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International Handbook of Health Expectancies

Springer

International Handbook of Health Expectancies

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Preface

In 1989, an international group of researchers met together to discuss health expectancy, and so the International Network on Health Expectancy and the Disability Process, known by its French acronym REVES, was born. Over the years following, REVES met at least annually but was a closed network. Then, in 1991, the meeting in Leiden was open to any researcher interested in the topic, and REVES has continued to grow from then on.

In the early years of REVES, subgroups were formed to focus on the key issues around the, then relatively new, population health indicator: conceptual harmonization, methods, and policy relevance. Although the subgroups no longer exist, these three issues have remained the primary focus of REVES. The first book on health expectancy, *Determining Health Expectancies*, was published in 2003 and catalogued research from the first 10 years of the REVES network. It has become a key reference for teaching and research on this topic. A few years ago a group of us decided it was time for a second book since the quantity and quality of research had grown so much. So, here is the *International Handbook on Health Expectancies*.

We have structured the book into four parts, reflecting, as in the first book, the three pillars of the REVES Network but also, in the final section, adding important new research areas on this topic. Many chapters provide in-depth reviews of the literature on, and look forward to future developments in, the specific area. In Part I, *Monitoring Trends and Gaps*, Chap. 1 reviews the conceptual models of health, disability, and frailty that have developed in the last 15 years and how these have changed the operationalization of health and disability for population health indicators. After a detailed description of how life and health expectancy can coevolve in relation to the three theories of compression or expansion of morbidity and dynamic equilibrium, Chap. 2 then describes the trends in health expectancy worldwide. In the last decades, work of REVES has moved from simply documenting trends in, and estimates of, health expectancies to understanding the underlying drivers of such trends. The final two chapters of Part I cover this in terms of inequalities or gaps by socioeconomic status, at the level of countries or regions within countries (Chap. 3) and at an individual level (Chap. 4).

Developing and disseminating methods have always been one of the pillars of the REVES network, and Part II, *Advances in Data and Methodology*, addresses the progress made since the first book. Chap. 5 details the substantial increase in data sources for calculating health expectancy, particularly the increase in harmonized longitudinal studies worldwide. Chaps. 6, 7, and 8

document the progress made in methods to understand the underlying drivers of gaps and trends in health expectancies, specifically attributing the causes of disability (Chap. 6), decomposing the gaps in health expectancies (Chap. 7), and assessing the impact of risk factors (Chap. 8). One of the methods to assess the impact of risk factors includes microsimulation, and this is covered in more detail in Chap. 9, with Chap. 10 describing this method to produce forecasts of health expectancies.

The REVES network has always seen the relevance for public health policy of a population health indicator that reflects both the quality and quantity of remaining life, rather than just the quantity. Part III, *Quantity and Quality of Life: Synergy or Trade-off*, reflects the importance of this topic. Chap. 11 brings new analyses to help understand why women live longer than men but spend a higher proportion of their remaining years in poorer health. Self-rated health is one of the main health measures used for health expectancy, and Chap. 12 discusses the discrepancies between this subjective and more objective measures of health status, proposing practical recommendations for using self-rated health in future studies on ageing. Perhaps the biggest change since the last book is the way that the governments in many countries now understand the value of health expectancy and are using it in targets. The final three chapters in the section document this rise in the uptake of the Healthy Life Years indicator in Europe (Chap. 13), Japan in the area of health promotion (Chap. 14), and the evaluation of health care and health systems (Chap. 15).

Part IV, *Assessing New Dimensions*, comprises six chapters on new dimensions of health or new thoughts on existing ones. The disablement process, rather than health expectancy per se, is the focus of two chapters: Chap. 16, which looks at the role of pain in the process, and Chap. 20, which takes a fresh view of the process in the context of other conceptual models. Mental health has always been a key health dimension considered for health expectancy estimates and, in cognitive impairment, has benefitted from much greater harmonization across studies. However, the growth in surveys, including measures of cognition and mental health, since the first book requires that evidence is reassessed, and Chap. 17 consolidates the findings from across the world on cognitive and mental health expectancies. With continued increases in life expectancy, countries are seeing the need to extend working life and delay the statutory retirement age. Working life expectancy is an existing indicator to monitor developments in this area, and Chap. 18 brings a novel approach for viewing working life expectancy alongside health expectancy to ascertain whether extending working life is possible given the population health around retirement. The remaining two chapters in this section cover new health dimensions of subjective well-being (Chap. 19) and oral health (Chap. 21).

The final chapter in the *International Handbook on Health Expectancies* brings an overall conclusion and consolidation of the research and looks ahead to where future developments in health expectancy might lie. We hope

this book will become, as the first book, a key teaching and research tool for current and future generations, as well as for those already well-versed in health expectancies and those new to the topic.

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Abbreviations

ADL	Activities of Daily Living
CIFLE	Cognitive Impairment-Free Life Expectancy
DALY	Disability-Adjusted Life Years
DemFLE	Dementia-Free Life Expectancy
DFLE	Disability-Free Life Expectancy
DLE	Disability Life Expectancy
DSM	Diagnostic and Statistical Manual of Mental Disorders
EC	European Community
EU-SILC	European Union Statistics on Income and Living Conditions
GALI	Global Activity Limitation Indicator
GBD	Global Burden of Disease
GDP	Gross Domestic Product
HALE	Health-Adjusted Life Expectancy
HE	Health Expectancy
HLE	Healthy Life Expectancy
HLY	Healthy Life Years
HRQL	Health-Related Quality of Life
IADL	Instrumental Activities of Daily Living
ICD	International Classification of Diseases
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
ICF	International Classification of Functioning, Disability and Health
LE	Life Expectancy
MEHM	Minimum European Health Module
OECD	Organization for Economic Cooperation and Development
QALY	Quality-Adjusted Life Years
REVES	Rèseau Espérance de Vie en Santè/International Network on Health Expectancy and the Disability Process
SES	Socioeconomic Status
SRH	Self-Rated Health
ULE	Unhealthy Life Expectancy
UN	United Nations
WHO	World Health Organization
YLD	Years Lived with Disability
YLL	Years of Life Lost

