Building systems to address functional decline and dependence in ageing populations

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Functional Decline and Dependency:

Proposing a Conceptual Framework

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Background Paper

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1 Introduction

As populations continue to age, responding to this demographic change will be an important public health priority in all regions of the world. With projected demographics being even more dramatic by 2050, timely responses are needed. Understanding the opportunities to redefine thinking and meet the needs of this emerging population will become increasingly important over the coming decades. However, the needs of older people are characterized by marked diversity with overall health status, vulnerability and place of residence. Chronological age is a poor indicator of need. Many people of quite advanced age can remain active and healthy, while younger old people can instead have poor health and difficulty remaining independent.

While we know that individuals are living longer, we do not know whether they are living healthier. It is still unclear whether morbidity is expanded, compressed or at an equilibrium over the additional years of life, both at an individual and population level. This makes individual care planning and population level policy development difficult. An alternative way to consider the needs of this age group is to focus on functioning and the declines in physical and cognitive domains that often occur in older age leading to a loss of independence.

This background paper will outline how functioning and levels of dependence are important determinants of an individual's needs, summarizing current knowledge and gaps in this field. The paper will also propose a conceptual framework for functional decline and increasing dependency, rooted in the World Health Organization's International Classification of Functioning, Disability and Health (ICF) framework. (1) Questions to guide discussions and move the agenda forward are presented at the end of the document.

2 Background

The diversity of older individuals is reflected in their varying risks of disability, falls, cognitive impairment, hospitalization, institutionalization and mortality. (2) Given this diversity, creating systems that respond to the full range of needs and provide care to optimize trajectories of functioning is needed. Biological age, focused on performance of tasks rather than disease diagnoses, has been proposed as an alternate to chronological age in defining older people's needs, and has been more strongly associated with subsequent death than chronological age. (3,4)

2.1 Defining Key Concepts

Despite the importance of understanding an individual's functional status and trajectories, defining function and functional decline is challenging. Many terms are often used interchangeably to address these concepts and a clearer understanding of functioning and its trajectories is needed. The ICF, developed by the WHO in 2001, is an accepted framework that provides consensus definitions of some of these concepts. According to this framework, functioning can be defined as the positive aspect of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors). (1) Functional decline is not as easily defined and no definition has been agreed upon. We thus propose a definition for functional decline that we hope to discuss during the upcoming meeting. Dependence is also a term that has been defined in various ways, particularly from the research community. (5,6) Again, a standard definition is lacking and we have proposed a definition for discussion. Frailty, disability, comorbidity and geriatric syndromes are all related concepts, and are also presented in Box 1.

Box 1: Definitions of Key Concepts

Comorbidity
'the concurrent presence of two or more medically diagnosed diseases in the same individual, with the diagnosis of each contributing disease based on established, widely recognized criteria' (7)

Dependence
In the absence of an accepted standardized definition, we propose the following:
The need for various levels of assistance based on (and depending on the severity of) the acute or persisting inability to participate or perform an activity.

Disability
An umbrella term for impairments (problems in body function or alterations in body structure), activity limitations or participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individuals contextual factors (environmental and personal factors) (1)

Frailty
An age-related decline in many physiological systems leading to vulnerability to sudden health status changes triggered by minor stressor events. (8)
Prevailing models of frailty include the *Phenotype Model* (9), the *Cumulative Deficits Model* (10) and Strawbridge's Model (11)

Box 1 continued: Definitions of Key Concepts

Functioning
An umbrella term encompassing the positive aspect of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors). (1)

Functional Decline
In the absence of an accepted standardized definition, we propose the following:
A fall over a defined period of time in an individual's ability to participate and perform activities (ie. in functioning according to the ICF). From a life course perspective, this decline is amenable to improvement through interventions such as rehabilitation, or increased assistance (through assistive devices or supportive services).

Geriatric Syndromes
Groups of symptoms which are highly prevalent in older adults and have adverse effects on quality of life and disability (include conditions such as delirium, falls, incontinence and frailty). (12)

The concept that has received the most attention in relation to functional decline from a pathophysiological perspective is frailty. The prevailing models of frailty refer to intrinsic component of functional decline, but potential improvements in function due to enabling environments and adequate care are not addressed. Thus, frailty is an important component of functional decline, but may not capture all aspects of such decline.

Determining levels of dependence may provide an innovative way to approach to define defining the needs of older people. In defining levels of dependence, the concept of domains is important. Body systems including the musculoskeletal, neurological, immune, metabolic and sensory are all important components of overall functioning. As such, impairments in any or all of these systems that increase the need for assistance in participation, activities of daily living and self-care are all related to dependence. Identifying factors related to the onset of dependence and reducing the time between onset of dependence and death should be a main goal of interventions to address the needs of older people.

