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Building momentum: People-centred cancer care at all ages

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Introduction

The global ageing population is a hallmark of successful development. The proliferation of policies and programmes to protect and promote health have led to substantial declines in infant mortality and have extended global average life expectancy from 64.2 years in 1990 to 72.6 years in 2019. (1) However, in many places around the world, increases in healthy life expectancy (that is, the number of years lived in self-assessed good health) have not kept pace and an increasing number of older adults are living with one or more health conditions.

The 2030 Agenda for Sustainable Development recognises these trends and prioritises health for all, at all ages, as a crucial element of sustainable social, economic and environmental development. This was further reiterated in 2019 in the Political Declaration on universal health care (UHC), which calls on governments to strengthen health systems to deliver people-centred care that leaves no-one behind (2) as well as in the UN Decade of Healthy Ageing (2021-2030), which recognises the importance of older adults' access to social and economic care as a component of sustainable development. (3)

In spite of this, there has not been comprehensive action regionally or nationally to translate these political commitments into policies and programmes for older adults. As the number of adults over the age of 65 continues to increase, so too does the number of older adults living with one or more non-communicable diseases (NCD) and who require treatment and supportive care. This brief aims to highlight the unmet needs of older adults living with NCDs and co-morbidities and explore how countries are responding and fostering healthy ageing as an integral part of UHC.

Background

Globally, we are experiencing a '*longevity revolution*' in which the proportion of the world's population over the age of 65 is increasing rapidly. (4) There are currently more than 703 million people worldwide over the age of 65 years, equating to 9.1% of the global population. Estimates suggest that the proportion of the population over the age of 65 is expected to rise to 15.9% (1.5 billion) by 2050 and 29.7% (2.4 billion) by 2100. (4,5) This will reshape social, political and economic landscapes at global, regional and national levels over the coming decades. (4)

The rate at which the global population is ageing is also accelerating. The fastest growth is likely to be seen across the least developed countries where the population of over-65s is projected to grow 31% between 2019 and 2050. (4) Given this, the time available to governments to adopt policies and establish the health and social systems necessary to care for older adults is reducing. For example, in France, the increase of over-60s as proportion of the population from 10% to 20% took place over nearly 150 years; however, WHO estimates suggest that Brazil, China and India will have just over 20 years to navigate the same demographic change. (6) This trend is widespread and, by 2050, estimates suggest that 80% of all older adults will live in low- and middle-income countries (LMICs). (6)

As older adults are more likely to live with at least one health condition, the '*longevity revolution*' is likely to increase the number of people living with at least one health condition and therefore demands on health and social care services. (7) Given the rate at which the population is ageing, the time available to governments to establish or scale-up services to support older adults is shrinking. This will pose a series of challenges as government must work to ensure countries have the political, financial, human and physical infrastructure in place to meet the needs of older adults.

COVID-19: Putting the health of older adults in the spotlight

The COVID-19 pandemic has demonstrated the importance of investing in robust and coordinated health and social care systems to protect and promote healthy ageing across older populations. Age is the most significant risk factor for severe COVID-19 infection and mortality across all countries. Compared to individuals under 55, one study found that adults aged 65 and over were 62 times more likely to die from COVID-19, while the mortality rates amongst those aged 55-64 years were 8.1 times higher. **(8)** The presence of a non-communicable disease (NCD), such as diabetes, high blood pressure, heart disease, lung disease or certain cancers, increases the risks of severe COVID-19 infection and mortality further. **(9)**

In addition to this elevated level of risk, essential health services for NCDs have been substantially disrupted. Pre-pandemic the strong focus health systems placed on managing acute health conditions, over managing more complex chronic health needs that tend to arise with increasing age, put many health systems at a disadvantage when it came to responding to the needs of existing patients during the pandemic. WHO estimates indicate that general NCD diagnosis and treatment services have been affected in 69% of countries, while cancer diagnosis and treatment services have been adversely affected in 55% of countries. **(10)** This has resulted from lockdowns or restrictions on movement, fear around accessing services driving down demand, disruptions or cancellation of clinical services and the reallocation of funding to national COVID-19 responses.