Part I

Monitoring Trends and Gaps

1 Operationalization of Concepts of Health and Disability

Renata Tiene De Carvalho Yokota
and Herman Van Oyen

Introduction

For a long time, the concept and measurement of health has focused on pathology. The disease-oriented definition was related to one of the main challenges of societies – disease control (Breslow 1972). The concept of health as "absence of disease", defined in the medical model (Larson 1999), was closely linked with the high impact of infectious diseases on morbidity and mortality in the nineteenth century. At the same time, pathology advanced and diseases were better defined, with the identification of their etiologic agents and pathogenesis. Although it seems contradictory, it was natural to define health based on disease, owing to the expansion of medical sciences (Breslow 1989).

Advances in medical therapies and improvement of living standards, work conditions, personal hygiene, food access, public sanitation, and immunization contributed to the control of infectious diseases at the beginning of the twentieth century. Population ageing accompanied by the insidious increase of chronic diseases and disability became a reality around the globe (Breslow 1989; Omran 2005). In the face of the shift in mortality and morbidity patterns, the World Health Organization (WHO) proposed a new concept of health – "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (International Health Conference 1946). Even though the WHO definition of health was considered innovative, as it, for the first time, focused on positive health (Breslow 1989), it has received numerous criticisms. For instance, a complete state of well-being is not achievable with the ageing of populations, which are growing older with chronic diseases and disability (Huber et al. 2011; Godlee 2011; Huber et al. 2016). Most individuals would not be considered healthy by the WHO definition, as anything less than this "complete state" is considered unhealthy (Smith et al. 2009). Yet, after 70 years of its proposal, it remains the most popular definition worldwide.

The concept of disability and its operationalisation has also evolved over time (see Chap. 20). Until the 1970s, the medical model was the dominant theory used to define disability, the focus being mainly on the individual, with disability considered a medical problem that requires treatment (Goering 2015). A first disablement model

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was proposed by Nagi (Nagi 1965), with the distinction of pathology, impairments, functional limitations, and disability. In 1980, the WHO proposed the International Classification of Impairments, Disabilities and Handicaps (ICIDH), as a taxonomy for disease impacts, in parallel to the International Classification of Diseases (ICD), the standard taxonomy of diseases (Verbrugge and Jette 1994). The ICIDH distinguished three dimensions on the disablement process: impairment, disability, and handicap (World Health Organization 1980). In 1994, Verbrugge and Jette (Verbrugge and Jette 1994) combined and extended the Nagi's and WHO ICIDH models, by considering the role of risk factors for chronic diseases, and intra- and extra-individual factors to the disablement process. In 2001, the WHO endorsed the International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001). The ICF is a result of the important shift from the medical model to the "biopsychosocial" model of disability that integrates environmental factors and emphasizes participation – the ultimate step on the disablement process. Within the ICF framework, disability became the umbrella term for impairments, activity limitations and participation restrictions. Participation restriction denotes the negative aspects of the interaction between an individual's health condition(s) and the individual's contextual factor (environmental and personal factors) (Jette 2009). As such, it refers to the performance of roles and social involvement in activities such as work, employment, school, parenting, community, social and civic life (Dijkers 2010). Recognizing that disability is an evolving concept and that it results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others, the ICF is in line with the definition of disability of the United Nations Convention on the Rights of People with Disabilities (United Nations 2006).

Another important concept emerged with population ageing in the 1990s, that of frailty. The first definitions of frailty were close to multimorbidity and disability (Hamerman 1999), but currently it has been used to describe vulnerable older individuals (Fried et al. 2004). Several operationalisations of the concept of frailty have been proposed: (i) the phenotype of frailty (Fried et al. 2001) which defines frailty as a clinical syndrome with three or more of the criteria: unintentional weight loss, weakness, self-reported exhaustion, slow walking speed and low physical activity; (ii) accumulation of deficit approach (Mitnitski et al. 2001), based on the frailty index, obtained by counting deficits, defined as health problems such as symptoms, signs, laboratory abnormalities, diseases, and disabilities (Rockwood and Mitnitski 2011); and (iii) integral conceptual model (Gobbens et al. 2010c), which defines frailty as a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, social) that increases the risk of adverse outcomes.

As health covers different domains (physical, mental, social) and each can be defined in different dimensions ranging from positive health, ill health, disease and disability there is no single measure of health but a range of measures that may tell (in)consistent stories about the health of the population as each of them cover different dimensions. This introductory chapter aims to review existing methods that operationalize the concepts of health, disability, and frailty in population health research. Several other chapters in this book cover these concepts in more detail, e.g. Chap. 5 discusses how, within different data sources, the concepts of health are brought into practice using appropriate instruments to fit particular research or policy questions.

Health

The measurement and operationalization of health has become increasingly important, as health is the aim of healthcare and research (Godlee 2011). The operational definition of health is crucial for: (i) evaluating public health interventions; (ii) assessing the quality of care; (iii) estimating the needs of a population; (iv) informing clinical decision-making; (v) allocating health-related

resources; and (vi) facilitating patients' autonomy (Ware et al. 1981; Huber et al. 2011).

