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A Life Course Perspective on Behavior and Health

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The life course is a framework that provides a way to integrate macro-level factors – social, cultural, environment – with individual-level influences that collectively contribute to health by pointing to the trajectories and transitions of persons (Elder & Johnson, 2002; Elder, Johnson, & Crosnoe, 2003). The importance of this orientation is highlighted by the Patient Protection and Affordable Care Act, which has extended health-care coverage to millions of Americans and has concomitantly focused attention on social and behavioral determinants of health (Institute of Medicine, 2014). The Institute of Medicine (IOM) has responded to this legislation by a recent call to delineate and capture these determinants within emerging electronic health records, information that can ideally be used by individual clinicians, by health-care systems, and by public health officials and researchers (Institute of Medicine, 2014; Adler & Stead, 2015).

Social factors can be attributed at the individual level or larger contextual level (e.g., neighborhood and community), and both have a profound effect on the health and health care of patients. Individual-level social factors, such as race/ethnicity, exert a substantial influence on how people view and rate their health (Gibson, 1991; Kramarow, Lentzer, et al., 1999), in addition to how frequently they use health-care services (Phillips, Hamel, et al., 1996; Greiner, Perera, & Ahluwalia, 2003). Contextual factors are features of the social and physical world (Berkman & Kawachi, 2000), and geographic location and the local distribution of health-care resources are strongly associated with the intensity of services that patients receive (Fisher, Wennberg, et al., 2003a, 2003b). Although much prior work has studied the separate effects of individual-level and contextual determinants (Han, Phillips, et al., 2005; Wen, Cagney, & Christakis, 2005; Covinsky, Eng, et al., 2003), a conceptual framework to examine how these factors jointly contribute to health and health services has not been fully developed.

The recent IOM report recommended a panel of largely individual-level domains and measures, such as race/ethnicity, tobacco and alcohol usage, and social connectedness (Institute of Medicine, 2014). Unfortunately many of these measures do not fully capture or delineate the contributory and differential effects of key social and behavioral determinants on health outcomes (Braveman, Egerter, & Williams, 2011). The report also has a restricted view of contextual factors, such as community-level social and environmental data

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© Springer Science+Business Media LLC 2018
E. B. Fisher (ed.), *Principles and Concepts of Behavioral Medicine*,
https://doi.org/10.1007/978-0-387-93826-4_16

(Bazemore, Cottrell, et al., 2015), a limitation that does not add understanding in how upstream factors contribute longitudinally to the health of populations (Braveman, Egerter, & Williams, 2011). In response, this chapter introduces the life course as a multilevel perspective that can frame how both contextual and individual factors jointly influence the health and health care of patients. This field of inquiry is characterized by locating people longitudinally along trajectories and characterizing their social contexts and situations as pathways in which their lives progress (Elder, Johnson, & Crosnoe, 2003). The life course has already gained wide acceptance across multiple disciplines, such as aging and gerontology, developmental psychology, and social epidemiology (Mortimer & Shanahan, 2003). A life course approach to chronic disease epidemiology, for example, examines the biological, behavioral, and psychosocial pathways that may be paved early in life and operate across an individual's life span, eventually contributing to the risk of developing chronic disease (Ben-Shlomo & Kuh, 2002; Kuh & Ben-Shlomo, 2004; Lynch & Davey, 2005). Conceptual models within life course epidemiology look at how the temporal ordering of exposure variables, such as stress, factor into later life risk of disease (Ben-Shlomo & Kuh, 2002).

Social Factors Contributing to Health and Health Care

The socio-ecologic model is addressed in many chapters throughout this book and underscores the importance of social and environmental influences within the life course perspective. Although individual-level social factors, such as race/ethnicity, are more commonly understood (Gibson, 1991; Kramarow, Lentzer, et al., 1999), contextual factors are less clearly defined features of the social and physical world (Berkman & Kawachi, 2000), but they account for many differences in the health-care experience of patients; geographic location and the local distribution of health-care resources are strongly associated with how much health-care services that patients receive (Fisher, Wennberg, et al., 2003a, 2003b). To illustrate these influences, this chapter will direct attention to the social and behavioral factors as they influence an important part of the life course, older adulthood, and the end of life.

As background, the overall health and health-care experience of older adults with serious chronic illness varies widely depending upon the local social and physical environment (e.g., geographic region, distribution of health-care resources) and individual-level factors (Dartmouth Medical School Center for the Evaluative Clinical Sciences, 1999). There are compositional and contextual explanations for such variation. A compositional explanation attributes area variation to differences in the characteristics of individuals in defined areas (Macintyre & Ellaway, 2000). For example, a larger concentration of frail, older adults in one geographic area would explain a higher rate of health service utilization when compared to another area. Contextual explanations, in contrast, suggest that there are features of the social and physical environment that influence the health of those exposed to it (Macintyre & Ellaway, 2000).