When combined, this is likely to result in an increased number of patients with cancer and other NCDs presenting for treatment with later-stage disease and greater complications. For older adults and people with co-morbidities, these delays are likely to increase the complexity of treatment and reduce the opportunities for cure. In this sense, the COVID-19 pandemic is making a compelling case for more extensively considering the needs of older adults as a unique population and revise policy and health systems changes to address preventable morbidity and mortality.

Health over the life course

Policy interventions have been effective in helping to improve health throughout the life course.[1] Over the last 30 years, high-income countries (HICs) have seen a decrease in the rates of severe disability in older people through coordinated health promotion and disease prevention policies, such as improving nutrition and screening for specific cancer types. However, these policies have not yielded substantial changes in mild to moderate disability amongst this age group, meaning that many individuals in these populations are living longer, but not necessarily in good health. (11)

At the same time, increasing exposure to key NCD risk factors over the life course has increased the likelihood of individuals developing one or more NCDs. The presence of multiple conditions, or co-morbidities, can occur because diseases share the same risk factors, or because some diseases predispose individuals to developing others. (7) Emerging data suggests certain conditions often occur together or "cluster" in individuals, such as diabetes and heart disease or the prevalence of certain cancers in HIV+ individuals. Over the past 20 years this trend appears to have increased with 13-95% of people accessing healthcare globally reporting co-morbid conditions; however, the wide range in the data indicates just how little is known about the burden. (12)

What is co-morbidity?

Co-morbidity, where a person lives with one or more disease or condition at the same time, is increasingly becoming the norm globally, and the number of people living with more than one NCD has steadily increased over the past 20 years. NCD co-morbidities can occur because diseases share the same risk factors, or because some diseases predispose individuals to developing others. **(13)**

Co-morbidities create a series of interconnected challenges for individuals, their families and communities, and clinical teams. Ageing is not a linear or consistent trend and, as such, individuals of the same chronological age may have significantly different capabilities. (14) Instead, ageing can be thought of as a universal set of biological processes that contribute to declines in functional capacity and increased risk of morbidity and mortality over time. (15) The ageing process is the product of a mixture of biological and personal characteristics (such as sex and ethnicity) and environmental factors (including social networks, housing and geography), making this group highly heterogeneous and worthy of greater focus in policy discussions.

For cancer, age is one of the leading risk factors. Cancers are more prevalent in older adults, with cases amongst the over-65s accounting for 51% of the global cancer burden and 59% of mortality, often as a result of these cancers being detected at a more advanced stage. (16) The impact of co-morbidities on cancer patients, and older adults in particular, is substantial. Data from the US indicates that around 40% of cancer patients had one additional condition, and 15% two or more. (17) However, the prevalence of co-morbidities varies by cancer type with those more closely associated with key external risk factors (like lung cancer and tobacco use) occurring more frequently with conditions like hypertension, COPD and diabetes. (18)

The impact on individuals can also vary. Some individuals with co-morbid conditions might have their cancer diagnosis picked up earlier as a result of more frequent engagement with health systems, while others, such as those with dementia, might have cancer symptoms missed or mis-attributed. (19) Of great concern, however, is emerging data which suggests that patients with co-morbid conditions are less likely to receive curative treatment, independent of patient age. (18,17)

[1] A life course approach to health explores "physical and social hazards during gestation, childhood, adolescence, young adulthood and midlife that affect chronic disease risk and health outcomes in later life. It aims to identify the underlying biological, behavioural and psychosocial processes that operate across the life span." WHO and ILC: https://www.who.int/ageing/publications/lifecourse/alc_lifecourse_training_en.pdf

For older adults, this has been attributed in part to the limited use of geriatric assessments, which help clinical teams systematically investigate factors crucial to a patient's wellbeing, such as co-morbidities, polypharmacy, functional status and quality of life. (20) Another key issue is that older adults are often missing from randomised clinical trials that provide the evidence base for developing cancer treatment decisions. (21) As a result, oncologists are required to extrapolate from existing data, generated from younger patients who may have fewer co-morbidities, higher tolerances and lower risks of adverse side effects, and therefore the dosages and impacts on older adults are often not well understood. (22,20)

