Building systems to address functional decline and dependence in ageing populations

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STRENGTHENING THE WORKFORCE TO ADDRESS FUNCTIONAL DECLINE AND DEPENDENCE IN AGEING POPULATIONS

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Background paper

1. INTRODUCTION TO THIS BACKGROUND PAPER

This background paper has been developed as part of preparations for the upcoming WHO high-level meeting at The Hague on building systems to address functional decline and dependence in ageing populations. This meeting, to be held in April 2013, is occurring as a result of the growing recognition that the global population is ageing and many people will experience significant functional decline towards the end of life and will require long-term support.

Within this context, there is a need for a new way of preparing, organizing and supporting formal and informal carers to meet the needs of ageing populations. Formal carers are defined in this paper as people who are typically paid for their services, including a range of professionals and paraprofessionals. Informal carers, on the other hand, include families, neighbours, and volunteers, and are typically unpaid for their services. The availability and mix of these carer subgroups vary substantially across countries.

The purpose of this paper is to highlight key issues and to stimulate discussion. As such, this paper is not a review of everything that has been written on this topic, nor does it attempt to capture the breadth of experiences across countries. Discussion points – included at the end of this paper - must be considered within the context of particular countries, because health and social care system configurations vary considerably from country to country, as does the composition of the workforce.

This paper is divided into four major sections:

- **Background and context.** This section describes trends that bear consideration: rapidly changing demographic and epidemiological profiles, towards ageing populations and chronic, noncommunicable conditions; global health workforce shortages; and the complex care needs of older adults.
- **Who cares for ageing populations and where?** This section describes the types of carers who can be involved with older adults. Professionals, paraprofessionals, informal carers, and community health workers are part of the potential mix. However, the type and number of health and social care workers vary substantially across different parts of the world.
- **How can the workforce be strengthened for the future?** This section identifies key areas in training, organization, support, and public policy that can be leveraged to strengthen the workforce.
- **Discussion points.** A series of discussion points for the meeting are suggested.

2. BACKGROUND AND CONTEXT

Three major factors must be considered as part of the workforce context of ageing populations: 1) rapidly changing demographics and disease epidemiology towards people living longer, older age groups as a whole, and increased prevalence of chronic, noncommunicable conditions; 2) shortages of essential health workers; and 3) the complex needs of older adults. These factors have been examined in great detail in previous publications. As a result, they are summarized only briefly below.

RAPIDLY CHANGING DEMOGRAPHICS AND EPIDEMIOLOGY

Between 2010 and 2050, the proportion of the world's population over 65 years is expected to double from about 8% to 16%: from 524 million to 1.5 billion.[1] This change is being driven by falling fertility rates and increases in life expectancy. With fewer children and people living longer, older people are making up an increasing share of the total population. The very oldest (those aged 85 or older) are increasing proportionally at the highest rates: this group is expected to increase by 351% from 2010 to 2050.[1]

As people grow older, they are at increasing risk for developing one or more chronic, noncommunicable diseases. In 2008, noncommunicable diseases (NCDs) caused an estimated 36 million deaths, representing 63% of all deaths globally. These deaths were due mainly to cardiovascular diseases (48%), cancers (21%), chronic respiratory diseases (12%) and diabetes (3%). Mental and neurological disorders, visual and hearing impairments, arthritis, and chronic pain are other health issues with which many older people must contend. The majority of older adults have more than one of these chronic conditions, creating complexities in their health care management.

NCDs are a major concern in low- and middle-income countries, where the burden of these diseases is rising disproportionately. Nearly 80% of NCD deaths occur in low-and middle-income countries and NCDs are the most frequent causes of death in most countries, except in Africa. Even in African nations, NCDs are rising rapidly and are projected to exceed communicable, maternal, perinatal, and nutritional diseases as the most common causes of death by 2030.[2]

By 2050, 80% of older adults will be living in low- and middle-income countries.[3] In these countries, the demographic transition towards older age groups and the epidemiological transition towards NCDs are happening at much faster rates than that which occurred previously in many high-income countries. This puts policy-makers in these countries under pressure to develop new strategies within short timeframes.

