Fall November, 2015

Older Adults with HIV/AIDS

Charles A Emlet, *University of Washington Tacoma*
Anne K Hughes, *Michigan State University*

CHARLES A. EMLET
ANNE K. HUGHES

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This chapter presents an overview of social work practice considerations that arise when HIV disease and aging intersect. The intersection of aging and HIV/AIDS creates a complexity for providers that can be challenging. Medical and/or social service practitioners frequently fail to identify and adequately serve HIV-infected older adults; thus, HIV-infected persons over 50[1] often remain hidden and their needs unaddressed. Despite recent advances in understanding this population, stigma (including ageism, homophobia, and HIV stigma) and lack of knowledge remain barriers to appropriate service provision. Throughout this chapter older adults living with HIV disease (including AIDS) are identified using the acronym OALH.

HIV-related advocacy, service provision, and policy analysis are compatible with social work because of our focus on forming productive partnerships with disenfranchised, oppressed, and marginalized populations (Shernoff, 1990). Examining and advocating for older adults impacted by HIV disease falls well within the role of advocacy and the promotion of social justice for oppressed and marginalized populations (Poindexter, 2010). Systems of care for people living with HIV and for older adults continue to be separate and fragmented, resulting in OLAH falling "through the cracks."

OLDER PERSONS WITH HIV

Advances in the clinical management of HIV disease, including the introduction of antiretroviral therapy (ART) in the mid-1990s, have altered HIV from a deadly disease to one that can be managed successfully (Kirk & Goetz, 2009). HIV disease is increasingly recognized as a disease impacting older adults. Data from the Centers for Disease Control and Prevention (CDC) indicate that the number of adults age 50 and over living with HIV continues to grow (CDC, 2013a). By 2015, half of all persons living with HIV in the United States will be age 50 or over (High et al., 2012). This growth is due to the intersection of incidence and prevalence; that is, the continued new diagnoses of HIV among older adults (currently 17% of all new infections) (Administration on Aging, 2012), along with aging of long-term survivors (Kirk & Goetz, 2009). This trend is best exemplified by the CDC's surveillance data, where we see increasing overall numbers of adults aged 50 and older living with HIV. Between 2007 and 2009 the prevalence

of HIV among older adults increased from 209,433 to 256,259. This reflects an increase in the rate per 100,000 from 240.9 to 280.6 in only 2 years. Racial and ethnic disparities exist in the aging population, as older African Americans and Hispanic/Latinos have rates of HIV infection 12.6 and 5 times, respectively, the rates of their White peers (CDC, 2013a).

BIOLOGICAL ASPECTS OF AGING WITH HIV/AIDS

Aging with HIV disease has a clear biological/physiological component. While there is not room in this chapter to discuss all these issues in depth, we have chosen to focus on several important physiological elements including disease management, late diagnosis, comorbidities, cognitive decline, and medication adherence.

Disease Management

Research suggests that OALH are more likely to receive a late diagnosis of HIV than their younger counterparts (CDC, 2013a). Late diagnosis is defined as receiving an AIDS diagnosis within 12 months of an HIV diagnosis, indicating long-term and unidentified infection. In 2009, at the time of HIV infection diagnosis, 41.5% of older adults were classified as stage 3 (having AIDS) (CDC, 2013a). Late diagnosis results in untreated HIV infection, acceleration of HIV symptoms, increased morbidity and mortality, and decreased effectiveness of antiretroviral therapy. Lack of clinical suspicion by providers and the parallel lack of identifying at-risk behavior among older adults themselves add unnecessarily to the potential of late diagnosis of HIV among older people.

Comorbidities

For older people, life can require the adjustment to and living with both HIV-related and age-related comorbidities. An increased number of comorbid health conditions among those living with HIV have been associated with increased age (Weiss, Osorio, Ryan, Marcus, & Fishbein, 2010), while age and comorbidity have been associated with decreased physical function (Oursler et al., 2011) and decreased physical health quality of life (Fredriksen-Goldsen, Emlet, et al., 2013). The issues of comorbidity among OALH are extremely complex. Conditions can be comorbid with HIV (i.e., hepatitis C, renal disease, peripheral neuropathy, and cancer) or associated with antiretroviral therapy (e.g., hyperlipidemia, cardiovascular disease, and diabetes), or can be non-HIV-related conditions associated with aging, such as chronic pulmonary disease, arthritis, and cardiovascular disease (Weiss et al., 2010). Mental health (especially depression) and substance abuse concerns are also common comorbidities.