Older adults may be more influenced by their social environments and emotional ties to their communities (Diez-Rouz, 2002; Krause, 1996; Robert & Li, 2001). These place effects play an important role in health outcomes, especially near the end of life. This is illustrated by the finding that the chance of an inhospital death varies more than twofold among hospital referral regions in the United States, from as few as 20% of deaths to more than 50% (Dartmouth Medical School Center for the Evaluative Clinical Sciences, 1999). In addition, for older patients with Medicare, the number of days spent in acute hospitals and the chance of being admitted to an intensive care unit during the last month of life vary by factor of more than five (Dartmouth Medical School Center for the Evaluative Clinical Sciences, 1999). These variations in hospitalizations are associated with the per capita supply of hospital beds and physicians (Wennberg, Freeman, & Culp, 1987; Wennberg, Freeman, et al., 1989; Fisher, Wennberg, et al., 1994), health services that are unfortunately associated with aggressive technical interventions and are frequently undesired and at odds with elders' individual life situations and expressed preferences (Stein, Lynn, et al., 1989).

From an economic perspective, regional differences in Medicare spending are largely explained by more hospital and specialty-based patterns of care (Fisher, Wennberg, et al., 2003b). Intuitively, older adults residing in areas with high concentrations of health-care resources (i.e., hospitals, physicians) would expect better health outcomes than residents in low-resource areas. However Medicare recipients in high-spending areas do not have better quality of care or improved health outcomes, such as decreased mortality or improved functional status, when compared to lower-spending regions (Fisher, Wennberg, et al., 2003a, 2003b). The local supply of specialist physicians and hospital resources is a major driving force to the use of discretionary services – hospitalizations, physician visits – in a geographic area (Fisher, Wennberg, et al., 2003b).

Individual-level factors (e.g., race and ethnicity) also exert a powerful influence on outcomes, including perceived health status (Gibson, 1991; Kramarow, Lentzer, et al., 1999) and health-care utilization (e.g., hospitalization, hospice usage) (Phillips, Hamel, et al., 1996; Greiner, Perera, & Ahluwalia, 2003). Over 60% of African Americans prefer to die in the hospital, opt for more aggressive medical care for terminal illness (Garrett, Harris, et al., 1993; Gramelspacher, Zhou, et al., 1997), and are less likely to use hospice when compared to whites (Greiner, Perera, & Ahluwalia, 2003). In addition to health service utilization, race and ethnicity also exert a powerful influence on self-reported health status in older adults (Gibson, 1991). Among persons 65–74 years of age, non-Hispanic black persons and Hispanics are more likely to report fair or poor health, when compared to non-Hispanic white persons (Kramarow, Lentzer, et al., 1999). Further, self-rated health status and other health-related quality of life indicators have been found to be consistent predictors of how often health service are utilized (Hulka & Wheat, 1985; Wan, 1976; Wolinsky & Arnold, 1988). These global measures are representations of the physical, emotional, and social aspects of health and have been found to be an independent predictor of mortality (Idler & Benyamini, 1997) and life expectancy in older adults (Lubitz, Cai, et al., 2003).

The Life Course Framework

The life course provides a framework for understanding how social and behavioral factors impact health. Life course theory emerged from three intellectual traditions: social relations, age and temporality, and life span development (Elder, Johnson, & Crosnoe, 2003). From a social science perspective, roles are patterns of expected behaviors and attitudes that are commonly held and defined within groups or by social situations (Theodorson & Theodorson, 1979). A foundation for framing such a social and relational dynamic begins with the sociological relationship theories that surfaced in the 1960s and 1970s and continues with the life course theory of today (Kertzer, 1983; Clausen, 1968; Brim & Wheeler, 1966).

Socialization describes how individuals move into and out of social roles (e.g., parent, student) accompanied with a set of proscriptive and prescriptive expectations (Clausen, 1968). Patients may occupy a sick role which can release them from their usual obligations and responsibilities, such as work or parenting (Mechanic, 1978). These social roles, however, are not isolated sets of expected behaviors and attitudes but are often characterized by a graded sequence and transitions across different periods of the life cycle (Antonucci & Akiyama, 1995). Older adults rather than children and adolescents, for example, are more readily recognized and accepted by others in the sick role, although individual members within each group may be afflicted with the same serious illness.

Role-theoretical perspectives – social roles, life cycles – are limited in their ability to conceptualize relationships since they are timeless and fail to locate individuals within their larger social or historical contexts. Life course theory fills this void by incorporating constructs of age and temporality developed from social anthropology (Riley, Hess, & Bond, 1983; Neugarten & Neugarten, 1996). These elements recognize the multiple chronological meanings of age (e.g., historical time, social time, biological time) and the remarkable individual variability in the timing and scheduling of events along a life course (Neugarten & Neugarten, 1996). For example, the health effects of life events and transitions often depend on when they occur (e.g., whether bereavement and widowhood occur early or later in life) (Wortman & Silver, 1990).

A life span concept of development represents the final intellectual strand of the life course, drawing upon contributions from developmental psychology and life course sociology. Life span concepts such as life review and autobiographical memory emphasize the importance of narrative and memoir accounts within lived lives (Thomas & Znaniecki, 1958), while human agency views individuals as central actors and producers of their own development (Clausen, 1993). In the United States, patient-centered movements such as end-of-life care and complementary and alternative medicine can be viewed as attempts by patients to reclaim their own voice and individual human agency within a system of health care that is often depersonalized and grounded in technology (Daaleman, 2004).

