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Psychology of Aging A Biopsychosocial Perspective

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ealth professionals are often called upon to intervene in complex ethical dilemmas that involve respecting an older adult's autonomy while also considering protective interventions to ensure safety. This chapter addresses the foundational ethical competencies for psychologists and geropsychologists including the unique challenges associated with surrogate decision making, legal, clinical, and psychosocial interventions specific to working with vulnerable older adults, ethical dilemmas that can emerge within various situations including assessment and integrated care settings, detection and intervention strategies in cases of elder abuse, neglect, and exploitation, and ethical approaches to research with older adults. Finally, the authors discuss the multicultural dimensions that influence how ethical and legal issues are conceptualized and addressed.

ETHICAL COMPETENCIES IN GEROPSYCHOLOGY

Psychologists make decisions every day involving fundamental beliefs and values about what is most appropriate in working with older adults, families, health care professionals, and within clinical or academic settings. A psychologist's comprehensive understanding of treatment is grounded in the ethical guidelines and principles of the American Psychological Association's (APA) Ethics Code (APA, 2017; www .apa.org/ethicscode/). The APA Ethics Code serves as a standard to direct the actions

^{*}Key references in the References section are indicated by an asterisk.

and decision making of psychologists in their work with clients, families, communities, and colleagues with an emphasis on promoting advocacy for social change.

Within clinical geropsychology practice, the Geropsychology Knowledge and Skills Assessment Tool (Karel, Emery, Molinari, & CoPGTP Task Force on the Assessment of Geropsychology Competencies, 2010) captures the foundational competencies of geropsychology involving legal and ethical standards in four specific areas. Competencies include one's ability to

... identify complex ethical and legal issues that arise in the care of older adults, analyze them accurately, and proactively address them, including: (a) tension between sometimes competing goals of promoting autonomy and protecting safety of at-risk older adults; (b) decision making capacity and strategies for optimizing older adults' participation in informed consent regarding a wide range of medical, residential, financial, and other life decisions; (c) surrogate decision making as indicated regarding a wide range of medical, residential, financial, and other life decisions; conservatorship, guardianship, multiple relationships, and confidentiality (Karel et al., 2010, p. 117).

ADVANCE CARE PLANNING FOR OLDER ADULTS

Many of the ethical issues that psychologists face when working with older adults revolve around health care decisions and whether the older adult is capable of making his or her own health care decisions. There are several terms that are commonly used when discussing health care decision making. Advance directives, also known as living wills, are documents that specify a person's wishes for end-of-life care. Hospitals are typically required to present information on advance directives prior to admission in accordance with the Patient Self-Determination Act of 1990. Any individual older than the age of 18 can complete an advance directive, though research suggests that only about a quarter of U.S. adults have completed advance directives is typically the most common reason for not completing one.

There are several pieces of information that are typically included in an advance directive. For the purposes for planning in the event of becoming unable to make decisions secondary to a disabling circumstance, individuals can specify their preference for medical treatment (full treatment vs. comfort-focused treatment), extraordinary measures (tube feeding, ventilator, etc.), and preferences for cardiopulmonary resuscitation (CPR), also known as a do-not-resuscitate (DNR) order. Individuals can also designate a health care surrogate to make decisions for them if they are unable to; this information may also be included in a medical power of attorney (POA) document, which is discussed in the next section. This person is sometimes referred to as a health care agent or health care proxy. If no surrogate is designated, the default surrogate is the next of kin, typically in the order of spouse/domestic partner, adult child, parent, sibling, or other relative. If no one is available to serve as the health care surrogate, the court may appoint a guardian to make the decisions. A guardian may also need to be appointed if the family is in conflict about the patient's wishes, though this is an ethical gray area. We revisit these issues later in the chapter when we discuss potential ethical problems around surrogate decision making.

Some advance directives include POA documents. A POA is a legal document that designates someone to make decisions on your behalf if you are deemed unable to make or express such decisions. With regard to older adults, a POA is typically designated for health care and/or financial matters. A financial POA is typically called a general POA, whereas a health care POA is typically called a medical POA. Individuals can choose whether a POA goes into effect immediately once it is signed (called a "durable POA") or whether it only goes into effect once the person is unable to make decisions, as verified by a health care professional (called a "springing POA"). Clinicians may be asked to help an older adult complete a living will or POA. It may be beneficial to choose a different person for the medical versus financial POA depending on who is most familiar with the older adult's views on life and death versus his or her financial affairs. Table 14.1 lists some example options that are typically included in forms that document treatment preferences. One example of this type of form that is used in California is the Physician Orders for Life-Sustaining Treatment (POLST). On the POLST, the patient can list their health care agent though the POLST does not include the level of detail regarding health care decisions that may present in a medical POA or advance directive. The POLST is freely available at www.capolst.org/polst-for-healthcare-providers/forms.