2.2 Current Understanding of Functional Trajectories

Research to date has provided a basis on which to develop a functional approach to meeting the needs of older people. Many factors are considered as contributing to overall functioning. These extend beyond the musculoskeletal components to include cognitive

impairments, mobility issues, emotional health, continence, nutritional state, skin integrity and hearing and vision problems. (13,14) Comorbidities and geriatric syndromes are also much more common in older populations and are important determinants of overall function. Functional decline is associated with both dependence and institutionalization and research has identified factors associated with these outcomes (including older age, lower education, poor mobility and balance, reduced muscle strength, and comorbidity). (4,15-21)

However, functional trajectories are poorly understood. Frailty models suggest overall declines in function (22) and chronic disease literature has characterized end of life trajectories for diseases such as congestive heart failure (23), but such work has been disease-specific, generally ignored the potential for rehabilitation and focused towards the end of the life course. For these reasons, such trajectories may not be applicable to other individuals. Further, the oldest old experience the highest concentration of functional limitations and will be very complex to manage, yet have been under-represented in current research. (24)

2.3 Current Models to Manage Functional Decline

In providing care to prevent and manage functional decline, common approaches include strengthening geriatric care and services, providing care in the home environment and targeted prevention and management programs. (25) Care in the home environment is a particularly attractive service option, as many older individuals express the desire to stay independent and remain in their own homes while health and finances permit. (26,27) While home visits which include comprehensive geriatric assessment, multiple follow up and target people with lower risk of mortality can be effective in preventing functional decline (28), evidence also suggests that current services do not adequately balance care of current disability with prevention of further decline. (25)

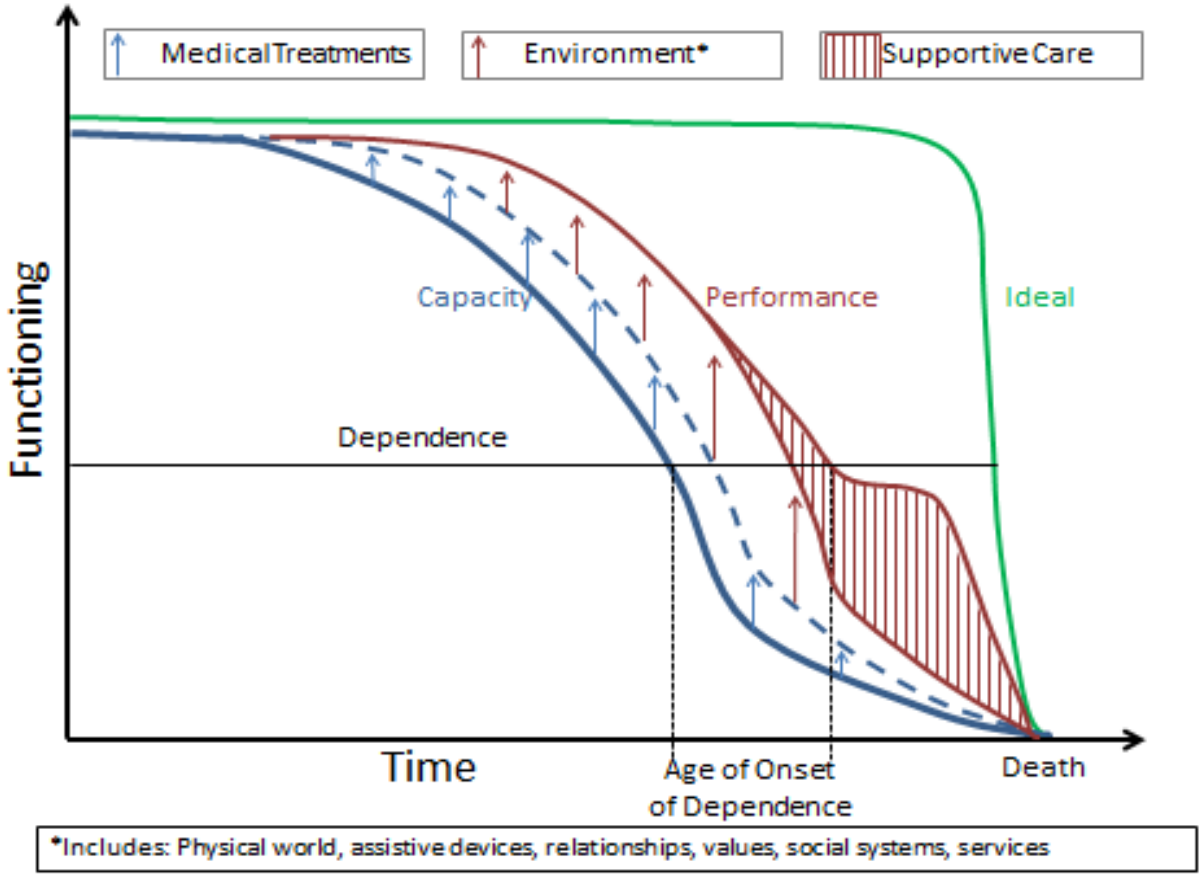
At this point, there is little good evidence about what kinds of care can best manage functional decline and prevent further decline. It is unclear which types of care are most effective and whether proven interventions such as falls prevention programs, geriatric screening and preventive home visits are effective over the long term. Understanding more about the effectiveness of interventions over the long term includes measuring and assessing whether care is making a difference. The impact of interventions on longitudinal trajectories, not only discrete

