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### **Developmental Influences on Health**

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The determinants of health across the entire lifespan are influenced by early life experience. Complex interactions of the physical and psychosocial environment with biological and genetic factors in early life determine health outcomes not just during childhood and adolescence but into adulthood and old age. Developmental influences on health are vital to understanding, predicting, treating and preventing poorer health outcomes and improving health across the lifespan. Such is a life-course perspective; it provides an important stance on understanding health trajectories from the cradle to the grave.

Due to developmental changes occurring during childhood and adolescence, early life experience can have a substantial effect on determining the trajectory of health throughout life, representing a pattern of logarithmic growth.

These changes centre around biological maturation, including the development of the immune and endocrine systems; cognitive understanding and language development; and attachment and social learning. Influences on these developmental processes, whether biological, psychological or social, and their interactions, can determine the degree to which vulnerability or resilience to ill health emerge. Biological influences include genetic predisposition and susceptibility; psychological factors include stress and coping responses, cognitions and emotions, and perception of social support; and social factors include social networks, socioeconomic status (SES), demographics, culture and lifestyle.

#### **Biological Influences**

Critical periods during childhood and adolescence are particularly influential in setting the subsequent health trajectory. The complex interplay between environmental context and biological characteristics has been referred to as biological sensitivity to context, biological embedding, differential susceptibility or developmental programming (Belsky *et al.*, 2007; Hertzman, 1999; Lupien *et al.*, 2001, 2009) and the experience of stress or early life adversity is central. The 'orchid gene hypothesis' (Ellis & Boyce, 2008) depicts two metaphoric descriptions, the 'orchid child' and the 'dandelion child', to describe the differential ways that underlying genetic variability interacts with the environment. The orchid child shows a heightened stress reactivity or sensitivity to their context or environment; under conditions of adversity this is likely to result in negative health effects, but with a sufficiently supportive context can result in positive health outcomes. Dandelion children, however, are naturally resilient, able to thrive and flourish in any environment.

From a biological perspective, the stress response, evolved in order to survive physical threats and challenges, can be activated through psychological threats, challenges and experience of loss or harm (see 'Stress'). Both the sympathetic nervous (SAM) system (producing adrenalin and

noradrenaline) and the hypothalamic-pituitary-adrenal (HPA) axis (the end product of which is the glucocorticoid, cortisol) become activated under stressful conditions (see chapters 'Stress' and 'Stress and Coping Assessment'). While stress responses are normal and necessary to cope with events, prolonged or repeated stress exposure can have health repercussions. Learning how to cope with stress therefore has implications not just at a psychological level but also at a biological one, with consequences for long-term health. Alterations in stress hormone levels can increase the likelihood of developing chronic conditions later in life as well as have health implications during childhood. The mechanism by which stress and other psychosocial factors can interact with developing biological systems to influence health is explained well by the concept of stability through change, known as allostasis (McEwen, 1998; Sterling & Eyer, 1988). While allostatic systems, such as the SAM system and HPA axis, promote change and enable adaptation, allostatic load occurs when there is an imbalance or overload in allostatic systems.

During childhood development, the HPA axis shows relative plasticity in the natural circadian rhythm until the age of approximately 3–4 years, indicating this as a critical period for the impact of life adversity. Evidence suggests that while infants show a cortisol increase in response to minor stressors (e.g. vaccination, bathing), there is increasing support for existence of a hyporesponsive period to stress between the ages of one year and the onset of puberty (Gunnar & Quevedo, 2007; Jansen *et al.*, 2010). Similarly, in laboratory social stress testing, cortisol results are mixed with respect to effects in children prior to puberty. However, there is evidence that a response is elicited, albeit at a lower magnitude to that seen in adolescent or adult stress testing and with no sex differences observed (Yim *et al.*, 2010).

# Psychosocial Influences: Stress and the Psychosocial Environment

The stress and coping paradigm (Lazarus & Folkman, 1984) describes stress as a transactional process that occurs between the person and their environment (see 'Stress'). The experience of stress is best seen as a 'mosaic' of simultaneously and dynamically overlapping stressors emanating from a number of sources at any one time (Michaud *et al.*, 2008:190). At its most generic, stress can be classified based upon duration and severity into acute (short term, mild to severe) and chronic (long term or enduring).

#### Childhood

With respect to stress experienced during childhood, the Center on the Developing Child, Harvard University (n.d.) classifies stressful events by level of severity, in order to distinguish between stressors. At the mildest end of the spectrum they classify events that produce momentary

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Figure 1.1 Illustration of health trajectory across the lifespan driven by early life experience.

alteration in physiological activity, as 'positive' (e.g. receiving an immunization injection or attending a new daycare). By contrast, 'tolerable' stress from events such as loss or injury is of greater severity but able to be adapted to with sufficient support. At the most severe end of the spectrum are 'toxic' stressors (e.g. poverty, neglect, abuse or violence) which pose the strongest risk for long-term negative mental and physical health outcomes. Such a distinction is important in delineating between stressors, acknowledging that not all stress is associated with negative outcomes particularly if countered by an enriched environment, while highlighting the negative consequences of more severe stressors or stress in the absence of a supportive environment.