Barriers to people-centred care

As the global population of older adults and those living with multiple conditions grows, greater pressure will be placed on health systems to meet these needs. However, the siloes within health systems are creating a series of interconnected challenges or barriers to older adults and those living with multiple NCDs to access the care they need. These can include:

Ageism. This term refers to the stereotypes, prejudice and discrimination directed towards people because of their age. (23) WHO recognises that it can be institutional, interpersonal or self-directed (24) and multiple studies have found that ageism shapes whether older adults will receive care as well as the type and quality of services which are delivered (25). A systematic review of cancer and ageism found that healthcare workers were far more likely to withhold treatments for older adults compared to younger adults, leading to significantly worse health outcomes in 95.5% of studies. (26) As countries explore innovations across the health sector, including the use of digital technologies, the impact of ageism becomes clearer. Older adults are often left out of the research and development process for technologies, and negative stereotypes can often be used in research and design, limiting their engagement or consultation and therefore the effectiveness of potential innovative solutions for older adults. (27).

Limited data on which to make evidence-based policies. Many national, regional and global health data systems (including the SDGs) focus on 'premature mortality and, as a result, cut off reporting at 70. Yet the average global life expectancy for both men and women exceeds 70. Likewise, many vital registration systems or disease registries are not able to systematically capture and report data people living with multiple NCDs (or co-morbidities) to monitor morbidity. This means that governments around the world are taking decisions with incomplete information, which is likely to skew where and how health resources are being utilised, including to support older adults and those with co-morbidities.

Separate policy approaches to ageing, cancer and NCDs. Despite the prevalence of cancer and co-morbidities amongst older adults, many governments and international organisations continue to respond to these interconnected topics through separate policy responses. This misses opportunities to integrate health and social care planning, service delivery and engagement of older adults in policy discussions.

Lack of financial protection measures. For many people living with more than one NCD the costs are "super additive", meaning an individual's total healthcare costs are greater than the sum of the costs for the each NCD. (28) As such, living with one or more NCDs at any age poses a major financial risk. Older adults may be particularly at risk as many are dependent on fixed incomes (such as pensions) or because they depend on support from family members and other networks. Globally, around 68% of the population above pensionable age receive a pension but this drops to 23% in sub-Saharan Africa. (29) Mechanisms to protect older adults and those with co-morbid conditions need to keep pace with this growing population as part of the drive to UHC and should be integrated into social protection measures. (30)

Limited understanding of the investment needs and returns. Governments rarely include co-morbidities within cost-benefit analyses for health interventions or policies, due in part to the limited data on people living with multiple NCDs. This excludes the full suite of potential health and social gains from proposed policies, in particular for those aimed at social determinants of health, disease prevention and improving primary health care. It also leaves questions unanswered such as the clinical and economic effectiveness of particular interventions, for instance extending screening to older adults and should be taken up as part of ongoing work to build the investment case for cancer and NCDs.

Poor public awareness around NCDs and what healthy ageing can look like. This is a major hurdle to improving the health and wellbeing of populations, in particular older adults and people with multiple NCDs. It leads to preventable exposure to risk factors, limited participation in screening and health promotion activities and potentially missing the signs and symptoms of early disease. Late diagnosis of cancer in older adults is common and reduces the opportunities for successful treatment; it may also contribute to higher levels of excess mortality that have been documented amongst older adults in the first few months after diagnosis. (31) Addressing this and reducing the stigma and misconception around ageing and NCDs will be critical to reducing the burden on individuals and health systems.

Limited health staff. Globally, there is a shortage of healthcare staff, with the most acute shortfalls seen in low- and middle-income countries (LMICs). (32) When looking at the availability of staff who have been trained to manage people living with multiple conditions and specialist staff with the expertise to manage more complex cases, the situation becomes even more concerning. A 2014 systematic review of surveys of undergraduate education found that only 41% of the countries reported some geriatric content in the medical school curricula. (33) This lack of resources and workforce training in the management of the complex needs is putting the wellbeing of older adults at risk.

Fragmented physical infrastructure. As a result of siloes within health systems, older adults and people living with multiple conditions can be required to visit multiple health facilities to receive the care they require, such as prescriptions or supportive care from different clinics. The indirect costs stemming from this physical fragmentation can present substantial time and financial barriers to accessing care, particularly where social support systems are not in place to address these opportunity costs. For older adults there may also be physical challenges accessing healthcare facilities, leading individuals to prioritise care from the most accessible provider, which might not always be able to deliver the most appropriate care.

