Chapter 2

Women's Developmental Stages and Quality of Life

LEARNING OUTCOMES

On completion of this chapter, the learner will be able to:

1. Explain how the developmental stages of adulthood have shifted since the "Baby Boomer" generation came of age.
2. Discuss the process of passage through the developmental stages of the adult life cycle.
3. Describe how the traditional normative roles of adult women across the life cycle have shifted dramatically since the 1970s.
4. Analyze the crucial issues of the complex role demands of adult women across the life cycle that threaten quality of life.
5. Explain the construct of quality of life and the challenges of conceptualization.
6. Analyze quality of life within the context of culture, race, ethnicity, acculturation, and humanness.
7. Explain the significance of quality of life consideration in women's health.
8. Evaluate the Ferrans Conceptual Model of Quality of Life as a framework for analysis of women's health issues across the life cycle.

Introduction

Over the past century, the life expectancy of women in the United States has increased by more than 30 years. This remarkable change is largely due to improved sanitation practices, eradication and control of communicable diseases, development of antibiotics, increasingly effective treatment of chronic diseases, and implementation of national public health policies that greatly reduced rates of death, diseases, and disability (Office on Women's Health U.S. Department of Health and Human Services [OWH], 2002). Quality of life has become a topic of great concern because realization has emerged that quality of life is as ultimately important as quantity of life.

The complex issues of women's health impact quality of life throughout the life span. Women's longer life span, unique major physiologic changes, greater tendency toward depression and mental

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stress, and increased risk of being victims of interpersonal violence are just a few examples of factors that can contribute to decreased quality of life in women ("Health-Related Quality of Life Among Women," 2003). Although women's life expectancy has nearly doubled, many women today can expect to live longer with the sequelae of serious injury, conditions, disorders or chronic illnesses. Certain injuries, conditions, and diseases are more prevalent among women at various points along the life cycle. These conditions can affect women's health and physical function, psychological and spiritual function, socioeconomic integrity, and family well-being, and in many cases can become life-threatening over time. Although advances have been made in many dimensions of women's health across the life cycle, the impact of women's health issues on quality of life must be acknowledged, explored, and kept in the mainstream of women's health care ("Health-Related Quality of Life Among Women," 2003; OWH, 2002). This chapter presents a starting point with perspectives on the psychological and social growth of women across the life cycle. This discussion creates a formidable setting in which to establish the conceptual model of quality of life that forms the organizing framework of this book.

A Perspective of Women's Developmental Stages Across the Life Cycle

Western culture throughout the ages has sought to partition human life into ages and stages. The need to determine order and predictability in the human life cycle has inspired a wide range of perspectives, opinions, and theories that describe predictable marker events of the life cycle. From the beginning of the 20th century up to the 1970s, major life events such as puberty, graduation, marriage, first job, first child, empty nest, retirement, widowhood, and death likely occurred for most women at predictable points in the life cycle (Sheehy, 1995). For the longest time, chronological age has stood as the criterion for normalizing the roles and responsibilities taken on by individuals throughout their lives. For example, prior to the 1970s, adulthood was considered to begin at the age of 21 and retirement to occur at age 65, thus benchmarking the lower and upper boundaries of participation in the adult world. However, since the 1970s, age norms have shifted and can no longer be considered normative. The criterion ages that have marked the movement of individuals from adolescence to young adulthood, to middle age and senescence have changed (Sheehy, 1995).

Since the post-World War II "Baby Boomer" generation came of age in the 1970s, the predictable points of life were no longer predictable. In the space of one generation, the entire shape of the life cycle became essentially altered. Social changes, economic demands, technological demands, as well as advances in health and health care have contributed to these changes. People leave childhood sooner but take longer to grow up and much longer to die. Puberty arrives earlier by several years and adolescence extends into the mid-to-late twenties. The arrival of true adulthood has been delayed until the thirties and forties. Middle age has been pushed into the fifties and the stages of life beyond the fifties have changed radically from what was experienced by pre-"Baby Boomer" generations. The gain in life expectancy in developed countries has redefined the sunset years. People entering older age are much healthier. Middle-aged and "young-old" Americans are likely to have a living parent, and this has produced unprecedented changes in family dynamics. A steady increase in the oldest old of the population has established additional life stages beyond middle age. These additional stages in the life cycle did not exist in previous generations and brought with them opportunities, discontinuities, expectations, and different social roles (Sheehy, 1995).

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Passage Through Stages of Development

Adulthood proceeds by stages of development throughout the life cycle. Unlike childhood stages, which are characterized predominantly by physical and intellectual growth, stages of adult life are characterized by steps in psychological and social growth. Marker events, such as marriage, childbirth, first job, and empty nest do not define developmental stages but concrete happenings of life (Sheehy, 1995). Developmental stages of life are defined by the underlying impulses toward change that signal people from the realms of mind or spirit. Moreover, the developmental stages are influenced by the meaning individuals give to their participation in the external world, especially their perceptions and feelings about their family, social, and occupational role (Sheehy, 1995). The underlying impulses toward change signal a necessity to move on to the next stage of development. Movement from one stage to the next is actualized when a predictable crisis or turning point is encountered, which ushers in a new stage. This predictable crisis or turning point is called a passage, a crucial period of decision between progress and regression. At the point of passage, individuals are in a state of flux, feeling exposed and vulnerable, yet enjoying a heightened potential for growth. The impulse for change can be ignored or embraced. Whatever direction is chosen will result in a restructured future (Sheehy, 1995).

