and, protect against functional decline, and promote resilience. 24,25 On the other hand, older people were observed to be content with smaller social networks than younger people,²³ and when faced with declining capacity, older people may find it harder to maintain social networks, which may consequently shrink.^{24,25} Many people within their social circle may die, which can be additionally isolating and also depressing. Furthermore, as people require geriatric care or develop dementia, it becomes more difficult for them to maintain social interactions without support, even in the case of familiar friendships, and they often become estranged from the friends they had before the onset of the disease.10



Housing and healthcare policy are closely related. Based on the concept of person-centred care, the individual and family members are at the centre of interdisciplinary care teams that include specialists in medicine, geriatric care, livelihood support, and administration. Furthermore, in addition to formal care networks, social networks are expected to expand to enable social participation in community activities, volunteer activities, and events in collaboration with various social stakeholders. Such person-centred collaboration may contribute to building an age-friendly community.

To realize the aging in place concept, it is not enough to simply provide housing and care for daily living; it is desirable to provide opportunities for social participation with individualized person-centred support through day services and other means. Therefore, it may be one option to gradually shift to participation in supported social activities open to community; these services can help older people stay connected to the community.

Practical examples of senior barrier-free rental housing, day-care services, and post-day care accommodation services for older people in need of care in Japan

This section describes the actual operation of a complex in Japan that provides rental housing, day-care services, and post-day care accommodation services exclusively for older people requiring long-term care. The decision to relocate and use services is made voluntarily by the individuals and their family members. (Fig. 1) For example, in the case of a man in his early 80s who had retired at age 60 and devoted the following 20 years of his life to caregiving for his wife decided to move in after using the accommodation service on a trial basis following her death. Rather than changing his living environment all at once, after using the trial, he relocated from living alone at home to a housing complex exclusively for the older persons.

However, even those who wish to remain at home may relocate for different reasons. For example:

- 1: Increased dependence on medical care. A man in his late 80s who had an abdominal aortic aneurysm had been living alone, but after he lost consciousness on several occasions, his family requested that he move into a facility where he could be cared for.
- 2: BPSD of wandering: A man in his late 60s with dementia relocated as he frequently failed to return home after he went out.
- 3: Difficulties in daily life due to dementia: Due to cognitive decline, a woman in her early 70s with dementia was no longer able to cook, manage her finances, or clean up her house, making it difficult for her to continue to live alone.
- 4: Concomitant symptoms of dementia. One of the comorbid symptoms of dementia is difficulty in feeling hot and cold, which is a risk factor for heat stroke in the summer. When the staff went to pick up a woman in her late 80s for day service use, she was sweating heavily. Her neighbours did not notice her condition since she had fewer opportunities to interact with them after the onset of dementia.
- 5: Withdrawal and isolation. A man in his late 80s had right-sided paralysis due to cerebral infarction. He tended to be withdrawn; physical disability and dementia often cause withdrawal, and disuse is a risk factor for functional decline.²⁶ A woman in her early 70s had relocated because she had become isolated from the community due

to neighbourhood problems. Dementia may worsen relationships with neighbours due to the risk of fire loss and other problems. Since many cases of dementia are left undiagnosed, Japanese governments have set up Dementia Initial-phase Intensive Support Teams, where medical and welfare professionals visit and provide support by referring people to welfare and medical services as needed. The team accepts consultations not only from the person with dementia and their family members, but also from neighbourhood residents.²⁷

6: Housing environments. A man in his late 80s was receiving home oxygen treatment due to chronic obstructive pulmonary disease. He moved to a barrier-free housing complex because he had previously lived on the 5th floor of an apartment complex that did not have an elevator, and he had difficulty going up and down stairs.

7: Caregiver burden. Two-location living is possible using the overnight stay service attached to the day service while continuing to live at home. Overnight stay at the day service can be temporarily used with the purpose of reducing caregiver burden. There are various cases where this is helpful, such as when the caregivers are old, the older people are alone during the day (even if living with family, the family may be away at work/school during the day), and caregivers may become ill. A woman in her late 80s with BPSD, including verbal abuse, wandering, and day/night disturbances, used day-services and overnight stays with the purpose of reducing the caregiver burden and alleviating her symptoms. A woman in her late 80s who used a wheelchair due to muscle weakness in her lower limbs, received physical function training at the day-care service and used overnight stays to reduce the care burden of her older husband.

8: Relocation after hospital discharge. In many cases, older persons relocate to barrier-free housing after hospitalization for femoral neck fractures caused by falls. In Japan, total hip arthroplasty and bipolar hip arthroplasty is conducted for those with dementia in their 90s by national insurance. As hospitalization can be risks for progression and functional decline of dementia, postdischarge support is important and increasing activity with appropriate support using day-care services can be effective. A woman in her late 70s with dementia was hospitalized for 6 months for a femur fracture. When she was discharged from the hospital, she was unable to maintain a standing position and was using a diaper for elimination. With functional training at day services and overnight stays, she became able to use the toilet with light assistance.

Intensive care before and after relocation

Empirically, changes in the environment, including relocation, pose a risk of functional decline; in dementia, BPSD has been observed to develop immediately after environmental and residential changes, and there seems to be much room for intervention in affective symptoms, since dementia severity was associated with an increase in the severity of agitation and apathy, but not affective symptoms. ^{28,29} A woman in her early 80s with dementia manifested affective symptoms of irritability after

relocation. As the day-care service can provide pro-social participation support for symptom relief, including peer support by other participants, she was supported to play an altruistic role toward others within the day service.

For physical functional decline, the use of overnight services allows for 24-hour assistance. A woman in her late 70s with dementia moved in after being hospitalized for a femur fracture. When she moved in, she was using a wheelchair and had difficulty transferring to a wheelchair, so she began functional training at the day service, and as her physical functions improved, she also began training with a walker. During the night, she was looked after using the extended stay at the day service. Another woman in her early 80s moved in after being hospitalized for a femur fracture. When she moved in, she was frequently incontinent (urine and faeces), so toilet training, wheelchair use, and gait training were provided at the day service. She also used extended stays at the day service for night-time support.

Issues to be addressed

As of 2022, Japan had the highest aging rate in the world, ¹² and there is an urgent need to simultaneously improve wellbeing of older people and reduce growing social security costs. One measure can be to provide safe and secure inexpensive rental housing and opportunities for social participation based on the aging in place concept. Regarding social costs, it has also been pointed out that reductions in long-term care insurance costs will lead to an increased burden on informal caregivers, including young and business carers. Furthermore, simply relocating to barrier-free housing will not increase activity levels or improve physical and mental function. ³⁰ The challenge for the future is to comprehensively examine measures to improve the wellbeing of older people and to control the increase in social security costs.

Limitation

The living environment of older people is highly individualized, and detailed case reports, including time course, are useful before quantitative studies can be conducted. The immediate task is to conduct detailed case reports that include physical and cognitive functions, mental symptoms, and disease status before and after changes in residence.