Health is a complex concept that includes a wide range of dimensions such as risk factors, disease, impairment and disability. Health encompasses what is happening within the body (the biomedical approach) and the impact of pathology or abnormal functioning of organs and body structure on the individual's ability to participate in society. As mentioned earlier, there is no single measure of health, but these different health constructs may reflect different operational needs. A first step in developing summary measures of health is to identify which aspects of health should be captured and to be clear on the choices made. We present definitions and operationalisations proposed by the medical model, the World Health Organization (Card 2017), EuroQol group (EuroQol Group 1990), Huber et al. (2011) (Huber et al. 2011) and self-rated health.

The Medical Model

The medical model uses a negative concept of health, as health is defined as the absence of disease and infirmity. The diseases are detected in accordance with standard accepted procedures, such as medical examinations, diagnostic tests, and symptoms. This model is considered narrow and incomplete (Huber et al. 2011) for: (i) excluding mental and social problems in the definition of health; (ii) focusing on negative aspects of health rather than the individuals' abilities and strengths; and (iii) discouraging patient empowerment (Swaine 2011). In the medical model and following the ICD taxonomy, health is measured by disease-specific incidence or prevalence and/or disease-specific death rates, which are insufficient to measure population health.

WHO Definition

In contrast to the medical model, the WHO definition of health – a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity – was considered visionary when it was proposed in 1946 (Card 2017), as health was not only considered the absence of diseases, but also included physical, mental and social components with a focus on positive health (Huber et al. 2011).

Nonetheless, this definition has been criticized for more than 70 years, owing to the epidemiological transition that the world is facing with the ageing of populations and the change in the disease pattern from infectious to non-communicable chronic diseases. The main limitations of the definition include: (i) an emphasis on "complete wellbeing" which is unachievable, leaving most of the population unhealthy, unintentionally contributing to the medicalization of societies (e.g. most individuals would be eligible for unnecessary screening or expensive interventions, resulting in higher medical dependency); (ii) the current global phenomenon of population ageing accompanied by the burden of chronic diseases and disability would classify older individuals with these conditions definitively as ill, ignoring the capacity to adapt and to be able to live independently with chronic diseases and disability; and (iii) the lack of operationalization of the definition (Huber et al. 2011; Godlee 2011). Despite these numerous criticisms, the WHO definition of health remains the most popular definition worldwide (Larson 1999; Card 2017).

In 2002, the WHO proposed a conceptual basis for reporting and measuring heath (Chatterji et al. 2002). In this report, health is a multi-dimensional concept, distinguished from well-being, that is comprised of states or conditions of human body and mind and is considered an attribute of an individual person, although aggregate measures of health may be used to describe populations or aggregates of individuals. Health is classified based on two WHO frameworks: (i) the International Classification of Diseases and Related Health Problems (ICD) (World Health Organization 2011a) to classify causes of death; and (ii) the International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001), to classify health states. The health states are described based on the following core domains: affect, pain, mobility, cognition, self-care, and usual activities (Chatterji et al. 2002).

EuroQOL

The EQ-5D instrument was developed by the EuroQol group and created in 1987 by multidisciplinary researchers with interest in health care evaluation (Cabasés and Rabin 2014). The EQ-5D instrument is a health-related quality of life questionnaire, which includes two components: (i) the EQ-5D descriptive system and (ii) EQ-Visual Analogue Scale (VAS). The EQ-5D descriptive system comprises five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, and is available with three (EQ-5D-3L) and five (EQ-5D-5L) level response options. The EQ-VAS is a vertical visual analogue scale used to capture self-rated health, with endpoints ranging from "best imaginable health state" to "worst imaginable health state". The responses to the EQ-5D instrument can be used to obtain a simple and generic measure of health status with a single index value (EQ-5D index) for all health states described by a 5-digit number. The EQ-5D index values can be used to estimate composite measures such as Quality Adjusted Life Years (QALYs), which are often used in economic evaluation to inform priority setting in health care, in clinical studies, and in population health surveys (Cabasés and Rabin 2014).

Health Concept Proposed by Huber

Huber et al. (2011) proposed the following concept of health: the ability to adapt and to self-manage, in the face of social, physical and emotional challenges. This definition contrasts with the WHO definition by emphasizing the ability of individuals to cope with chronic diseases and disability.

This definition has also received criticism, mainly related to the emphasis on adaptation and self-management which: (i) could encourage reactive instead of proactive actions for health, as the life challenges are unknown until they occur (Becker 2011); and (ii) also denies the fact that some social determinants may preclude the ability of individuals and communities to adapt to their circumstances (Macaulay 2011). A qualitative study conducted with public health and health care professionals from the Netherlands highlighted that this definition does not focus on the relation between individual and population health, resulting in a low priority of prevention measures; secondly, it may promote socioeconomic inequalities in health, as individuals are not equally capable of taking care of their own health (Jambroes et al. 2016). Similar to the WHO definition, the definition proposed by Huber et al. also neglects socioeconomic, cultural, and environmental determinants of health.

Self-Rated Health

Self-rated health (SRH) is a self-reported measure of general health, which asks individuals to evaluate their health status ("In general, would you say your health is…) based on a scale ("excellent," "very good," "good," "fair," or "poor" (Jylhä 2009; Bombak 2013) or "very good", "good", "fair", "poor" or "very poor" (De Bruin et al. 1996)). SRH is a well-known global or single item instrument with a satisfactory reliability (Cox et al. 2009) and validity (DeSalvo et al. 2006). It is one of the most used health indicators in sociology, epidemiology and economic studies, often being part of health and non-health surveys (Jylhä 2009; Wu et al. 2013). It has also been used in comparisons of health status between populations (see Chap. 12 for further discussion of the use of SRH in population surveys), in risk assessments and clinical practice and as an outcome variable in clinical trials (Jylhä 2009).