Principles of the Life Course

Life course principles focus on individual choice and decision-making, promote an awareness of larger social and historical contexts, and foster an understanding of the timing of events and the various roles that change in a lifetime (Daaleman & Elder, 2007). These principles also think of human lives as embedded in relationships with significant others and help us consider a holistic understanding of lives over time and across changing social contexts (Elder, Johnson, & Crosnoe, 2003). As a whole, the principles are (1) *human development and aging as lifelong processes*, (2) *human agency*, (3) *historical time and place*, (4) *timing*, and (5) *linked lives* (Elder & Johnson, 2002).

The principle of *lifelong development and aging* embraces a longitudinal, often intergenerational, perspective that links earlier life influences with events and outcomes in subsequent years (Amick, McDonough, et al., 2002). Life course epidemiology, which was introduced earlier, is representative of this principle and examines the long-term effects of physical, environmental, or social exposures during childhood on subsequent health or disease risk in later life (Kuh, Ben-Shlomo, et al., 2003). This approach casts light on the behavioral, biological, and psychological processes that are in play across an individual's lifetime, or across generations, and that can contribute to the risk of developing disease or that can help maintain health and functional status (Kuh, Ben-Shlomo, et al., 2003). In its ideal form, life course epidemiology integrates the contributions of well-established risk factors for disease – smoking, obesity, and hypertension, for example – with the social and environmental processes (e.g., lower socioeconomic status) that may be operational. Consider, for example, the prevalence of heart disease, which peaked in the 1960s for a cohort of men born around the turn of the twentieth century (Lynch & Davey, 2005). After this decade there was a marked, progressive decline in heart disease, which reflects both the reduction in smoking and advances in blood pressure control in the general US population (Lynch & Davey, 2005). However the drop-off in heart disease in subsequent years was not uniform for all populations, illustrating the differences across subsequent birth cohorts in how early and later life exposures to smoking and hypertension – as well as to other social and psychological factors – predispose to developing heart disease (Lynch & Davey, 2005).

A life course epidemiologic approach looks at how socially developed and patterned exposures to risk factors in early life may account for marked differences and inequalities –which may not solely be attributable to genetic or biological factors – in later life mortality, disease, and health (Kuh, Ben-Shlomo, et al., 2003). Socioeconomic factors at different periods of the life course can function through an accumulation of risk or via a chain of risk (Kuh, Ben-Shlomo, et al., 2003). The accumulation of risk describes the gradual accrual of multiple behavioral risk factors (e.g., smoking, limited physical activity), adverse environmental conditions (e.g., limited access to clean air and water), and repeated illness or injury episodes that cumulatively cause physiological damage and subsequently increase the risk of disease and mortality (Kuh, Ben-Shlomo, et al., 2003). A chain of risk model, in contrast, is a sequence of linked exposures that raise the risk of disease; different types of social, biological, or psychological chains may mediate or moderate an increased or decreased risk of disease (Kuh, Ben-Shlomo, et al., 2003). In either risk model, there can be a critical period, which is a limited window of time in which an exposure can have a hazardous or protective effect on subsequent outcomes (Kuh, Ben-Shlomo, et al., 2003).

Agency is the second principle in the life course, and this reflects and characterizes the sense of control that people seek to gain over the events in their lives (Bandura, 1997). Human agency views individuals as active participants who construct their own life course through the choices and actions they take, given the opportunities and constraints of their personal history and social circumstances (Clausen, 1993; Bandura, 1997). Human behaviors, particularly health behaviors, are governed by a myriad of factors and individuals contribute to – rather than being the sole influencers of – what they do or what happens to them (Bandura, 1997). Agency is tied to individual actions that are done intentionally, and these actions are driven and guided by a person's personal efficacy (Bandura, 1997).

Self-efficacy beliefs are key in personal agency; if people do not believe that they are capable of executing a given plan of action and that the actions will produce a desired outcome, they will not initiate an activity or see it through to completion (Bandura, 1997). These beliefs can be drawn and developed from several sources: enactive mastery experiences that reinforce capability, vicarious experiences that promote efficacy beliefs through comparison with others, verbal and other types of social persuasion, and physiological and affective states through which people gauge their readiness and potential for change (Bandura, 1997). Personal agency does not operate autonomously and individually but emerges from a network of social structures that have both constraints and opportunities for personal growth and development (Bandura, 1997).

Personal agency and efficacy beliefs have provided the theoretical foundation for many interventions that have promoted health behaviors and enhanced the self-management of chronic disease. These beliefs that people can motivate themselves and regulate their health behaviors impact each phase of the personal change process, the contemplation and consideration of changing health behaviors, garnering the motivation and resources that are needed to be successful, and sustaining the desired change and dealing with setbacks (Bandura, 1997). One effective strategy that draws upon human agency is peer support or mentoring. Peer supporters provide the needed practical and emotional support of behavior change that can potentially facilitate and enliven the efficacy beliefs of people who live with comorbid disease by sharing a personal knowledge and an illness experience in authentic and meaningful ways (Solomon, 2004). There is a substantial evidence base – from patients living with chronic conditions such as diabetes, cancer, cardiovascular disease, mental illness, and HIV/AIDS – that has demonstrated the effectiveness of peer support in sustaining health behavior change (Davidson, Chinman, et al., 1999; Parry & Watt-Watson, 2010).