Decision	Description and Options
Cardiopulmonary resuscitation (CPR)	If the patient has no pulse and is not breathing Options: Administer CPR or not (DNR order)
Medical interventions	If patient has a pulse and/or is breathing Options: Full treatment—Prolong life using all medically effective means (for example, intubation, ventilation) Selective treatment—Treat medical conditions but do not intubate (for example, intravenous fluids or antibiotics). Avoid intensive care Comfort-focused treatment—Maximize comfort. Do not use full and selective treatments unless consistent with comfort goals. Examples include oxygen or suctioning
Artificially administered nutrition	Whether to offer food by mouth is feasible or desired Options: Long-term artificial nutrition, including feeding tubes Trial period of artificial nutrition, including feeding tubes No artificial means of nutrition, including feeding tubes
Health care proxy	Specify name and contact information of someone who can make decisions for you if you are unable to

 Table 14.1
 Sample Questions Typically Used When Documenting Treatment Preferences

DNR, do not resuscitate.

While the POLST is the form used in California, most states have similar forms that capture treatment preferences. For example, Colorado uses the Medical Orders for Scope of Treatment (MOST) form, which is freely available at www.coloradoadv ancedirectives.com/most-in-colorado.

ETHICS IN LONG-TERM CARE

While the majority of older adults receive care from family members, approximately 14% of adults older than the age of 65 receive services in nursing home or long-term care settings, assisted living, or retirement communities (National Alliance for Caregiving [NAC], 2015). Results from the AARP/NAC study suggest that 16% of care recipients residing in retirement communities, assisted living, and skilled nursing facilities have dementia due to Alzheimer's disease or other causes. Ethical challenges can first emerge from the initial transition from independent living to a higher level of residential care.

For many of us, regardless of age, change can be difficult and typically requires time to adapt to any new circumstance or environment. You might recall events in your life which required changes that were anxiety provoking: the first day of high school; leaving home for college; starting a new job; moving to a new city or immigrating to a different country. Similar anxieties and fears are present for the older individual who may be faced with leaving a home and condensing a lifelong accumulation of sentimental possessions into a small room or apartment. Let us consider the following scenario:

Mr. Watsby, an 83-year-old widowed gentleman, was sent to the emergency department (ED) after he fell while showering in his single-family home. At the ED, he reported that it took him 2 hours to "crawl" from the bathroom to his phone to call for emergency help. He suffered bruises on his left arm and leg, but did not sustain a head injury. Prior to this injury, Mr. Watsby had undergone a left hip replacement for a fracture. He has lived alone for the past 3 years following his wife's death due to a motor vehicle accident. Mr. Watsby is treated for multiple medical conditions including congestive heart failure (CHF), atrial fibrillation, hypertension, diabetes, and chronic obstructive pulmonary disease (COPD). His two adult sons live out-of-state but each has offered him to live with them due to their increased concerns about his ability to continue living alone. Mr. Watsby had repeatedly declined their offer as well as their suggestion to move to an assisted living facility. His sons did not insist for him to move because they knew that their father's favorite pastime was to look at his wife's paintings, which were hung on every wall of the matrimonial family home. There would be too many paintings to bring to any other home.

On examination at the ED, Mr. Watsby was found to have back sores that had ulcerated and was poorly nourished with a weight of 125 pounds, down from 168 pounds the previous year. His mental status deteriorated rapidly on the second day of admission with delirium, but the agitation had resolved by the end of the week. A cognitive screen a week later indicated problems with memory, but Mr. Watsby denied any difficulties managing things on his own, including his medications. On the day of the hospital discharge, Mr. Watsby declined home-health services and stated he would be sure to carry his cell phone in his pocket to call for help when needed. He denied feeling depressed and expressed excitement at the thought of returning to the comfort of his own home. Mr. Watsby's sons had spoken to the attending physician and committed to taking turns to check in on their father by phone each day.

Three days after discharge, Mr. Watsby fell again in his home. This time, he fell in the kitchen and was found 9 hours later by paramedics with blood on his forehead. He was lying semiconscious on the floor close to his front door. Although he did not seem to have sustained any major injury, he was hospitalized and given intravenous fluids. The clinical team and one of Mr. Watsby's sons agreed that in the interest of maintaining his safety, he should be discharged to a subacute rehabilitation stay in a nursing home with plans to transition into long-term care. His sons shared responsibilities for his health care in a springing power of attorney (POA). Mr. Watsby reluctantly agreed but stated a preference to remain in his own home. After 20 days in the rehabilitation facility, his physician determined he was incapacitated and the medical durable POA was activated. Mr. Watsby was transferred to permanent long-term care. His physical and mental health conditions worsened over the next 5 months. The advance directive documents had not been completed and Mr. Watsby was placed on a feeding tube. In the days that followed, he had multiple episodes of breathlessness that required several resuscitation attempts that finally failed. Mr. Watsby died after living 5 months in the nursing home. On review of the admission chart record, he was noted as "depressed and disoriented."

In Mr. Watsby's case, several ethical and legal questions arise for psychologists and other health care professionals:

- **1.** To what extent does the health care team promote Mr. Watsby's autonomy and independence versus implementing protective interventions to maintain his personal safety?
- **2.** What more do we need to know about family dynamics and the strength of the relationship between Mr. Watsby and his two sons? Do his sons have the capacity to serve as surrogate decision makers? To what extent is it our role to ascertain this? If not them, then who? Do they know their father's values, preferences, and wishes for his care and end-of-life decisions?
- **3.** How much weight do we place on Mr. Watsby's preference to return home in the face of declined physical functioning? What information do we need to gather to appreciate his refusal to receive care in a rehabilitation or skilled nursing setting?
- **4.** And finally, who on the health care team is responsible for gathering relevant familial and psychosocial information and how is it shared with the family and the rest of the care team? Most importantly, how is the plan of care communicated with Mr. Watsby? Who should be involved in those discussions?