Lack of guidelines for the diagnosis and clinical management of co-morbidities. Once successfully diagnosed, the presence of multiple NCDs can present challenges to the effective treatment or management of each individual disease. For example, once an older adult has received a cancer diagnosis, the presence of co-morbidities can complicate the development and delivery of appropriate care pathways. While there has been an increase in the number of guidelines available to support clinicians, many take a disease-centred approach and do not address co-morbidities and the additional burden that they may place on an individual's physical and mental health. (34) This can lead to increased risk of medical errors, as healthcare professionals are required to extrapolate from existing data, and it may also increase barriers to effective self-care.

Driving change

Responding to the growing burden of people living with multiple NCDs, particularly older adults, will require health systems to break down many of the siloes that currently exist to improve the coordination of person-centred care and integration of services.

Below are examples that demonstrate how different countries are working to respond to the needs of growing populations of older adults and people living with multiple NCDs.

Rwanda: Advocating for integrated care services through Primary Health Care

Older adults are highly respected in Rwanda; however, they often lack a clear political voice, tending not to be represented in public consultations. The Rwandan genocide has limited the number of older adults living in the country today but it is forecasted that the number of Rwandans over 60 years will increase by 300% over the coming decade. With a rapidly ageing population, the Rwandan health system is faced with the need to adjust to an increasing demand for NCD prevention and care services, with 63% of deaths in those aged over 40 years already due to NCDs[2].

Building community services for co-morbidities

The right to health is reflected within Rwanda's constitution and UHC is the cornerstone of the Health Sector's Strategic Plan. To support the provision of healthcare to older adults, the government has recently started to subsidise health insurance for older adults, which would otherwise be prohibitively expensive and seen as competing directly with the need to meet essential needs such as food and shelter.

Rwanda has also been working towards a steady decentralisation of the health system across its 30 districts, by making substantial investments in community and primary healthcare services, which are vital to the provision of care for older adults living with co-morbidities. 58,000 community health workers (CHWs), 885 health posts, 510 health centres, 36 district hospitals and four provincial hospitals are linked by a referral pathway with national referral hospitals. Nurse-led NCD clinics in health centers bring NCD care closer to the community and integrate lessons learnt from the country's experience running HIV clinics. National NCD management and clinical guidelines linked to NCD medicines available on the country's essential medicines list support the quality of care provided.

However, cancer services still tend to be centralised, for example the Rwanda Cancer Centre, which is equipped with radiotherapy, was opened in 2020 close to Kigali, the country's capital city.[3] This results in cancer patients facing long-distance travel and high costs of care, which can pose a huge barrier for older adults who may be frail or lack the necessary resources.

Advocacy activities

The NCD Alliance Rwanda recognised that the growing burden of cancer and other NCDs in Rwanda has the potential to overwhelm the health system in future years. They also identified an opportunity to further integrate NCD prevention, early detection and basic care through the country's existing community health worker system as well as through existing health posts and health centres.

To respond to the need, the NCD Alliance Rwanda created a coalition of 24 civil society organisations, including people living with cancer, with the following mission:

- Advocate for the need to fund and strengthen policies and services aimed at NCDs, particularly those for NCD prevention and early detection, to reduce the NCD burden in the long run. The group calls for high level political support and emphasises the importance of community involvement and a multi-sectoral approach. This work has led to the establishment of an NCD prevention programme in all provinces in the country.
- Improve patient care by facilitating coordination between a number of organisation's providing healthcare services in partnership with the government in the country (e.g. Rotary Club Rwanda,[4] Team Heart Rwanda[5] and Partners in Health[6,7]). The healthcare workforce is currently insufficient due to financial constraints and this is a major challenge to providing comprehensive health services to older adults in Rwanda. The coalition has been working with local leaders to identify and use existing resources and funds to address this challenge.

With kind thanks to the NCD Alliance Rwanda.