Peer support strategies offer emotional, social, and practical assistance on how to achieve and sustain complex behaviors that are essential for managing conditions and staying active and healthy (Brownson & Heisler, 2009; Dunn, Steginga, et al., 2003; Fisher, Brownson, et al., 2005). In addition, this approach often complements and adds value to existing health-care services that help people adhere to care management plans in daily life, to stay motivated and cope with the stressors of chronic illness, and to maintain continuity with their health-care providers, often in a cost-effective manner (Whitley, Everhart, & Wright, 2006).

Individual lives are located in a specific *historical time and place*, another core life course principle. The individual life course is embedded in and shaped by the places that a person experiences over a lifetime (Elder & Johnson, 2002). The same historical event may differ in impact and meaning across different countries or regions, as evidenced during the immediate postwar years of World War II which saw widespread devastation in parts of Europe but prosperity in the United States (Elder, Johnson, & Crosnoe, 2003). A more contemporary example is the social and economic effects of the current AIDS epidemic on African children. Homelessness, migration, malnutrition, and reduced access to health care and education are staggering problems which have greatly increased the probability of illiteracy, poverty, and chronic illness in subsequent adulthood for this population (Foster, 2002). These place effects can be viewed as historical and ecologic constraints that limit the range of potential opportunities and choices along the life course.

In health care, there has been longstanding interest in the geographic variations found in the distribution of health-care services and a growing recognition that many social determinants of health may operate at local levels through neighborhoods and communities (Diez-Rouz, 2001). A number of health problems, such as low birth weight and infant mortality, tend to be aggregated and studied at the neighborhood level (i.e., census tract or block) and are tied to the cumulative disadvantage and geographic isolation of many African American populations (Sampson, Morenoff, & Gannon-Rowley, 2002). Here it is important to clearly define the characteristics of geographic boundaries or areas in ways that are applicable to specific health outcomes (Diez-Rouz, 2001). The terms neighborhood, area, and community have frequently been interchangeably used, often referring to an individual's immediate residential environment (Diez-Rouz, 2001). Administrative boundaries (e.g., zip code or census block) have been traditionally used in many studies to operationally define neighborhoods and communities that are situated in a specific geographic location (Diez-Rouz, 2001).

Over the last decade, geographic information systems (GIS) have been increasingly employed as tools that have been more discretely used to define the social and physical environment of individuals, as well as a way to capture the distribution of health-care resources (e.g., physicians, hospitals) in a spatial context (Ricketts, 2003). Geographic software programs can now generate precise area coordinates that reflect more meaningful regions of human activity – rather than by administratively set boundaries – that are marked by commerce (e.g., markets and shopping centers), work locations, places of worship, and the sites of health-care services, such as hospitals and physician practices (McLafferty, 2003).

The life course principle of *timing* acknowledges that the concept of age has several meanings and interpretations (Neugarten & Neugarten, 1996). Similar events and life experiences can impact individuals in different ways depending on when they occur in the life course (George, 1993). For example, the differential experiences of young people who go through very early transitions from adolescence to adulthood (e.g., leaving home, marrying or cohabitating, becoming a parent) have detrimental effects on mental health (Elder, Johnson, & Crosnoe, 2003). Health-care providers commonly limit their understanding of time to strictly biological terms that are marked by developmental or physiological changes, such as childhood language acquisition, puberty, and menopause. However, the life course broadens this view to include other ways of thinking about time. For example, social time looks at how chronologic age (i.e., age in years since birth) distinguishes and differentiates role expectations among individuals, an understanding that is illustrated by ongoing discussions regarding the appropriate age for younger adults to have legal access to alcohol, to vote, or to serve in the military and for older adults to receive Social Security and Medicare benefits (Scanlon, 2006). Subjective time, in contrast, is a person's self-perception of how old they are or how old they wish to be (Neugarten & Neugarten, 1996).

Timing focuses on the assumptions and expectations regarding when life events should occur and are normative in areas such as childbearing and family life. Timing comes into greater play for patients and family members particularly around the beginning and end of life (Lynn, O'Connor, et al., 1999). This principle takes into account the developmental antecedents and consequences of life events and transitions which may vary according to their timing in a person's life (Elder, Johnson, & Crosnoe, 2003). In addition, it recognizes that the same events or experiences may impact individuals in differential ways, depending on when they occur in an individual's life course (George, 1993). For example, the very early transition to adult responsibilities (e.g., getting married or becoming a parent) at a relatively young age has been found to negatively impact subsequent mental health (Elder, Johnson, & Crosnoe, 2003).

The principle of timing also takes into account that individuals may view themselves as synchronous ("on-time") or asynchronous ("off-time") with their expectations regarding their social time (i.e., is the life event concordant with their age) or subjective time (i.e., is the life event concordant with how old they see themselves). This principle is illustrated by variations in the timing of a terminal illness, whether early or later in life. For example, a 35-year-old woman who is unexpectedly diagnosed with an aggressive breast cancer would be considered in a "too early" age group and asynchronous according to the timetable of her birth cohort.