Although the normative benchmarks of the life cycle have shifted in the past few decades, broad, general stages of adulthood with predictable passages between them still exist, yet with a more prolonged timetable. Age norms for major life events have become highly flexible. Individuals in their twenties, thirties, and forties face drastically changed social, economic, and technologic conditions as compared to previous generations. These altered conditions generate disequilibrium in their lives (Sheehy, 1995). Rather than a flat, linear progression through life, individuals lead cyclical lives that require starting over and over again in many domains. As a result, early and young adulthood is lived at an accelerated pace even though many of the responsibilities of full adulthood may be delayed. Middle age cannot be about coasting to retirement but must be a preparation for the sunset years. Most people who reach the sunset years (over 65) are likely to continue to work in some way or another in employment, as volunteers, or in endeavors that maintain a sense of purpose or self-worth (Sheehy, 1995).

Changes in the Life Cycle of Women

Globalization of economic competition and the progression of the women's movement have greatly contributed to the changes in the life cycle. Women have experienced a continuous expansion of opportunities, greater participation in the workforce, and assumption of multiple life roles. Social roles and developmental tasks formerly associated with one stage have been ignored or postponed. As a result, multiple life tasks accumulate in the same stage and create tremendous either/or conflicts. The shape of life stages, as well as the sequence, have been altered, and a surfeit of new choices has been made available by technological advances that diminish limitations of biology and longevity. The most radical voluntary change to the life cycle has been the reproductive revolution that has enabled women to defer childbirth by 10 to 20 years (Sheehy, 1995).

Roles of Women in Childbearing Years

Traditionally, the normative life cycle of women was perceived as bound to the reproductive aspects of their lives. The societal norms were grounded in the pre-1970s expectation that the primary

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and frequently preferred and exclusive roles of women orbited the private, domestic sphere of wife and mother. The normative societal roles of adult women have since shifted dramatically to include domestic and work roles that take place over the course of women's lives. Women have numerous role choices. Some women postpone marriage and children until well established in their careers, while other women may choose to marry young and simultaneously establish career identities along with roles as wives and mothers. Other women may choose to postpone their career and work lives until children have entered school or are outside the home. Still others may choose to focus on career building and economic self-sufficiency, choosing to remain child free and/or single (Shrier & Shrier, 2009). Currently the adult lives of women are all the more complex with the multiple dimensions of biology, family, and work interacting and influencing each other. The multiple dimensions influence alternatives regarding life choices and the timing of major career choices and family events (Shrier & Shrier, 2009). Consequently, the lives of women do not progress in a linear trajectory. Rather, women's lives move in a spiraling, circle-like progression in which the biologic–reproductive dimension, the family–marital dimension, and the educational–vocational dimension are bound together, interacting, overlapping, at times enhancing, and at times conflicting with one another (Seiden, 1989).

Approximately 95% of women are employed outside the home for at least part of their adult lives. The decision to work outside the home is motivated by societal expectations, financial necessity, or both. The traditional marriage in which the man is the sole breadwinner and the woman stays at home full time is found in only about 3% of American families (Shrier & Shrier, 2009). Women's labor force participation is significantly higher today as compared to the 1970s, particularly among women with children, with a large portion working full time and year round. Moreover, women have attained progressively higher levels of education, with a tripling of the number of college degrees since the 1970s. As of 2012, approximately 70.9% of mothers with children younger than 18 years of age participated in the workforce, with greater participation more likely among women with older children (6 to 17 years of age) than mothers with younger children. Moreover, approximately 76% of unmarried mothers participate in the workforce as compared to approximately 68.5% of married mothers. The educational attainment of women in the labor force aged 25 to 64 has shown substantial increase since the 1970s. As of 2012, college degrees are held by 38% of women in the labor force as compared to 11% in 1970. The percentage of women who are high school dropouts declined from 34% in 1970 to 7% in 2012 (U.S. Bureau of Labor Statistics, 2014). These statistics underscore that the developmental phenomenon of women in their childbearing years—married or single—juggling children, career development, and educational pursuit while experiencing the maximum role demands of each has become normative. It is precisely this developmental phenomenon that makes women at this stage of their life cycle particularly vulnerable to psychosocial morbidity when faced with life-threatening diseases or conditions (Bloom & Kessler, 1994). The crucial issues of illness superimposed upon the complex role demands of women profoundly influence quality of life (Sammarco, 2001).

Roles of Women in Midlife and Beyond

From a chronological perspective, midlife is viewed as occurring from age 45 to age 65 and overlapping with old age. Old age has come to be viewed as having three periods: the young-old from ages 60 to 75; the old-old, from ages 75 to 85; and the oldest-olds, from the late 80s and beyond. Women's passage from childbearing years into midlife and beyond brings with it psychological,

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interpersonal, health, and economic issues that differ for each of these periods. Social class, birth cohort, ethnicity, and health contribute great inter-individual variability to women in each of these periods (Shrier & Shrier, 2009). Hence the more important indicators in determining who is young-old, old-old, or oldest-old are likely the individual differences in health and vigor rather than chronological age (Seiden, 1989).

In 1900, women were likely to live on average to about age 48 if they were white, or to age 33 if they were African-American. Moreover, many women died in childbirth or during their childbearing years from infectious diseases (OWH, 2002). Over a century later, the 30-year increase in life expectancy signifies that greater than ever numbers of women will be reaching their 80s and beyond. The average age of menopause is 51 years. Most women can anticipate living more than 30 years post menopause if they follow guidelines for healthy diets, maintain a healthy weight, employ stress reduction measures, engage in aerobic and weight-bearing exercise, practice healthcare prevention and maintenance, stay socially and intellectually engaged, and are secure financially. Many women in the postmenopausal years can enjoy lives that are physically and psychologically fulfilling and even more creative than earlier in their lives (Shrier & Shrier, 2009).