SRH is considered an independent predictor of mortality probably for being a very inclusive measure of health, reflecting aspects related to survival that may not be covered by other health indicators (Mackenbach et al. 2002). It has also been associated with morbidity and disability (Crimmins and Saito 1993; Bailis et al. 2003). SRH is also a comprehensive, inclusive and non-specific global measure of health status of populations. Nevertheless, these advantages can also be seen as limitations since the lack of specificity

results in a lack of control of the aspects of health to be considered in individual assessments. Also, SRH is not necessarily comparable between cultural and distant age groups, as e.g. older individuals tend to report more positive SRH than younger individuals (Jylhä 2009).

Disability

The remarkable increase in longevity observed worldwide has been followed by a shift in causes of mortality and morbidity in the past century. Populations are growing older in parallel with the burden of chronic diseases and disability. This has considerable social and economic consequences for societies, posing public health challenges for the next decades especially related to the health care of people with disability (World Health Organization 2011b). Measuring disability becomes crucial to monitor population health and to promote healthy ageing.

The measurement of disability is challenging, as it is a complex, dynamic, and multidimensional experience (World Health Organization 2011b). To better understand the disablement process, several models have been proposed. Nagi's model was proposed in 1965 (Nagi 1965). In this model (Fig. 1.1), pathology is the interference with normal processes; impairment refers to a loss or abnormality at the tissue, organ, and/or body system level; functional limitations refer to restrictions in the performance of specific tasks by a person; and disability is defined as limitation in performance of socially defined roles and tasks within a sociocultural and physical environment (Jette 2009).

In 1994, Verbrugge and Jette (Verbrugge and Jette 1994) proposed an extension of Nagi's model, by using a similar main etiological pathway from diseases to disability, but also considering the role of risk factors for chronic diseases, intra-individual factors (e.g. lifestyle and behavioural changes; psychosocial attributes and coping; and activity accommodations) and extra-individual factors (e.g. medical care and rehabilitation; medical therapy; external support; and built, physical and social environment) factors, which can affect the level and pace the disablement process (Fig. 1.2). Chap. 20 further discusses these models.

Despite the difference in terminology, the framework used in the WHO International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001) describes the aetiology of decrements in functioning and disability not only in association with underlying health conditions, in line with the pre-

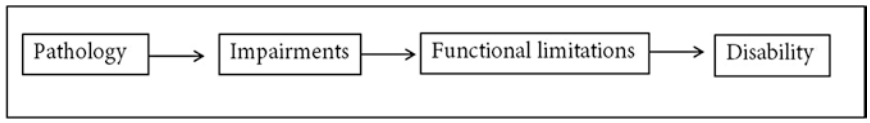

Fig. 1.1 Representation of the disability model proposed by Nagi (1965)

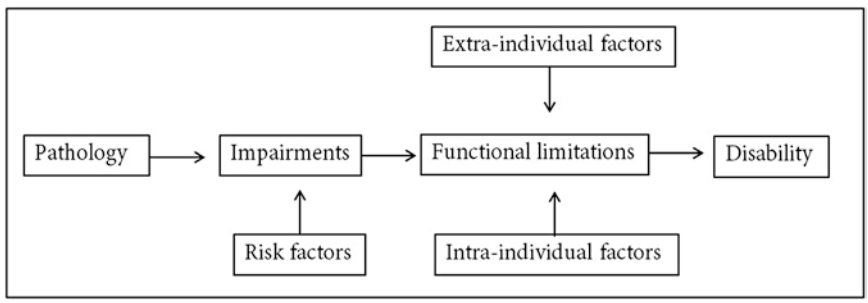

Fig. 1.2 Representation of the disability model proposed by Verbrugge and Jette (1994)

vious two models. Similar to the disablement model proposed by Verbrugge and Jette (Verbrugge and Jette 1994), it also takes into account the association with personal and environmental factors, i.e. disability is the result of the interaction between health conditions (such as diseases, disorders, injuries) and contextual factors – environmental (social attitudes and architectural characteristics) and personal (gender, age, education) factors (Jette 2009). The main difference is the bi-directionality of the associations in the main etiological pathway (Fig. 1.3).

The different domains covered by the disability models have, with the exception of impairments, been operationalized by different survey instruments as shown in Fig. 1.4. These instruments are discussed below.

Washington Group Questions

Since the ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2001 (United Nations 2006), the Washington Group (WG) was assigned to develop a culturally neutral and standardized instrument to measure disability suitable for censuses and surveys (Madans et al. 2011). According to the CRPD, disability is the result of the "interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" (United Nations 2006). The WG questions focus on measuring functioning in six basic actions or activities: seeing, hearing, walking/climbing, cognition, self-care and communication, with the aim to identify individuals with high risk of experiencing functional limitations in the population studied. The short set question is "Do you have difficulties in …?", with response options: no, no difficulty; yes, some difficulty; yes, a lot of difficulty; and cannot do it at all (Madans et al. 2011). The WG set with six questions and the WG short set with four questions (seeing, hearing, walking/climbing, and cognition) has been widely adopted in censuses and surveys (Verbrugge 2016) and cog-

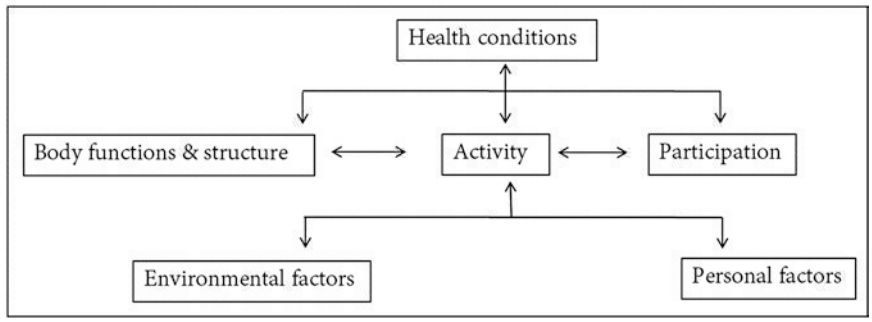

Fig. 1.3 Representation of the disability model proposed by the International Classification of Functioning, Disability and Health, World Health Organization 2001