[2] Rwanda Noncommunicable Diseases National Strategic Plan 2014-2019, https://www.iccp-portal.org/system/files/plans/RWA_B3_NCD_NSP_strategic_plan_2014-2019_v12.pdf
[3] https://www.afro.who.int/news/rwanda-cancer-centre-inaugurated-world-cancer-day-2020-president-paul-kagame
[4] https://www.newtimes.co.rw/section/read/200884#:~:text=Established%20in%201966%2C%20the%20Rotary,first%20Rotary%20Club%20in%20Rwanda
[5] https://www.newtimes.co.rw/news/featured-team-heart-surgeons-continue-saving-hundreds-lives-rwanda
[6] https://www.mhinnovation.net/innovations/inshuti-mu-buzima-expanded-mesh-model-address-mental-disorders-rwanda
[7] https://www.pih.org/article/rwanda-oncology-doctor-global-community-must-reduce-disparities-cancer-care

Chile: Driving change from local to national

Chile has one of the fastest ageing populations in Latin America, with adults over the age of 65 accounting for 12% of the population. Ensuring the health and wellbeing of older adults has climbed up the national political agenda in recent years and Chile has seen the development of several innovative approaches to healthy ageing.

Older cancer patients face a heterogeneous reality in Chile as there is no national structured oncogeriatric program. Oncogeriatric units have not been implemented across the country, which limits the ability of oncology teams to tailor treatment and support plans to the cancer type and of each patient. Instead, many older cancer patients are offered standard treatments for their cancer type, but these might not take into account the impact of increased toxicity or other side effects on older adults.

Where facilities have developed services, the lack of national guidance has meant that each healthcare centre has developed its own management protocols and there is no standardised oncogeriatric evaluation prior to starting treatment for elderly patients with cancer. One of the main challenges has been access and adherence to management recommendations, which often results in the need to make modifications of the originally proposed treatment.

Given the high volume of older adults with cancer who are cared for in the Arturo Lopez Perez Foundation (FALP), FALP decided to respond to this challenge in 2018 by creating the oncogeriatric unit whose objective to provide a comprehensive geriatric assessment of older adults with cancer. This allowed oncology teams to personalise a patient's treatment more effectively, taking into account factors such as comorbidity burden and prevalence of geriatric syndromes.

FALP cares for patients over 70 years of age with systemic therapies (chemotherapy, immunotherapy, molecular therapies, hormone therapies), surgery and radiation therapy. Patients undergo an oncogeriatric assessment that includes: the patient's history, estimation of functionality, nutritional evaluation, cognitive evaluation, sarcopenia[8] evaluation, investigation of main geriatric syndromes, chemotherapy toxicity estimates and mortality estimates. From this assessment, recommendations are made which take into account the health condition of each patient and which help to shape conversations with patients around their treatment goals and plans.

The oncogeriatric unit is made up of three geriatricians who work in coordination with other professionals, including nutritionists, kinesiologists, speech therapists and psychologists. Their role is to investigate the different geriatric syndromes that require a multidisciplinary approach, such as malnutrition, depression, sarcopenia and falls syndrome, among others. Since the implementation of geriatric assessments, the quality of information that multidisciplinary teams have to develop and refine treatment plans has improved significantly. It has also provided valuable information on the geriatric characteristics of this population, which are being shared globally. In January 2021, FALP also started a pilot plan of kinesic prehabilitation[9] in pre-frail older adults, with the goal of following patients as part of a prospective study on the subject. One of the key takeaways from this work has been that the physical and functional conditions of a cancer patient are variables that change very rapidly. Serial evaluations and early interventions are therefore important to avoid dysfunctionalisation and associated adverse events for patients, which improves both quality of life and reduces the costs associated with care for patients and health systems.

Recognising the opportunity for substantially improving care, FALP is developing evaluation and management protocols with other national health centres in order to support the standardisation of patient care and address some of the inequities in geriatric cancer care currently. As FALP is the largest oncogeriatric centre in Chile to date, the team is working with other geriatricians nationwide to replicate the care model and build capacities in all cancer centres.