Unsurprisingly, the traditional normative roles of mid-life to older women have also shifted dramatically since the 1970s, and consequently manifest diverse issues that threaten quality of life. With the increase in life expectancy, women need to be prepared to finance an additional two decades of life. This is especially challenging since older women, especially if they are African-American or Latina, are more likely to be poor than older men (Cawthorne, 2008). Women need to acquire education, prepare career tracks, build pension and individual retirement accounts, and demand greater help from society to care for the frail elderly in their families (Sheehy, 1995). Thus, older women are remaining in the workforce longer and postponing retirement. A vast majority of women over the age of 60 have the benefit of increased independence in lifestyle (Sheehy, 1995). Nonetheless, aging women are at risk for declining physical function and the development of chronic illnesses. Although advancing age brings with it increased emotional resilience, there is greater likelihood that older women will experience a reduction in resources of social support. The support network frequently shrinks from outliving a spouse or partner, friends, pets, or from limited social interaction associated with disability or declining health (Sammarco, 2003). Older women are more likely to transition to living on their own through late divorce or widowhood, and frequently grapple with fear and loneliness, especially after losing a spouse or partner. Older women who never had children fear having no family members alive to look after them in their old age (Sheehy, 1995).

A problem frequently cited in the literature is that the "burden of caring" is carried by women throughout the life cycle. Statistically, women care for their children and parents more so than do men. This phenomenon is likely a holdover from the time of traditional domestic arrangements of women employed in the home, when they could incorporate the care of an ill or older person into that setting (Seiden, 1989). A study of 1,666 family caregivers of cancer survivors found that 78.9% were women (Kim, Kashy, Spillers, & Evans, 2010). Most of the caregivers of older Americans are women (Cawthorne, 2008). Nonetheless, many older women face a caregiving crisis resulting from becoming the unpaid caregivers of elderly spouses, partners, parents, or even young grandchildren. Some women may have to relinquish outside employment and consequently, salary, health insurance, and pension benefits (Sheehy, 1995). Yet national surveys show that many family caregivers maintain working outside the home and few have other unpaid help to care for the ill family member (Barrett, 2004). Employed women

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often try to find other resources to augment their caregiving because they may not wish to—or may be unable to—forfeit their income or time to provide these services.

At the start of the second decade of the 21st century, five generations of women span the adult life cycle, with a steadily increasing aged population in the sunset years. Dramatic and evolving changes have occurred in both societal and internalized expectations of women's roles and normative life cycle since the 1970s. Today, women's adult life cycle is complex and spans multiple and varied life choices associated with family, career, and personal fulfillment. Without a doubt role strain, overload, and conflict, as well as other stresses related to efforts to combine career, family, and a personal life, may occur. For many women, multiple roles tend to be mutually enriching and result in a greater sense of well-being than experienced by women in a single role (Shrier & Shrier, 2009).

Conceptualizing Quality of Life

Quality of life is a commonly used, broad, multidimensional construct. However, the construct is often unclearly defined and poorly understood (Mandzuk & McMillan, 2005). References to quality of life have appeared in Greek philosophy, as well as in the reflections of Aristotle with respect to the universal nature of happiness and its association with "the good life" (Ferrans, 1990b, 1996). Existential quality of life has also been discussed in the writings of authors such as Kierkegaard, Satre, Maslow, Frankl, and Antonovsky (Mandzuk & McMillan, 2005).

Perceptions of quality of life emerged in America following World War II. At this time people's expectations of satisfaction, well-being, and psychological growth increased as a result of economic growth and improvements in the standard of living. The term "quality of life" was introduced by Lyndon Johnson in his Great Society program that promoted advancing quality of life through social programs such as education and manpower, community development and housing, and health and welfare. In addition to the political arena, quality of life discussions have appeared in education, family studies, environment, and, of course, health care (Mandzuk & McMillan, 2005).

Defining Quality of Life

Extensive literature review has identified definitions of quality of life that could be grouped into five major categories: (1) normal life, (2) happiness/satisfaction, (3) achievement of personal goals, (4) social utility, and (5) natural capacity (Ferrans, 1990b). The first category of quality of life definitions focuses on one's ability to live a normal life. These definitions encompass concepts such as the ability to function at a level comparable to healthy persons or typical of the same age. Normal life definitions of quality of life can be problematic in that standards of normalcy vary widely and disagreement regarding criteria for measuring quality of life can occur (Ferrans, 1990b).

The second category of quality of life definitions focuses on an individual's happiness and satisfaction. Although not synonymous, happiness and satisfaction are closely related concepts, which have been found to behave somewhat differently across the life span in the general population. Happiness tends to decrease with advancing age whereas satisfaction tends to increase (Ferrans, 1990b). Happiness implies short-term positive feelings, while satisfaction indicates a longer-term cognitive experience, which is the outcome of a judgment of life's conditions. Accordingly, satisfaction, rather than happiness, comes closer to capturing the essence of the concept of quality of life (Campbell, Converse, & Rodgers, 1976).

The third category of definitions focuses on the achievement of personal goals. These definitions tend to be more closely aligned to the

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happiness/satisfaction definitions in that goal achievement results in a sense of satisfaction and failure to achieve goals results in a sense of dissatisfaction. However, the difference is that the goal achievement definitions focus specifically on the success or failure of goal achievement, rather than one's happiness/satisfaction with success or failure. The definitions of this category emphasize an individual's own goals rather than general goals that are applicable to all people (Ferrans, 1990b).

The fourth category of quality of life definitions focuses on social utility. These are definitions that characterize quality of life as the ability to lead a socially useful life, such as fulfilling socially valued roles or making contributions to the national economy through gainful employment. These definitions are frequently used in decision making concerning healthcare policy where economic matters are foremost, such as decisions pertaining to allocation of healthcare resources. Social utility definitions of quality of life can be problematic in that socially useful behavior has a wide range of meanings, and disagreement regarding measurement criteria can occur. Furthermore, discriminating prejudices can be hidden beneath the surface of apparently benign criteria. For example, if quality of life is measured in terms of earned income through gainful employment, bias against women who are homemakers or retired can result (Ferrans, 1990b).