Ethical Consideration

With regard to the description of care practices, the authors have received confirmation from a lawyer whose scope of practice includes personal information protection and code of ethics that the description does not contain personally identifiable information and does not violate ethical guidelines regarding the protection of personal information.

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Letter to the editor

Interaction between hip-fractures and dementia in older adults

Jorge Luis Passarelli, Hanadi Al Hamad

Dear Editor,

We are writing to voice our suggestions for the article entitled "Rehabilitation in older adults with dementia after hip fractures: A narrative review, composed by Afolabi et al.¹ The article enlightened a critical yet overlooked topic: interaction between hip fractures and dementia in older adults, and enlisted various in-patient, community-based and cognitive interventions for dementia-sustaining hip fractures patients (DMSHP).¹ However, it missed some crucial details.

As marked by previous literature, patients with dementia often forget to consult doctors, causing delays in medical attention and accurate diagnosis. The authors discussed complications like delirium, mobility decline, post-operative complications, and prolonged hospital stays. However, additional complications like cognitive decline after hip fracture/surgery, higher mortality, and poor prognosis, compared to non-DMSHP have not been discussed. In DMHSP, a 67% higher risk of mortality was observed within 30 days (Incidence Rate Ratio: 1.67, 95% CI: 1.60-1.75, p < 0.001), and 70.1% prevalence of cognitive impairment (CI), compared to 41.8% CI in hip-fracture patients without dementia.

Afolabi et al. substantiated several cognitive therapies (CTs), including cognitive stimulation, cognitive rehabilitation, cognitive training, and reminiscence therapy, but there is a lack of studies demonstrating the comparative therapeutic potential of these CTs. Analyzing comparative potential is pivotal to expedite the recovery and successful implementation of these therapies in the reflection of DMSHP complexities including, behavioral issues (agitation, confusion, aggression, anxiety), deep venous thrombosis, pressure ulcers, pneumonia, UTIs (urinary tract infections) and other complications.

Comparing therapies optimizes rehab, personalizes care, reduces complications, and helps manage resources. Cognitive stimulation has a 49% efficacy in improving global cognition immediately after the intervention, indicating a moderate improvement for dementia patients. The statistical efficacy of reminiscence therapy on DMSHP is unknown as per available literature but it improves symptoms of depression, cognition, and quality of life. Combining cognitive and reminiscence therapies enhances cognitive function, emotional status, and quality of life. 9,10

Authors have stressed the importance of rehabilitation models, however, descriptions of the total intervention duration, stages of dementia and the severity of fractures should also be included, as rehabilitation programs are tailored to accommodate diverse preferences and individual needs, ensuring a personalized and distinct experience for each participant. By focusing on individual needs, maximizing independence, cognitive function, and quality of life, rehabilitation outcomes can be optimized, providing person-centered care that enhances overall well-being.

Additionally, adding current barriers and challenges in using these rehabilitation techniques for hip fractures and dementia would be more beneficial. One of the significant challenges is the varying levels of cognitive impairment in dementia patients. Advanced dementia causes limited attention span, and a reduced tendency to engage in physical activity and acknowledge the continuously altering stimuli. 12 Additionally, there is still a lack of standardized implementation of cognitive reminiscence therapies for DMSHP, which makes it challenging to implement effectively. Other challenges include the limited availability of resources and healthcare units for the targeted population and limited compliance or motivation of the patients. 13 To address these barriers, strategies to improve care for older adults with hip fractures and dementia should also be discussed.

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Review

Emerging challenges for disaster risk reduction: special reference to elderly

Renaldo Stanley Rajkumar, Devasagayam Nancy, Francis Xavier Lovelina Little Flower

Abstract

Background: Disaster risk reduction is a systematic process of practising and reducing the risk of disaster. The elderly people are more vulnerable and are usually neglected in the process of disaster risk management. Aim: This paper reviewed the risk reduction processes and particularly the challenges faced by the elderly population and their needs. Method: Recent literature was reviewed from global reports, in the field of elderly health, disaster management, sustainable development, and risk reduction. Results: This paper highlights the challenges and issues faced by the elderly population during disaster preparedness and the strategies to reduce the risk. The importance of including the elderly population in the disaster risk management process; and utilizing their knowledge and experience in planning and organizing the process and methods of disaster relief management is reemphasized. Conclusion: There is a need for inclusion, networking, and advocacy for elderly While prioritising people in disaster management. disaster related rescue, relief and support for elderly, promoting disaster-resilient living environments for the elderly with reduced risk of damage has been suggested.

Keywords:

Aged, Disaster, Elderly, Risk, Vulnerable.

Introduction

Disaster risk reduction is the process of practising and decreasing the risk of disaster through systematic efforts which scrutinize and manage casual factors. The factors involve reducing coverage of hazards, lessening the vulnerability of people and possessions, administration of land and environment, and improving attentiveness to disaster risk.¹ Many proportions of the global population have been directly or indirectly affected as a result of disaster but one of the most vulnerable among them is the elderly population. The elderly population is easily affected by the challenges,² during disaster situations for multiple reasons.³ The millennium development goals and sustainable development goals represent major disaster risk reduction strategies designed and drafted in their targets, creating a responsibility for the global government and civil society organizations which are to be entitled and working towards its achievement by 2030.⁴

The increase in the size of the ageing population and life expectancy represents the global advancement in health care; but an extreme climatic event or a combination of natural and manmade disasters threatens the vulnerability of the ageing population further, particularly in the low and middle-income countries.⁵ The risk can be overcome with certain practices including advocacy, food security, livelihood, health, social, community, water, sanitation, etc. In addition, early warning, relief, and reconstruction help for preparedness and response to tolerate the impact of a disaster,⁶ stabilizing the vulnerable and elderly population.

The main objective of this paper is to review concepts and approaches, particularly on the risk reduction and challenges faced by the elderly population during the disaster conditions, and the current need for the elderly population.

Methods

The background and method adopted in this article are a collection of published reports from various global organizations such as the United Nations, World Health Organization, World Bank, and Help Age. This article has focused on reviewing the ideas related to the elderly in disaster risk reduction, management, elderly care support, and the challenges faced by the elderly during a disaster crisis in these reports. Peer-reviewed journals or published research articles were referred to write this article. A total of 37 reports were analyzed. The themes are presented below.

Elderly population statistics at a glance

Ageing is a global phenomenon and every country in the world experiences a growing proportion of the older population. Population ageing is an inevitable and irreversible demographic reality that nations should be well prepared in advance for the multi-dimensional challenges to be faced. In the year 2019, there were 703 million people aged 65 in the world population; it is estimated that by the year 2050, it may double to 1.5 billion. In Eastern and South Eastern Asia, the elderly population has risen from 6 percent to 11 percent between the years 1990 to 2019. Developing countries are ageing faster than developed countries; a survey report shows that 80 percent of the world's elderly population will be

living in developing countries by 2030.⁸ The old-age dependency ratio and population ageing have intensified its growth rate in almost all the countries making the government face a stressful situation during any disaster.