The last principle in the life course, that of *linked lives*, refers to the interdependence and network of shared, social relationships that surround individual lives. Larger social changes can impact individuals through their interpersonal contexts on more microlevel settings, such as family units (Elder, Johnson, & Crosnoe, 2003). For example, economic hardships can negatively impact the mental health of parents, which in turn affects the growth and development of their children. Social relationships can be thought of as the relational ties between individuals (i.e., interindividual) or changes in these connections that take place within one individual over time (i.e., intra-individual) (Elder & Johnson, 2002). There are basic characteristics of social relationships, including the size of the personal network and the varying strengths of the social ties among network members (Antonucci & Akiyama, 1995). These ties and networks serve multiple functions, such as emotional and instrumental support, and often provide resources in the areas of caregiving and personal care services.

Social network is a conceptual approach which recognizes that individuals are embedded in a web of relationships and are influenced by the behaviors and activities of those around them (Christakis & Fowler, 2007). In analyzing social networks, the concept of a node is used to describe people who may or may not be connected to others in the network; the connection between two nodes is termed a tie (Christakis & Fowler, 2007). Social networks acknowledge the human tendency of individuals who choose relationships with others that have comparable attributes and behaviors, and the grouping of nodes – each of which is connected to at least another node – is called a cluster (Christakis & Fowler, 2007). A longitudinal study, for example, examined the linkage between the social network and obesity among 12,000 people who participated in the Framingham Heart Study and found that a person's risk of becoming obese increased by 57% if he or she had a friend who also became obese (Christakis & Fowler, 2007).

The convoy model is another organizing framework of social relationships, one that adds a life course dimension to the concept of networks. The model views relationships as a series of interactive sequences involving significant others (e.g., important family members, longtime friends) that aggregate and disassemble across different periods of the life course (Antonucci & Akiyama, 1995). This way of thinking emphasizes the longitudinal character of relationships and conveys a fluid aspect that is often not captured by social support or family network concepts (Broadhead, Gehlbach, et al., 1988). The social convey model views an individual as moving through their lifetimes surrounded by different groups of people who are close and important to them, an alliance of others who have a critical influence (either positive or negative) on their life and well-being (Antonucci & Akiyama, 1995).

Trajectories and Transitions

The concepts of trajectory and transition are central, unifying themes, and they represent both the long and short perspective of life course principles. Lived lives, for example, take place over an extended span of time, a social trajectory of work or marriage or a developmental trajectory of self-rated health. In contrast, a sense of agency or personal control may be developed within a short time span that is marked by the transition of specific life events, such as graduating from college and getting married. The life course emphasizes the importance of trajectories, as well as transitions and turning points, as core concepts in its framework. Trajectories are sequences or long-term patterns within a given area (e.g., health, family, or work situations) and are formed by linking states (e.g., health status, poverty) and transitions across successive years (Duncan, Brooks-Gunn, et al., 1998; Clipp, Pavalko, & Elder, 1992). Trajectories are not individual events in time, but are embedded in social pathways that are defined by social institutions and relationships that provide social support. That is, they are socially determined. Trajectories reflect the cultures and communities in which they evolve as well as the individuals whose lives they characterized. Transitions are inflections and changes in direction of the trajectory (Elder & Johnson, 2002).

Illness trajectories go beyond the physiological unfolding of disease to encompass the total organization of work done over the course of the illness and take into account the impact that this work has on those involved in the accompanying activities (Strauss, Corbin, et al., 1984). Work here refers to the physical and emotional tasks and activities performed by patients and caregivers. When a trajectory and its transition place people in new environments and alter behavioral and social patterns, they are referred to as turning points (Sampson & Laub, 1993). Turning points are individual or institutional sentinel moments that result in a change of direction along the life course (Clausen, 1998). For example, a seriously chronically ill patient who declines aggressive medical care has reached a turning point. The probable subsequent decline in health and functional status and entry into long-term care or hospice would constitute both a trajectory and a turning point. Trajectories are influenced by and directly impact social relationships (e.g., family caregivers) and provide a way to understand and conceptualize the important factors that potentially affect a patient's experience of health, illness, and well-being.

Trajectories have been mapped out to depict the patient experience of serious chronic illness and are distinguished by variations in their duration and shape (Glaser & Strauss, 1965; Pattison, 1977; McCormick & Conley, 1995). A report from the Institute of Medicine, for example, offered three plausible functional trajectories specific to serious illness and dying: (1) sudden death from unexpected cause, (2) steady decline from a progressive disease with a "terminal" phase, and (3) advanced illness marked by slow decline with periodic crises (Fig. 16.1) (Glaser & Strauss, 1965; Field & Cassel, 1997). A subsequent study of Medicare beneficiaries examined the degree to which these three trajectories accurately characterized