The fifth category of quality of life definitions focuses on natural capacity. Natural capacity pertains to an individual's actual or potential physical and/or mental capabilities. These definitions are often used in decision making associated with whether to try to save a person's life or allow the person to die. These definitions are mostly used to justify decisions as to whether lifesaving measures should be continued or withdrawn in patients who are terminally ill. These definitions are clinically useful for assistance in decision making rather than guiding measurement of quality of life (Ferrans, 1990b).

The Quest for Conceptual Clarity

Quality of life has been widely addressed in the literature but, as the preceding discussion has shown, there is no consensus on the meaning of the construct. There is no consensus on how quality of life is to be conceptualized or operationalized, even within the scholarly community. Authors define quality of life in different ways and conceptualize quality of life as having differing dimensions. Consequently, achieving conceptual clarity concerning the definition of quality of life has been difficult because people often ascribe their own personal meanings without ascertaining whether their definitions are shared by others (Cella & Tulsky, 1990; Ferrans, 1990b). This lack of consensus has hindered efforts to compare findings and develop a sound theory of quality of life that can predict outcomes and inform practice.

Despite areas of conceptual disagreement surrounding quality of life, areas of conceptual agreement have been accomplished. Quality of life is nearly always conceived as multidimensional. Moreover, there is growing agreement that satisfaction with the dimensions of life seems to be the most important indicator of quality of life (Ferrans & Powers, 1985). The most frequently cited dimensions are physiological, psychological, and sociological (Donovan, Sanson-Fisher, & Redman, 1989; Fawcett, 2005; Ferrell, Wisdom, & Wenzl, 1989; Padilla, Ferrell, Grant, & Rhiner, 1990). Many scholars include a spiritual or existential domain as well (Fawcett, 2005; Padilla, Grant, & Martin, 1988). In considering the various dimensions of quality of life, it is fair to question whether all dimensions count equally in defining quality of life or if some dimensions are weighted with more importance than others. Since people differ as to how important various aspects of life are to their quality of life, especially among those of different ages and sexes, people will differ

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regarding which dimensions of quality of life are most important. Accordingly, it is logical to conclude that all dimensions of life do not impact equally on quality of life (Ferrans, 1990b).

Another area of conceptual agreement is that quality of life is determined not only by an evaluation of several domains of life but also by an individual's evaluation of the importance of those domains, and the construct is best studied from the perspective of the individual (Cella, 1992, 1994; Cella & Tulsky, 1990; George & Bearon, 1980; King et al., 1997; Padilla, Ferrell, Grant, & Rhiner, 1990). The individual is the only proper judge of his or her quality of life in that quality of life rests in the experience of life and the essence lies in their own evaluation of the experience. The judgment of the individual is fundamental because individuals vary in what they value in their lives (Ferrans, 1990b; Ferrans & Powers, 1985). Although the subjective perception is most essential for evaluating quality of life, objective indicators are also useful and important considerations, even though subjective and objective assessments of quality of life produce different results (Ferrans, 1990b; George & Bearon, 1980). Objective quality of life indicators include characteristics such as assets, income, education and housing, and these may supplement people's subjective quality of life evaluation (Campbell et al., 1976; Mandzuk & McMillan, 2005). Perceived quality of life involves a relationship between subjective and objective indicators of well-being. Thus it can be viewed that objective indicators influence the experience of quality of life (Campbell et al., 1976).

Health-Related Quality of Life

Health-related quality of life is a construct that has evolved over the past 30 years and includes those aspects of overall quality of life that can be clearly shown to affect health (Centers for Disease Control and Prevention [CDC], 2011). For the individual, health-related quality of life encompasses physical and mental health and their correlates, including health risks and conditions, functional status, social support, and socioeconomic status. From the community perspective, health-related quality of life includes resources, conditions, policies, and practices that influence the health perceptions and functional status of the population (CDC, 2011). This construct excludes aspects of quality of life that are unrelated to health or do not affect health, such as cultural, political, or social attributes. For example, factors such as quality of the environment, public safety, education, standard of living, transportation, political freedom, or cultural amenities are examples of aspects that would likely be excluded from health-related quality of life (Ferrans, Zerwic, Wilbur, & Larson, 2005). However, the distinction between health-related quality of life and non-health–related quality of life cannot always be clearly determined. The argument can be made that factors such as crime, environmental pollution, lack of education, poor standard of living, lack of transportation, oppressive reproductive laws, or cultural incompetence can have very serious implications for health. In fact, in the presence of chronic illness nearly all areas of life are affected by health, and thus become "health-related." Although the construct of health-related quality of life has helped to focus attention on those aspects of overall quality of life that affect health, further work is needed to identify and clarify the critical elements of the construct and the causal relationships among them (Ferrans et al., 2005).

Quality of Life in the Context of Culture, Race, Ethnicity, Acculturation, and Humanness

Culture. Culture is defined as shared patterns of behaviors and interactions, cognitive constructs, and affective understanding that are learned

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through socialization. These shared patterns distinguish the members of a cultural group as well as differentiate those of another group (Center for Advanced Research on Language Acquisition, 2010). Culture is purposeful and prescribes the ways of life for a group to ensure its survival and well-being. Culture provides beliefs and values to give meaning and purpose to life (Kagawa-Singer, 2000, 2006; Spector, 2004). Culture addresses three basic and universal needs: safety and security, sense of integrity and meaning or purpose in life, and sense of belonging as an integral member of one's social network (Kagawa-Singer & Chung, 1994). Culture is fundamental to life and is an important determinant of quality of life in the context of health because it defines the purpose and prescriptions for living a meaningful life in wellness and sickness.