Cognitive Decline

Cognitive decline can occur among OALH for many reasons: normal aging, direct HIV infection, psychiatric disorders, substance abuse, non-HIV-related neurodegenerative diseases, opportunistic infections, and medication side effects (Skapik & Treisman, 2007). HIV-associated dementia (HAD) is three times more likely to occur in older than in younger adults with HIV (High, Valcour, & Paul, 2006). Changes in memory, attention, verbal skills, and other executive functions are common among OALH, regardless of the cause. Decreased neurocognitive functioning has been implicated in poor medication adherence among OALH (Barclay et al., 2007). Neuropsychological testing should be used to assess cognitive decline in this population; however, use of the Mini Mental State Examination (MMSE) is not recommended as it is not sensitive to HIV-related cognitive problems (Skapik & Treisman, 2007).

Pharmaceutical Treatment

Antiretroviral medications suppress the ability of the HIV virus to replicate, keeping a person's viral load down and protecting immune function. They function most effectively when patients strictly adhere to the prescribed regimen. Most OALH have been found to have better adherence rates than their younger counterparts (Hinkin et al., 2004), however adherence worsens in the presence of cognitive impairment. HIV-positive persons tend to be able to adhere to their medication protocols better when they receive and perceive supportive interest from healthcare providers (Powell-Cope et al., 1998). Comorbidity can mean juggling many complex medication protocols that may result in confusion about which cognitive or physical symptoms are caused by which conditions (Manfredi, 2002). Social workers

should be familiar with the importance of medical and pharmaceutical adherence, because viral suppression increases longevity.

Psychosocial Aspects of Aging with HIV/AIDS

Many OALHs face numerous and serious psychosocial challenges that can be exacerbated by the aging process. Social isolation, stigma, and depression are some of the primary psychosocial issues faced by this population. Because OALH have a high likelihood of living alone (Fredriksen-Goldsen, Emlet, et al., 2013; Grov, Golub, Parsons, Brennan, & Karpiak, 2010), they may be more socially isolated than their HIV-negative age counterparts (Cahill & Valadez, 2013). A recent study of social isolation among OALH found increased social isolation to be associated with increased hospitalizations and mortality (Greysen et al., 2013).

Stigma

HIV stigma continues to be a major and well-documented social problem among older populations living with HIV (Emlet, 2006; Foster & Gaskins, 2009; Haile, Padilla, & Parker, 2011). HIV stigma is a complex array of intrapersonal and interpersonal experiences including enacted stigma (prejudice/discrimination), internalized stigma (the internal acceptance of negative attributes and beliefs about people living with HIV), and anticipated stigma (the anticipation of enacted stigma, resulting anxiety and fear) (Earnshaw & Chaudoir, 2009). Stigma is associated with negative outcomes, including depression, poorer quality of life, lack of disclosure, and loneliness (Grov et al., 2010; Haile et al., 2011). Many OALH face the potential of duel stigma based on age and HIV status (Emlet, 2006). This phenomenon has been termed "layering," which occurs when one experiences stigma from HIV and from other personal characteristics, such as sexual orientation, age, race, or ethnicity (Reidpath & Chan, 2005). Social workers who are working with OALH must assess the experiences of stigma among this population and carefully consider the intersection of HIV stigma and other forms of discrimination when considering psychosocial support and advocacy. In a recent study of HIV stigma among older Canadians, Emlet, Brennan, and colleagues (2013) noted the importance of social support and mastery as means of counteracting the negative impacts of stigma.

Mental Health Needs

Mental health concerns, particularly depression and substance abuse, are common among OALH. While in the general population depression risk decreases with age, the opposite is true for OALH. Rates of depression as high as 50% have been identified in various studies (Brennan, Karpiak, & Cantor, 2009; Frontini et al., 2012; Justice et al., 2004). Rates of substance use and abuse among OALH are higher than those of older HIV-negative individuals (Justice et al., 2004). Use of illicit substances was identified by 20% of one sample of OALH (Frontini et al., 2012), with the majority reporting the use of marijuana or cocaine. Both mental health status and substance use can be risk factors for HIV infection and can also occur as a result of the crisis associated with an HIV diagnosis. Social workers need to monitor both as they offer services to OALH.