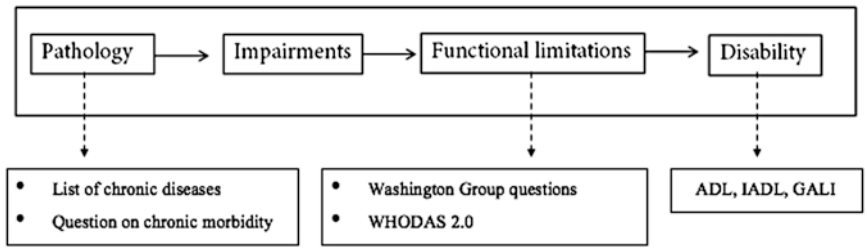

Fig. 1.4 Operationalization of the Nagi's (1965) and Verbrugge's (Verbrugge and Jette 1994) models

nitive interviewing was performed in several countries (Miller 2016).

WHO Disability Assessment Schedule (WHODAS) 2.0

The WHODAS 2.0 is a practical and generic assessment instrument to measure health and disability at a population level or clinical practice, directly linked to the WHO ICF (World Health Organization 2001), corresponding to the activity and participation dimension in the ICF (Üstün et al. 2010a). It captures the level of functioning in six domains of life: (i) cognition – understanding and communicating; (ii) mobility – moving and getting around; (iii) self-care – attending to one's hygiene, dressing, eating and staying alone; (iv) getting along – interacting with other people; (v) life activities – domestic responsibilities, leisure, work and school; and (vi) participation – joining in community activities, participating in society. Similar to the ICF, in WHODAS 2.0, health and disability are placed on a continuum, with disability defined as "a decrement in each functioning domain" (Üstün et al. 2010a).

The instrument includes questions related to difficulties in functioning experienced by the respondent in the six domains of life during the previous 30 days, with response options: none, mild, moderate, severe and extreme. Two versions are available: with 12 and 36 items and both versions can be self, interviewer or proxy-administered. Summary scores using the WHODAS 2.0 can be obtained by two methods: (i) simple – the scores assigned to each item are summed without recoding or collapsing any response category and without weighting of individual items; and (ii) complex – based on item response theory, which takes into account the level of difficulty in responding each item of the instrument. The resulting summary score of the complex approach is linear-transformed into a metric scale ranging from 0 (no disability) to 100 (full disability). WHODAS 2.0 has good psychometric properties, such as good reliability, being robust to different cultures and populations, and concurrent validity compared to other disability measures (Üstün et al. 2010a, b).

WHO Model Disability Survey

According to the WHO ICF (World Health Organization 2001), disability involves problems in one or more dimension: impairment, activity limitation, and participation restriction (Fig. 1.3). In 2011, the WHO and the World Bank proposed the use of the Model Disability Survey (MDS; https://www.who.int/disabilities/data/en/) with an extensive questionnaire including several dimensions related to disability grounded in the ICF (Sabariego et al. 2015). The MDS aims at providing detailed information on the lives of people with disability. It explores disability as the experience of a person with a health condition or impairment encountering a facilitating or hindering environment, instead of solely focusing on the individual's health status.

In line with the conceptual framework of the ICF, the MDS considers that: (i) disability is not an internal attribute of a person but an experience; (ii) disability is etiologically neutral; (iii) disability is a continuum, a quantity, and a matter of degree, ranging from no disability to extreme disability; (iv) disability is universal, meaning every person can be located on the disability continuum.

The MDS questionnaire includes modules on socio-demographic characteristics (18 questions), work history and benefits (23 questions), environmental factors (79 questions), functioning (48 questions), health conditions and capacity (46 questions), health care utilization (46 questions), well-being (26 questions), and empowerment (20 questions). The MDS has been implemented in several countries, such as Chile, Sri Lanka, Cambodia, Oman and Pakistan. A brief version of the MDS has also been proposed to facilitate integration in surveys. This shorter version includes three modules: environmental factors (15 questions), functioning (12 questions), and health conditions and capacity (13 questions). The brief MDS was recently imple-

mented in the 2019 Gallup Word Poll (Gallup 2019) of India, Laos and Tajikistan.

The MDS takes the approach that disability is a universal phenomenon characterized by a continuum ranging from low to high disability levels. Following an approach similar to the one used in the World Report on Disability (World Health Organization 2011b) and using modern test theory, the functioning questions are used to build a disability scale with metric properties using the Rasch model. The whole general population sample is used to create this metric, which is then linearly transformed to range from 0 (lowest level of disability) to 100 (highest level).

Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL)

The most used definition to assess disability in an older population is based on the ability to perform personal care activities, also known as activities of daily living (ADL) and household management, called instrumental activities of daily living (IADL) (Verbrugge 2016). ADL were originally proposed by Katz (Katz 1963) as a measure of functioning to be used among chronically ill and ageing populations, to assess the degree of independence in six basic tasks: bathing, dressing, going to the toilet, transferring, feeding and urinary continence. The idea behind the use of ADL indicators is that loss of functionality is a result of the biological process of ageing and the social environment (Fuentes-García 2014). The IADL were proposed later by Lawton and Brody in 1969 (Lawton and Brody 1969), which includes more complex tasks than ADL. Those tasks are required for independent living, such as cooking, shopping, using transportation, taking medications and managing finances. Since IADL are usually lost before ADL functions, the assessment of the first may identify incipient decline in older adults. The ADL and IADL questions usually focus on the degree of difficulty to perform the tasks, with possible responses defined as a scale, e.g. no difficulty, some difficulty, a lot of difficulty, ability to perform only with assistive devices, ability to perform only with personal assistance, and inability. To assess the disability prevalence in surveys, a score can be created based on all the ADL and/or IADL questions and different cut-offs are used to define the prevalence. Another approach is to aggregate the response options of the questions. For example, several studies considered disability present when the respondent replies at least some degree of difficulty in one or more ADL and/or IADL questions (Klijs et al. 2011; Van Oyen et al. 2014).