Culture influences perceptions of illness, of cognitive impairment, and of other physical and mental health problems. Negative perceptions and stigmatization of these conditions, in turn, influence health-related quality of life. Documentation of this relationship was shown in a cohort study of HIV-positive persons from five African countries, in which increases in HIV-related stigma over 1 year were significantly associated with decreases in life satisfaction with rates of change differing by countries (Greeff et al., 2010). Decreased life satisfaction was reflected in reduced living enjoyment, loss of control in life, decreased social interaction, and decreased perceived health status. Likewise, HIV-positive Hispanics who reported feeling stigmatized when receiving medical care had poorer physical and psychological functioning and a decreased ability to complete daily activities (Larios, Davis, Gallo, Heinrich, & Talavera, 2009).

To comprehensively operationalize the construct of culture, the measure should encompass health, ethnicity, and sociodemographic variables (Kagawa-Singer, 2006). Health characteristics include diet, physical activity, and alternative health practices such as healers and parallel or complementary health practices. Ethnic factors include parental heritage, ethnic self-identity (i.e. generation, degree of integration into mainstream society, language proficiencies, beliefs and practices, degree of personal identification and public identity, number of identity groups, and degree of overlap), interethnic social interaction choices (e.g. by circumstance or choice, by regional or community geographic residence), and religiosity and spirituality (e.g. beliefs, practices, internal/external locus of control). Sociodemographic variables consist of family structure and support system (e.g. composition and age), socioeconomic status (e.g. wealth, education, percent of money sent to home country or to support other households), generation in the United States, and reason for immigration.

Race and racism. Racial categories are based on genetic factors expressed as physical or biochemical characteristics. However, the scientific basis for making racial distinctions is weak (Hirschman, Alba, & Farley, 2000; Kagawa-Singer & Blackhall, 2001; Montagu, 1997). Many traits cross over "races," and "racial" identity can change over time. Data from the Human Genome Project and from human genome variation dispute the validity of the term "race" (Royal & Dunston, 2004). Race and other preexisting definitions of the population, such as ethnicity, religion, language, nationality, and culture, are inclined to be controversial concepts that have polarized discussions about the ethics and science of research into population-specific human genetic variation. By contrast, a wider consideration of the many historical sources of genetic variation conveys a whole-genome perspective on the ways in which existing population definitions do and do not explain how genetic variation is distributed among individuals (Foster & Sharp, 2004). Studies of health and quality of life disparities

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continue to use race and racial group categories to predict and understand why some people are better or worse off than others, what genetic variations exist between groups, and what behavioral, social, and environmental factors put some racial or ethnic groups at greater or lesser risk than others for poor health and health-related quality of life outcomes. Racism, the belief in the superiority of one group over another because of genetic traits, justifies the exertion of power and discriminatory action by the "superior" group over the "less superior" group. Disparities in care and reduced health and quality of life outcomes result from racially related beliefs and actions (Institute of Medicine, 2001).

Ethnicity. Ethnicity is that which holds a group together because of a common identity based on some or all of the following shared characteristics: culture, history, language, religion, genealogy, and ancestry. Ethnicity encompasses both culture and "race." Members of multicultural societies form ethnic bonds for solidarity. These bonds assure their way of life and meaning in life, particularly when the universal need for safety and security, sense of integrity and meaning or purpose in life, and sense of belonging as an integral member of one's social network are threatened (Kagawa-Singer & Chung, 1994). Ethnic mores also specify behaviors to promote or maintain health, to prevent disease or illness, and to manage seemingly random events.

Theories of culture, race, or ethnicity can contribute to strategies to promote or maintain health and well-being (Kagawa-Singer, 1995, 2006). The cultural beliefs and values that bind an ethnic group in their approach to health, and the racial identity that places an ethnic group in a position of more or less power and status in their ability to access and use the healthcare system ultimately influence health-related quality of life (Kagawa-Singer, 2001).

Acculturation. Acculturation means learning the beliefs, values, and standards of behavior of another cultural group to function comfortably in that group, typically the dominant culture, and, in the case of immigrants, the host culture. *Assimilation* means taking on the beliefs, values, and practices of the host culture and giving up those of one's own native culture. Individuals may acculturate to varying degrees without necessarily assimilating to the host culture. Acculturation can modify the significance of factors that contribute to disparities in disease incidence and mortality between ethnic groups, such as attitudes, beliefs, and behaviors regarding health or illness. Culturally influenced attitudes, beliefs, and behaviors about illness or specific diseases can, for example, delay early detection, increase consequences of late diagnosis, influence compliance with treatment plans, create mistrust or misunderstanding about the role of healthcare practitioners, and engender social stigma. Acculturation can lead to changes in the health-seeking practices of cultural groups that can narrow health disparities.

Acculturation is a multidimensional construct. A common conceptualization of acculturation encompasses the domains of preferred language, self-identity, friendship choices that determine social boundaries, standards of acceptable behavior, generation since family immigration to the host country, country of origin, and attitudes (willingness to behave in certain ways) (Suinn, Rickard-Figueroa, Lew, & Vigil, 1987). Acculturation has also been defined generically by length of residence, age at arrival in the host country, and by media influence (Marin, Sabogal, Van Oss-Marin, Otero-Sabogal, & Perez-Stable, 1987). However,

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these last are less important indicators of health-related quality of life. To these lists, type of neighborhood was added and language proficiency was expanded to include usage and preferences (Alarcon et al., 1999). Measures of acculturation may also be specifically determined by knowledge and practices concerning the traditions of a culture, such as knowledge and practices about the way of life of the members of the cultural group, valuation and maintenance of beliefs and non-beliefs, blood quantum, and specific cultural traditions, folklore, and language proficiency (Hishinuma et al., 2000).