FOUNDATIONAL ETHICS OF DECISION MAKING

To appreciate the underpinnings of ethical dilemmas, clinicians must be familiar with the complexity and range of life events and decisions encountered by older adults, family members, and other health care professionals. Specific decisions have been identified (American Bar Association [ABA] & APA, 2008) and include the following: (a) medical decision making that can range from simple decisions—such as medication management—to complex decisions such as end of life or choosing a medical treatment (Karlawish, Quill, & Meier, 1999); (b) financial decision making ranging from balancing one's checkbook to managing investments and assets (Marson, 2001); (c) independent living decisions regarding the level of supervision or independence needed in one's living situation (Moye & Braun, 2007); (d) driving ability—for example, at what point does a person discontinue driving?; (e) decision making around sexual consent and relationships, particularly in situations where either one or both individuals have cognitive impairment; and finally, (f) the ability to make a will (referred to as *testamentary capacity*; Marson, Herbert, & Solomon, 2005). In addition, a psychologist may be called upon to evaluate the capacity to make a wide range of other decisions (e.g., capacity to marry, capacity to refuse or accept visitors in a hospice setting, etc.).

At the center of developing ethical competencies is the tension between autonomy, protection, and *beneficence—the intention to do good and no harm on behalf of the patient* (APA, 2010)—all of which must include appreciation for an individual's right to make life decisions and choices that are consistent with his or her beliefs and values. In most situations, those principles can be a guiding force in treatment planning, provision of education, and discussion with patients and families about interventions and best course of action for the patient. However, in some situations, conflict arises between what the patient wants and what the provider or family believes is best for the patient. A common challenge for professionals is discerning whether or not an older individual can be their own decision maker, particularly in situations where he or she is engaging in seemingly poor decision making. Such situations include neglecting one's health care needs (i.e., taking psychiatric or other chronic disease medications as prescribed, attending health care appointments, and general hygiene care), changing directives in a last will and testament, entering intimate partnerships or new relationships, or engaging in risky behaviors such as alcohol or substance use, and cigarette smoking.

AUTONOMY AND SURROGATE DECISION MAKING

In situations where others (health care professionals, friends, family, coworkers) question the type of decisions made by an older adult, concerns may be raised about whether the individual has the ability to make decisions and if not, what should be done to protect that individual from endangering himself or herself or others. Two core principles—autonomy and protection—are maximized when responding to these issues. Clinicians and physicians are often called to assess whether an individual has the cognitive capacity to function in any particular domain of decision making. Eight domains of capacity specific to older adults have been identified by

Moye and Marson (2007): (a) independent living; (b) financial management; (c) consent to treatment; (d) testamentary capacity; (e) consent to participate in research; (f) sexual consent; (g) voting; and (h) driving.

Capacity is delineated into either clinical capacity or legal capacity (also called competency). Clinical capacity is based on the judgment of health care professionals and usually revolves around whether the patient has the ability to express a choice, understand the risks and benefits of the decision, appreciate the significance of the decision, and state rational explanations for their decision (ABA & APA, 2008). Clinical capacity determinations are domain specific. As outlined in the eight domains of capacity, an older adult may lack capacity for financial decisions but capacity may be intact for medical decisions/consent to treatment. The assumption behind a capacity assessment is that the individual could possibly eventually regain capacity to make decisions in that area. For example, if the older adult is experiencing delirium due to various medications, the effects of this would be expected to clear over time.

Judgments about clinical decisional capacity are commonly made through informal information-gathering processes that involve interviewing persons within the familial and psychosocial network such as caregivers, family members, clinicians, attorneys, adult protective service caseworkers, and law enforcement. Neuropsychologists, psychologists, and physicians use various formal assessment measures for determining multiple domains of clinical capacity. If a patient is found to lack clinical capacity in a specific domain, the health care team may turn to the surrogate decision maker to provide insight into the person's wishes. The decisions made by a surrogate should be guided by two standards: (a) substituted judgment and (b) best interests. Substituted judgment involves the surrogate's understanding and appreciation for the individual's preferences, values, and wishes, to inform their decision making based on what the individual would have decided if he or she had the capacity to do so (Bush, Allen, & Molinari, 2017). In cases where there is insufficient information to make a substituted judgment, the surrogate's decision making should be guided by the best interest standard. In other words, the surrogate's decision would be considered in the best interest of the incapacitated person. Courts may become involved if the surrogate objects to a recommended treatment or if there is conflict within the family about what the patient would want.