Global assessment of disaster risk for the vulnerable population

The changes especially in social, environmental, and economic areas have threatened nations, which has led to the emphasis on sustainable development. Human beings have undergone evolution as superorganisms through many challenges. Though humans have been credited for multi-dimensional developments, the concept of sustainability is still a question. The lack of sustainability in many areas has contributed to further challenges in dealing with risk and damages. According to global assessment information, the risk is the combination of hazard, exposure, and vulnerability.

In this context, more vulnerable people are women, children, aged, sick, and physically challenged populace who need additional care and support, especially during the disaster situation. The need for the protection of the elderly during disaster was intensely realized by the nations during the 2003 European heat wave; and 2004 tsunami in Indonesia, Sri Lanka, India, Thailand, and other countries of South East Asia. There are many such examples such as the South African drought in Bophirima, between the year 2002-2005, the British Columbia firestorm in 2003, the Kobe Japan earthquake in 1995; and hurricane Katrina USA in 2005, etc. These disasters recorded intense difficulties for the elderly population and they have suffered to the core. 12

Assessment based on international agreement projects, shows the world is moving towards a better future for the people and society as a whole. Some of the international agreements and agendas on disaster risk reduction include 1. Transforming the World, 2. Paris Agreement, 3. Addis Ababa Action Agenda, 4, New Urban Agenda and 5, Agenda for Humanity. These are some of the frameworks that many countries agreed to address and estimate the pre and post-effects of disaster, especially on the vulnerable, particularly the elderly population. ¹³

Emergency and disaster risk management

When a disaster strikes the risk of emergency prevails within all the global communities, the disaster may be categorized starting from infectious diseases to natural and technological hazards. During an emergency the importance of disaster risk reduction focuses on certain characteristics including infrastructure, assert, new emerging risks, and building back better considering the required interventions, framework, and policies feasible for implementation. ¹⁵

United Nations Disaster Risk Reduction Sendai Framework emphasizes overall three most important strategic objectives drafted for disaster risk reduction. They are: '1. Strengthening global monitoring, analysing, and coordination of Sendai framework implementation, 2. Support to regional and national Sendai framework implementation, 3. Catalyse action through member states and partners.' In which the outcome of this framework was the reduction of disaster risk and losses for a sustainable future. ¹⁶

Disaster management in India

Disaster management policy and framework have an important role in the county as they directly affect the poor, underprivileged, and vulnerable sections. The Government of India has adopted prevention and mitigation regarding disaster management and the tenth five-year plan details a chapter on disaster management. Globally, India is one of the top 10 disaster-prone countries; out of 36 states and union territories, 27 states are declared as disaster-prone. The geological setting and extreme weather condition of the country is one of the basic reasons for the increase in vulnerability to disasters.¹⁷ The country has witnessed and recorded many disasters over the last two decades which significantly have affected the nation with many negative pre and postconsequences.¹⁸ Initiatives planned and executed by every stakeholder through risk-informed planning have contributed to addressing the vulnerability and made the vulnerable population resilient to the impacts of disasters.

Older persons in emergencies: an active ageing perspective

Emergency management involves good preparedness, effective response, and recovery with planning, coordination, and deployment of resources and supplies to the people who are experiencing the crisis. The inability of the elderly population due to physical illness, lack of mobility, disability, and other factors has contributed to increased risk for the elderly.²¹

Despite the vulnerability of older people, their resourcefulness and experience might help to tackle the hazards in many situations, at least on certain parameters. The age-appropriate community-based assessment for disaster responses and relief prioritized preparedness strategies for the elderly might mitigate the impact of disaster.²²

Active ageing is based on a variety of social, structural, and material determinants upon individuals, families, and communities; and these factors interplay between vulnerable groups and build resilience within the elderly population. The active ageing index by the United Nations in the year 2019, specifics certain concepts particular to disaster risk reduction, and concentrates on the physical environment, social determinants, economic determinants, health and social services, behavioural determinants, and personal determinants.²³ In the longer term, experience and understanding the active ageing framework can build resilience within individuals and communities to face disaster emergencies better for the vulnerable population.

Inclusive disaster risk reduction: contribution of elderly

The aged population's local knowledge and experience can be used for disaster risk management.²⁴ Disaster risk reduction focuses on reducing damage caused by natural hazards and manages the factors causing the disaster. Age inclusion is a subset goal that ensures active inclusion and participation irrespective of vulnerability, and the commitment from key stakeholder such as government organizations, and public and private institutions to bring an inclusive approach to policy and strategy to enhance and develop resilience within the aged population for their self-survival during the disaster.

Four factors define vulnerability among the elderly population; they are 1. physical decline, 2. inadequate service for older people, 3. age discrimination, and 4. poverty. These factors make the elderly population more dependent on the working-age population leading to helplessness and hopelessness during the situation of crisis. Many reports suggest that elderly women are more affected than men in disasters, as the physical and mental risk factors are disproportionally high in them, highlighting the existing discrepancies in their basic standards of social security.²⁵

Disaster risk and age index

The World Health Organization studies from the years 2006 to 2007, examined how the older individuals faired in divergence-related and naturally caused emergencies in developed and developing countries. According to global statistics, nearly twelve percent of the global population accounts for 60 years of age and above. Older people are precious resources in the way of their life experience and understanding of risk, but their age factor often excludes them from getting involved in most catastrophic situations. International organizations are working towards building a community involving the aged population's resourcefulness at the time of disaster risk. The organizations, globally, are working towards disaster risk management planning for vulnerable groups facilitated through older populations of high and lowincome countries. Older people's resourcefulness should be given importance to demonstrate a change for the improvement from social pensioners to proactive disaster risk managers.26

Decreasing the disaster risk for older persons emphasizes community-based estimation in preparedness and relief response, community disaster preparedness plan, and the mechanism to mitigate the impact of disaster; along with the roles and responsibilities for relief activities and reconstruction of long-term developmental programmes through networking and advocacy. The level of experience and knowledge of the aged population regarding the local resources helps the younger generation to understand the measures to be taken for the survival of post-disaster. They can also help in the assessment of risk analysis to identify the risk zones and pre and post-preparedness for disaster risk reduction.

Networking with older people: a decline in risk

Networking is a process of connecting the required resources via local, national, and global platforms, and it helps to exchange ideas for development. The process of elderly networking in the context of disaster risk reduction initiates the exchange of ideas through representation and experiences. Many reports across the world have suggested that older women tend to have stronger networking relationships than men. Inclusion of the elderly population benefits the working community on innovation which is through the process of communication benefiting the governance, agencies, and organizations on planning and executing with less chance of error. ²⁹

Creating a collaborative network with elderly experts and experienced groups assists in meeting special needs during an emergency. The recent innovation in information and communication technology (ICT) has eased the task for the global community in prediction and exchange of knowledge and resources in advance;³⁰ which also reduces factors related to elderly isolation and enhances stability for social support.