Yet the health effects of stress are not necessarily linear with respect to severity, and reactivity to stress is influenced by a myriad of individual difference factors. What has been labelled as the 'shift and persist' strategy is a good demonstration of one way that individuals from disadvantaged backgrounds have been found to adapt to the stressful experiences they encounter and improve their likelihood of a positive outcome (Chen et al., 2012). The 'shift' part of the strategy is focused around the use of secondary control: making cognitive adaptions to cope with an unchangeable stressor rather than using primary control where the situation can itself be changed (Chen et al., 2012). This enables the individual to 'persist' in the stressful situation while looking to the future with hopeful expectation. Children raised in low socioeconomic status (SES) conditions who as adults show this coping technique of shift and persist have been found to have a more adaptive outcome with a lower allostatic load than those who did not develop this strategy; for those without early deprivation there was no additional benefit to using this technique (Chen et al., 2012).

The experience of childcare and transition to school have both been used as vehicles for observing stress reactivity and examining the impact of stress on developing physiological functioning. In these contexts the quality of care and the temperament of the child have been highlighted as important interacting factors influencing endocrine and immune parameters (Dettling *et al.*, 2000; Vermeer *et al.*, 2012). An increase in salivary cortisol levels has been identified in four-year-olds transitioning to school as well as raised cortisol levels up to six months in anticipation of starting school (Turner-Cobb *et al.*, 2008). This response links to vulnerability for subsequently developing an upper respiratory tract infection (common cold) (Turner-Cobb *et al.*, 2011). The experience of mild and moderate stressors is important in learning to cope with stress both at psychological and physiological levels, and the ability to mount a stress response may be protective in the short term. However, repeated stress from different sources, being unable to adapt in the absence of protective environments or the experience of more severe stressors, may have long-term damaging effects on health.

#### Adolescence

Adolescence is seen as a stress-sensitive period in which the combined effects of accumulated childhood stress and current state of stress reactivity have the potential to influence health. The effect of stress during adolescence represents another critical period, with an increase in basal levels of cortisol and steeper stress reactivity following pubertal development, and effects of early life adversity often emerging during adolescence. Lupien *et al.* (2009) highlight the vulnerability of the frontal cortex of the developing brain during these teenage years as an explanation for this being a critical developmental period for subsequent health.

#### **Prenatal Psychobiological Influences**

The effect of psychosocial influences on developmental and health outcomes begin not at birth but in the prenatal environment, representing another critical period. Some studies extend this to the pre-conception environment in respect to parent health practices and endocrine/immune environment around conception or between pregnancies (Guardino *et al.*, 2016). The natural state of pregnancy represents for the mother a period of constant relative high levels of cortisol (Mastorakos & Ilias, 2000) with the development of the HPA-placental axis. There is considerable evidence to suggest that although the foetus is to some extent protected from maternal stress effects during pregnancy, if the mother experiences high levels of stress at certain points in the pregnancy, most notably during the second trimester, this can create a heightened stress hormone environment for the foetus and possibly result in pre-term delivery and low birth weight, indicators for subsequent poorer health outcome.

Prenatal stress also can set the HPA axis response, nervous system and immune parameters to function at an altered level of alert. Such biological rewiring, known as prenatal programming or foetal imprinting (Merlot *et al.*, 2008) is thought to be enabled via a combination of stress-induced reduction of the enzyme 11-beta-hydroxysteroid dehydrogenase type 2 (11beta-HSD2), required to convert cortisol to its inactive form, and abnormal uterine blood flow (O'Donnell *et al.*, 2009; Van den Bergh *et al.*, 2005). The effects of maternal prenatal stress on child postnatal outcomes have included: increased cortisol reactivity, poorer mental and motor development, and behavioural/temperament difficulties in infants; increased

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acute stress reactivity, neurodevelopmental and cognitive endangerment, and learning and memory problems in children 2–9 years old; and alterations in diurnal cortisol profile in 10–15-year-olds (for review see Turner-Cobb, 2014).

#### **Early Childhood Adversity**

Interest in the health effects of early adversity that reach into adulthood and across the lifespan has grown in recent years.

#### **Maternal Stress**

Children exposed to mothers with postnatal depression have been found to have raised or more variable morning cortisol at 13 years, indicating a possible route for intergenerational transmission of depression (Halligan *et al.*, 2004). Shirtcliff *et al.* (2009) have termed this type of delayed effect a 'lingering influence', referring to evidence for raised levels of latent antibodies to herpesimplex virus (HSV) type 1 in 9–14 year-olds who experienced physical abuse or institutionalization shortly after birth and were subsequently adopted.

Literature linking early life stress and physical health outcomes has frequently focused on the impact of family environment and exposure to maternal stress and depression, across a range of ages throughout childhood and adolescence. Among young children (3–4.5 years), higher cortisol has been found in those whose mothers had lower job satisfaction or higher work-related emotional exhaustion (Chryssanthopoulou *et al.*, 2005). Exposure to maternal depression during the first two years of life has been reported as a strong predictor of baseline cortisol at age seven years (Ashman *et al.*, 2002). The combination of ongoing chronic family stress and acute stress events induced asthma symptoms and a Th2 inflammatory response (IL-4/IL-5) in children aged 9–18 years (Marin *et al.*, 2009). Similarly, in 8–18-year-olds with asthma, the perceived stress of their parents predicted greater production of the cell-mediated T-helper 2 (Th2) inflammatory cytokine interleukin 4 (IL-4) than in healthy control children over a period of six months (Wolf *et al.*, 2008).