The decision of clinical capacity is usually done through clinical interview without a formal measure. However, there are formal measures available that may assist in the interview process, although the ultimate decision about capacity should involve multiple informants and methods and not rely solely on one source of information. Formal measures of decisional capacity are typically domain specific and focus on areas such as the capacity to make medical and/or financial decisions. Instruments typically present hypothetical vignettes, which allow the clinician to understand the individual's reasoning process in how he or she approaches the vignette. Examples of these type of instruments for capacity to make medical decisions include the MacArthur Competence Assessment Tool for Treatment (Grisso & Appelbaum, 1998), the Hopemont Capacity Assessment Interview (Edelstein, 2000), and the Capacity to Consent to Treatment Instrument (Marson, Ingram, Cody, & Harrell, 1995). More information about these and other capacity assessment instruments is available in a handbook designed for psychologists, *Assessment of Older Adults with Diminished Capacity*, written jointly by the American Bar Association Commission on Law and Aging and the APA (ABA & APA, 2008). This handbook, as well as handbooks designed for lawyers and judges, is freely available at www .apa.org/pi/aging/programs/assessment.

When older adults can no longer manage their affairs and there is no one available to act as surrogates, or the surrogates are in conflict, the court may need to appoint guardians or conservators. This decision is made by magistrates and judges. The judge decides about the level of supervision that may be needed to support or protect the older individual or their assets (Greene & Gibson, 2013). Although it varies by state, the following requirements are typically needed to file for a competency hearing: (a) a disabling condition (dementia, mental, or medical disorder), (b) a lack of cognitive ability to evaluate information and communicate preferences, (c) an inability to care for oneself without intervention, and (d) a determination that guardianship is the only feasible way to protect the person. Two forms of legal protections commonly used by courts are guardianship and conservatorship.

The responsibilities and duties associated with designated guardians or conservators vary from state to state. In most states, a guardian is a person who is legally responsible for someone who is unable to manage his or her own affairs, which can include domains of health care, personal affairs, and financial management. They are typically responsible for making sure that the individual receives appropriate services. A conservator is typically and primarily responsible for protecting and handling financial affairs for a person who is deemed incompetent. Federal laws do not govern guardianship practices; thus, duties or responsibilities associated with a guardianship role are left to individual states and jurisdictions to outline and uphold. Most determinations are made in probate court. Probate court is part of the state court system where cases involving wills and estates are presented to and ruled by a magistrate. In contrast, criminal courts are designated for criminal cases that typically involve a juried trial.

When a guardian or conservator is designated by the court, the older adult loses his or her right to make independent and autonomous decisions about living arrangements, medical treatment, selling or purchasing property, changing a will, driving, entering marriage or getting a divorce. Surrogate decisions can even be made and upheld despite objections from the incapacitated adult (Grisso, 2003). That said, the guardian or conservator is encouraged to always keep the older adult's preferences and values at the forefront of his or her decision making. Consider the following example:

Ms. Samson is a 78-year-old widowed, Caucasian woman who resides in an assisted-living facility following a stroke that resulted in cognitive, speech, and mobility impediments. Her sister-in-law, who is also widowed, is designated as Ms. Samson's guardian for all decision making around medical, personal, and financial affairs. Ms. Samson is a lifelong tobacco user. Her sister-in-law purchases cigarettes weekly and drops them off at the care facility. After the first of the year, the sister-in-law decides to quit smoking and simultaneously, stops bringing cigarettes to Ms. Samson. The facility staff notices increased negative behaviors such as agitation, bouts of crying, decreased attendance of activities, and isolation in her room. The facility administrator speaks to the sister-in-law about staff's observations and gently

reminds her of Ms. Samson's preference to continue smoking. The sister-inlaw agrees to purchase cigarettes and Ms. Samson's behavior returns to a pleasant and content baseline.

Recall that decisions made by surrogates should be guided by the standards of substituted judgment and the patient's best interests. In Ms. Samson's situation, the sister-in-law likely understood her preference to continue smoking although Ms. Samson was unable to effectively communicate her preferences. In the absence of knowing a person's preferences or wishes, surrogate decision makers base their decisions on what would be in the *best interest* of the individual. Again, in Ms. Samson's case, the surrogate substituted her own values (to quit smoking) for the values of Ms. Samson. This illustrates the risk that surrogate decision makers take, either intentionally or unintentionally, when making decisions for an incapacitated person. Hence, it is important for surrogate decision makers to evaluate their own biases and preferences regarding the individual's care so as to not pervert their decision-making processes.

The previous paragraphs focus mostly on a person's capacity to make medical decisions. As noted in the beginning of this section, there are other domains of capacity, some of which are encountered more often in working with older adults. If an older adult is giving money to someone or spending a lot of money in a potentially irresponsible way (i.e., gambling), a provider may begin to question the person's capacity to make financial decisions. As discussed earlier, a financial POA may need to be appointed if the person is found to lack capacity to make financial decisions. One formal measure of financial capacity, the Financial Capacity Instrument (Marson et al., 2000) enables a clinician to obtain more detailed information about an older adult's ability to understand financial activities such as cash transactions, checkbook management, and financial judgment. Other capacity assessment instruments such as the Hopemont Capacity Assessment Interview (Edelstein, 2000) or the Independent Living Scales (Loeb, 1996) include a section on financial decision making, which can be used to inform a decision about financial capacity. The Lichtenberg Financial Decision Rating and Screening Scales (Lichtenberg et al., 2016) provide a structured interview to assess an older adult's ability to make a sentinel financial decision, such as making a large donation or entering into an annuity.