Social and Interpersonal Resources

While OALH face numerous challenges in biological and psychological realms, strengths and resilience can aid in adjustment and serve as protective factors against the deleterious impacts of HIV disease. Interpersonal and intrapersonal factors have been associated with decreased psychological distress and improved quality of life in this population. Social support has been repeatedly found to benefit older, HIV-positive adults. Studying 378 older adults living with HIV in Ontario Canada, Emlet, Brennan, and colleagues (2013) found emotional and informational social support to be associated with decreased HIV stigma. These findings parallel Logie and Gadalla (2009), who found a negative relationship between HIV stigma and social support. Recently Fredriksen-Goldsen, Emlet, et al. (2013) found increased social support to be a protective factor associated with improved mental health quality of life among 226 older gay and bisexual men living with HIV disease in the United States.

Research has also noted the importance of intrapersonal characteristics including mastery, optimism and spirituality. Moore and colleagues (2013) found optimism and mastery to be associated with

improved self-rated successful aging, as well as physical and psychological functioning in OALH. Mastery has also been associated with reduced stigma in HIV-positive older Canadians (Emlet, Brennan, et al., 2013). Recent inquiry into HIV disease has identified the importance of resilience as a means of coping and managing HIV (De Santis, Florom-Smith, Vermeesch, Barroso, & DeLeon, 2013; Emlet, Tozay, & Raveis, 2011). Social workers need to ensure that their assessment processes identify and capitalize on strengths and resilience in this population, as often the focus has been on the deleterious effects of this disease.

SPECIFIC CONCERNS AND RESPONSES

Older adults living with HIV/AIDS are heterogeneous, and it is important to consider that subgroups within this population may have special concerns and responses that will require an approach to service delivery that honors these experiences. In this section we highlight several of these issues, including the episodic nature of the illness and resultant continued grief and loss, decisions about disclosure, and the need for safe behavior assessment and education. As you consider the information that follows, consider also that the following subgroups within the older HIV-positive population may have differential responses: gay men who have suffered multiple losses; women infected by a (perhaps long-term) partner who she was unaware was HIV-positive; African American older adults affected by ageism, racism, and HIV; people infected at a younger age and aging with HIV; people infected in older age and aging with HIV or AIDS; and serodiscordant couples.

Living with Episodic Disability, Grief, and Adjustment

While the success of HAART has extended longevity for people living and aging with HIV, it has at the same time created uncertainty related to physical, emotional and social determinants of health (O'Brien, Bayoumi, Strike, Young, & Davis, 2008). This uncertainty can create and extend periods of crisis and require new approaches to service provision. Solomon, O'Brien, Wilkins, and Gervais (2014) have concluded that OALH may experience age-related uncertainties including episodic health challenges, providers who are uninformed about aging and HIV, financial uncertainty (including issues of disability and retirement), and questions about who will care for them. Additionally, OALH who were diagnosed prior to the advent of HAART may continue to have unresolved issues of grief, loss, and survivor's guilt, having lost friends, lovers, or partners, or having been "at death's door" themselves (Emlet, 2013). Social workers should be observant for serial and serious HIV-related crises in the lives of those they serve, and respond with immediacy, sensitivity, and flexibility. Many of the uncertainties discussed here can trigger significant existential crises that will require support and/or referral to mental health treatment.

Need for Safe Behavior Assessment and Education

Because of deeply ingrained ageist attitudes and misinformation, providers are often blind to the possibility that an older person is at risk for or has HIV. Stereotypes that older people are asexual, heterosexual, do not inject drugs, and do not employ sex workers fuel this lack of awareness. Social workers should strive to forge a climate conducive to discussing health concerns, including HIV status and risk. Adults over the age of 65 have the lowest HIV testing rates in the United States (Nguyen & Holodniy, 2008); thus social workers can be a valuable resource in connecting older clients with information about local testing sites. Studies of HIV-positive older adults have found concerning rates of unsafe sexual practices. Of sexually active OALH in one large study, 41% had unprotected sex (Brennan, Karpiak, & Cantor, 2009), while another study found that 33% of their sample did not use condoms when sexually active (Lovejoy et al., 2008). Social workers must be knowledgeable about prevention and risk issues and offer services to reduce secondary infection (an HIV-positive individual infecting another person), also known as prevention for positives (CDC, 2013b).