Knowledge of acculturation and assimilation provides insight into health-seeking attitudes of ethnic groups, reasons for success or failure of prevention and treatment regimens, ways to best reach diverse ethnic groups with health-related messages, and strategies for opening access to health care for ethnic groups (Padilla & Perez, 1995). Acculturation is associated with health-related quality of life when demographic, medical, socioecologic, and healthcare access factors are controlled (Kim, Ashing-Giwa, Kagawa-Singer, & Tejero, 2006). However, large race or ethnic categories such as "Asian American" commonly used in research can mask the different effects of acculturation among ethnic subgroups, such as Phillipino, Korean, or Japanese. For example, Kim and colleagues found that Korean Americans reported poorer quality of life than other Asian subgroups (Kim et al., 2006). It is important for cross-cultural studies to include a measure of acculturation.

People can acculturate without assimilating into the host culture. The ability to gain sufficient knowledge about a culture to transact easily within that culture does not necessarily mean that one gives up his or her original culture. In fact, an individual can belong to several cultural groups. An understanding of the influence of culture on health-related quality of life needs to consider ethnic affiliation as well as level of acculturation and assimilation into another—usually the host—culture.

Humanness. An important philosophical question integral to the discussion of quality of life asks what it is to be human. Cultural in origin, beliefs about humanness include values about life and about quality of life compared to other desirable outcomes. Positive human criteria have been identified as minimal human intelligence, self-awareness, self-control, a sense of time, a sense of futurity, a sense of the past, the capability to relate to others, concern for others, communication, control of existence, curiosity, change and changeability, balance of rationality and feeling, idiosyncracy, and neocortical function (Fletcher, 1990). This view of humanness means that health-related quality of life assessments are made by conscious-thinking, socioemotional individuals who view their health condition or that of others in a time span encompassing past, current, and potential future health states, who view life events as not totally random but somewhat controllable, and who are unique from others.

Pertinent to this discussion is whether people from diverse cultures view humanness similarly. The indicators of humanness listed previously stem from a Judeo-Christian orientation, which is neither more nor less valid than other views. Perhaps Buddhism, Islam, or other religions or philosophies would change, add, or otherwise revise the preceding list of human criteria (Fletcher, 1990). The uniqueness of a culture is less about the array of indicators of humanness, but rather what a culture singles out and emphasizes as key components of humanness. A culture for which

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control of existence is the most important aspect of humanness would value health-related research differently than a culture for which balance of rationality and feeling is the key component of humanness. The first culture might emphasize cure, while the second culture might balance cure with care research. The cultural view of what it is to be human informs the relevant dimension of quality of life for that culture and the level of well-being for an individual, a group, a society, and a nation.

In a sense, health-related quality of life is not only an outcome of care, treatment, or medical decisions, but also a prescriber of behavior based on cultural beliefs, values, and norms. In the case of an infant born with severe health conditions or deformities that require extensive and prolonged medical treatment, parents and health professionals may believe that the infant has no chance for a meaningful life with even minimal quality. The parents and professionals may decide to take no action and let the infant die. This is a painful and terrifying decision fraught with ethical challenges, but a decision ultimately based on cultural norms that define a minimally acceptable health-related quality of life. These types of culturally rooted health-related quality of life decisions are made every day.

Quality of Life and Women's Health

Consideration of quality of life is essential for women's health. Quality of life is a major concern in making decisions regarding life-sustaining therapies. It figures in debates on revising treatment guidelines and practice standards. Indicators of quality of life are used in clinical practice and in clinical trials to evaluate outcomes in terms of human costs and benefits. Quality of life is significant in the healthcare system in terms of decisions of care allocation (Ferrans, 1996). It is a prominent priority on the research agenda for health care as well as central to the national objectives for improving the health of the population of this country (CDC, 2011). Accordingly, the eminence of quality of life as an indispensable dynamic in health care confirms the significance of exploring women's health issues within the context of a quality of life framework. This process is facilitated by the selection of a definition of quality of life suitable to the purposes of this work, as well as an applicable conceptual model of quality of life relevant to women's health.

A Conceptual Model of Quality of Life for Women's Health

A conceptual model constitutes a formal explanation of a phenomenon of interest created according to the philosophical views and assumptions of the model's designer. A conceptual model allows for the efficient integration of observations and facts into an orderly scheme. The concepts of the phenomenon are assembled into a coherent structure because of their relevance to a common theme (Polit & Beck, 2012, 2014). In this context, the phenomenon of interest is quality of life, and the concepts central to quality of life and their relevance will be presented in the following discussion.

Ferrans and Powers (1992) defined quality of life as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her" (p. 29). The underlying ideology of this conceptualization is based on an individualistic view. Ferrans (1996) asserts that the essence of quality of life is grounded in the experience of life, and the individual is the only suitable judge of their experience. Thus, this evaluation is subjective in nature,

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and emphasizes the experience rather than conditions of life (Ferrans, 1996). Because individuals value different things, diverse aspects of life have varying impact on their quality of life. Hence, there is no single quality of life for all people with the same life experience. A condition that makes life intolerable for one person may be no more than a nuisance to another. Consequently, satisfaction implies an evaluation derived from comparing the desired to actual conditions of life (Ferrans, 1996).