Disaster-resilient smart cities for the elderly

Smart cities are the concept of upgrading the town plan with feasible technological improvement for the luxury of the people. Globally the concept is not new for the developed nations but as developing nations, smart cities have been an emerging phenomenon in India since the year 2014 and the government has finalized to upgrade 100 smart cities all over India. Smart cities are designed as per the global sustainable models to withstand and protect people from disaster and risk.³¹

The implementation of ICT has improved a lot in the design and development of smart cities without destroying the natural habitat. Elderly and vulnerable sections of society are given utmost importance in designing smart cities like mobility, health, technological accessories, and emergency support.³²

The age-friendly cities promote determinants like health and social service, behavioural determinants, personal determinants, physical environment, social determinants, and economic determinants for successful implementation and execution of active ageing among the elderly population. Age-friendly cities recognize resources, provide preferences, and make the lifestyle with ample choices for vulnerable people, for upgradation in all areas of community life.³³

Approaches for the elderly and their contribution to disaster risk reduction

Disaster risk management involves certain characteristics which are risk analysis, disaster prevention and mitigation, disaster preparedness, and disaster resilient recovery. Currently, vulnerable groups are often not taken into consideration during this process. They could participate resourcefully in disaster risk reduction. The

vulnerable groups include many but speaking of the elderly they have vast experience and knowledge in the local areas. They are also respected people in the community thus they can influence people in decision making and conflict resolution activities. The elderly should be provided with support in the planning and decision-making process for changing their environment to more disaster-resilient.³⁴

During hazardous situations, elder people should be given priority considering their vulnerability. The specific strategies for preparedness for present and future disasters should be thoroughly determined. The preparedness should be based on the reconstruction and long-term developmental programs benefiting the vulnerable section with resilience.³⁵

Many international frameworks like the International Strategy for Disaster Risk Reduction, Sendai Framework, Early Recovery Framework, etc., have come out with strategies to engage older people in the preparedness, relief, and recovery phase during an emergency including early warning systems to reduce the mortality rate among the elderly population during the disaster crisis.³⁶

Challenges in providing elderly care during disaster

Elderly care especially during disasters is a challenging process because handling the elderly population with utmost care and support requires expertise that is not commonly available. Globally many rescue resources initiate their rescue response to vulnerable populations like women, children, and elderly population. Though the aged population usually has positive support in the family and community, they have challenges such as ill health, mobility problems, and disability for which the resources may not be available to family or community to support. These factors vary in terms of age, education, poverty, integration, available support, etc., which make them depend on others in society. Various stakeholders like crisis councillors, volunteers, health care professionals, and other elderly support services must understand the needs of this population so that they are aware of these issues to handle these challenges better.

Rescue and post-disaster care of the elderly

Many elderly following exposure to disaster have difficulty returning to their usual state as they develop mental health-related problems. The disaster caregivers often encounter emotional, cognitive, and behavioural reactions from the elderly people. Effective post-disaster care, interventions with appropriate solutions can help the elderly population who have been exposed to the predictable and un-predictable disaster scenario.³⁷

Conclusion

The elders face massive challenges during disasters. Their vulnerability and risk need to be appropriately assessed and managed. During the emergency preparedness, rescue, and relief planning and development process, they need to be engaged strategically which may help in

disaster risk reduction. It needs to be highlighted that disaster-related care and support should be provided to them without their rights and dignity being violated. When older people engage in these disaster risk reduction processes and activities, they might develop resilience within themselves and for the community. Through activities implemented in connection with the risk and emergencies, and with the previous lessons learned it might be possible to save lives. Furthermore, the inculcation of knowledge and training through systematic planning of intervention programs may help the vulnerable population respond spontaneously during a disaster. On top of that, governance and voluntary activities in disaster management need to be updated periodically to face the risk more effectively.

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Insight

Is the UK still the best place to die?

Ayesha Bangash

Abstract

End-of-life care is an important component of health care for the elderly. It needs to be holistic covering physical, mental, social, and spiritual contexts. The UK has been the top-scoring country for quality of death worldwide. It is also the founder of modern palliative care. However, things are not as perfect as they seem. More needs to be done to improve the standard of palliative and end-of-life care, particularly in the aftermath of the COVID-19 pandemic. Various methods are being employed by countries to improve the quality of care at the end stage of life, which can address social deprivation, isolation, and other maladies. This article discusses the palliative and end-of-life care situation in the UK, with a brief reference to Japan. It also focuses on the changed scenarios following the pandemic.

Keywords:

Care, COVID-19, Death, End-of-Life, Palliative Care

Introduction

End-of-life care is usually defined as care for people likely to die within a year. For some people, it is obvious that the end-of-life phase is approaching well in advance, but others may sadly only have months or weeks before that time comes. Palliative care refers to care provided when conditions cannot be cured and aims to make the individual as comfortable as possible, relieve pain, and provide psychological, social, and spiritual care. ¹ Japan is among the top countries in the world for high-quality endof-life care and palliative care. Maki et al discuss how the national problem of "lonely deaths" is being dealt with. They remind us that end-of-life care is not just about curing the individual of diseases but holistically supporting the individual's well-being.² This encourages a review of the current care scenario in the UK which has been at the forefront of elderly care.

Palliative and end-of-life care in the UK and Japan

Maki et al state that end-of-life care does not end the biological life but provides 'care for living' to the final stage of the biographical life in accordance with the individual's own values. End-of-life and death-related preferences share crucial features such as pain control, explicit decision-making, being perceived as a person, and altruism although they can vary between individuals

and change over time. Japan has been encouraging a policy shift from hospital deaths to deaths at home. More and more older people are living alone. There has been an increase in the number of 'lonely deaths' in which a person dies without being cared for by anyone. Japan is focussing on day service communities where quality of life can be ensured by establishing relationships with staff and other users. Those who qualify for long-term insurance can make use of day services. Maki et al mention other benefits of these services in reducing behavioural and psychological symptoms of dementia as well as providing protection to people who would have become victims of financial abuse had they stayed at home.²

The UK and Japan have well-developed care systems that face rapid population ageing. They have created unique policy approaches in accordance with their socio-cultural dynamics. In the UK, advanced care planning encourages people to record their preferences for end-of-life care before losing their decision-making capacity.³ Under the Mental Capacity Act,⁴ people can refuse particular treatments and appoint a lasting power of attorney to make decisions on their behalf. Legislation to ensure patients' autonomy in decision-making remains largely absent in Japan.³ There are no legal mechanisms to ensure patients' rights and to guide healthcare professionals. Therefore, requests such as those relating to forgoing lifesustaining treatments may cause difficulties concerning end-of-life care. However, to reduce the predominant role of healthcare professionals in decision-making processes, advanced care planning was introduced in 2018 as a potential solution to better support patients' wishes and dignity.