Concerns About Disclosure

The disclosure of one's HIV status is a significant challenge at any age. Disclosure may open the door to support and care but also to possible stigma and discrimination. A meta-analysis of HIV disclosure found those who disclosed their status received increased

social support (Smith, Rossetto, & Peterson, 2008). In a qualitative study of 19 older women, Psaros and colleagues (2012) noted what they called the disclosure dilemma, which was characterized by a strong sense of obligation to disclose HIV status and the inherent fear of reactions to disclosure. Social workers need to engage openly and nonjudgmentally with those who may be experiencing disclosure dilemmas, whether the issue is with family, friends, providers, or current or potential sexual partners. Social workers can help older persons practice approaching others about painful topics or being assertive with physicians and others using various forms of rehearsal or coaching.

GENERAL PRACTICE IMPLICATIONS

When working with OALH, social workers can offer information on HIV transmission, sexual safety, pathogenesis, treatment, and adherence; care management, crisis intervention, and referrals; supportive individual, dyadic, family, or group counseling; legal services; concrete services and logistical help; and benefits advocacy. In addition to the social work responses to the concerns discussed above, the general practice considerations discussed in this section may help in designing services for HIV-infected older persons and HIV-affected caregivers.

Offering Specific Outreach and Services

Practitioners in the Aging Network, hospitals and clinics, and AIDS Service Organizations should strive to identify the concerns of OALH so that they can be steered to the most appropriate services. Older people can feel out of place in AIDS Service Organizations, which they perceive as geared to younger people, and in the Aging Network, which has historically been unwelcoming to persons with HIV. Social workers within AIDS Service Organizations should be proactive in addressing the specific needs of this population. Likewise, gerontological social workers should ask older people, in a way that is nonjudgmental and normalizing, whether they have any HIV-related concerns they wish to discuss, and make sure that staff are adequately trained regarding HIV.

Inviting Individual Participation

Social workers need to gently open the door so that older persons can discuss their sexual and drug histories, HIV status, and caregiving realities. It helps to ask people about their knowledge and experience with HIV as a matter of course, just as you would approach any other health concern. Modeling discussion of difficult subjects, such as sexual health and HIV risk, helps to normalize this practice and may even encourage older adults to proactively address them with their healthcare providers (Hughes, 2013). Gerontological social workers can begin by identifying those service applicants and recipients who have HIV concerns. HIV practitioners can ask HIV-positive persons about their social networks and identify older caregivers who may need information and support.

Older HIV-Affected Caregivers

Although HIV/AIDS is no longer considered a terminal disease, partners and loved ones of OALH may still find themselves in a caregiving relationship. For example, Fredriksen-Goldsen, Kim, and Goldsen (2011) found that more than one-quarter of lesbian, gay, bisexual, and transgender (LGBT) older adults in a national survey were in caregiving roles. Midlife and older caregivers can experience stress as they work to balance multiple needs, and consequently their own emotional, financial, and physical stability can be at risk (Leblanc, London, & Aneshensel, 1997). Social workers need to be sensitive to the needs of caregivers and be aware of the possibility that caregivers have historically experienced or are currently experiencing enacted and/or secondary stigma.

Assessment

A social worker who is working with an HIV-affected or HIV-infected older person should first acknowledge the intense struggle inherent in the situation. It is then necessary to conduct a mutual, comprehensive, culturally competent and HIV-knowledgeable assessment, including both assets and needs. Assessments should include HIV as well as aging concerns. Table 34.1 provides nine domains that should be considered and included in an assessment of older adults impacted by HIV disease.