Other areas of decisional capacity include whether an older adult has the capacity to enter into a sexual relationship or to continue driving. These types of decisions are often challenging for family and health care professionals. Most of the concerns around capacity to enter into sexual relationships center on patients with dementia. Consider a situation where two older adults are living in a long-term care setting and want to initiate a sexual relationship. There may be concern that one or both of the individuals are unable to understand the pros and cons of this type of relationship due to the dementia (Moye & Marson, 2007). Alternatively, consider a situation in which a person with dementia lives in a long-term care setting and his or her longterm partner lives in the community and does not have dementia. Would you have concerns about them continuing to have sexual intercourse, even as the person with dementia continues to experience cognitive decline?

Although sexual consent decisions are rarely a legal concern, it can become complicated due to balancing the principles of autonomy and to do no harm, while also considering the negative attitudes that exist regarding older adults' sexuality (Tarzia, Fetherstonhaugh, & Bauer, 2012). Lichtenberg and Strzepek (1990) suggest that an assessment of sexual consent capacity should include the patient's awareness of the relationship, the patient's ability to avoid exploitation, and the patient's awareness of potential risks such as sexually transmitted diseases. Any assessment of sexual consent capacity should include a review of medical records (including an assessment of conditions that may impact sexual functioning), a clinical interview to assess values around sex as well as understanding, reasoning, and choice, collateral interviews (i.e., family or nursing home staff), neuropsychological testing, and discussion with other team members at the facility (Syme & Steele, 2016). Even if the older adult is found to lack capacity to consent to sex, some researchers advocate that certain sexual behaviors may still be allowable based on a committee decision that includes nursing home staff and family members (Wilkins, 2015). This approach is suggested to avoid a condescending attitude toward sexual expression among older adults with dementia.

Determining an older adult's capacity to continue driving is also complex. For many individuals, the decision to stop driving has a major impact on perceived independence. However, family members may become concerned that an older adult with dementia lacks the judgment to continue driving, depending on the severity of the condition. In a longitudinal study of men with dementia, the decision to stop driving was often made abruptly after a physician recommendation (Adler & Kus-kowski, 2003). Follow-up interviews 2 years later indicated that approximately half of the participants had stopped driving but the other half continued to drive up to 5 days per week.

Psychologists are often asked to assist with the decision to stop driving, either in terms of assessing the older adult's functioning with regard to skills involved in driving, or by initiating a discussion with the older adult around his or her views about driving and whether the individual has any concerns or motivation to reduce or stop driving. There are several components of a driving evaluation, including a medical exam, psychological exam, and an evaluation by a driving specialist (ABA & APA, 2008). Although the core part of the psychological exam should focus on cognitive functioning, it should also include assessment of symptoms of depression and anxiety, as these conditions can impair reaction time and lead to distraction when driving (ABA & APA, 2008). The evaluation by a driver specialist is critical because impairments observed in psychological testing may or may not impact driving skills.

Although this varies across jurisdictions, there are steps that health care professionals and family members can take if they are concerned about an older adult's ability to drive safely. In California, for example, physicians are required to report a medical condition, such as dementia, to the Department of Motor Vehicles (DMV), which will trigger a reexamination of driving ability. In some cases, based on the physician's report, the DMV may decide that the diagnosis is not severe enough yet to require a reexamination. Therefore, when a physician provides this information to the DMV, it does not necessarily mean that the person's license will be revoked. In some states, certain health care professionals are required to notify the DMV when certain conditions are diagnosed, whereas in other states, health care professionals are not allowed to share this type of private health information. In most states, family members can file a report with the DMV that will trigger a reexamination of driving ability.

ELDER MISTREATMENT, NEGLECT, AND EXPLOITATION

An important area where ethical and legal tensions arise is in cases of suspected or identified elder abuse and exploitation. According to the Centers for Disease Control and Prevention, elder abuse is defined as "an intentional act or failure to act by a caregiver or another person in a relationship involving an expectation of trust that causes or creates a risk of harm to an older adult" (Hall, Karch, & Crosby, 2016, p. 25). Various forms of elder abuse have been identified and include physical, sexual, emotional, caregiver and self-neglect, and financial exploitation. Important to note is that most states vary in their definitions of the various forms of abuse to older or at-risk adults, thus creating barriers for collecting and analyzing national data to describe the prevalence and incidence rates of elder mistreatment and exploitation. Some scholars have attempted to provide empirical evidence for the prevalence of elder abuse. The most recent prevalence study published by Acierno and colleagues (2010) used randomized telephone dialing methodology to survey 5,777 older adults. Results suggested that one in 10 respondents reported experiencing some form of abuse in the past year. The highest prevalence rate reported was financial abuse by a family member (5.2%), followed by potential neglect (5.1%), emotional abuse (4.6%), physical abuse (1.6%), and finally, sexual abuse (0.6%). The authors concluded that the most consistent correlates with abuse were low social support and previous exposure to a traumatic event.