time points, is critical. Only with an understanding of trajectories can resources be used to make the best investments to maintain optimal trajectories of functioning.

3 A Proposed Conceptual Framework

We need to approach ageing issues from a clear, conceptual model that accounts for personal factors, like age and sex, but also health states and the environment one lives in. Further, consideration of the interactions between these factors over time is important. The ICF allows a starting point in developing such a model, with modification to disease and health states, environments and personal characteristics all being targets for interventions.

Figure 1: Conceptual Model for Functioning and Dependence



Rooted in the concepts of the ICF, the schematic above represents a conceptual framework from which to begin the discussion about defining needs using functioning and long term trajectories.

Functioning over time is depicted in the diagram. The ideal situation, in which an individual continues with maximum functioning throughout life, is represented by the green curve. The reality is that the majority of older people will experience functional decline as they age. Capacity is represented as the blue curve and refers to an individual's intrinsic ability to function, without the support of assistive devices, or any medical treatments. An individual's capacity can be improved with medical treatment (dotted blue curve). For example, an individual with osteoarthritis of the hip can take medication to relieve the associated pain and inflammation and achieve a higher intrinsic capacity level.

The performance curve – in red – shows the impact of environments on individual capacity. The ICF considers many factors as environmental, including the physical world, other people in different relationships and roles, attitudes and values, social systems and services, policies, rules and laws. Environmental factors can be facilitators or barriers, shifting the performance curve up or down. For the individual with osteoarthritis of the hip, accessible transportation and grab bars in the bathroom can help to increase performance. With barriers in an individual's environment, the performance curve would shift towards the capacity curve(s). Environments also include the care and services an individual receives. The area shaded in red represents social care, which becomes increasingly important as individuals become more dependent.

In adapting ICF concepts to provide a framework for functioning as a basis for defining needs, we have incorporated the concept of dependence (the black line). Though not well defined, the issue of dependence is perhaps the most important in determining an individual's needs. The level of dependence will be determined by health status, participation, IADLs, and ADLs. As an individual's functioning changes, the need for care can be matched to this dependence level. Health conditions themselves will affect dependence and are targets for medical care. Someone who is dependent in participation may require special transport services to perform optimally, while another who is losing IADL skills may require help managing money or medications. As ADLs decline, more supportive care including help with toileting will be necessary and individuals may eventually become totally dependent in all self-care activities.

Determining factors that can shift the onset of dependence are important. Treatments will shift the onset of dependence to a later age, while environmental supports, including the right mix of care, have the potential to further shift the onset of dependence to an older age.

Minimizing the time between onset of dependence and death should thus be an over-arching goal of all types of long term care services.

While the level and age of dependence are important in determining needs, it is equally important to recognize the potential to alter the slope of the capacity and performance curves with appropriate interventions. At critical points in the life course of an older individual, for example, following an acute health crisis or the death of a spouse, there may be the potential for the individual to follow a trajectory of steep decline. Ensuring that care needs are assessed and met will prevent such decline and may even mean a stable trajectory is reached (one in which the slope of the capacity and performance curves approaches 0).

From a care perspective, it is more important to intervene higher up these curves to obtain a more optimal ageing trajectory for an individual. On an aggregate level, this type of policy will provide the best investment of health care resources as the time spent in a dependent state will be more costly.

This model is only meant to be a starting point and we hope to have a chance to discuss these concepts during the meeting. As the ICF was not developed specifically for ageing populations, adapting it to such populations with an emphasis on how the states and relationships change over time will be important next steps. Nevertheless, the ICF can help both clinically and in setting social policy. As a clinical tool, the ICF provides a framework for assessing needs, matching treatments with conditions, rehabilitation and outcome evaluation. In policy design and implementation, the ICF provides a scientific basis and common language upon which to assist with social security planning, compensation systems and policy implementation.

4 How to Move Forward?

In moving ahead with a functioning based approach to the longer term needs of older people, some current initiatives may be particularly useful. However, a broader research agenda that addresses some of the limitations in the current field will be critical in driving future policy. Addressing these issues through a multidisciplinary lens, and incorporating international experiences will be useful as well.