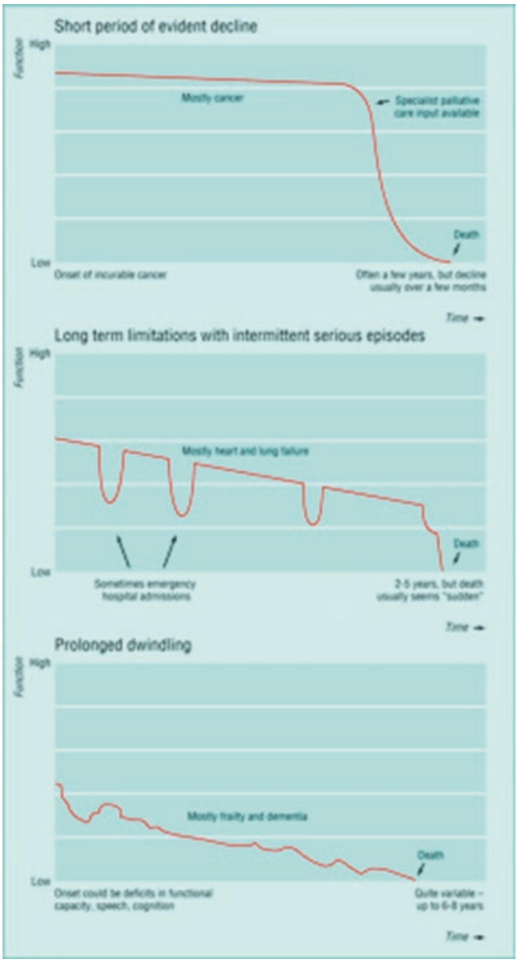

Fig. 16.1 Functional trajectories of serious chronic illness (Murray, Boyd, & Sheikh, 2005; Lynn & Adamson, 2003)

seriously ill and dying patients, and four trajectories were able to characterize 92% of individuals' pathways at the end of life: (1) sudden death, (2) terminal illness, (3) organ failure, and (4) frailty (Lunney, Lynn, & Hogan, 2002).

An Analytic Approach to Determining Trajectories

Statistical methods that integrate repeated observations over time and identify different paths of progression are central to characterizing trajectories. This analytical approach is different than simply using discrete observations at baseline and at one or more points in time. With trajectories, the focus is less on determining the outcome of interest as it is in describing the sequence of events that contribute to and sustain it. Since analytic strategies used in characterizing trajectories may not be commonly understood, the following section describes one approach by illustrating the functional trajectories of older adults with serious chronic illness (i.e., a subset of chronic diseases which are marked by a progressive loss in health and functional status leading to death) (Stein, Lynn, & Stein, 1989).

The primary strategy assumes a continuous-scale outcome and relies on the use of hierarchical linear models (HLM) to account for repeated measures; these are also known as linear mixed models. When the outcome is categorical or discrete, generalized linear mixed models may be used. The methods include: (1) equations for population-averaged trajectories and their corresponding residuals that are used to aggregate individuals into subgroups based on a specific outcome measure (e.g., older adults with a pattern of physical functioning over time), (2) explanatory models that identify factors associated with different outcome pathways, (3) estimating individual trajectories with prediction equations that include random individual-level effects to account for deviation of an individual's trajectory from the population-averaged trajectory for the group to which he/she belongs, and (4) validating the trajectories with respect to conceptually related measures.

Using our example, older adults with serious chronic illness (SCI) might be categorized into the following groups: (1) terminal illness (cancer, solid or hematologic malignancy, or malignant tumor of any type), (2) organ failure (ischemic heart disease, congestive heart failure, chronic kidney disease, chronic obstructive pulmonary disease), and (3) frailty (stroke, cerebrovascular accident). Life course principles, that were described earlier, can inform the selection of data elements to be used in modeling trajectories for specific patient populations and patients. The following section illustrates how analyses might proceed in differentiating and then describing these three groups and the extent to which they provide a representation of the variety of pathways among those with serious chronic illness.

Identifying the Pathways: Population-Averaged Trajectories and Residuals to Identify Resilient or Vulnerable Functioning

For each of the three groups with serious chronic illness, an average trajectory can be estimated by adjusting the intercept for baseline severity (and comorbid conditions, such as depression) and then identifying individuals for whom the model does not have a good fit. For simplicity, an analysis for a single group can be considered, although models can be specified to analyze all three groups simultaneously as this provides improved precision when regression parameters are shared across the three groups. Specifically, a longitudinal data model may be fit with up to a cubic effect of time (i.e., an individual's age is used instead of calendar time (t) in order to address age cohort effects):

$$E\left[Y\left(t\right)\right] = b0 + b1 * t + b2 * t^2 + b3 * t^3$$

In conjunction with this model for the mean value of functional status, an appropriate covariance model can be specified within the context of a hierarchical linear model (Cnaan, Laird, & Slasor, 1997) in the case of a continuous outcome or a generalized linear model (GLM) estimated by generalized estimating equations for a categorical outcome (Liang & Zeger, 1986; Diggle, Heagerty, et al., 2002). Once the regression parameter estimates have been obtained, a set of residuals can be computed, one for each observation that an individual contributes to the analysis. An individual with a particularly large (i.e., positive) residual (e.g., about the estimated mean regression line) is one who has functional status better than expected at that particular age. An individual with a particularly small (i.e., negative) residual is one who has functional status poorer than expected at that particular age. In this way, we can define so-called "resilient" (i.e., those who maintain their functioning) and "vulnerable" (i.e., those with declining functioning) older adults.