Japan has developed Long-Term Care Insurance (LTCI) to provide need-based social support for people aged over 65 through which patients can access various levels of support including day-care services and home-based Health care.3 The National Service (NHS) provides healthcare to all legal UK residents with most services free at the point of use for most people. Immigrants living in the UK can also be entitled to free NHS services, however, this depends on the type of service and the individual's immigration status.⁵ Some people approaching the end-of-life may be eligible to receive NHS continuing healthcare which includes care home fees or homecare. In some areas, individuals can access personal health budgets during the end-of-life stage which gives them greater control over the care they receive.6

How the UK reached the top

Palliative care was introduced to the world by the UK in 1958 when Dame Cicely Saunders, a British physician, produced a publication on terminal care. However modern palliative care was set up in 1967 when she founded the St Christopher's Hospice in London.⁷ The Royal College of Physicians recognised palliative medicine as a subspecialty in 1987. By the end of the 20th century there were many charity-run hospices across the UK. The National Council for Hospice and Specialist Palliative Care Services was established for England, Wales, and Northern Ireland in 1991, becoming the National Council for Palliative Care in 2004. The hospice movement significantly developed the specialism of palliative care in the UK and worldwide. In 2010, the UK ranked at the top of 40 countries measured in a 'quality of death' index developed by the Economist Intelligence Unit in London. 9 In 2015, the National Partnership for Palliative and Endof-life Care, a collaboration of 27 national organisations across health and social care in the UK, produced the Ambitions For Palliative And End-of-life Care: A National Framework For Local Action: 2015-2020. The framework included findings and recommendations of reports, reviews, and inquiries into palliative and end-oflife care in recent years. Its vision was described in the form of six high-level ambitions. 10

In 2015, the Economist Intelligence Unit stated that the quality of palliative care offered in the UK was ranked the best of 80 countries around the world. Reasons for this included a robust hospice movement, availability of specialised palliative care workers, community engagement, the extensive integration of palliative care into the NHS, and comprehensive national policies. The UK was working to integrate hospice care more intensely into the healthcare system.¹¹ In 2022, a Singapore-based study ranked 81 countries on how well their health systems provide for the physical and mental well-being of patients at the end-of-life. Across the globe, 181 palliative care experts were asked to grade their countries' health systems on factors including pain management, having a clean and safe space, being treated kindly, and treatments that addressed quality of life, rather than simply extending life. The UK earned the highest ranking in the study. 12 The UK, therefore, has long been considered an international leader in end-of-life care. But is all as wonderful as it seems?

Before and during the pandemic

Social inequalities and unevenly distributed medical resources have persistently deterred end-of-life care access for those from deprived backgrounds, ethnic minorities, and non-cancer patients.³ Informal carers, mostly family members, provide 75-90% of care to people at home during the end-of-life stage. Most people would prefer to die at home.¹ This can move some costs for care on to informal carers who may find the situation to be problematic in the face of poverty. More research is needed to understand the costs of informal end-of-life care. When people with dementia approach the end-of-life, rates and lengths of unplanned hospital admissions

increase. This signifies the need for improving end-of-life community care. A shortage of palliative care expertise and training, particularly in the social care and community settings, is a barrier to provision as there is not enough NHS staff to match patient demand. Information is not shared effectively between care providers which can prevent out-of-hours staff and paramedics from responding in accordance with patients' wishes. Approaches to end-of-life care vary widely across religions and cultures. Having a basic knowledge of world religions is a necessary skill for clinicians. ¹³

During the pandemic, deaths at homes, hospitals, and care homes increased whilst hospice deaths fell. People experienced poorer end-of-life care. There were restrictions limiting family and friends visiting. Symptom management often took precedence over the more holistic aspects of end-of-life care. The pandemic exacerbated inequalities in accessing end-of-life care for minority ethnic groups and visitor restrictions prevented families from being able to fulfil religious and cultural practices. Those without digital skills or access to digital technology and those with connectivity issues struggled with remote consultations. In contrast to other health care services, roughly a third of funding for palliative care services is provided by the NHS, whilst the rest is funded through fundraising and donations. The COVID-19 pandemic affected the fundraising activities of hospices. In response, the Government made around £400 million available to hospices to enable patients to be discharged from hospitals. However, according to Hospice UK, the financial sustainability of hospices is still worrying.¹

The COVID-19 pandemic caused primary healthcare services to dramatically alter their traditional designs of service delivery within a brief short period. Palliative and end-of-life care for people at home was affected from the start of the pandemic. Deaths at home increased while deaths in hospices dropped leading to larger workloads for primary care.¹⁴

To ensure the UK maintains its top position

Existential distress is a profoundly painful fear that one's life, memories, and narratives are increasingly forgotten, unvalued, and irretrievably lost in the past. Policies tend to overlook the complexities of existential distress in endof-life care. Very little UK research has focused on existential distress in contrast to other European countries. Therefore, there is little guidance available for practitioners to understand this issue. The emphasis on autonomy could be a cultural barrier impacting on practitioners' motivation to address the relevant experiences of their patients. The highly professionalised structure of end-of-life care may underestimate the role of patients' significant others thus failing to include their insightful views about the patients' lives in care. Practitioners would benefit from being equipped with the essential skills or tools to manage this issue appropriately.³

In 2021, the National Palliative and End-of-life Care Partnership produced the Ambitions For Palliative And End-of-life Care: A National Framework For Local Action 2021-2026, a refresher of the 2015 version with a reminder that more work needed to be done. Six Ambitions were set out specifically: 1, Each person is seen as an individual; 2, Each individual gets fair access to care; 3, Maximizing comfort and well-being; 4, Care is coordinated; 5, All staff are prepared to care; and 6, Each community is prepared to help. The Ambitions would improve personalised palliative and end-of-life care and reduce health inequalities in light of the pandemic.

The widespread use of electronic systems needed to be encouraged which required investment in information technology. There was a requirement for quality improvement work and building up the evidence base for palliative and end-of-life care. The Local Education and Training Boards were advised to support widespread educational opportunities in palliative and end-of-life care. Systems of end-of-life care were best designed in collaboration with people who had personal and professional experience with palliative and end-of-life care. Distress, whether this was related to physical, psychological, emotional, social, or spiritual reasons, or a combination of these should be addressed. However, the term existential distress was not specifically mentioned. Volunteers are a vital resource in creating good end-oflife care and should be used more effectively. Those with influence over end-of-life care, the bereaved, the carers, and their communities were encouraged to use the framework to disrupt the cycle of poor care. 15,16

The Health and Care Act 2022 supported further integration between the range of services that may be involved in end-of-life care at home.¹⁷ It also placed a duty on integrated care boards specifically to commission end-of-life care. Commissioners have a general duty to ensure that appropriate services, including end-of-life care, meet the needs of the local population. The trend of increasing numbers of people dying at home is welcome as it indicates that outcomes are increasingly reflecting individuals' preferences. It also makes clear the need to plan for increases in demand for community-based services. Integrated care systems should ensure that endof-life care reflects the change that has already started. Very little is known about whether those who died at home during the pandemic had a good death or had care that was well coordinated. Also, little is known about carers' experiences of end-of-life care. 13,18