TABLE 34.1 Assessment Domains

Domain	*Older Persons with HIV/AIDS*
Physical Functioning	Comorbidity may result in decline in functioning from various sources. Functioning may decline more rapidly and more sporadically with HIV disease than typical chronic diseases associated with aging. Some data suggest that functional dependence is more important than diagnosis in determining reactions to illness and quality of life. Assessments should include a thorough accounting of HIV-related issues as well as comorbidities and their associated functional decline.
Cognitive/Affective	Cognitive decline in older adults may be due to a variety of factors including dementias normally associated with aging in addition to HIV dementia. Consider use of instruments or questions designed to detect HIV-associated cognitive decline. See Valcour, Paul, Chiao, Wendelken, and Miller (2011) for discussion of appropriate instruments.
Strengths and Resilience	Older adults living with HIV disease routinely express feelings of resilience in the midst of a long-term declining illness. Self-mastery, social support, spirituality, and contextualizing HIV are important factors associated with intrapersonal and interpersonal strengths in this population. Strengths and resilience should be an integral part of the assessment process.
Social Support	Older adults with HIV/AIDS, depending on their history, may have limited contact with biological family. Additionally, social supports common to younger persons with HIV, such as parents and even siblings, may be unavailable to older adults due to death or frailty of family members. Both quality as well as quantity of social relationships could be considered as part of the assessment process.
Sexual and Drug Health	Taking sexual and drug histories with older adults requires an understanding of cohort terminology and may require altering language typically used with younger clients. Ageist attitudes among professionals about sexuality and drug use must be recognized. Research indicates that older, HIV-positive adults continue to be sexually active and engage in at-risk sexual and drug use behavior. Nonjudgmental and nonageist approaches are critical.
Spirituality	Older adults may need assistance with disclosing diagnosis to clergy or may need to locate spiritual resources that are HIV sensitive. Individuals may have broken ties with religious organizations from the past who engaged in "blaming" behaviors. Spirituality is an important component to resilience among HIV-positive older adults and should be included in the assessment process.
Immune Function	Senescence of the immune system (aging process) may serve to accelerate the decline of CD4 T-cells that are diminished through HIV. Older adults will need to be educated about the importance of CD4 and viral load and may need to be assisted with regular and ongoing testing.
Disclosure	Determine whom the client has disclosed their HIV status to. This may include various family members, friends, healthcare providers, clergy, and coworkers. The client may need help assessing the pros and cons of disclosure to a variety of individuals and/or groups.
Caregiver well-being	Caregivers (including partners) of individuals with HIV suffer from many of the same physical, emotional, financial, and social burdens of other caregivers. In addition, associative stigma may exist, depending on the disclosure of the care receiver's HIV status.

SERVICE DELIVERY SYSTEMS

People living with HIV/AIDS can access services from a variety of sources including private, community based, and governmental. Service needs can be addressed through numerous systems including health (physical and mental), home care, rehabilitation, and pharmaceutical services. Many OALH may have Medicare coverage due to their age or disability status. Medicare Part D covers prescription medications, including those used to manage HIV disease. Social work responses will depend on the OALH's perceptions of his or her needs, as well as the local availability of services. Professionals

working with OALH must be familiar with the range of services from both the Aging Network and the HIV Network.

HIV Network Services

Services for persons of all ages living with HIV may be provided through public health and social services, university medical centers and clinics, and AIDS Service Organizations (ASOs) supported through the Ryan White CARE Act. The Ryan White Comprehensive AIDS Resources Emergency [CARE] Act (PL101-381) of 1990 was the first federal service delivery mechanism to aid persons with HIV. The Act was reauthorized in 2009 as the Ryan White HIV/AIDS Treatment Extension Act of 2009 (PL 111-87), and funds programs that provide services to those with HIV/AIDS who are uninsured or underinsured and who lack financial resources to pay for HIV care. AIDS Service Organizations are community-based agencies developed to ensure the delivery of health-related and social services to HIV-affected individuals and families (Burrage & Porche, 2003). AIDS Service Organizations may not specifically target older adults, and this may serve as a barrier for some older adults. Research suggests that ASOs do not uniformly understand the risks and impact of HIV on older adults (Wood, 2013). The Ryan White HIV/AIDS Treatment Extension Act includes the AIDS Drugs Assistance Programs (ADAPs), which provide HIV-related medications to those who do not have drug coverage and are an essential resource for older adults who do not yet qualify for Medicare.