Practically, using longitudinal data from electronic health records can inform the categorization of an individual as resilient or vulnerable. This categorization will be time dependent, as an individual may have better functioning than expected at a younger age and subsequently poorer functioning than expected at an older age. At each of several ages, which can be determined based upon the distribution of ages in the data, the upper quartile of residuals can be defined as the resilient older adults, and the lower quartile of residuals as the vulnerable older adults. Two logistic regression analyses can be conducted, the first assessing whether individual factors, such as linked lives and agency, predict resiliency and the second assessing whether these factors predict vulnerability. These analyses (i.e., one for resiliency and one for vulnerability) can provide an assessment of individuals' longitudinal indicators in order to summarize findings across the life course. For example, do stronger social network ties with others explain resiliency across all ages or only for some age groups? To address such questions, modeling approaches for longitudinal binary data such as generalized estimating equations can be used (Liang & Zeger, 1986; Diggle, Heagerty, et al., 2002).

Understanding Differences Among the Pathways: Explanatory Models That Identify Factors Associated with Different Functioning Pathways

This approach, which extends that of the previous section, assesses directly, within the context of an HLM (or GLM, in the case of a categorical outcome), whether or not trajectories of functional status differ by individual characteristics. For simplicity, consider a covariate, X, and the longitudinal data model for a single SCI group:

$$E\left[Y(t)\right] = \left(b0 + a0^{*}X\right) + \left(b1 + a1^{*}X\right)^{*} t + \left(b2 + a2^{*}X\right)^{*} t^{2} + \left(b3 + a3^{*}X\right)^{*} t^{3}$$

If X is equal to 0 or 1, then a test that the regression coefficients, a0, a1, a2, and a3, are simultaneously equal to 0 is a test of whether or not the trajectory of functional status is identical for the two groups determined by X. A fully saturated model including several categorical covariates, informed by life course principles, would estimate intercept, linear, quadratic, and cubic time effects for each group resulting from the cross-classification of the covariates. In accordance with the richness of the data, a sequence of regression models can be fit.

The first set of models can include severity factors retaining main effects in order to adjust the intercept b0 above, but dropping nonsignificant polynomial time effect interactions as more complex but parsimonious models are built to describe varying trajectories. In this regard, the second set of models can additionally include individual factors, and the third set of models can add potentially protective factors, such as social networks. For example, do protective factors alter the group trajectories of functional status after controlling for symptom severity and other individual factors? The focus here is on estimating functional status trajectories for the three SCI groups and determining whether subgroups within those three primary groups have different trajectories.

Identifying Individuals' Pathways: Estimating Individual Trajectories Using Prediction Equations

Hierarchical linear models, also known as random coefficient models in the context of repeated measures, can be used to estimate a trajectory of a continuous outcome for each individual; generalized linear mixed models (e.g., logistic models with random coefficients) (Diggle, Heagerty, et al., 2002) could be used for dichotomous or categorical outcomes. In the parlance of linear mixed models, the individual-level trajectories can be based upon best linear unbiased predictors of model random effects. It would be possible to estimate a trajectory for each individual using only person-specific data, for example, a cubic polynomial curve for an individual with at least four data points. However, these trajectories can be poorly estimated if there is little data. The strength of the HLM approach is that individual trajectories can be estimated by also using information from a comprehensive data set from electronic health records via the particular model that is used. Ideally, random coefficients would be fit for each of the four polynomial terms in the model above. However, this model is very complex and it may not be computationally feasible to test it. Therefore, a simpler model that specifies a random intercept and linear term may be employed. Considering one of the mean models above, the model for the i-th adult at the t-th time is:

$$\mathrm{Y}\left(it\right)=\mathrm{E}\left[\mathrm{Y}\left(\mathrm{t}\right)\right]+bi0+bi1^{*}\mathrm{t}+\mathrm{e}\left(it\right)$$

In the above equation, Y(it) is the observed functional status for the i-th adult at the t-th time, E[Y(t)] is the mean trajectory for a particular SCI group (or subgroups if individual-level factors are included), bi0 and bi1 are individual-level deviations from the overall group mean intercept and slope, and e(it) is a random error term. With the usual zero-mean normality assumptions of these random deviations, empirical Bayes estimation is used to provide estimates of bi0 and bi1 for each individual. Plugging these estimates into the above equation (with zero for e(it)) gives a predicted trajectory for each individual. For each SCI group, the individual trajectories can then be plotted to reveal their variation about the overall group mean trajectory, allowing characterization of variability of trajectories within each SCI group.

The potential contribution of using a life course approach in developing trajectories for older adults with SCI is highly relevant for both policymakers and care providers, since the number of older Americans continues to grow and will be facing disability, functional decline, and reduced quality of life (Merck Institute of Aging & Health, 2002). At the policy level, the striking geographic variation in health service utilization highlights that increasing services and resources do not improve mortality or quality of life, but result in less satisfaction with care for this population (Dartmouth Medical School Center for the Evaluative Clinical Sciences, 2006). And for providers, gaining a richer and longitudinal understanding of how individual-level social and behavioral factors contribute to the health of their patients can improve their care that they provide (Adler & Stead, 2015).