WORKFORCE SHORTAGES

Many countries are experiencing a shortage of health workers to at least some degree. An estimated four million additional doctors, nurses, midwives, and healthcare workers are needed in the 57 countries experiencing the most serious workforce deficits – 36 of these in sub-Saharan Africa. In addition, the health workforce itself is ageing, leading to concern in some countries about future shortages due to retirement of current workers in large numbers. [4]

Long-term care for ageing populations has been an area particularly fraught with worker shortages. Poor working conditions lead to recruitment problems, high turnover, and workers leaving the sector altogether.[5] Many countries have relied on family members to provide the majority of long-term care. However, the pool of potential family carers is likely to shrink in the future as fertility rates decline, populations become older on average, and more women – who comprise most family carers – enter the formal workforce and no longer have the time to care for family members.

COMPLEX NEEDS

The health and social needs of ageing populations are typically complex. Older adults usually have numerous health conditions that require ongoing monitoring and treatment. In addition, they might need help with at least some activities of daily living such as such as bathing, shopping, or food preparation. Social needs are also important and can range from legal and financial matters to help maintaining full participation in their communities.

Because many older adults have several chronic health issues, multiple health professionals with different roles and specialities can be involved with an individual's care. This necessitates a high degree of coordination over time, among health professionals, and across treatment levels and settings. Health systems usually fall short in facilitating this coordination, leaving the burden on the older adult or the family to communicate relevant health information as and when needed. Omissions and errors of vital medical information are the common result.

Cognitive decline – meaning losses in memory, reasoning, speech, and other cognitive functions - increases sharply with age. For most people, cognitive decline happens slowly but progressively over time. An estimated 25% to 30% of people aged 85 years or older have some degree of cognitive decline.[6] This places a substantial burden on families, communities, and societies. The challenges are greatest in low- and middle-income countries, where few resources are available.

Legal, financial, and housing issues are also common among older adults. As people age and leave the labour market, they become at increased risk for financial insecurity and poverty. Access to affordable and accessible housing becomes more difficult. Social participation sometimes wanes as older adults become increasingly isolated from their communities. Ensuring legal rights and protections, especially in cases of disability or cognitive decline, are other common challenges facing older adults and their families.

For these and other reasons, many older people become functionally dependent on others for meeting at least some of their daily needs. In low- and middle-income countries, the number of dependent older adults is forecast to quadruple by 2050.[7]

3. WHO CARES FOR AGEING POPULATIONS AND WHERE?

Any general discussion of the workforce for ageing populations must begin with an important caveat: the type and number of health and social care workers vary substantially across different parts of the world. Some countries are relatively human resource-rich in terms of the number and diversity of workers available for ageing populations; others must rely on next to nothing. In addition, large differences exist in 'who does what, and where', depending on the configuration of the broader health system.

For the purpose of general discussion, carers for ageing populations can be grouped into two broad categories: *formal carers*, who are typically recognized and paid for their work; and *informal carers*, who are typically unpaid for their work. Formal carers include both professionals and paraprofessionals.

Depending on the country, *professionals* are comprised of physicians, nurses, social workers, pharmacists, dieticians, rehabilitation therapists, psychologists and case managers, to name only some of the possible categories. Some have specialized training in gerontology or long-term care, whereas others are generalists whose scope of responsibility includes older adults.