The conceptual model (**Figure 2–1**) developed by Ferrans (1990a) describes four major domains of quality of life: health and functioning, psychological/spiritual, socioeconomic, and family. These domains are interrelated and overlapping (Ferrans, 1994). The four domains encompass 34 aspects of life, conveying the multidimensionality of the construct. The conceptual model illustrates the hierarchical relationships between the global construct of quality of life, the four major domains, and specific aspects of the domains (**Figure 2–2**) (Ferrans, 1990a). Ferrans's Conceptual Model of Quality of Life was developed based on qualitative inquiry, which determined the components of a satisfying life; extensive literature review, which revealed dimensions of life satisfaction that were assessed from representative studies; and exploratory factor analysis performed on data from study participants who completed the Ferrans & Powers Quality of Life Index. The Ferrans and Powers Quality of Life Index was designed to measure quality of life of healthy as well as ill individuals. The instrument takes into account the life domains noted by experts, the subjective evaluation of satisfaction with the domains, and the unique importance of the domains to the individual (Ferrans & Powers, 1985). The Ferrans conceptual model, which links satisfaction and quality of life, has a strong

Figure 2–1 Ferrans Conceptual Model of Quality of Life.

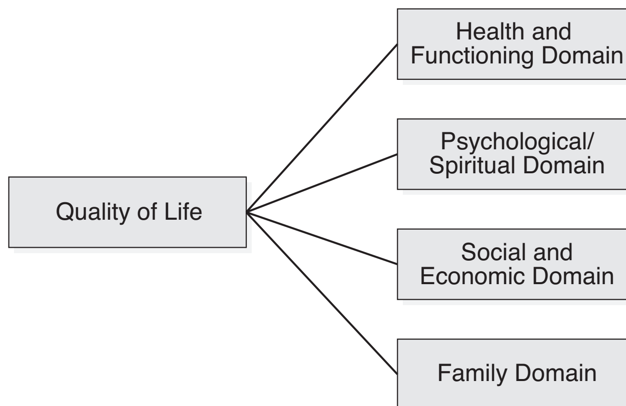

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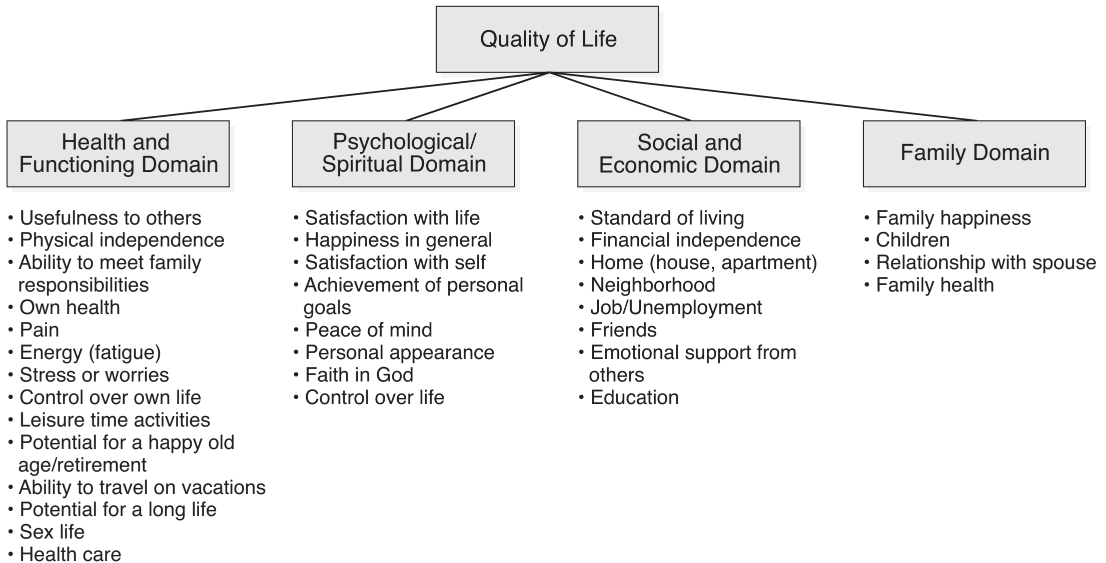
Figure 2–2 Hierarchical relationship between the global construct of quality and life, four major domains, and the specific aspects of the domains.



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conceptual basis, clearly distinguishes between the domains, and provides a solid example of the connection between theory and research. External validation of the conceptual model was provided by the work of Ferrell, Padilla, Grant, and their colleagues (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Ferrell et al., 1992; Ferrell, Grant, & Padilla, 1991; Ferrell, Wisdom, & Wenzel, 1989, Grant et al., 1992; Padilla et al., 1990), who developed a similar conceptual model of quality of life based on qualitative analysis of data from cancer patients. Mutual validation of the two models was shown by their independent and simultaneous development on the basis of patient data from diverse samples taken from different locations in the United States (Ferrans, 1996). The Ferrans Conceptual Model of Quality of Life and the Ferrans and Powers Quality of Life Index have been used extensively, both nationally and internationally, as a basis for many research studies that have investigated the quality of life of women with a wide range of health issues. The Ferrans Conceptual Model of Quality of Life will be integrated into the analyses of women's health issues across the life cycle in subsequent chapters of this text.

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Research Review

What are the predictors of quality of life in younger and older breast cancer survivors?

Sammarco, A. (2009). Quality of life of breast cancer survivors: A comparative study of age cohorts. *Cancer Nursing*, *32*(5), 347–356.

The purpose of this study was to describe the differences between older and younger breast cancer survivors in perceived social support, uncertainty, quality of life, and on various demographic variables. Furthermore, this study sought to explore the role of these variables in explaining and predicting quality of life. A conceptual framework based on the Ferrans Conceptual Model of Quality of Life and the Mishel Uncertainty in Illness Theory guided this study. A descriptive research design was employed. A sample of 163 older and 129 younger breast cancer survivors was recruited from multiple sites in the New York metropolitan area and study participants completed the Northouse Social Support Questionnaire, the Mishel Uncertainty in Illness Scale Community Form, and the Ferrans and Powers Quality of Life Index-Cancer Version III. Data were analyzed using descriptive statistics, t test, chi-square, and hierarchical multiple regression.