[8] Sarcopenia is the progressive and generalised loss of skeletal muscle mass and strength and is closely correlated with physical disability and poor quality of life.
[9] Prehabilitation is the process of improving an individual's functional capacity in order to enable them to tolerate upcoming cancer treatment

This in turn will create a greater need for geriatric specialists, but in the long run a decrease in the adverse effects associated with treatment toxicities and untreated geriatric syndromes and will reduce costs and demands on the health system associated with the side-effects of cancer treatment in older adults. Recognising this challenge, oncology teams are working with the Chilean Geriatric Society to develop oncogeriatric training programmes in the country and share expertise and lessons learned in service development at national meetings.

The first wave of the coronavirus pandemic presented a number of significant challenges, in particularly in ensuring the continuity of care for patients as face-to-face care was significantly reduced. In response, FALP implemented oncogeriatric evaluations by telemedicine, which facilitated the evaluation of patients remotely and to avoid postponing their treatments. This was part of the centre's commitment to supporting all long-term care channels that guarantee access to geriatric evaluation and associated benefits by maintaining both face-to-face and remote evaluations.

With kind thanks to the Arturo Lopez Perez Foundation (FALP), Santiago, Chile

Ireland: The importance of patient support services

In Ireland there is no difference in the way cancer treatment is decided between the young and the geriatric patients. Patient's performance status (PS) is used as an important part of cancer care and treatment, as it provides a score that estimates the patient's ability to perform certain activities of daily living. It plays a role in both shaping and determining the best treatment for the cancer patient. PS status is used for every patient and, in some cases a 30-year-old may have a much lower score than a 70-year-old.

For patients with a lower PS score support services are critically important; however, experience has shown that older cancer patients are slower to look for support outside of the hospital setting. In response the East Galway and Midlands Cancer Support Centre has developed a very close working relationship with the local hospital. The hospital refers patients to the centre for a range of services such as psychological support, complimentary therapies, transport to treatment, and support group meeting for individual cancers. Some of the key services include exercise and yoga classes which are designed to keep the older person as fit and mobile as possible which research indicates is a huge benefit to patients. For patients with nutrition problems, the centre organises an appointment with the in-house nutritionist.

The centre has innovated by integrating different ages, bringing together the younger patient with the older patient. By doing this, patients support and learn from each other, which eases isolation, with one patient commenting: "*A problem shared is a problem halved*."

Cancer does not care about age or gender, and the East Galway and Midlands team has found that with a more holistic approach to supporting older patients, individuals are much more likely to engage with the centre and find the extra support they need.

One of the key challenges facing the centre is securing sustainable funding, as all the services are provided at no cost to the patient. This has been exacerbated by COVID-19, which constrained fundraising activities. At the same time there is limited political will to support the work of voluntary organisations, despite the fact that they save the health system substantial amounts of money every year. An unintended consequence is that as long as this work is done without funding, it remains low on the list of political priorities.

With kind thanks to East Galway & Midlands Cancer Support, Ireland

Looking ahead

Given the diversity of each health system, how governments will approach improving care for older adults and those with co-morbidities will vary from country to country, but there are several key enable success in most contexts:

- **Take a person-centred approach to health**. Map and assess the challenges faced by people living with one or more NDCs, including older adults, and adapt national health strategies, UHC benefit packages and financial protection mechanisms to support people-centred care rather than diseased-based approaches. This should be delivered and supported by quality, affordable and accessible primary health care and with siloes broken down in care.
- **Collect data on the prevalence of co-morbidities**. Collect data on the number, health and economic status of people living with multiple conditions, including adults above the age of 70.
- **Invest in research** to better understand the impacts and challenges faced by people living with co-morbidities, including older adults, at global, country and regional levels. Identify effective policy solutions to support their prevention and management.
- **Include co-morbidities into national cost-effectiveness analyses for national policies**. Ensure that the super-additive costs of co-morbidities are not excluded from national plans and investment cases, and are therefore left to individuals and families to cover.
- **Ensure that financial and social protection mechanisms cover older adults and those with multiple conditions**. Progressively increase protection mechanisms for these populations, as they are among the most exposed to financial catastrophe, stigma and discrimination.
- **Integrate training on NCDs and geriatric care** into core curricula and continuing medical education and support the development and adoption of clinical guidance for healthcare workers on the management of co-morbidities, including training and support for patient caregivers at home.

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