#### **Early Childhood Stress**

Literature on post-traumatic stress in children suggests a higher level of physiological reactivity, which has the potential to develop into the paradoxical pattern of hyporeactivity (low reactivity/inability to respond at usual levels), has been observed in adults with PTSD (see Heim *et al.*, 2000).

In a review of the effects of child abuse in adult life, Wegman and Stetler (2009) concluded that the increased risk for poorer physical health outcomes is comparable to that of psychological health outcomes. For example, childhood abuse has been linked with an increased adult risk for developing cardiovascular or coronary heart disease (Roy *et al.*, 2010) and multiple sclerosis (Spitzer *et al.*, 2012) in younger adults. Similarly, childhood trauma has been linked with chronic pain in adulthood (fibromyalgia, osteoarthritis) and greater diurnal salivary cortisol in middle-aged women (Nicolson *et al.*, 2010). C reactive protein (CRP), an inflammatory marker associated with atheroscleroisis and heart disease, was found to be significantly higher in middle-aged men and women who reported having poorer emotional functioning at age seven years (Appleton *et al.*, 2011).

Accelerated ageing associated with psychological stress exposure early in life has been assessed through measurement of chromosomal telomere length (an indicator of the degree of deterioration of the telomeres or DNA protective caps at the end of chromosomes which shorten with age). For example, in a sample of Alzheimer's caregivers and controls, the experience of multiple adversities during childhood was associated with shorter telomeres, predicted to reduce lifespan by 7–15 years (Kiecolt-Glaser *et al.*, 2011). However, with the exception of the study of emotional functioning in childhood and adult CRP (Appleton *et al.*, 2011), all of these studies have relied on retrospective self reports of early life adversity and prospective designs are needed to address these relationships more robustly (Wegman & Stetler, 2009).

Two further domains are important in describing the impact of psychological factors that contribute to developmental influences on health. These are the level of a child's cognitive development and a consideration of the prenatal influences.

# Cognitive Development: Children's Understanding of Health

A child's developmental understanding of health and illness also influences their ability to engage in health-related behaviours or to cope with the stress of illness itself. While discrete stages of development in cognitive understanding of illness have been proposed (Bibace *et al.*, 1994), others have suggested a more complex approach accounting for individual differences. There is also evidence that children have some innate understanding of illness that allows them to comprehend more about illness, and from an earlier age, than previously thought (Hergenrather & Rabinowitz, 1991; Normandeau *et al.*, 1998). Knowledge and experience of illness have also been found to affect children's understanding (Crisp *et al.*, 1996). In one study, children as young as six years are able to comprehend a link between stress and illness (Cheetham *et al.*, 2016).

# Social Influences: Demographic, Socioeconomic and Lifestyle Factors

Social influences on development that impact on health outcomes include a range of factors from health behaviours including diet, exercise, exposure to tobacco smoke, alcohol consumption or drug use, to lower SES, particularly the early life experience of poverty. These factors may occur through prenatal exposure to parental health behaviours or those experienced in early childhood.

Evidence suggests that low SES is associated with higher basal cortisol levels at least up to the pre-teen years (Lupien *et al.*, 2001). Miller *et al.* (2007) found low SES at age 2–3 years to influence pro-inflammatory markers of gene expression (including glucocorticoid receptors) in ado-lescence, which may provide a mechanism through which stress has an influence on respiratory infection and cardiovascular disease (Miller *et al.*, 2007). The interaction of lower SES and race is illustrated in a study of middle-aged African-Americans who experienced early life poorer living and working conditions, suggesting that lower SES and racism in childhood have synergistic effects (Slopen *et al.*, 2010).

The longitudinal social patterning of disease is demonstrated well by Evans and Kim (2012), who examined the amount of time spent in poverty during the first nine years of life, in combination with psychological (family turmoil, separation from family, exposure to violence) and physical (noise, crowding, housing problems). They found a relationship between poverty during early life and allostatic load at age 17 years mediated by cumulative risk at the interim age of 13 years. Interestingly, allostatic outcome at age 17 years was unrelated to cumulative risk at this age, showing the importance of social embedding during childhood and early life on illness vulnerability in adulthood.

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#### Summary

There is an increasing amount of evidence that biopsychosocial factors and perhaps more importantly their interactions are key factors in considering developmental influences on health. Experience during early life and particularly during critical periods in pregnancy, childhood and

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adolescence are powerful drivers of vulnerability and resilience for future adult health. Increased understanding of these biopsychosocial influences in operation during childhood and of the timeline of influence over the health trajectory provides evidence for the development of interventions to improve health outcomes during childhood and across the lifespan at all stages of adulthood.