Caring for Patients and Populations Through the Life Course

The US health-care system is in the midst of a transformation to value-based care, which will focus on high-quality, cost-effective, patient-centered care for individual patients. In this new system, health-care providers will also be responsible for managing the care of populations of patients, such as those with type 2 diabetes mellitus, depression, and hypertension. The life course can provide both the intellectual and practical grounding for professionals who will be managing population in a system that seeks to optimize health and reduce disease burden not just in the short term but over the life span (Halfon & Conway, 2013). This orientation will shift the focus away from discrete, unlinked episodes of care, such as office visits, hospitalizations, and treatments for episodic or time-limited problems, to longitudinal trajectories of health and illness. In the foreseeable future, electronic health records and other sources will allow the measurement and creation of longitudinal data across the life course of patients, allowing the categorization of individual trajectories in specific health and wellness domains, such overall health and functional status.

A major challenge of health care in the twenty-first century will be a paradigmatic shift from an acute and largely communicable disease model to one that reflects chronic disease. Over a hundred years ago, communicable diseases –tuberculosis, diphtheria, and influenza – were the leading causes of death that largely contributed to infant and child mortality rates (Brim, Friedman, et al., 1970). The advent of antimicrobial therapy and major public health initiatives, such as vaccinations, have reduced mortality in these early years of life. As a result, chronic diseases – heart disease, cancer, stroke, lung disease – have displaced acute infectious diseases as the major causes of morbidity and mortality today (CDC, 2003; Jemal, Ward, et al., 2005). This shift may be illustrated in considering a 45-year-old woman who is newly diagnosed with diabetes mellitus and will require care over the next three to five decades. From a life course perspective, the biometric goal for her will not be a targeted level of glucose control at the next medical visit but a sustained trajectory of glucose control. The identification of major contributing factors – biological, social, and behavioral – in the early stages of her disease will confer an accumulation of risk providing a way to look at these trajectories that will inform treatment decisions and other interventions that last many years. Life course principles and trajectory analyses offer this way of thinking.

For health-care providers and public health officials, life course health data will allow a more complete understanding of how health is maintained or how disease develops over the life span. Practically, this information will transform the way health promotion and disease prevention programs are designed and implemented (Halfon & Conway, 2013). For example, predictive models using a life course approach may identify patients who are most likely to develop heart disease or diabetes, based on their cumulative individual (e.g., lack of exercise) and larger contextual (e.g., residence in a high-stress community) risk factors, facilitating the creation of targeted preemptive and preventive interventions (Halfon & Conway, 2013). At the same time, modeling pathways will support evaluation not in terms of "snapshots" of current status but of status and change in status over many years.

Health insurers and other payors will have greater incentives to promote health trajectories for populations of patients and to augment the longitudinal integration of health-care services, such as extending coverage and benefits from years to decades, creating incentives to manage risk and assume accountability for specified health outcomes (Halfon & Conway, 2013). An effective and efficient health-care system, as illustrated in Fig. 16.2, would ultimately require not only health-care services that are vertically integrated across medical, educational, and social service sites (e.g., worksites, schools) but also the

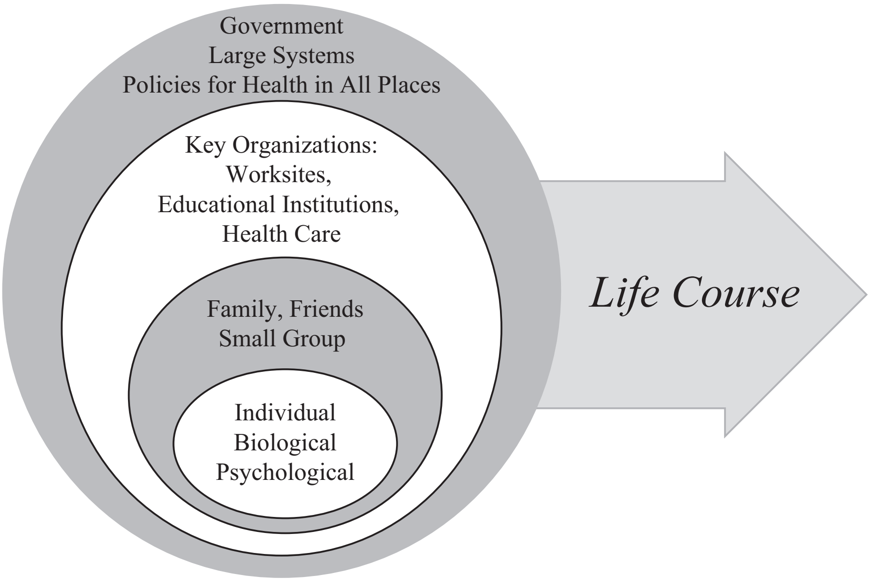

Fig. 16.2 Vertical levels of influence and the life course

horizontal integration across the entirety of the life course (Halfon & Conway, 2013; Halfon & Hochstein, 2002).

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