Many professionals are unprepared to deal with care needs of older adults. Current training models for health workers were first developed in the early 1900s,[8] when acute, infectious diseases were the world's most prevalent health problems. As a result, health workers were trained primarily to identify and treat acute symptoms and conditions using an episodic care approach. Today, epidemiological profiles have shifted considerably, but the training of the health workforce generally has not. Most health workers are insufficiently prepared to help patients manage behavioural risks such as poor diet, physical inactivity, and tobacco use. They do not work from a paradigm of proactivity, but rather, in response to pressing health concerns. The demographic shift towards the very old (the fastest growing segment of the population) poses a different set of challenge for health workers. These include lack of gerontological and geriatric knowledge and training and lack of treatment guidelines for severe multimorbidity and the onset of frailty.

Paraprofessionals are the front line workers who are responsible for helping frail and disabled older adults with their daily needs such as bathing, dressing, or food preparation. They are also known as aides, helpers, or assistants, depending on the country. In many countries, paraprofessionals comprise the majority of all long-term care workers. They typically are women from low-income backgrounds and with low educational attainment.[9] Salaries tend to be low while the work is highly demanding. Work-related accidents and injuries are common.

Most developed countries have a shortage of paraprofessionals, due to problems with both recruitment and retention. To help compensate, some developed countries are using active immigration strategies for international recruitment of paraprofessionals.[9]

Informal carers include families, neighbours, and local volunteers. Collectively, informal carers provide the vast majority of all care for older adults around the world. Yet as the relative number of older people increases while the proportion of younger adults available to provide care declines, informal, unpaid care is unlikely to be sustainable over time as the dominant form of support to older adults.

Spouses and adult children, especially daughters and daughters-in-law, are the most common informal carers.[10] Many assume this role without knowing a great deal about how care should be provided; how to interact productively with formal health and social care systems; or how to cope emotionally with the burden of caregiving. It is perhaps then not surprising that informal carers often experience high levels of strain, psychological problems, and poor physical health.

Those informal carers who adopt significant caregiving roles often experience challenges maintaining their employment or other income-earning activities. Caregiving can be incompatible with a full-time job and can constrain usual career progression. For those of working age, informal caring is associated with a higher risk of poverty. Because the vast majority of informal carers are women, these considerations have implications for gender equity in the workplace and beyond.

In some countries, *community health workers* are part of the mix of diverse carers. They provide links between the formal health system and the community, and they provide outreach into people' homes. Typically, community health workers come from the community where they work and therefore have both cultural competence and credibility with the people they serve.

Collectively, the carers described above operate across a wide range of settings. In some countries, numerous settings are available and accessible to older adults, whereas in other countries, settings are more limited. However, in almost all contexts a primary service setting is the *older adult's home*. Various health and social care services can be provided on site, with the goal of supporting and maintaining functional independence to the extent possible. Many developed countries, especially in Europe, are in the process of moving long-term care services from institutional care to home care provision.[9] In nearly all OECD countries, between half and three quarters of all formal long-term care is provided in home-care settings.[5] Local *primary health care centres* also have a central role to play in most contexts. They serve as the main health care access point, and ideally also as a hub of coordination. Other community-based settings might include *senior centres and adult day care*. Secondary and tertiary health care settings provide older adults with more specialized and intensive care. They include *specialist outpatient clinics*, as well as *district and tertiary hospitals*. Finally, *residential or assisted living facilities* come into the mix when it is no longer practical or feasible for older adults to live at home.

4. How can the workforce be strenghthened for the future?

Carers – both formal and informal – must be prepared for the roles they assume. In addition, they must operate in broader systems that make the best use of their skills. A supportive policy and financing environment is the umbrella under which all these actions can take place.

A defined set of competencies for formal carers

As noted earlier, workforce training models have generally not kept pace with rapid epidemiological and demographic transitions. In general, carers are being trained to address a different set of people and problems. Thinking about core competencies needed by formal carers for managing ageing populations is a useful starting point for planning training reforms.

A WHO review previously identified five core competencies for delivering effective care for chronic conditions.[11] [12] The chronic care competencies were selected in part for their applicability to all health workers, irrespective of discipline. They were not meant to supplant existing competencies, such as the practice of evidence-based and ethical care, but rather to underscore the need for new areas of expertise. The five identified competencies were: patient-centred care; partnering; quality improvement; information and communication technology; and public health perspective. More details are provided in the box below.