Global Activity Limitation Indicator (GALI)

In 2001, the Global Activity Limitation Indicator (GALI) was proposed as an indicator of participation restriction to monitor population health (Robine and Jagger 2003). In contrast to previous instruments that use several questions to assess disability, the GALI was developed to be a global measure, with a single question that can be easily introduced to surveys to assess disability, thereby improving international comparability (Berger et al. 2016; Verbrugge 2016). The question used to define the GALI is "For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do?", with possible answers: severely limited; limited but not severely; and not limited at all. The GALI implicitly refers to social participation in different settings (work, leisure activities, and environments) (Berger et al. 2016). The GALI has been used in the calculation of Healthy Life Years (HLY) to monitor population health in Europe since 2000, reflecting the Lisbon strategy (2000–2010) and later the Europe 2020 strategy (2010–2020) (Lagiewka 2012). To assess disability prevalence or the prevalence of participation restriction using the GALI, previous studies have grouped the response options (Jagger et al. 2008; Jagger et al. 2010; Berger et al. 2015b), or analysed them separately to assess different severity levels (Van Oyen et al. 2006; Mäki et al. 2013; Berger et al. 2015a). The GALI has good concurrent and predictive validity, being robust to differ-

ent cultures and populations, and good reliability (Van Oyen et al. 2018; Hsiao et al. 2019).

Importance of Including Disability Severity

Although most studies have defined disability as a dichotomous outcome by grouping response categories of questions, with exception of the MDS, which measures disability as a continuous outcome, the assessment of different severity levels of disability is essential to better capture the disability progress in ageing populations. Information on severity is important for the definition of public health policies to reduce disability at older ages, as severe disability is associated with worse health outcomes, institutionalization, long-term care need, and death (Gill 2010). More importantly, severity information is essential when estimating secular trends in health expectancies and to evaluate the theories of compression of morbidity, expansion of morbidity or the dynamic equilibrium as discussed by Robine et al. in Chap. 2.

Evolution of the Disability Concept and Importance for Public Health Policies

In the last decade, there has been an important shift from the medical model to a "biopsychosocial" model of disability that integrates environmental factors and emphasizes participation – the ultimate step in the disablement process. As a higher order functional dimension, participation encompasses and involves body functioning and structure, and activities (Madans et al. 2004; Mont 2007).

Besides monitoring the UN CRPD (United Nations 2006), the use of a harmonized measure of disability is essential for public health policy. For instance, the MHADIE project (Measuring Health and Disability in Europe: Supporting policy development) at the European Union level recently highlighted the "need for valid outcome measures for EU governments to monitor and evaluate the effectiveness of their disability policy, in terms of the primary ICF dimension of participation" (Leonardi 2010). Additionally, monitoring disability is particularly relevant in the context of ageing societies, as fostering active and healthy ageing has become a public policy priority. Within the European Union, active and healthy ageing is seen as fundamental to the pursuit of smart, sustainable and inclusive growth and better jobs (Berger et al. 2014).

Most of the operationalisations presented above are complex constructs based on various set of instruments. The lack of parsimony has hampered the use of these instruments; e.g. logistics and cost result in survey developers selecting subsets of the instrument questions with a negative effect on the standardization and comparability (Verbrugge 2016). An example of a parsimonious operationalization of the concepts health, disease and disability is the Minimum European Health Module (MEHM) proposed by the Euro-REVES 2 Project – "Setting up of a coherent set of health expectancies for the European Union" in 1998 (Robine and Jagger 2003). The MEHM consists of a short instrument with three global questions, covering three health domains: self-rated health, chronic (long-standing) conditions and long-term activity limitations measured by the GALI (Cox et al. 2009; Hsiao et al. 2019). The MEHM was developed to collect harmonized information on health-related and non-health related surveys in European countries, being adopted as part of the European Health Survey System by the European Statistical Agency (Eurostat) (Cox et al. 2009). The institutionalization of the MEHM instrument has stimulated the widespread use of especially the GALI as the underlying health measure of the HLY by EU Member States and the European Commission for policy making in different domains such as health promotion, the functional capacity of the work force; impact assessment (impact of healthy life styles on disability) and monitoring in health and social protection (Bogaert et al. 2018). Chapter 13 further discusses the use and uptake of the GALI in policy by EU Member States and the European Commission.

Frailty

The term frailty is often used to describe older populations vulnerable to adverse health outcomes, such as disability and mortality (Fried et al. 2004; Clegg et al. 2013; Tocchi 2015; Dent et al. 2016). The term originated in the 1970s by the Federal Council on Ageing in the United States, with the definition of "frail elderly" (Hogan et al. 2003). With the ageing of populations, the concept has evolved and gained relevance at individual and population levels. Yet, there is no internationally accepted definition of frailty (Dent et al. 2016), hindering its operationalization and measurement. Several conceptual models of frailty have been proposed and most of them consider frailty to be a syndrome of decline at advanced ages, which reflects a multi-systemic dysfunction with dynamic transition rates between severity states, resulting in increased risk of adverse health outcomes, such as falls, disability, long-term care, and death (Fried et al. 2004; Clegg et al. 2013; Dent et al. 2016).