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### 2

### Lifecourse Perspective and Health

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#### Introduction

A lifecourse perspective provides important insights into maintaining health in later life. This has become more complex as the lifespan has reached 122 years of age (so far). Data needed to understand this generally come from cohort studies. A cohort is any defined group of people, often by year of birth or a location or some combination of factors. That is, studies often look at one cohort over time or multiple cohorts at one time to make conclusions. While different studies have different enrollment criteria, the studies themselves are also aging: some have data collected for up to 75 years. Thus, they provide us with important information about what the lifecourse is for the persons studied over their lifespan. This is conditioned by the location of the individuals within their social classes and the geographic location of the persons. The psychological literature had adopted Schaie's (1965) developmental model, which focused on age, cohort and time of measurement. This model organizes the complexity of the information found in deceptively simple descriptions of how particular individuals age. The important point that Schaie makes is that these are not independent components. For example, a person who is 70 in 2017 was born in 1947. For people born in 2017, it is unlikely that their experience of 70 years of life will be the same in the future as it has been in the past. Birth cohort is also a useful way to think about the age when major historical events happened and to study the impact that they have on psychological development.

Power *et al.* (2013) provide a very useful framework that recognizes the levels of the environment (national, neighborhood and household levels) combined with family generational influences (grandparent, parent and offspring generations) that move through time together. Trying to understand what in the lifespan is only due to aging and what is due to other factors is a complex problem. Useful interventions to improve health of

persons wherever they are in the lifecourse depend on understanding these interacting components accurately.

In this chapter, we cite some published reviews of the findings from lifespan research sources for data across the lifecourse. We then review a case study of our own work that illustrates the usefulness of a lifecourse perspective and conclude with some observations about the status of this enterprise. We use the terms lifespan and lifecourse together to include the range of work in the behavioral, social science disciplines that contribute to our knowledge and the work in epidemiology representing the biomedical and public health disciplines.

We next turn to a case study reflecting how a lifecourse perspective on health can contribute to our understanding of one disorder, posttraumatic stress disorder (PTSD). This case study illustrates how knowledge concerning how the developmental timing of exposure to stressors impacts lifespan development, by adding new outcome measures to an ongoing study population.

#### PTSD in the UNC Alumni Heart Study (UNCAHS): A Case Study

The UNCAHS was originally designed to examine personality as a predictor of coronary heart disease in a cohort of college attendees who completed the MMPI during college registration (Siegler, 2016; Siegler *et al.*, 1992;). Based on a growing body of evidence concerning the link between coronary heart disease and PTSD (e.g. Boscarino, 2008; Kubzansky *et al.*, 2007), the scope of the UNCAHS was expanded in 2008 (wave 12) to investigate the relation between these two important health conditions in a non-clinical sample. An inventory of traumatic life events and a measure of PTSD symptom severity were included in the 12th wave of the UNCAHS, followed

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by a second measure of PTSD symptoms in the 13th wave. Measures of several individual difference factors shown to be important to the development and persistence of PTSD symptoms were also added at wave 13, including event centrality, measures of the phenomenological properties of trauma memories and adult attachment. With 13 waves of data collection spanning five decades of the lifespan now complete, the UNCAHS contains an extensive archive of data concerning lifecourse personality, psychological health and disease outcomes.

Through a series of papers utilizing the data on post-traumatic stress symptoms (PTSS)<sup>1</sup> in the UNCAHS cohort, we have advanced knowledge of the impact of stressful and traumatic events on psychological health and wellbeing in older adults. It has become critically important to understand the factors that contribute to poor psychological health and wellbeing during older adulthood following recent demographic changes that have resulted in older adults comprising an increasingly larger proportion of the population in industrialized countries, and the implications of these changes for economic and health care policy. Moreover, given that community-dwelling older adults are typically underrepresented in epidemiological research on the frequency of traumatic life events and PTSD symptom prevalence, our first goal was to provide base rate information on lifetime exposure to stressful and traumatic events in community-dwelling older adults with exposure to a broad range of negative and traumatic events across the lifespan. Our initial findings revealed when particular types of traumatic events are likely to occur during the lifecourse, as well as which types of negative and traumatic life events are most likely to cause psychological distress, including PTSS during older adulthood (Ogle et al., 2013b). In our subsequent work, we further investigated the differential effects of exposure to traumatic life events during developmental periods throughout the life cycle (Ogle et al., 2013a). Specifically, we compared traumas experienced during childhood, adolescence, midlife and the young-old period of older adulthood to determine the developmental period during which individuals are most vulnerable to long-term negative post-traumatic outcomes. An extensive body of research has shown that each of these developmental periods is characterized by age-related changes in cognitive, emotional and social processes that may influence the likelihood of negative outcomes following trauma exposure, including the onset of autobiographical memory during early childhood, development of the sense of self during adolescence, increases in social support from romantic partners and coworkers during young adulthood, and declines in social connections coupled with the increase in risk factors for chronic disease during middle and older adulthood. In addition to PTSS, we also examined the influence of the developmental timing of trauma exposure on several psychosocial measures that have been linked to psychological adjustment following trauma exposure, including perceptions of the quality of support individuals receive from others, the ability to cope with stress and subjective happiness. Our results showed that older adults who experienced traumatic events in childhood - 40 or more years prior to our investigation - reported more severe PTSS and lower psychosocial functioning compared to individuals who experienced relatively recent traumas in adulthood. The differential effects of early life compared to adulthood trauma exposure emerged across a wide range of indices, including current PTSS and measures of psychosocial functioning. Furthermore, our results showed that the differential effects of childhood compared to adulthood trauma exposure were not fully explained by differences in the objective and subjective characteristics of the traumatic events. Overall, these results illustrate the enduring nature of traumatic events experienced early in the lifecourse, and suggest that individuals exposed to early life trauma are at greater risk of a wide range of adverse outcomes in older adulthood compared to individuals exposed to traumatic events after the transition to adulthood.