Several risk factors increase older adults' vulnerability to mistreatment and exploitation. Factors include physical, cognitive, and sensory deficits, emotional instability (i.e., mental illness), physical and psychosocial isolation, a recent major life transition (i.e., widowhood), relocation, and/or poor access to resources such as medical care, mental health treatment, or spiritual/social activities. Several studies have investigated the association between dementia and older adult victimization. Aggregated findings suggest a higher prevalence of abuse among older individuals with a diagnosis of dementia (Cooper, Selwood, & Livingston, 2008) with upward of 50% of persons with dementia experiencing some form of abuse (Cooper et al., 2009). Another study, which surveyed caregivers of older adults with dementia, reported 47% of care recipients had been mistreated by their caregivers (Wigglesworth et al., 2010).

The ethical dilemmas in most cases of elder mistreatment, neglect, and exploitation return to the principles of autonomy and beneficence. As discussed earlier in the chapter, all persons are viewed to be competent unless determined otherwise by a physician or psychologist. Law enforcement and adult protective services—the human services agency commonly involved in investigating and intervening in cases of elder abuse—are sometimes confronted with an older adult's right to refuse services, particularly if the older person appears capable of understanding the consequences of doing so. Self-determination is an important component in intervention and can be a limitation to implementing services and resources. For example, a caseworker may determine that an at-risk adult may benefit from meal preparation services and home health care. The at-risk individual has the right to accept meal services yet refuse home health care. Unless there is a law, code, or ordinance prohibiting or limiting a person's choice, the at-risk adult has the right to make lifestyle choices that others may feel is objectionable or even dangerous, such as:

- Refusing medical treatment
- Refusing to take necessary medication
- Choosing to abuse alcohol or drugs
- Living in a dirty or cluttered home
- Continuing to live with a perpetrator
- Keeping a large number of pets
- Engaging in other behaviors that may not be safe (i.e., gambling, having multiple intimate partners)

Regardless of mental capacity, most states mandate health care professionals to report suspected or confirmed maltreatment; still, several states are not legally mandated to report and each state may have a different definition or criteria to identify an "at-risk adult." Health care professionals, including psychologists, need to be familiar with state laws guiding the reporting of mistreatment of older adults in their jurisdiction. A list of national resources for information about elder rights and protections can be found in Table 14.2. Familiarization can help psychologists identify a course of action to either protect or prevent abuse of an at-risk older adult (Bush et al., 2017).

and Protections		
Organization	Website	
Administration on Aging	https://www.acl.gov/about -acl/administration-aging	
American Bar Association Commission on Law & Aging	https://www.americanbar.org/ aba.html	
Gerontological Society of America	www.geron.org	
National Adult Protective Services Network	www.apsnetwork.org	
National Center on Elder Abuse	www.ncea.acl.gov	
National Clearinghouse on Abuse in Later Life	www.ncall.us	
National Committee for the Prevention of Elder Abuse	www.preventelderabuse.org	
Psychologists in Long-Term Care (PLTC)	www.pltcweb.org/index.php	

Table 14.2 Resources for Information About Elder Rights and Protections

RESPECTING CULTURAL DIFFERENCES IN CASES OF ELDER ABUSE

Cultural competence and respect for normative practices among all individuals from diverse backgrounds must be the first guiding principle when caring for older adults and when determining whether elder abuse has occurred. Introspection of any biases or awareness of any lack of knowledge of the relevant culture might be a helpful start in determining the course of action necessary to be a competent clinician. Culture and diversity in this context are not limited to understanding different racial and ethnic practices, but includes knowledge of how different groups embrace the meaning of being disabled, homosexual, or bisexual, gender role expectations, loyalty to family, caregiving, financial dependence, intergenerational communication, and perception of age or illness-related burden. This is obviously not an exhaustive list as every micro- and macrosystem of function brings with it different complexities as well as creativity for problem resolution and life celebrations. As in all clinical work, there are several ways to ensure that a reasonable amount of consideration has been made not to cause any additional harm to the older adult identified for protection. Any underestimation of the needs and efforts to clarify the situation from which elder abuse is suspected could be detrimental. Not only could it hurt the wellbeing of the identified older adult, it could also likely place a tremendous amount of emotional burden on that individual due to feelings of shame for being the cause of the family's additional hardship as imposed during investigations (Lee & Eaton, 2009).

It is prudent for clinicians to refer to the APA Ethics Code (2010) that clearly states under the general principles that psychologists "do no harm" (Principle A: Beneficence and Nonmaleficence), "exercise reasonable judgment and take precautions to ensure that their potential biases, the boundaries of their competence . . . do not lead to . . . unjust practices" (Principle D: Justice), and "respect the dignity and worth of all people, and the rights of individuals to . . . self-determination . . . are aware of and respect culture, individual and role differences . . ." (Principle E: Respect for People's Right and Dignity). Unless the older adult is determined through assessment to be clinically or legally incapacitated and therefore unable to self-protect or self-determine the desirable treatment from others, professionals who are often mandated to report elder abuse (psychologists and others) are encouraged to carefully navigate the terrain of varied and even conflicting information before taking any action.