More recently, the UCL Institute on Health Equity published a report on how health professionals can be engaged to promote health equity.[13] Among its recommendations, the report called for health professionals to receive intensified skill development in the areas of communication, partnership, and advocacy. More specific skills included taking a social history and making patient referrals to external support services. While coming from a different perspective, these competencies have great resonance with the chronic care competencies noted above.

Core competencies for delivering care for chronic conditions[11] [12]

Patient-centred care
- Interviewing and communicating effectively
- Assisting changes in health-related behaviours
- Supporting self-management
- Using a proactive approach

Partnering
- Partnering with patients
- Partnering with other providers
- Partnering with communities

Quality improvement
- Measuring care delivery and outcomes
- Learning and adapting to change
- Translating evidence into practice

Information and communication technology
- Designing and using patient registries
- Using computer technologies
- Communicating with partners

Public health perspective
- Providing population-based care
- Systems thinking
- Working across the care continuum
- Working in primary health care-led systems

REFORMS TO PRE-SERVICE TRAINING

Once the core competencies needed to provide effective care for ageing populations are determined, pre-service training reforms can help ensure that these competencies are part of professionals' (and in some cases, paraprofessionals') curricula. Capacity of educational institutions might need to be developed to make it possible for them to reach established standards.[14]

A recent report on transforming education to strengthen health systems for the 21st century identified 10 proposed reforms for improving pre-service training.[15] Those most relevant to this discussion include adoption of competency-based curricula (see above); promotion of interprofessional education; and expansion of training from academic centres into primary care settings and communities.

Interprofessional education involves students of two or more professions learning together by interacting with each other on a common educational agenda. Because ageing populations require services from diverse formal carers, it is essential that students learn how to work effectively with a range of different professional groups.

Ideally, most care happens in community-based and primary health care settings. It therefore makes sense that students be trained in these environments – the third relevant area of educational reform. Pre-service experience in community-based and primary health care settings helps prepare students to move seamlessly from their educational phase into the workforce caring for ageing populations.

STRENGTHENING OF IN-SERVICE TRAINING

In-service training is essential to consolidate formal carers' existing knowledge and to upgrade their skills. In addition to receiving training on evidence-based care for ageing populations, formal carers might benefit from opportunities to:[12 13]

- Work effectively as a member of a multidisciplinary team;
- Work in a community-based setting;
- Work in an economically-deprived area;
- Experience patient care across the continuum from clinical prevention to palliative care;
- Learn how to support patient self-management efforts;
- Learn how to organize and implement group medical visits for patients who share common health problems;
- Care effectively for a defined group of patients over time.

Ongoing support and supervision from those who understand care for ageing populations is another aspect of strengthening in-service training. Collaborative or shared care, in which joint consultations and interventions are held between generalists and specialists, is a proven approach for consolidating new skills.

THE FORMATION OF MULTIDISCIPLINARY TEAMS

The basic rationale for multidisciplinary teams is that because older adults have varying and complex needs, they can benefit from the wide range of knowledge and skills that a team can offer. As such, multidisciplinary teams should be considered as a key mode of care delivery for ageing populations. Teams ideally are comprised of professionals and paraprofessionals, and both health- and social-care workers. Sometimes, all team members work within the same setting (referred to as co-location of services; see below). In other cases, team members work across multiple settings, including the older adult's home, and are connected by information and communication technologies and supported by occasional face-to-face meetings.

It is important to note that a group of carers under the same roof do not necessarily comprise a team. A team is formed only if carers meet together regularly, share information, explicitly define roles, and perform complementary yet coordinated functions for the same people.[16]

Where possible, collaborative workspaces can be used to promote multidisciplinary teamwork among carers. This is accomplished by placing carers from multiple specialty areas in open spaces that encourage communication and teamwork. These arrangements have the added benefit of convenience for older adults: instead of the usual situation whereby they must navigate through a wide range of settings, in this setup a large group of carers are under the same roof, and ideally in a shared workspace.