In 2022, an online survey, sent to a broad cross-section of relevant stakeholders, was conducted to identify where the National Framework for Local Action 2021-2026 had been used. It also identified examples of how it had been used, which Ambitions were being addressed, its utility, and an understanding of the opportunities and challenges involved in its use. Participants noted the desire for resources and education to support service development and implementation. Further research would enhance an understanding of resource availability and the impact of the COVID-19 pandemic. Studies are needed to understand how Ambition 6 (each community is prepared to help) is being understood as well as how it relates to NHS England's and commissioners' approaches to

incorporating 'community' within palliative care. The Framework appears to guide principles and values for service development rather than give direction or benchmarks. Further development of the Framework to bridge the gap between values and action is recommended especially the enactment of the Ambitions. Support on how to create business cases for service development suggested by Ambitions would be beneficial. This support is crucial given that most of the reported service examples were NHS and/or charitable funded. Over half of respondents cited co-design as required to create or sustain their service. ¹⁵

Conclusion

Taking everything into account, numerous publications have highlighted concerns about the limitations of the delivery of palliative and end-of-life care. These limitations may be more noticeable in areas where funding for services is limited or where care is being delivered across wide geographical areas. There is good evidence that palliative care can reduce unplanned hospital admissions. There is a need to create integrated approaches between General Practitioners, community teams, and specialist palliative care services. Policies and service models must focus on multidisciplinary team relationships that are necessary to deliver this care in a productive manner. Establishing support for those involved in the provision of this care through team relationships and training opportunities also merits attention. Improving palliative care can provide an evidence-based approach to set policies prioritizing integrated and personalised care.

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Information

Healthy Ageing 2023: recent updates, reviews and discussions

Anupama Senapati, Prasanta Kumar Mohapatra

GeriCaRe (Geriatric Care and Research Organisation) organized the Healthy Ageing 2023 International Conference on 30 December 2023 as a webinar. This conference allows older adults, their family caregivers, and professionals to participate. This is a free-to-attend conference that brings together professionals and the general public on one stage to share practical knowledge based on recent advances and develop clarity about the issues affecting older adults.

Deliberations

Dr Jayashree Viswanathan, MD, DNB, MRCPsych, Consultant Psychiatrist, Older Age Psychiatry, St John of God Midland Public and Private Hospitals, Midland WA, Australia. She talked about Healthy Ageing and provided practical information about various recent developments. She highlighted individual variations in the ageing process, the role of exercise, the life curve, determinants of healthy ageing, and healthy ageing programmes. She also informed about the vision, guidelines, and support from WHO, UN, and other organisations for older adults.

Prof Nilamadhab Kar, MD, DNB, FRCPsych, University of Wolverhampton, UK informed about the recent developments in old age care. The specific highlights of the availability of three new dementia drugs (lecanemab, donanemab, and remternetug) and one medication (daridorexant) for insomnia. He also mentioned about the digital health gadgets that are available for older adults which can be useful for health monitoring. He emphasized the need for improving health literacy among older adults and their caregivers.

Recent updates on digital health

Continuous and longitudinal monitoring of physical signals of the body can be done by wearable physical sensors. Examples of the measurements include heart rate, respiration rate, body temperature, oxygen saturation, blood pressure, and electrocardiogram (ECG), They can also measure mobility, steps, fall events, gait disturbances, etc. This monitoring can be done remotely with measurements transmitted to the clinicians. ¹

Non-invasive chemical sensors are being introduced which can provide chemical composition of various biofluids, such as sweat, tears, saliva, interstitial fluid, etc. Similarly, glucose levels, potassium levels, stress hormone cortisol, etc. can provide clinically useful

information about the health status in real-time and can be remotely monitored. ¹

These digital sensors are available through various devices such as smartwatches, wristbands, rings, skin patches, microneedles, socks, shoes, insoles, and glasses; or placed directly on the skin at different body locations. Some of these can be operated through the smartphones. Many of these applications are already available and are commonly used. Digital healthcare can improve access to healthcare, provide real-time monitoring, and can be preventative, comprehensive, and cost-effective. There is a need to encourage its use among older adults and healthcare professionals.

Understandably, digital e-health can be helpful in providing timely, effective, and acceptable health care for physical and mental health.³ However despite the acceptance that these digital advancements will help in healthcare and improve the well-being of older adults, robust mechanisms about safety, confidentiality, and ethics are needed to be in place,⁴ before its widespread use, and more studies are needed on their overall effectiveness.⁵

Panini Samman, 2023

For the year 2023, Dr Dilip Kumar Samal received the prestigious Panini Samman from Geriatric Care and Research Organisation, (GeriCaRe) for his work in supporting the care of the older adults in the Angul district in Odisha. Dr. Dilip Kumar Samal started a voluntary organisation called The Medic in 1992 to work on community health. He worked for patients with HIV and AIDS for more than two decades. Later in 2017, he started taking care of destitute older persons, following a request by the district administration. Soon this service grew with more number of older adults being supported by his organisation. In a couple of years, he was running old age homes at Talcher and Chhendipada in Angul district in Odisha. By 2023, his organisation was supporting more than fifty older adults, most of whom have physical and mental health concerns. Besides residential support, his organisation has also supported more than a hundred older adults to return to their family homes. He has supported many older persons during the coronavirus pandemic (COVID-19) and the old age homes had no casualties. Over the years, he has performed the last rites of many older persons from poorer families.

In his journey of social service and endeavours, he has been supported by various national and international donors, many philanthropic individuals, and organisations. The facilities now include a purpose-built old age home. He is planning an orphanage alongside to develop it further as an extended family. As a person, he is very kind, compassionate and religious.

Discussion

The major topic of discussion centered around loneliness in old age and how to address that, especially when older adults have multiple illnesses and mobility issues. It was recognised as a common problem. Continuing or rediscovering hobbies for engagement, attendance at religious or spiritual meetings, maintaining social connectedness, and remaining busy in family roles as much as possible were discussed as some of the options to beat loneliness.

Spirituality is linked to the well-being and quality of life of older adults;⁶ and it helps them lead a positive life despite the usual challenges of old age.⁷ It can also help them cope better with the transitions of life; suffering and pain. It facilitates the process of developing a sense of inner peace, and ability to accept the challenges with calmness. Spiritual care is a core element of palleative intervention. Spirituality can be regularly encouraged for older adults. There are various ways to remain active in a spiritual way of life; that will be satisfying.