Harbison and colleagues (2005) highlighted the tendency of elder abuse legislators to ignore the wishes of older adults, specifically those living in rural areas, by reporting elder abuse that would consequently subject the older adult to increased emotional turmoil such as shame and also fear of being further abused. They pointed to the possibility of achieving a more successful intervention outcome by attending to the specific culture of older adults living in rural settings. There are implications for professionals to more thoughtfully and collaboratively work with older adult victims. In so doing, mandated reporters and legislators could better help balance older adults' rights and wishes with what seems to be in the best interest of the victims. Other research involving different ethnic groups and individuals from diverse cultures also lends support to the need for an in-depth understanding of the context from which such important decisions pertaining to claims of elder abuse are usually made. Consider the following examples:

1. Financial/material exploitation:

An 85-year-old woman with end-stage cancer and fluctuating mental status lives at her oldest daughter's home. Although physically frail, she is still able to ambulate with some assistance. Her son visited and took her to the bank to transfer a substantial amount of money into his account because he recently lost his job. Her oldest daughter filed a report of elder abuse because her mother did not have enough funds needed for her medical treatment.

Cultural/ethical query: How would knowing the cultural background make a difference when understanding whether or not elder abuse had occurred?

2. Emotional abuse:

A 94-year-old man lives in his matrimonial home with his youngest son. Most friends and family are aware that he has an enmeshed relationship with his son. This enmeshment has been known to involve occasional arguments followed by reconciliations and mutual overprotection from the criticism of others. Alcohol abuse within the family has been a norm and altercations are frequent among male siblings and relatives after an evening of binge drinking together at the older adult's home. Such behaviors affect the older adult emotionally as his son yells vulgarities when intoxicated and then apologizes the next morning when sober. The older adult, when interviewed, denied any evidence of abuse despite noticeable bruises on his forearm.

Cultural/ethical query: Are there any specific ethnic groups that might tolerate such a pattern of coexistence whereby a report of elder abuse would bring more hardship to the older adult?

Although elder abuse is largely defined to include seven different types, mainly physical abuse, sexual abuse, emotional abuse, financial/material exploitation, neglect, abandonment, and self-neglect (Hall et al., 2016), the definition of "abuse" could be different for older adults in minority ethnic groups, especially when the concept could only be translated to mean "violence" or when disrespect could be considered "a major form of abuse" such as within the Chinese community (Bowes, Avan, & Macintosh, 2012). Lee and colleagues (2012) argue that the existing definition of financial abuse may be inaccurate because it is based on perceptions of supposedly highly educated professionals and policy makers, but not from older adults. In their study, for example, they found that Korean immigrants defined financial abuse as adult children either taking (stealing) possessions and/or assets from their parents or failing to financially support their parents.

Similarly, in an attempt to define elder abuse in culturally relevant terms, Parra-Cardona and colleagues (2007) sought to identify the "ecological framework" that could be at play for sustaining elder abuse and neglect among Latino older adults. They noted that acculturation status and differences in cultural beliefs and identity between the family caregiver and the older adult care recipient may be viewed as important factors for understanding elder abuse in Latino families. For example, the younger generation of Latinos are perceived to value traditional cultures less than their immigrant parents. This might explain their lack of awareness and also their likely different definition of elder abuse. Similarly, the family's financial standing and beliefs about aging should be considered when determining whether elder abuse or neglect has occurred because multiple ecological stressors could have been responsible for the outcome. Consequently, attending to these factors might help the development of interventions that would avoid placing blame solely on the abuser.

There remain many controversies regarding the meaning and definition of elder abuse and it is therefore not surprising that there is a lack of consensus and even confusion among health care professionals. Elder abuse is further made difficult to define due to the lack of training in geropsychology for psychologists, which would otherwise allow a greater appreciation of diversity issues in the competent care of older adults (Scheiderer, 2012). Koocher and Kieth-Spiegel (2016) proposed a six-item self-assessment as part of training in diversity to reflect upon one's biases and cultural competence. One item relevant for decision making in reporting elder abuse involves the question: "As I seek to protect myself, what are my ethical obligations when I notice a cultural incongruity in values between my professional association, my employer, legal obligations, and the people I serve?" (p. 132).

A review of the prevalence and risk factors for elder abuse in Asia (China, India, Singapore, Japan, and Korea) emphasized the need for sensitivity to the different normative definitions of elder abuse. They stressed the importance of establishing rapport with suspected older adult victims due to their unwillingness to share their experience of abuse that they likely perceive to be shameful or determine as a family affair to be kept private (Yan, Chan, & Tiwari, 2015). Hence, elder abuse might not simply be a matter of whether reporting is warranted, but rather, a term to be sensitively considered in the context of culture, diversity, and socioeconomic status. It is important to be mindful of different perceptions of older adults from minority groups and their sociocultural barriers to seeking help, such as lack of dominant language proficiency and isolation (Zannettino, Bagshaw, Wendt, & Adams, 2014).

ETHICS IN RESEARCH

Adhering to ethical standards when recruiting prospective research participants should be the standard practice of every researcher. Specifically, researchers are responsible for ensuring that best efforts are made to help participants understand as fully as possible the information depicted on informed consent forms. Older adults and individuals with lower education can be more vulnerable to inadequately understanding informed consent (Sugarman, McCrory, & Hubal, 1998). With the projected exponential increase in the geriatric population in the coming decades (see Chapter 1 and Ortman, Velkoff, & Hogan, 2014), it is expected that research on aging using older adults as participants will also increase accordingly. There have been concerns and fears over the unethical inclusion of older adults with cognitive impairment in research, but the exclusion could deprive them the opportunity to benefit from research where their well-being and quality of life could otherwise be improved.