Our subsequent work advanced research on post-traumatic outcomes in older adults by demonstrating that the cumulative burden of exposure to multiple traumatic events across the lifespan persists into older adulthood among individuals from the Baby Boomer generation (Ogle et al., 2014a). Due to their education and cohort membership, the Baby Boomer generation may have greater access to resources that protect against the detrimental consequences of negative and stressful life events compared to other generations. Despite these potential advantages, our results indicated that compared to other known predictors of PTSD, including event severity. personality traits, social support and subjective appraisals of trauma, cumulative trauma exposure predicted greater PTSS in a manner consistent with an accumulation of risk model, whereas the severity of individuals' single most distressing life event did not explain unique variance in PTSS. Comparisons of distinct categories of traumatic events revealed that greater cumulative exposure to childhood violence was the strongest predictor of PTSS, followed by adulthood physical assaults. Analyses concerning individual difference factors further showed that the extent to which older adults construed their most distressing trauma as central to their identity accounted for the largest percentage of explained variance in PTSD symptom severity. This finding is commensurate with a core principle of Life Course Theory (Elder, 1998), which holds that the degree to which cumulative disadvantages negatively impact an individual's developmental trajectory depends on the individual's perceptions of their personal circumstances and their ability to mobilize resources. Perceptions of the centrality of a traumatic event may be especially consequential during older adulthood, given that the process of evaluating and accepting the events of one's life is the primary developmental task of older adulthood (Erikson, 1982). This finding concerning the role of event centrality in post-traumatic outcomes suggests that treatment efforts aimed at reducing the centrality of traumas as they are evaluated during the life review process (Butler, 2002) may be especially beneficial for older adult trauma survivors. Overall our results underscore the importance of examining the broader context of lifetime exposure to traumatic events, in particular cumulative exposure to assaultive violence throughout the lifespan, when seeking to identify factors contributing to current distress in older adults.

Our examination of PTSS in the UNCAHS has also focused on advancing knowledge concerning mechanisms that promote the development and maintenance of post-traumatic stress. The rich archive of data in the UNCAHS concerning lifecourse personality, psychological health and disease outcomes provided the opportunity to test the most extensive set of PTSD risk factors measured in a single participant sample to date (Ogle et al., 2016a). Furthermore, our analysis of prospective data and comparison of factors assessed before and after traumatic event exposure allowed us to elucidate the temporal order of PTSD symptoms and their correlates. Results indicated that individual difference measures assessed after the traumatic event exposure, including insecure attachment and characteristics of the current trauma memory, better accounted for symptom severity than factors measured before the traumatic event occurred. These findings support a model of post-traumatic stress in which characteristics of the individual that represent stable personality factors and phenomenological properties of the current trauma memory combine to account for severity of PTSS. This work also provides empirical evidence of factors that are most likely to be important in treating PTSD. In particular, our findings suggest that intervention and treatment programs targeted at altering particular properties of individuals' trauma memories, such as diminishing the physiological experience of the trauma memory and the centrality of the memory to one's personal identity, may be effective at reducing PTSS.

In addition to advancing our understanding of post-traumatic outcomes in older adults, our research on the UNCAHS cohort has contributed to the

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understanding of the relationship between personality and health. Our findings indicate that individuals with particular personality profiles characterized by higher levels of neuroticism, lower conscientiousness and lower agreeableness are at an increased risk of PTSS in older adulthood (Ogle et al., 2014b). Furthermore, among individuals exposed to lifethreatening traumatic events, our work has shown that older adults with histories of severe early life traumatic events, compared to those whose traumatic event exposure occurred during later developmental periods, are at an increased risk of PTSS as a result of higher levels of neuroticism (Ogle et al., 2014b) and attachment anxiety (Ogle et al., 2015). The repeated measures of personality at different developmental stages in the UNCAHS, coupled with the study's assessment of several PTSD risk factors, also make the UNCAHS cohort uniquely suited for investigations of the processes through which personality influences vulnerability to post-traumatic stress. Our results to date indicate that neuroticism increases the risk of PTSD symptoms by enhancing phenomenological properties of trauma memories that amplify the availability of the memory in mind, including the intensity of physiological reactions to the memory and the frequency of involuntary rehearsal (Ogle et al., 2017). We first demonstrated these effects prospectively using MMPI and NEO data collected approximately 45 and 18 years prior to traumatic event exposure and PTSS reporting among UNCAHS members, and then replicated the findings using cross-sectional data from a clinical sample of individuals exposed to life-threatening traumatic events

Collectively, our work on PTSS in the UNCAHS cohort demonstrates the value of adding measures to ongoing longitudinal cohort studies to advance cumulative knowledge of a given health-related research area. This research method has significant advantages over the research paradigms currently used to study chronic disease outcomes, including PTSD. A similar methodological approach could be widely adopted to facilitate the development of a more advanced empirical base for understanding other complex health outcomes with many contributing factors, as well as other topics traditionally examined within a lifespan development framework. New waves of existing cohort studies can be customized to efficiently answer important reoccurring and emergent questions when the data, methods and timing of measurement are appropriately matched to the research question of interest.