Care coordinators can serve as overseers and directors of care for the entire team. Case management by a person other than the primary care provider has been shown to be effective in producing positive health outcomes for older adults with chronic conditions,[17] especially for those who have comorbid and/or severe chronic conditions, and when care coordinators have ongoing in-person interactions with the person.[18]

In the process of reorganizing professionals and paraprofessionals into teams, it might become apparent that new types of formal carers are needed. While traditionally considered as a way to address workforce shortages, the development of new cadres also can serve to meet the unique needs presented by ageing populations. Care coordinators and self-management counsellors are examples of new cadres that have been developed in some countries to fulfil population needs.

POLICIES TO ATTRACT AND RETAIN PARAPROFESSIONALS

Finding better ways to recruit and retain paraprofessionals will be key to the future of caring for ageing populations. Attracting new employment pools, such as men, might be part of the answer. Immigrants provide another potential employment pool, but the practice of relying on foreign-born workers to fill paraprofessional positions is fraught with legal and ethical considerations.

Higher levels of pay and benefits would likely help with paraprofessional retention. In addition, improved working conditions – such as flexible work hours or opportunities for career progression – would be important.[19] Paraprofessionals whose work is valued and appreciated, and who feel part of a clinical team, have higher levels of job satisfaction and are more likely to stay in their jobs.[20 21]

Building the competencies of paraprofessionals also might enhance recruitment and could, ultimately, assist in reducing shortages if retention improves. Many countries are already investing in targeted training and career development. Further skill building would not only create a more productive workforce, but also would address the perception of paraprofessional work as a dead end job.[19] On the other hand, building base competencies of paraprofessionals might raise barriers to entering this type of work and result in few workers overall.

SUPPORT TO INFORMAL CARERS

Various forms of support can be developed for informal carers. Areas of support include education and training, respite care, tax benefits and payments, and legislation to help informal carers maintain their employment.[22]

Education and training typically include information about the older adult's health condition, its expected progression, and ways to help the person self-manage at home. In addition, carers might be taught a range of practical skills, such as how to safely transfer a person from chair to bed or how to help with bathing. Information about community-based resources available to the older adult and/or to the carer also might be included. Education and training can occur one-on-one, in classroom formats, or as part of carer support groups, which lend the additional benefits of social support and normalization of experiences and feelings.

Respite care is short-term relief care that allows primary informal carers time away from their responsibilities. A main goal of respite care is to help reduce stress among informal carers while still meeting the daily needs of care recipients. Volunteers or paraprofessionals sometimes provide respite care at home. In other situations, the older adult is admitted temporarily into a residential or nursing facility. Adult day care is another form of respite care, in which the older adults spend part of their days engaged in social programmes.

Tax benefits or cash payments to informal carers recognize the importance of their work and help them mitigate reduced working hours and/or increased expenses as a result of their caregiving activities. Payments can be made directly to informal carers, or via disability benefits to older adults.

Payment models can be found in OECD countries, the majority of which provide some form of financial support to informal carers. Specific conditions for and mechanisms of compensation vary considerably across countries. For example, Nordic countries (Denmark, Finland, Norway, and Sweden) employ family carers as such via their municipalities; in Spain, an allowance is paid directly to the care recipient to help organize home care services from family members; in Canada, caregiver tax credits are available.[5]

To facilitate informal caregiving, some governments have passed legislation that requires leave from work for family members so that they can care for older adults. Conditions vary, however, in the preconditions and length of available leave, and whether employers or employment insurance policies are required to pay workers for this period. In addition to

leave from work, the option of part-time or flexible working arrangements have been legislated in some countries. In many of these countries, however, employers can deny worker requests on operational or business grounds.[5]

SELF-MANAGEMENT SUPPORT FOR OLDER ADULTS

Traditional medical models regard patients as passive recipients of health care. Negative and erroneous stereotypes about the capacities of older people, which are widespread in certain cultures, only amplify this issue for ageing populations.

