June 8, 2018

An Evidence-Based Policy Brief

Community-Based Palliative and Supportive Care for Older Persons in Nigeria

Executive Summary

Key messages

Problem Statement

- Palliative care needs are increasing in Nigeria, due to a combination of population growth, longevity, and increasing incidence of chronic diseases.
- Although older persons in Nigeria prefer to die at home, the majority cannot do so, due to lack of supportive structures in the village or community. This results in inappropriate use of more expensive acute services
- Awareness and benefits of community based palliative care, which could meet the desires of older presons to die at home, is limited.
- The Government currently devotes few resources to health care, and prioritises investments in maternal and child health and infectious diseases. Discrimination against older persons, who are treated as a minority, is widespread, and limits their access to care. Few have health insurance.
- National health policy in Nigeria is insufficiently robust to support the East and Southern Africa home-based care and community support model

Policy options

- Require all units of government to implement programs of palliative care for older persons as per their stipulated constitutional rights to healthcare and dignity (Articles 17 3(d) and 34 (1) Constitution of Nigeria)
- Require national/state assemblies to sponsor and legislate social security for the older persons and support informal caregivers
- Expand workforce capacity in palliative and end-of-life care for older persons by adopting task-shifting policies to empower the Community Health Extension Workers (CHEW)
- Make basic palliative care education mandatory for all different categories of staff to ensure every patients needing palliative care receives it is as part of primary health care services.

Implementation strategies

- Sensitize government officials, healthcare workers, and other stakeholders within the community regarding the benefits of this model of palliative care
- Use existing healthcare facilities within the community to strengthen the referral process along three tiers of care
- Establish a home based care service
- Expand knowledge and capacity of community health workers to provide palliative care through train the trainers programs
- Scale up balanced opioid availability and accessibility for palliative care providers

The problem:

Currently, more than 6 millions older persons in Nigeria lack adequate care for their health-related challenges. Older persons now constitute 20% of the Nigerian population. Like many countries, Nigeria is currently experiencing the growth of rapidly ageing populations, a large number whom will, in the nearest future, constitute the frail elderly terminally ill. Age discrimination against elderly people contributes to their being treated like minors, with no rights. Challenges range from lack of social support and care, fragmented budgetary resources, and no specific patterns of health system care delivery. The erroneous believe that palliative

care is exclusively for cancer patients and dying people induces phobia among patients and health care providers to integrate this service for other life-limiting non-oncologic conditions.

Vulnerable older persons suffer from life-limiting diseases associated with older age such as end-stage cancer, cardiovascular conditions, liver and renal failure, and metabolic, respiratory and neurological issues. In addition, they experience disability (frailty), lack of adequate family support, loneliness, abandonment, self-neglect, poverty, pain, anxiety, depression, fatigue and existential despair.

Most Nigerian older persons live in rural areas with no geriatric specialists or clinics. Evidence-based studies, cultural norms, and logistical limitations have confirmed their preference have life-limiting illness managed at home. Access to home-based palliative and supportive care services has been shown to improve the quality of life and dignity of older persons, empowering them and providing the opportunity to be surrounded by their loved ones at home. Integration of palliative and supportive care into the Nigerian health system is hampered by lack of trained staff, lack of facilities, lack of robust home-based care culture, and no funding. Basic palliative care services for patient and their families would lower the burden of severe health related suffering on the families and facilities, lowering hospitalization rates.

Palliative care services are gradually spreading across Nigeria but most facilities are still concentrated at the tertiary level of care. The service is unavailable at the community level; this is not unexpected as the country is yet to invest on Home-based care services as observed in other African countries like Kenya, Uganda and South Africa.

Size of the problem

Older persons in Nigeria are expected to number 25.5 million in 2050 (United Nations, 2012) Severe Health Related Suffering (SHS) related to the burden of cancer, heart disease, kidney and liver disease, mental health problems, dementia, and other conditions, is largely untreated in this population, especially in rural areas.

Factors underlying the problem

Ageism and systemic discrimination against older persons results in their being treated as minors. Challenges range from lack of geriatric care, no specialised budgets no specific patterns for health system care delivery. The erroneous believe that palliative care is meant for cancer and dying people induces phobia among patients and health care providers and prevents integration of this service for other life-threatening non-cancer conditions.

Three policy options

Policy option 1:

Provide community-based palliative and supportive care for the older persons

Despite the fact that Nigerian culture abhors discussions about illness and dying, death is inevitable among the population of seriously ill older persons, who most would benefit from the end-of-life care. The patients' burden of serious health related suffering (SHS) includes stress, chronic pain, disability, and social, emotional, psychological and spiritual issues that also affect their family and informal caregivers. Inasmuch patients always wish to, or prefer to die at home peacefully in dignity, it is the responsibility of the health system to ensure good quality of life to both the patient and the family to access good health preferably within their domains.

Benefits

- Increases comfort and the opportunity for terminally-ill patients to die at home

- Reduces hospitalization rates and out of pocket expenses for resource limited households.