The findings revealed that the younger cohort perceived significantly more social support than the older cohort, most notably from spouses and nurses. Both younger and older cohorts reported moderate levels of uncertainty, yet no significant difference was noted. Although both cohorts reported having acceptable overall quality of life, the older cohort reported significantly better psychological/spiritual and socioeconomic quality of life than the younger cohort. The findings also indicated that perceived social support, older age, and not having had adjuvant treatment predicted a better quality of life in breast cancer survivors, whereas uncertainty and having had a mastectomy predicted poorer quality of life. The most influential variable on the quality of life of both cohorts was uncertainty, followed by having additional illnesses, perceived social support, older age, not having had adjuvant treatment, and having had a mastectomy.

Nurses and other healthcare providers need to be mindful of the age-related differences that exist among breast cancer survivors regarding perceived social support, uncertainty, and quality of life, as well as factors that are predictive of better or poorer quality of life. This understanding will help nurses and other health practitioners to determine the resources and vulnerabilities of breast cancer survivors and better assist them in maintaining an acceptable quality of life.

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Chapter Summary Points

- Over the past century, the life expectancy of women in the United States has increased by more than 30 years. With this increase in longevity, realization has emerged that quality of life is as ultimately important as quantity of life.
- Although advances have been made in many dimensions of women's health across the life cycle, the impact of women's health issues on quality of life must be acknowledged, explored, and kept in the mainstream of women's health care.
- Chronological age once stood as the criterion for normalizing the roles and responsibilities taken on by individuals throughout their lives. However, since the 1970s, age norms have shifted and can no longer be considered normative.
- Puberty arrives earlier by several years and adolescence extends into the mid- to late twenties. The arrival of true adulthood has been delayed until the thirties and forties. Middle age has been pushed into the fifties and the stages of life beyond the fifties have changed radically from what was experienced by pre-"Baby Boomer" generations.
- Women have experienced a continuous expansion of opportunities, greater participation in the workforce, and assumption of multiple life roles.
- The most radical voluntary change to the life cycle has been the reproductive revolution that has enabled women to defer childbirth by 10 to 20 years.
- Currently the lives of adult women are all the more complex with the multiple dimensions of biology, family, and work interacting and influencing each other and alternatives regarding life choices and the timing of major career choices and family events.
- The traditional normative roles of mid-life to older women have also shifted dramatically since the 1970s, and consequently manifest diverse issues that threaten quality of life.
- Quality of life is a commonly used, broad, multidimensional construct that is often unclearly defined and poorly understood.
- Authors define quality of life in different ways and conceptualize quality of life as having differing dimensions. Achieving conceptual clarity concerning the definition of quality of life has been difficult because people often ascribe their own personal meanings without ascertaining whether their definitions are shared by others.
- Multidimensionality of the construct, the importance of satisfaction with the dimensions of life, and studying the construct from the perspective of the individual are areas of conceptual agreement on quality of life.
- Health-related quality of life includes those aspects of overall quality of life that can be clearly shown to affect health.
- Culture is fundamental to life and is an important determinant of quality of life in the context of health. Culture defines the purpose and prescriptions for living a meaningful life in wellness and sickness.
- The conceptual model applied to the subsequent analysis of women's health issues across the life cycle describes four major domains of quality of life: health and functioning, psychological/spiritual, socioeconomic, and family. These domains are interrelated, overlapping, and encompass 34 aspects of life, conveying the multidimensionality of the construct.

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Critical Thinking Exercise

Questions for Seminar Discussion

1. What were the traditional marker events and age criteria of the stages of the adult life cycle?
2. What global, economical, and social events in the 1970s triggered a shift in the normative roles and criterion ages of the adult life cycle?
3. In what ways did the developmental stages of the adult life cycle change since the 1970s?
4. What is entailed in the process of passage through the stages of development of the adult life cycle?
5. In view of the changes to the normative roles and stages of the adult life cycle, what challenges do adults face in passing through the stages, especially older adults?
6. How have the normative societal roles of adult women changed across the life cycle since the 1970s?
7. Describe the "burden of caring" carried by adult women throughout the life cycle. How has this tradition led to a caregiving crisis in older women?
8. What is quality of life? Why is there difficulty associated with conceptualizing the construct of quality of life?
9. Describe the categories of definitions of quality of life.
10. What limitations do some categories of quality of life definitions present in assessing quality of life?
11. What areas of conceptual agreement regarding quality of life have been achieved?
12. What is the meaning of health-related quality of life and what does it encompass?
13. What is culture and how does it influence quality of life?
14. Discuss the controversy surrounding race and racism. How is quality of life affected?
15. What is ethnicity? How do theories of culture, race, or ethnicity contribute to strategies that promote or maintain health and well-being?
16. What is the difference between acculturation and assimilation? How can acculturation influence health-related quality of life?
17. How does the cultural view of humanness shape quality of life?
18. How is consideration of quality of life essential for women's health?
19. Discuss the definition of quality of life developed by Ferrans and Powers. Explain how this definition remains consistent to the discussion of conceptual agreement.
20. Explain the Ferrans Conceptual Model of Quality of Life, the major domains, and the specific aspects of each domain.

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Internet Resources

Center for Advanced Research on Language Acquisition (CARLA): provides a variety of definitions of culture. http://www.carla.umn.edu/culture/definitions.html

Center for American Progress: provides information and education about women's health and rights. http://www.americanprogress.org

Centers for Disease Control and Prevention: provides information and education about health-related quality of life. http://www.cdc.gov/hrqol/

Ferrans and Powers Quality of Life Index: provides information and education about the Ferrans and Powers Quality of Life Index for measuring quality of life. https://www.uic.edu/orgs/qli/

Healthy People 2020: Provides information about health-related quality of life and well-being. http://www.healthypeople.gov/2020/about/QoLWBabout.aspx

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