#### **Concluding Thoughts**

Disciplines, and their methods, have lifespans of their own. 'Big Data' that pools resources from entire populations, independent of geography, are becoming the norm in biology and genetics. New understanding of the role of epigenetics with the inclusion of biomarker and genetic data on individuals (Engelfriet *et al.*, 2013) and of environmental indictors that measure lifespan stress (Singh *et al.*, 2015) make studies of genes by environment interactions possible for entire populations. In addition, technological changes in measures of functioning that assess biomarkers and structural components of the brain, as well as analytic strategies that combine measures, are continually evolving and may eventually make interventions into the aging process possible.

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#### Note

1 In the majority of our published papers on post-traumatic outcomes in the UNCAHS, we report a continuous measure of PTSD symptom severity

rather than a dichotomous measure of PTSD diagnosis. Thus, we use PTSS in this chapter to describe our findings from the UNCAHS cohort.

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## Disability and Health

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#### **Disability and Health**

Disability has been described in many ways, and these definitions and their corresponding theoretical foundations maintain some degree of influence in modern society. In American and other Western societies, disability has also been defined by prevailing medical and legal systems. Contemporary academic models emphasize social, contextual and experiential explanations. The various – and at times, disparate – definitions of disability in clinical, legal, academic and everyday life inadvertently compromise efforts to develop effective services for persons who live with disabiling conditions.

#### **Prevalence of Disability**

Recent estimates indicate that almost one in five adults in the United States report some form of disability (Courtney-Long *et al.*, 2015). The Census Bureau estimated in 2012 that nearly 57 million (18.7 percent) people in the United States live with some type of long-lasting condition or disability, with an estimated 38.3 million of these individuals possessing a severe disability (US Census Bureau, 2012). Estimates provided by the American Community Survey (a part of the Census Bureau) in 2014 estimated that nearly 40 million people, or 12.3 percent of the population, had disabilities (Houtenville *et al.*, 2016). By the year 2020, it is estimated that chronic, disabling conditions and mental disorders will account for 78 percent of the global disease burden in developing countries (WHO, 2002: 13).

The overall increase in disabling health conditions may be attributed to the increased rates of chronic diseases (e.g. diabetes, hypertension) and to the aging of the nation's population (Institute of Medicine, 2007). Disability rates escalate with age for both men and women; in 2010 58.8 percent of adults reported a disability in one domain and 38.4 percent reported a disability in more than one domain (US Census Bureau, 2012).

Although disabilities can be experienced by individuals of any age, older individuals have the highest levels of disability. Of those 65 and older, 9.7 million (22 percent) report a sensory disability involving sight or hearing, 10.35 million (23 percent) have a condition limiting basic physical activities, such as walking, climbing stairs, reaching, lifting or carrying; 3.8 million (8.4 percent) have difficulty in dressing, bathing, or getting around inside the home; 6.8 million (15.2 percent) live with a condition that make it difficult to go outside the home; and 4.1 million (9.1 percent) live with a disability affecting memory or concentration.

#### **Costs of Disability**

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Disability imposes serious economic consequences on individuals, families and the nation's economy (WHO, 2002). Direct and indirect

costs associated with disability are expected to escalate with the increasing number of persons who will live with a disability over the next several decades. Persons with disabilities are less likely to be employed; of the 20.46 million individuals with disabilities aged 18–64, only one-third were employed, and 5.7 million (28.2 percent) of people aged 18–64 with disabilities are living in poverty (below the poverty level; Houtenville *et al.*, 2016). However, these may be underestimates.

Higher health care costs are associated with chronic physical disability, secondary complications, loss of employment productivity, impaired quality of life, care and management of chronic disease and disability, along with acute episodes of care associated with such conditions, and problems with psychosocial functioning. In the fiscal year 2010 for the United States, 43.5 percent of the total amount of Medicaid payments were to people with disabilities (Houtenville, 2013). Yet individuals with disability are more likely than nondisabled peers to have lower rates of preventive care and health screenings, forego physical activity (often for lack of access), report poor to fair health status, develop chronic diseases (e.g. diabetes, obesity) and be unemployed (Iezzoni, 2011). Individuals with multiple limitations that restrict their mobility may experience more pronounced disparities in access to services and subsequent treatment (Horner-Johnson et al., 2014). People with disabilities are more likely than others to experience severe psychological distress, and higher rates of chronic disease and health conditions and decreased access to health care and prevention services are associated with greater distress (Okoro et al., 2014). They are also less likely than persons without disabilities to receive mental health care services for their distress (Houston et al., 2016).