The benefit of exercise even in small measures was highlighted, which can be done repeatedly. Guidelines on exercise for different age groups of older adults were provided. Yoga has a special place supporting physical and mental health which can be utilised in daily routine. The problem of muscle wasting in old age and its impact was underscored, and it was suggested that exercises to build up muscles need to be incorporated into the activity plan. The relevance of exercise in preventing illnesses and disabilities, while improving longevity was communicated.

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Manuscript Preparation

Instructions for authors

Introduction

The *Journal of Geriatric Care and Research (JGCR)* (ISSN 2397-5628) is the official publication of Geriatric Care and Research Organisation (GeriCaRe).

Aims and scope

JGCR publishes articles from all fields relevant to old age, with an objective of encouraging evidence based practice in the care of elderly and to share information about good practice.

It is a multidisciplinary, peer-reviewed, scholarly journal covering diverse areas such as geriatric medicine, psychiatry, neurology, nursing care, end of life care, public health and related fields like gerontology, sociology, psychology, culture and law along with Allied Health Sciences like occupational therapy and physiotherapy, etc. Examples of broad areas covered by the journal are: Care and intervention for various specific conditions, disorders or disabilities, standards of care, examples of good practice, end-of-life care, elder abuse and its prevention, legal aspects relevant to old age and support; cultural and ethical issues associated with care, etc. Its readership includes not only the professionals in these fields but also older persons and their caregivers.

Besides regular issues, theme based special issues focusing one aspect of care are also published periodically.

Editorial process

The *JGCR* follows in principle the Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals by the International Committee of Medical Journal Editors (ICMJE) and the Committee on Publication Ethics (COPE).

Contributions for *JGCR* are accepted for publication on the condition that their substance (whole or part) has not been published or submitted for publication elsewhere, including internet. If there are other papers from same database, then the authors must send all details of previous or simultaneous submissions.

All submitted articles are peer reviewed. At the first step, the articles are assessed by the editorial board for its suitability for the formal review.

If found suitable, the manuscripts undergo a double-blind peer review. The suggestions received from reviewers are conveyed to the corresponding author. When appropriate, the author is requested to provide a point by point response to reviewers' comments and submit a revised version of the manuscript.

Manuscripts accepted for publication are copy-edited to improve readability and to ensure conformity with *JGCR* style.

Authorship

Authorship credit should be based only on substantial contribution to:

- Conception and design, or analysis and interpretation of data
- Drafting the article or revising it critically for important intellectual content, and
- Final approval of the version to be published

All these conditions must be met. Participation solely in the collection of data or the acquisition of funding does not justify authorship. In addition, the corresponding author must ensure that there is no one else who fulfils the criteria but has not been included as an author.

Group authorship is permitted, but in this case individual authors will not be cited personally.

If a professional medical writer was used for manuscript preparation, their name and contact details must be given in the acknowledgement and any conflicts of interest must be disclosed.

The corresponding author must sign the contributors form on behalf of all the authors, once a manuscript has been accepted. This author must take responsibility for keeping all other named authors informed of the paper's progress.

Unless otherwise stated corresponding author will be considered as the guarantor of the article. However one or more authors/contributors can be guarantor. The guarantor accepts full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

Declaration of competing interest

All submissions to the *JGCR* (including editorials and letters to the Editor) require a declaration of competing interest. This should list fees and grants from, employment by, consultancy for, shared ownership in, or any close relationship with, at any time over the preceding three years, an organisation whose interests may be affected by the publication of the paper.

Ethics approval of research

The *JGCR* expects authors to follow the World Association's Declaration of Helsinki and base their article on researches conducted in a way that is morally and ethically acceptable. The research protocol must have been approved by a locally appointed ethics committee or institutional review board.

Every research article must include a statement that the investigators obtained ethical approval for the study (or an explanation of why ethical approval was not needed) in the methods section of the manuscript with the name and location of the approving ethics committee(s).

Patient consent and confidentiality

A statement regarding informed consent must be included in the methodology. Studies involving humans must have written informed consent from the patients. Where the individual is not able to give informed consent for lack of mental capacity, it should be obtained from a relative (ideally next of kin), legal representative or other authorised person. If the patient is dead, the authors should seek permission from a relative (ideally next of kin), legal representative (usually next of kin) or other authorised person as a matter of medical ethics. If consent cannot be obtained, the head of medical team/hospital or legal team of the authors' institute must take responsibility that exhaustive attempts have been made to contact the family and that the paper has been sufficiently anonymised not to cause harm to the patient's family. Anonymisation means that neither the patient nor anyone could identify the patient with certainty. Such anonymisation might, at an extreme, involve making the authors of the article anonymous.

The authors should check the specific laws in their country. Contributors should be aware of the risk of complaint by individuals in respect of breach of confidentiality and defamation; and must archive the signed informed consent form.

The process used to assess the subject's capacity to give informed consent and safeguards included in the study design for protection of human subjects should be mentioned.

Publication Ethics

Authors should consider all ethical issues relevant to publication. This includes (but not restricted to) avoiding multiple submission, plagiarism and manipulation of figures/data. Any concerns in this regard must be brought to the attention of the Editor and these will be investigated by procedures recommended by the Committee on Publication Ethics (COPE). If conclusive evidence of misconduct is found, the *JGCR* undertakes to publish a correction or retraction of article as necessary.

Clinical trial registration

All clinical trials must be registered in a public trials registry. This is a requirement for publications of the trials.

Qualitative research

The *JGCR* welcomes submissions of reports of qualitative research relevant to the scope of the care of elderly.

Article submission

Manuscripts for publication are submitted via email <jgcr.gericare@gmail.com>.

The *JGCR* is not responsible for statements made by authors. Material in the *JGCR* does not necessarily reflect the views of the Editors or of GeriCaRe.

Type of manuscripts

Research article

The research article should normally be between 3000 and 4000 words in length (excluding references, tables and figure legends). Only the essential references should be given, preferably not more than 25 beyond those describing statistical procedures, psychometric instruments and diagnostic guidelines used in the study. Authors are encouraged to present key data within smaller tables in the appropriate places in the running text. This applies also to review articles and short reports.

A structured abstract not normally exceeding 150 words should be given at the beginning of the article, incorporating the following headings: **Background**, **Aims**, **Method**, **Results**, **and Conclusions**.

Key words: Up to six key words should be provided. Please use Medical Subject Headings (MeSH) as key words.

Article should have **Introduction, Method, Results and Discussion** sections. Authors may use relevant subheadings under these sections. Introductions should normally be no more than one paragraph; longer ones may be allowed for new and unusual subjects. The Discussion should always include limitations of the paper to ensure balance. A paragraph of practical implications of the observations is encouraged.

Short report

Short reports (brief communications) are based on original research, observational or evaluation studies, clinical audits etc. These are structured as research

articles and require an unstructured abstract of one paragraph, not exceeding 100 words; and key words. The report should not exceed 1500 words (excluding references, tables and figure legends) and contain no more than one figure or table and up to 10 essential references beyond those describing statistical procedures, psychometric instruments and diagnostic guidelines used in the study.