The Aging Network

The Older Americans Act (OAA) of 1965 created the Administration on Aging (AOA) and authorized grants to States for community planning and services programs. The OAA created the aging network, which includes 57 State Units on Aging and approximately 650 Area Agencies on Aging. Currently, through the newly established Administration for Community Living (ACL), providers in the aging network will be increasingly able to provide services to younger, disabled adults. This integration will expand the availability and access of Aging and Disability Resource Centers, while continuing to serve older adults through established programs (Hooyman, Mahoney, & Sciegaj, 2013). While gerontological social workers are commonly knowledgeable about services available under the aging network, many area agencies on aging are not familiar with the needs of OALH. Emlet, Gerkin, and Orel (2009) surveyed Area Agencies on Aging in Washington State and found that while the majority agreed that serving older adults impacted by HIV was part of their mission, only 16% offered some type of HIV education to consumers. Continued efforts to improve knowledge and programming from both the HIV and aging service delivery sectors are needed.

SUMMARY

When working with HIV-infected older persons, social workers need to be creative and flexible. HIV-positive persons, as well as older persons, often do not fare well in the complexity of human services and healthcare provision. Social workers must monitor their own attitudes and behaviors related to ageism and HIV stigma, along with other prejudgments, so that the helping relationship does not become another place where people suffer from maltreatment and misunderstanding.

Over the past three-plus decades, we have learned a great deal about the needs of and the differences among older adults living with HIV disease. Social work has contributed substantially to this knowledge base. Research is beginning to examine the "positive" side of aging with HIV through studies on resilience. From there, we can develop intervention strategies that improve care for this vulnerable population, while learning from those who are doing well naturally. The development of evidence-based practice models through intervention studies is a reasonable next step for the profession.

SUGGESTED RESOURCES

Administration on Aging (AOA)

http://www.aoa.gov/AoAroot/AoA_Programs/HPW/HIV_AIDS/GrayingHIVAIDS.aspx

- Webinar on services available to the aging services network on positive aging and prevention.

http://www.aoa.gov/AoARoot/AoA_Programs/HPW/HIV_AIDS/index.aspx

- Links to HIV testing sites, health centers, and community aging organizations. Website includes HIV/AIDS and aging resources.

http://www.aoa.gov/AoARoot/AoA_Programs/HPW/HIV_AIDS/toolkit.aspx

- Resources and materials to use in promotion of HIV/AIDS education for older adults.

http://www.aoa.gov/AoARoot/AoA_Programs/OAA/How_To_Find/Agencies/find_agencies.aspx

- Find a local State or Area Agency on Aging. Searchable by state, then county.

ACRIA (AIDS Community Research Initiative of America)

http://www.ageisnotacondom.org/index.html

- Website has facts about HIV/AIDS, aging, and sexuality. Includes resources and links to publications regarding OALH.

Centers for Disease Control and Prevention (CDC)

http://www.cdc.gov/hiv/library/reports/surveillance/2010/surveillance_Report_vol_18_no_3.html

- CDC surveillance report specifically on HIV in adults age 50 and over.

National Institute on Aging

http://www.nia.nih.gov/health/publication/hiv-aids-and-older-people

- Basic information about HIV and aging.

Ryan White HIV/AIDS Program

http://hab.hrsa.gov/abouthab/aboutprogram.html

- Basics about local and state HIV programs, factsheets, a glossary, and details about coverage offered by the Ryan White program.

National Resource Center on LGBT Aging

http://www.lgbtagingcenter.org/resources/index.cfm?a=1

- Information to aging service providers on creating LGBT-affirming organizations and working with older members of the LGBT community. Site has a

Professional Association of Social Workers in HIV and AIDS (PASWHA)

www.paswha.org

- This is a professional membership organization for social workers who provide service at all levels in the field of HIV/AIDS social work. Website access is restricted to members.

NOTE

1. When the CDC began monitoring incidence and prevalence of AIDS in 1982, age was reported by categories with the oldest category being "over 49". Older persons became defined as 50-plus years.

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The Oxford Handbook of Social Work in Health and Aging

SECOND EDITION

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EDITORS

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Argentina Austria Brazil Chile Czech Republic France Greece
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Published in the United States of America by
Oxford University Press
198 Madison Avenue, New York, NY 10016

Cataloging-in-Publication data is on file at the Library of Congress
ISBN 978–0–19–933695–1

9 8 7 6 5 4 3 2 1
Printed in the United States of America
on acid-free paper