#### **Models of Disability**

Lay models of disability are typically rooted in a 'moral' model (Dunn, 2015; Dunn & Andrews, 2015). Influenced primarily by religious beliefs, disability is viewed as a result of a moral failing or sin on the part of the individual or family members (e.g. parents). Consequently, the 'disability' – congenital or acquired – is a punishment for a past misdeed, or it may be a trial or burden for the person to bear, and in that process learn humility, or to serve as a role model for others by living a virtuous life under duress. A person with a disability could then be justifiably treated with pity and acts of charity, or with scorn and avoidance. Although this model does not inform contemporary clinical practice or research, it was influential in the use of terminology that is clearly derogatory by current standards (e.g. 'moron'; Dunn & Andrews, 2015). Throughout recorded history the moral model has been invoked as a device in literature and cinema, and it is not uncommon to encounter these beliefs from

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individuals (and patients) in casual (and clinical) interactions (e.g. in searching for a reason why a person incurred a disability).

The professional community relies on definitions of disability that have traditionally evolved from the health care disciplines that study and serve persons with disabling conditions. More contemporary perspectives embrace criticisms of the pervasive, long-standing medical model of disability and recognize the broader policy, psychological, contextual and socioeconomic issues associated with the management of disabling conditions over the lifecourse. Although several overarching models of disability will be discussed, an overview of psychological models is beyond the scope of this chapter (see Rath & Elliott, 2012).

#### Medical Model of Disability

The medical model of disability is the traditional and predominant model. To a great extent, this perspective emerged from the medical community in response to the large number of wounded and impaired military personnel in World War I and World War II. Essentially, this model assumes a 'find it and fix it' perspective: health problems are diagnosed and specialized services are prescribed to cure or remedy the problem (Kaplan, 2002). There are several clear benefits to the medical model. It prompted the effective detection and treatment of acute health problems and needs of persons with physical disabilities and other chronic health conditions, and it guided the development and status of medical training, facilities and specialties. It is responsible for policy initiatives to address issues of improved care, survival and quality of life. In the United States, medical definitions of disability provide the cornerstone for determining disability for legal and occupational purposes - for example, determining eligibility for financial assistance or services. This model places a clear and unambiguous premium on the diagnosis of a specific cause for a health problem, and on the expert delivery of a curative and remedial treatment. These treatments may include rehabilitative services and restorative training to enhance reintegration. For many decades, rehabilitation services to persons with disabilities were predicated on the medical model.

The medical model has difficulty accommodating the permanent and chronic trajectory of an incurable condition in which symptoms or impairments may be managed over the lifespan, and preventive and long-term changes in personal behavior, or to environmental constraints that may be required for optimal health and quality of life. The increasing number of persons with chronic health conditions across cultures is not adequately served by institutions that were designed to focus primarily on the delivery of services for acute, short-term conditions.

#### Social Models of Disability

Social and minority models of disability are fairly contemporary perspectives that shift a focus away from a diagnostic condition and away from the individual to address the structural, attitudinal and general environments that define disability. The barriers imposed by these environmental factors limit participation in valued personal, social and occupational roles. Disability may be construed as a fairly neutral and natural form of human diversity. Social models are often championed in disability rights scholarship, in which disability 'as it is conceived in disability studies, is a culturally composed (and shared) narrative of the body ... a study of the unequal distribution of power, material, and economic resources, and status (class, etc.) within both social and architectural environments' (Brueggemann, 2013: 283). Consequently, the goal for full participation is realized as external barriers (e.g. inaccessibility, physical structures) and sociocultural impediments (e.g. attitudes, misinformation, prejudice, discrimination) are alleviated (Dunn & Andrews, 2015).

#### The Minority Model of Disability

The minority model recognizes that the larger community of persons with disabilities constitutes one of the largest minority groups in a given society (Dunn, 2015; Dunn & Andrews, 2015). It recognizes the ways in which living with a disability may assume aspects of a culture. Unfortunately, the social and minority models have yet to clarify who qualifies as a person with a disability, or how disability is best measured.

#### **Biopsychosocial Perspectives**

Contributions from psychological scholarship and practice do not form a consensus model of disability, as these contributions typically serve disparate strands of inquiry for different purposes (e.g. theory testing, instrument development, interdisciplinary projects, rehabilitation outcomes). Biopsychosocial models attempt to integrate medical aspects of a diagnostic condition with important psychological and social variables, and interactions among them, that account for adjustment and wellbeing among persons living with disabling conditions.

The World Health Organization (WHO) expanded upon the biopsychosocial model in its description of disability and its various components published in the *International Classification of Functioning, Disability, and Health* (ICF; WHO, 2001). The ICF uses categories at multiple levels and across multiple dimensions to permit separate ratings along dimensions of body structure and function/impairment at the organ level, activity (vs. activity limitation) at the person level and participation (vs. participation restriction) at the societal level. The scheme also conceptualizes environmental factors, such as accessibility to housing, health care services and leisure pursuits as important contributors of disability.

This conceptual framework recognizes that a specific medical condition or diagnosis is insufficient for explaining, understanding, anticipating or rehabilitating any aspect of disability experienced by an individual. The ICF model provides a greater appreciation of the environmental context in which disability occurs, and a recognition of the degree to which an individual engages in desired activities and participates in valued personal and social roles. It applies to a wide array of disabilities, and recognizes that an injury may not necessarily lead to impairment, an impairment may not result in functional limitations and that activity limitations may vary based on environmental factors. The WHO model is not a testable theory and it may be best described as a 'workable compromise between medical and social models of disability' (WHO, 2011: 5).