Policy option 2:

Support informal caregivers

Informal caregivers are family members, friends, and neighbors who bear a stressful burden of care in that many have to also work , go to school, and care for other household members. Negative consequences of stress include preventable non-communicable diseases such as cancer, heart disease, and substance use disorder, exhaustion, inadequate sleep, anxiety and depression. Home based palliative and supportive care and the presence of empowered formal caregivers provides respite as well as employment potential for other seriously ill community members, leading to improved quality of life, health, and sometimes income for family members.

Benefits:

- Trained and supported family caregivers guarantee better psychological coping outcomes in the presence of distress;
- Ensures improved quality of life, health, education, and respite for family caregivers

Policy option 3:

Invest in, and formalize the community health workforce (CHW)

The limited workforce at the community level is compounded by inadequate facilities, medicines, and funding. The task is to identify the necessary resources, establish a collective, participatory, multi-stakeholder planning and implementation process to draft policies and budgets. Sustainable health workforce education, training, and deployment must replace unsustainable outside donor funding. Existing staff can also be utilized, following a task-shifting model in the context of local public health system clinics that could provide basic primary and palliative care.

Benefits:

- Adequate funding and success of the program enhances continuity, sustainability and community participation as part of a social-welfare package
- A long lasting adequate health workforce development whose availability at the community level would guarantee sustainability.
- The evidence shows that home care services provided by community health workers who receive adequate training and compensation is cost-effective and cheaper than emergency health system usage, and precludes the need for new capital investment.

Below are the identified barriers and issues related to the implementation of the identified three policies and some feasible implementation strategies:

Implementation considerations

Barriers to implementation	Strategies for implementation
Inadequate knowledge about home-based palliative and supportive care. - This includes lack of awareness by the public, health care providers and the health care policy makers	Strategies must include sensitization and advocacy to government officials, health care workers and mobilization of stakeholders within the community around this model of care.

Lack of supportive structures for home based care provision and poor referral processes. - Nigeria lacks a home-based care culture and some people maybe skeptical, as this is not yet entrenched into our national health system. There is lack of good referral system between the community health facilities and the urban hospitals.	▪ More effective use of existing health facilities within the community; strengthening the referral process across the three tiers of care. ▪ Establishment of home–based care services program through adequately compensated CHWs. ▪ Government should invest and empower the people towards effective utilization of both formal and informal caregivers. It is also important to entrench a standard and good monitoring protocols.
Knowledge, competence and attitudes of health workforce - Some clinicians are wary of embracing this model of care believing it is meant only for the dying people. Lack of good prognosticating skill often leads to a late referral. - The formal and informal caregivers and community volunteers are good asset towards supporting and assisting elderly ones in the community but they lack the appropriate skills needed for effective interventions.	▪ Improve the knowledge; competency and attitudes of the community-health care workers under the supervision of specialist in palliative care to raise generalist practitioners by organizing training of trainer's education and trainings. ▪ Train caregivers and volunteers in the community to improve confidence and cooperation of all stakeholders.
Non-availability of essential medications especially opioids The stockout syndrome at the grassroots or rural health care facilities could be a challenge considering funding and other logistics.	▪ Adequate provision of essential medicines, especially opioids, is crucial. ▪ Strengthened supply chains are essential for scaled-up opioid accessibility and affordability. This requires multi-stakeholder dialogues to empower health workers to prescribe opioids in the community.
Inadequate financial resources - Accessing good health requires resources. Health funding in Nigeria is *"fee for service,"* a resource most older persons lack. Few have health insurance and most rely on their families, who are also struggling.	▪ Public funding and cost sharing for health care financing by the community is essential. ▪ Introduce Community Health Insurance ▪ Create special budgets to alleviate the sufferings of cancer patients and frail elderly through gains realized by tobacco taxes and reduction of agricultural subsidies.
Competing priorities and Government preference investment for *under-5 age* group and communicable diseases.	▪ There is need to fully integrate this care into the health care policies and a paradigm considerations for the older persons with chronic health challenges.
Lack of National health care policy for Palliative Care in Nigeria.	▪ The approval and implementation of palliative supportive health care policy for the aged is needed to facilitate equity recognition of the rights of older persons.

Next steps

The aim of this policy brief is to foster dialogue and judgements that are informed by the best available evidence. The intention is *not* to advocate specific options or close off discussion. Further actions will flow from the deliberations that the policy brief is intended to inform. These might include, for example:

- Convene a multi-stakeholder dialogue with ministry officials from the Departments of Health, Education, Finance, Drug Control, and Social Services; include palliative care, and primary healthcare providers from different regions of the country, as well as patients and families if possible, to assess the extent of the problem and plan for change;
- Inform the Hospice and Palliative Care Association of Nigeria and other professional associations about this initiative and invite them to the Stakeholder Dialogue;
- Build transversal relationships with Nigerian human rights organisations, faith based organisations, and other civil society organisations to create more diverse awareness of the need for, and benefits of community based palliative care for older persons.

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