Frailty should be distinguished from the physiological ageing process (Dent et al. 2016). Whilst a gradual decline in the physiological reserve occurs with ageing and most individuals still function well, in frailty this decrease is accelerated resulting in impaired homeostasis (Hogan et al. 2003; Clegg et al. 2013; Dent et al. 2016). Recent frailty models also distinguish frailty from disability and multimorbidity, although frailty is closely linked to these concepts (Fried et al. 2004; Dent et al. 2016). Multimorbidity is considered an etiologic risk factor for frailty (Gobbens et al. 2010c) and disability an adverse outcome of frailty (Fried et al. 2004; Gobbens et al. 2012).

Figure 1.5 shows a representation of increased vulnerability to a stressor of frail compared to "fit" older people (Clegg et al. 2013). Frailty is presented as a state of increased vulnerability to poor resolution of homeostasis after a stressor event, which increases the risk of adverse outcomes, such as disability. In the diagram, mobility problem is used as example. A stressor event such as a minor infection results in reduced mobility in both fit and the frail older people. In frail older individuals, the event triggers a disproportionate change in the health state – mobility problems. In addition, frail older individuals are not able to recover fully to the baseline state.

In frailty, the decrease in physiological reserves that normally occurs with ageing is accelerated, resulting in impaired homeostatic mechanisms. This decline is determined by genetic and environmental factors and is influenced by the individual physical activity level and nutrition status.

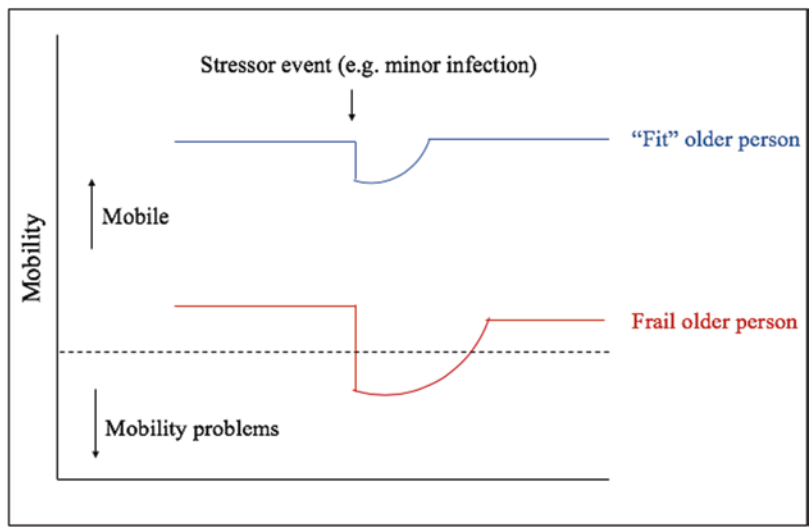

Fig. 1.5 Vulnerable state of frail compared to "fit" older people after a stressor event. (Adapted from Clegg et al. (2013))

We focus on models that include an operational definition of frailty, i.e. that propose a measurement of frailty in practice and especially in population health research: (i) the phenotype of frailty (Fried et al. 2001); (ii) the accumulation of deficits approach (Mitnitski et al. 2001); and (iii) the multidimensional approach proposed by Gobbens et al. (Gobbens et al. 2010b). Aguayo et al. (2017) compared 35 frailty scores in the general population and showed that the scores based on the accumulation of deficits approach presented the highest agreement while the scores based on the multidimensional approach were the most accurate.

Phenotype Model

This model was proposed by Fried et al. (Fried et al. 2001), based on analysis of the Cardiovascular Health Study in the United States, a prospective study with individuals aged 65 years and older. Frailty was defined as the occurrence of at least three of five criteria: slow walking speed, unintentional weight loss, low physical activity, self-reported exhaustion, and impaired grip strength. Individuals were classified as frail (≥3 criteria), pre-frail (1 to 2 criteria), or not frail or robust (no criterion). Frail individuals showed increased risk of adverse outcomes: falls, disability, hospitalization, and death (Fried et al. 2001).

The model is the most widely used as it is very attractive in population health research settings. However, it is difficult to implement in clinical settings, as it includes components that are not measured routinely, such as grip strength (Sternberg et al. 2011). Another limitation is the lack of social components, as this model focuses exclusively on the physical aspects of frailty (Clegg et al. 2013; Dent et al. 2016; Gobbens et al. 2017).

Cumulative Deficit Model

This model was based on the analysis of the Canadian Study of Health and Ageing, a cross-sectional study with a longitudinal component to investigate the burden of dementia in older individuals (Rockwood et al. 2005). Frailty is considered as the cumulative effect of individual deficits (Rockwood and Mitnitski 2011), including a wide range of health problems, such as symptoms, signs, laboratory abnormalities, diseases, and disability. A frailty index is then calculated as the proportion of existing deficits, i.e. the number of existing deficits/total deficits investigated. For instance, an individual with 20 existing deficits out of 80 investigated has a frailty index of 20/80 = 0.25. The frailty index is assumed to follow a gamma distribution (Mitnitski et al. 2001). Some studies have shown that the accumulation of deficits contributes to adverse health outcomes, such as institutionalization and death; e.g. a cut-off point of 0.67 is used to identify individuals with high risk of death (Clegg et al. 2013).

This model is attractive in clinical practice as the deficits can be identified in routine clinical assessment. Further, frailty is defined as a continuum instead of a binary outcome (frail/not frail) (Rockwood and Mitnitski 2011), better capturing the dynamic nature of frailty. A major limitation of this approach is that diseases and disability are considered as deficits, and thus included in the definition of frailty. The fact that the range of all possible deficits is variable hampers the standardisation of the instrument and the feasibility for use in (international) population health research.