A new paradigm has emerged in recent years, in which patients and health workers are regarded as equal partners and both experts in their own domains: health workers concerning their areas of clinical expertise, and patients concerning their experiences, needs, and preferences.[23] Within this broader framework of patient-centred or collaborative care, priority is placed upon supporting older adults to be active decision-makers and care partners to the extent feasible.

Self-management support for older adults consists of providing them with the information, skills, and tools that they need to manage their health conditions, prevent complications, maximize their functional independence, and maintain their quality of life. This approach does not imply that older adults will be expected to 'go it alone' or that unreasonable or excessive demands will be placed on them. It does, however, recognize older adults' autonomy and abilities to direct their own care, in consultation and partnership with their families and a range of other carers.

Successful self-management support should not be viewed as a one-time activity, but rather as an ongoing opportunity to activate the older adult in shared decision making and shared responsibility for his or her health and well being. Various clinical models[24] [25] [26] have been developed to guide carers through these interactions. Carers' ability to elicit and discuss beliefs and to activate the person in shared decision making has been shown to improve a range of health outcomes.[27] [28] Further research shows that self-management support techniques can be taught successfully to carers.[29] [30] [31]

5. DISCUSSION POINTS

In summary, while the world is experiencing a rapid transition towards ageing populations, workforce practices have not kept pace. Many formal carers are being trained to address a different set of problems, and moreover, they are being organized and deployed in ways that don't make best use of their potential contributions. A critical shortage of paraprofessionals exists in many countries. Around the world, informal unpaid carers, usually female relatives of the care recipient, provide the majority of care. As people have fewer children and live longer, and as countries develop economically and women increasingly enter the paid workforce, reliance on unpaid informal carers is unlikely to be sustainable. Ultimately, a prepared and well-functioning formal workforce will be essential for the health and well being of ageing populations.

A number of potential areas for action are introduced within this paper. Yet policy-makers and planners need to prioritize those actions that seem most pertinent, both overall and to their specific contexts. To help with this task, a series of meeting discussion points is suggested, below.

CONCERNING FORMAL CARERS

1. Can a common set of core competencies for managing ageing populations be defined for all formal carers? If so, what are these competencies?
2. Alternatively or additionally, do different professional cadres (e.g. physicians, nurses, paraprofessionals) require competencies unique to their roles? If so, what are some of the key distinctions?

3. How should pre-service training be reformed to better prepare professionals to manage ageing populations?
4. How should in-service training be reformed to better prepare professionals to manage ageing populations?
5. What are some innovative ways to recruit more paraprofessionals to long-term care for ageing populations?
6. What are the ethical considerations of recruiting paraprofessionals from foreign countries?
7. What are the advantages and downsides of licensing/credentialing paraprofessionals in a manner that is consistent with professionals?
8. If paraprofessionals are licensed/credentialed, what pre-service qualifications are needed?
9. What are some innovative ways to retain more paraprofessionals in long-term care for ageing populations?
10. How can a multidisciplinary team for older adults be formed in a resource-poor setting with few health workers?

CONCERNING INFORMAL CARERS

11. To what extent and how should informal carers be compensated financially? How can this concept be justified in countries with limited resources?
12. How else – in non-financial ways - can public policy and legislation best support informal carers?
13. What kinds of support do older adults need to participate in shared decision-making about their care and self-management of their conditions?

CONCERNING GOOD PRACTICE EXAMPLES

14. Are you aware of schemes that have been attempted in low- or middle-income countries to improve the ways that carers are recruited, trained, organized, supported, and/or compensated? What lessons can be learnt from these experiences?

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