#### **Implications for Service Provision**

Criteria for eligibility for services vary according to the working model of disability used. For example, the medical model relies on diagnosis and

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assessment by experts. Consequently, the development and use of instruments to assess aspects of a disability is a hallmark of clinical research and service associated with the medical model. With this model, the subjective experience of quality of life and wellbeing is devalued, and by extension, are patient input concerning treatment options and recommendations for prescribed regimens. This reflects, in part, professional concerns about the occasional incongruence between subjective reports and objective indicators of disease activity. The successful diagnosis and treatment of acute conditions does not hinge solely on the accuracy or quality of patient input.

#### **Provision of Services**

Medical perspectives traditionally place greater emphasis on the management of a specific diagnosis and related condition. Other health professions tend to focus their services to the individual with the disabling conditions and persons who live with them, necessitating the need for policies and practices that address environmental and social impediments. The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) taskforce included the WHODAS 2.0 to align with the WHO ICF model of disability, to assess the degree of impairment and functioning in the larger community context.

#### **Measurement of Disability**

Professions allied with the medical model have made considerable advances in developing measures to (1) evaluate and quantify the extent of physical disability and capacity for self-care (including measures of range of motion, impairment in activities of daily living, mobility); (2) identify limitations for discharge and/or rehabilitation; (3) identify outcomes associated with rehabilitation interventions; and (4) inform the identification of goals for rehabilitation. Increasingly, these measures incorporate participant self-report.

More recently, increasing pressure for accountability (and financial reimbursement) have compelled health care services (including rehabilitation) entrenched in the medical model tradition to develop consensus in defining and measuring critical outcomes associated with specific diagnostic conditions (e.g. spinal cord injury, traumatic brain injury). This has prompted, in part, efforts to develop consumer-relevant outcome measures that benefit clinicians, researchers, service delivery systems, patients and policymakers. The Patient Report Outcomes Measurement Information System (PROMIS; www.nihpromis.org/default.aspx) projects, funded by the National Institutes of Health, represent coordinated and systematic efforts to develop and determine the feasibility and applicability of measures across a variety of diagnostic conditions associated with disability.

An example of one of the more widely used functional status measures is the Functional Independence Measure (FIM; Hamilton *et al.*, 1987). The FIM was designed to rate the severity of disability and the outcomes of medical rehabilitation and has been successfully used with a variety of disabled populations. However, in many cases, measures more specific to a diagnostic condition are required (e.g. spinal cord injury, cerebral palsy) to take into account unique aspects of that condition.

Although measures of functional ability (like the FIM) have considerable utility in the medical setting (and various professions and literature bases that identify with the medical model), most of these instruments 'do not capture function as a person-environment interaction' (Heinemann & Mallinson, 2010: 149). They are typically designed to assess functioning in a fairly controlled and structured health care setting, unsuitable for use in home and community environments. Assessments appropriate for use in these settings require a systematic, omnibus evaluation of abilities, barriers, the home environment, resources and factors that impede or facilitate full participation, consistent with the WHO ICF model.

#### **Provision of Services**

Services developed from a medical model are logically derived from assessments that provide information relevant to the health care setting and the services aligned with that model and environment. Services for community and home-based settings are much more complicated, but traditionally policymakers have deferred to a medical model to make determinations about these services. For example, to determine eligibility for home-based nursing and personal care services, state evaluations range from a list of 100 medical conditions that can qualify a child with severe disability for services to reliance on the opinion of a physician, neither requiring an interview or evaluation of the home environment, the family or the functional abilities, limitations or comorbid behavioral and mental health issues (Musumeci, 2011). The development and utilization of assessment tools sensitive to person–environment interactions are essential to inform and guide meaningful public and health policy and services for persons with disabilities.

Typically, in medical settings interdisciplinary team members participate in physical medicine and rehabilitation programs to collaboratively set goals with patients admitted with severe disabilities to facilitate their functional independence (e.g. ambulation, mobility; with or without the use of adaptive equipment), transfers, dressing and other activities of daily living. Rehabilitation programs are tailored to meet the unique needs, goals and abilities of each patient. Interventions may be blended, although preference is given to medical management and physical therapies in the contemporary setting. Additional therapies may be provided following discharge, but these are highly variable, depending on issues of reimbursement and availability of qualified providers. Financial and administrative pressures have systematically reallocated rehabilitation from traditional acute and post-acute inpatient settings to outpatient and home-based programs. This has stimulated keen interest in telehealth applications to provide ongoing treatment to patients after they are discharged from the medical setting and return to the community.

The WHO model of disability offers tremendous opportunity for psychologists to further demonstrate the respectable utility and impact of research, service and interventions that are informed by psychological theory and expertise, and in this process, offer a more prominent role for psychology. It compliments social and minority models that champion advocacy and consumer perspectives. It also embraces the effective and strategic provision and use of assistive devices and computer technologies that may promote independent living and participation.

The WHO model of disability is the preferred perspective in the international community, due to its recognition of the many factors that determine the disability experience. This emergence is causing some conflict in Western societies that subscribe to a medical model, compelling policymakers to debate issues related to reimbursement, resource allocation and the development and management of institutions and service delivery programs, generally. It is also bringing the disparities

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