Multidimensional Model

The multidimensional model defines frailty as a dynamic state affecting individuals who experience losses in one or more domains of functioning (physical, psychologic, social) that increase the risk of adverse outcomes (Gobbens et al. 2010b). The model describes the pathway: life course determinants → diseases → frailty → adverse outcomes (Gobbens et al. 2017). As a dynamic state, frailty is measured as a continuous variable. This model is operationalized in the Tilburg frailty indicator (TFI) (Gobbens et al. 2010b), based on a screening questionnaire for frail community-dwelling older people including only self-reported

information. The TFI has shown good reliability and validity (Gobbens et al. 2017).

The main advantage of this model compared to the previous ones is that it focuses not only on the physical aspects of frailty as the phenotype model, but also includes psychological and social domains (Gobbens et al. 2010a). In addition, frailty is distinguished from multimorbidity and disability.

Importance of Developing a Global Frailty Measure

Although different definitions are needed for different purposes, both clinical practice and population health may benefit from some general guidelines on the definition of frailty (Gobbens et al. 2017). Because frailty is a dynamic process, i.e. it is potentially reversible, and has a preclinical stage (Fried et al. 2004), early detection and interventions are essential to reduce it. Additionally, as a pre-disability state, frailty is prone to interventions to reduce the disability burden (Hogan et al. 2003).

Measuring frailty in clinical practice allows health care providers to identify and manage frailty to avoid progression (Dent et al. 2016). For population health, a common frailty definition is needed to compare estimates between populations, to identify high-risk populations, and to develop interventions to prevent, delay and reduce frailty and adverse outcomes in older individuals.

Similar to disability, one important aspect of the frailty definition that should be kept in mind is the possibility to grade it for severity (Clegg et al. 2013). This is important to identify individuals in different risk groups and to target resources and interventions to specific groups.

Composite Health Measures

Composite health measures combine information on mortality and morbidity into a single measure of population health (Hyder et al. 2012). They are used to: (i) monitor population health; (ii) supply a comprehensive reference for epidemiological estimates; (iii) facilitate health planning; (iv) contribute to decision-making for health policy; (v) guide research priorities; (vi) provide a comprehensive assessment of interventions; and (vii) guide patient care decisions (Murray et al. 2002). The evidence provided by composite health measures contributes to societal debates on questions such as (i) priority setting within health and health care; (ii) quantity versus quality of life; and (iii) whether the investment in longer lives coincides with living longer healthy lives and living less unhealthy lives (Saito et al. 2014).

Two types of composite health measures have been proposed: (i) health gap measures, such as disability-adjusted life years (DALYs) (Murray et al. 2002; Hyder et al. 2012) and quality-adjusted life years (QALYs) (Whitehead and Ali 2010; Saito et al. 2014); and (ii) health expectancies (Saito et al. 2014), such as disability-free life expectancy (DFLE) and life expectancy with disability (LED). Information on deaths, morbidity and disability is used to estimate either (i) the healthy life time lost as a measure of the impact of mortality and non-fatal outcomes; (ii) the healthy life time gained as a measure of a (medical) intervention or (iii) the expectation of duration of life in different health states: the total expectation of life is split over the expectation of life in good health and in different degrees of ill-health.

Each of the composite health measures provides different insight to the interaction between mortality and health-morbidity-disability.

- DALY sums up the loss in healthy life due to disability and years of life lost due to premature mortality. As such it represents, at population level, the years of healthy life lost. DALY is based on the medical model. This enables priority setting through ranking of burden causes in terms of DALY's; mortality and morbidity. At the same time, the disease-driven approach set high data requirements (disease-specific mortality and morbidity data (incidence and duration or prevalence)). The definition of the disability as translated in dis-

ability weights does not necessary correspond to the different models described in this chapter. A disability weight reflects the severity of the disease on a scale from 0 (perfect health) to 1 (equivalent to death). For each disease, Years Lost due to Disability (YLD) are calculated by multiplying the incident cases by duration/prevalence and disability weight.

- QALY is a summary measure of health outcomes that reflects the years lived in perfect health gained due to a medical or public health intervention. In economic evaluations, it is important to enable comparisons across different disease areas, different types of interventions and different populations to assess the value for money of the interventions. QALY measures the duration in different health states multiplied by a health related quality of life (HRQoL) weight or utility weight. The preference-based measure of utility (a scale from 0 (equivalent to death) to 1 (perfect health)) remains an issue of controversy not only related to equity concerns but also related to underlying theoretical assumptions and methodological problems with the validation techniques (validity, reliability) (Whitehead and Ali 2010; Pettitt et al. 2016).
- In contrast to the DALY and the QALY, the composite health measure health expectancy is very easy to understand and interpret. Health and morbidity data requirements are less especially when the Sullivan method is used. Data are most often survey-based. Morbidity and disability are then self-reported prevalence data. Combined with mortality (incidence), an assumption of steady state is required. Health expectancy allows the study of the interaction of mortality and health through the triangle "duration of life", "duration of healthy life" and "duration of unhealthy life". Health expectancy estimates are therefore central in the debate related to (1) quantity versus quality of life and (2) the question if longer living populations are living longer healthy life and at the same time living less long unhealthy life. Chapter 2 discusses this latter question in detail.

Conclusions

In this chapter we described the operationalization of the concepts of health, disability, and frailty in population health research. Given the complexity of the concepts, there is no 'one size fits it all'. In all three domains – health, disability, and frailty – there is an evolution from pure medical models to biopsychosocial models. For each of the domains, differences in the results of the operationalisation can often be linked to differences in objectives and setting. The instruments developed for population health research range from extended multiple question instruments to parsimonious single item instruments. Several instruments are complementary to each other providing different insights to the health of populations.

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