Case report

Case reports and series require up to unstructured 100 word abstract, and the length should not exceed 1000 words (excluding references, tables and figure legends). The written informed consent of the individuals must be obtained and submitted with the manuscript. Please refer to patient consent and confidentiality paragraph for further detail. In general, case studies are published in the *JGCR* only if the authors can present evidence that the case report is of fundamental significance and it is unlikely that the scientific value of the communication could be achieved using any other methodology.

Review

Systematic and narrative review articles should be structured in the same way as research article, but the length of these may vary considerably, as will the number of references. It requires a structured abstract like that of research articles.

Short review

These articles focus on highly topical issues based on evidence. Professional perspectives, viewpoints, commentary and opinion are included here. It can also include clinical review relevant to the practitioners. These articles are usually more broad-based than editorials. They can include tables and figures. Usual length is around 1500 words (excluding references) with an unstructured abstract up to 100 words.

Editorial

Editorials require an unstructured summary of one paragraph, not exceeding 50 words. Editorials should not exceed 1000 words and may contain no more than one figure or table and up to 10 essential references.

Letters to the Editor

Letters may be submitted either as responses to published articles, to inform about particular situation or raise pertinent issues, as expert opinion or as general letters to the Editor. Letters may be up to 400 words in length with a maximum of 5 references.

Insight

These articles include variety of topics which may reflect an individual perception, involvement or contribution to geriatric care. It can include good practice examples, inspirational experiences and highlight neglected areas. Essays in descriptive prose can be submitted on any topic related to geriatric care. These are usually written by a single author but a second author may be included occasionally. The length of the articles may vary considerably depending upon the topic and may be up to 2000 words excluding references. An unstructured summary of around 100 words is preferred but not mandatory. Use of subheadings is encouraged.

First person account

In first person accounts *JGCR* publishes experiences of older persons or their care providers about the care and concerns of the elderly, that can be considered significant and provide learning points for others.

Columns

These comprise a range of materials considered to be of interest to readers of the *JGCR*. This section includes reviews on book, film or web resources as short articles up to 400 words. Some other examples include News regarding developments that can influence the care of elderly, poems, paintings, photographs, quotations, information about important internet links, etc. These articles are published individually or as fillers at the end of other articles where space allows.

Preparation of Manuscripts

Prepare article in Word, A4 size page, with 1 inch margin, double spaced throughout.

Article information page

- 1. Type of manuscript:
- 2. Title of the article: Brief and relevant
- 3. Name of all the authors: (underline Last name)
- 4. Details of authors: academic degrees, professional position, institutional affiliations, professional address, email
- Corresponding author: name, address, phone, e-mail and ORCID
- 6. Contributions of each author:
- 7. Word count for abstract:
- 8. Word count for the text (excluding references):
- 9. Number of tables: (total number of tables and figures should not be more than 10, preferably less than 5.)
- 10. Number of photographs/images (to be provided separately in high quality JPEG files):
- 11. Acknowledgement:
- 12. Competing interests:
- 13. Funding
- 14. Suggested Reviewers Up to 3, (not from authors' institution). Name, Position, Institution and Email

No identifiable details beyond this page.

Article Text pages

The article text pages do not contain any identifiable information, for a blind review. It should contain: Title of the article, Abstract and Key words (depending upon the article type) and the Text of the article. Please refer to article types for detail information. As a general rule,

please have an Introduction and Conclusion subheadings whenever possible along with other required subheadings.

References

Authors are responsible for checking all references for accuracy and relevance in advance of submission. All references should be given in superscripted number in the order they appear in the text. Place superscript reference number after commas and full stops, unless the superscript is attached to authors name or title of book/database. At the end of the article the full list of references should follow the ICMJE style. If there are more than six authors, the first six should be named, followed by 'et al'.

Example of journal articles:

The authors' names are followed by the full title of the article; the journal title abbreviated according to the PubMed; the year of publication; the volume number; (issue number in bracket); and the first and last page numbers:

1. Singh SP, Singh V, Kar N, Chan K. Efficacy of antidepressants in treating the negative symptoms of chronic schizophrenia: meta-analysis. Br J Psychiatry. 2010; 197(3): 174-9.

References to books should give the names of any editors, place of publication, editor, and year. Examples are shown below.

- 2. Murray PR, Rosenthal KS, Kobayashi GS, Pfaller MA. Medical microbiology. 4th ed. St. Louis: Mosby; 2002.
- 3. Meltzer PS, Kallioniemi A, Trent JM. Chromosome alterations in human solid tumors. In: Vogelstein B, Kinzler KW, editors. The genetic basis of human cancer. New York: McGraw-Hill; 2002. p. 93-113.
- 4. Foley KM, Gelband H, editors. Improving palliative care for cancer [Internet]. Washington: National Academy Press; 2001 [cited 2002 Jul 9]. Available from: http://www.nap.edu/books/0309074029/html/.
- 5. Cancer-Pain.org [Internet]. New York: Association of Cancer Online Resources, Inc.; c2000-01 [updated 2002 May 16; cited 2002 Jul 9]. Available from: http://www.cancer-pain.org/.

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Tables

Tables should be numbered and have an appropriate heading. The tables should be mentioned in the text such as Table 1 and the desired position in the manuscript should be indicated. Information in tables must not be duplicated in the text. The heading of the table, together

with any footnotes or comments, should be self-explanatory. The table should be placed at the end of the manuscript after references, each in a separate page. Authors must obtain written permission from the original publisher if they intend to use tables from other sources, and due acknowledgement should be made in a footnote to the table.

Figures

Figures must be of high quality and provided in JPEG files separately. They should be clearly numbered and include an explanatory legend. Legends can be provided at the end of the article after the references. All figures should be mentioned in the text (such as Fig 1) and the desired position of the figure in the manuscript should be indicated. Authors must obtain written permission from the original publisher if they intend to use figures from other sources, and due acknowledgement should be made in the legend.

For ease of formatting please use the available article template.

Abbreviations, units and footnotes

All abbreviations must be spelt out on first usage and only widely recognized abbreviations will be permitted. Abbreviations usage should be consistent throughout the article. Use abbreviations sparingly; consider using one if it is repeated more than three times.

The generic names of drugs should be used.

Generally, SI units should be used; where they are not, the SI equivalent should be included in parentheses.

Footnotes are not allowed, except table footnotes.

Statistics

Methods of statistical analysis should be described in language that is comprehensible to most readers. Raw data for the studies may be asked at any time up to 5 years after publication of research in the *JGCR* and the authors are suggested to keep these safe.

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For its activities, GeriCaRe has received the Vayoshreshtha Samman, an Indian National Award in 2016 as the 'Best Institution for Research in the Field of Ageing' by the President of India.

Sharing knowledgebase and making the research evidence utilisable in the community is a key focus of GeriCaRe. It conducts and supports various research and development projects in various disciplines including health, psychology, sociology and other allied fields.

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