Collecting better evidence about trajectories of functioning and outcomes must be a priority. In such a research agenda, agreement on concepts such as functioning, functional decline and dependence must form the cornerstone. It is still unclear how functioning is used to

assess an individual's care needs. The need for health care services must take into account physical and cognitive functional limitations, but also the presence of a caregiver and environmental factors, leaving this somewhat open to subjective assessment. (29) More explicit ways to match functional needs to care, taking into account the availability of supports is important. They would also allow better evaluation of the impact of this care on functional trajectories and therefor help to identify the best type of care for each individual circumstance.

Measurement issues compound the problem of defining needs from a functional perspective. Currently the most commonly used measures of physical function are ADLs and IADLs (30,31), both of which are crude. Frailty models incorporate different measures in determining an individual's status, again leaving little clarity and sometimes requiring special equipment. Both approaches are categorical, making it difficult to identify subtle changes in an individual's functional status. For measuring cognitive abilities, many different assessments are used, many of which are time consuming. Such measures do however give a score that allows monitoring of cognitive status over time. Measures of social supports are less defined and integration of assessments across these domains into an overall level to define need is critical, but often lacking. Integrating assessments across domains to identify individuals at risk of decline is also important, and identifying critical moments in the functioning trajectory will help design intervention strategies. Moreover, assessment strategies in low-income settings must also be developed and could include things such as gait speed at usual pace as a measure of physical function.

Beyond measurement, understanding long term outcomes and outcomes of relevance to older populations also demands research attention. For example, many clinical trials focus on mortality or hospitalizations, often in younger populations. To be of more relevance, inclusion of older participants and examination of outcomes such as cognitive or physical decline and institutionalization would be directives for future research. Of the studies and interventions that have focused on prevention and management of functional decline, many have focused on physical aspects of such decline, come from high-income settings, included short follow-up periods and examined hospitalized populations or those with a particular disease. Such studies have not captured changes in or interactions between health indicators related to outcomes. Taking the opportunity to improve these shortcomings is demanded by the ever-growing older populations around the world.

Having an understanding about how different levels of dependence link to resource utilization will also help with meeting the needs of older people and also policy planning. Case-mix algorithms may prove useful here and were originally designed to match long term care resources (in institutional care settings) to individuals most in need. (32) Such algorithms assess an individual's need for services based on the mental, physical and medical characteristics and classify individuals into resource utilization groups based on care utilization patterns. These algorithms show that physical function is a very important predictor of care time and have been validated in institutional and home care settings. (32-35) Thus, case-mix demonstrates the importance of functioning (mainly physical function) as a driver of care needs and may also provide a way to link functional needs with appropriate care.

Perhaps the most important area for improvement is in collecting longitudinal evidence. Ageing is a dynamic process and this is poorly reflected in much research to date. Longitudinal, population level data are needed to gain an understanding of individual and aggregate needs. Transitions in functioning and dependence must be better categorized and influence care plans and intervention strategies. The time aspect of such longitudinal data is also critical in establishing causal relationships and developing interventions to target causal factors will be important contributions to current knowledge. Large data sets are becoming increasingly available, for example through the ADHOC, SHELTER, ANCIEN and SHARE studies in Europe, and the many longitudinal studies on ageing around the world. Through initiatives like the SAGE and COURAGE study, the WHO is contributing to knowledge generation from low and middle-income countries, and beginning to fill another persisting knowledge gap. Utilizing such data to better answer questions about functioning is a realistic next step.

5 Summary and Questions for Discussion

In summary, functioning may provide a basis upon which to define the care needs of older people. However, a consensus on key operational definitions and more evidence about functional trajectories and longitudinal outcomes in older individuals are needed. It is hoped that the proposed conceptual framework will form a basis for discussion, as will the questions below.

Questions to Guide Discussion

Definitions

We have identified a number of areas where there appears to be an absence of consensus definitions. Are these correct and are there areas other areas where clarification of terminology may help?

Is the ICF an appropriate model on which to base such definitions?

Is the proposed function based model useful in framing a future agenda in this field?

Generating Evidence

Are initiatives underway, in both high- and low-income countries, which can help provide insight into functional trajectories?

What else needs to be done to build this evidence base?

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European Studies

AdHOC = Aged in Home Care

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ANCIEN = Assessing Needs of Care in European Nations

see: http://www.ancien-longtermcare.eu/

SHARE = The Survey of Health, Ageing and Retirement in Europe

see: http://www.share-project.org/

SAGE = Study on global AGEing and adult health

see: http://www.who.int/healthinfo/sage/en/

COURAGE = Collaborative Research on Ageing in Europe

see: http://www.courageproject.eu/