These considerations bring rise to an important question of participants' varying levels of cognitive functioning. How might researchers ethically obtain consent from older adults who may present with impaired cognition without violating the ethical code to protect individuals from any potential harm as a research participant? As mentioned earlier, education level could also impact the understanding of informed consent information, but if cognition is also impaired, the challenge is much greater to warrant additional attention. One other important question is: Should the participants or the authorized representative consent to research when prospective participants are cognitively impaired? Several studies have attempted to provide guidance, which are summarized as follows.

Capacity to consent or decisions about who should provide consent on behalf of the older adult participant undoubtedly requires careful consideration. Specifically, it has been noted that ethical dilemmas begin at the level of capacity evaluation where the full range of contextual biopsychosocial information, including medical conditions, family relation, social function, and financial situation, need to be considered for accuracy of capacity judgment (Jimenez, Esplin, & Hernandez, 2015). Feliciano and colleagues (2011) explained how the capacity to consent for research participation is dependent on the older adult's cognitive ability and the study's complexity. They discussed the "principle of proportionality of the capacity to consent" wherein the amount of risk, time, and benefit involved in the study would determine how stringent the "standards of capacity to consent" should be (p. 477). That is, if a study involves more risk and time, the greater the importance to show adequate capacity to consent, whereas, if benefits are involved, the lesser the need to prove adequate capacity. In the same light, Bravo and colleagues (2003) found in their survey of older adults, informal caregivers, researchers, and institutional review board members, a unanimous opinion that for older adults with dementia, the need for a legal guardian's consent to participate in research becomes greater as the risks of the study increase. Despite the consensus, it was highlighted that many cognitively impaired older adults do not have a legal guardian. In a survey of older adults, informal caregivers, physicians, researchers, and research ethics board members, level of comfort with using proxy consent increased when risks to participants with dementia was lower (Dubois et al., 2011).

Some brief screening tools can assist a researcher in evaluating capacity to consent to research participation. Resnick and colleagues (2007) validated a five-item Evaluation to Sign Consent (ESC) measure in a randomized controlled trial using mainly European American nursing home residents aged 79 to 93 with a mean Mini Mental Status Examination (MMSE) score of 18. They found 63% of residents did not pass the ESC. As a comparison, a similar four-item capacity-to-consent screen was also validated for older adults in Korea using culturally and educationally appropriate questions (Lee, 2010). The majority (72%) had either no education or completed only elementary school. Lee demonstrated sensitivity to demographic backgrounds of participants by asking, "If you don't want to, do you have to be in the study?" versus Resnick and colleagues' directive, "Explain what he or she would do if he or she was experiencing distress or discomfort," which was more suitable for the study's predominantly White participants. Such attention to language when designing capacity measures is essential for protecting the rights and interests of research participants. While thoughtful planning is required when working with older adults with cognitive impairment, Gatz (2006) reminded researchers of the complexities of evaluating older adults' abilities to consent to participate in research or medical treatment. Gatz cautioned against the assumption that normal cognition equates to sound decision-making capacity because of the potential for cognitive changes in the older population and the existence of "a range of statuses between cognitive competence and decisional incapacity" (p. 468). Hence, it is important that researchers carefully weigh the risks and benefits of their study as well as attend to the nuances of capacity to consent that might not depend only on cognitive status at the time of recruitment. Researchers are also encouraged to observe legislative guidelines for research in their practice jurisdiction to ensure that prospective participants with impaired decision-making capacity are protected accordingly, such as whether proxy consent is absolutely required for research regardless of risks (Bravo, Duguet, Dubois, Delpierre, & Vellas, 2008).

CONCLUSION

As the U.S. older adult population grows, a number of ethical issues—only a few of which were discussed in this chapter—are increasingly coming into view for clinicians and health care providers. The micro- and macrosystems in which older adults live and thrive require a level of cultural sensitivity, an understanding of aging processes, and knowledge about professional ethics and legal standards involved in decision making. We have discussed the complexities of elder abuse and victimization, which involves complex judgments about capacity and potential surrogate decision making for an older adult. At the heart of ethical principles and guidelines is the challenge between autonomy and protection. We have also documented some of the real-world dilemmas faced by practitioners and families navigating long-term care placement and information sharing that occurs between providers, older adults, and the family. And finally, we addressed the ethical standards required for older adults to consent to participate in research—an important component to furthering the science and thus, expanding our knowledge and understanding of aging adults and families, and the communities in which we flourish together.

DISCUSSION QUESTIONS

- **1.** Define the following terms and provide an example of when it would be useful to have each document: advance directive, power of attorney, health care surrogate.
- **2.** Describe the difference between clinical capacity and legal capacity (competence), and discuss instruments used to assess capacity in older adults.
- **3.** Define the domains of capacity discussed in the chapter and provide examples of ethical challenges that may be encountered in each domain.
- **4.** Describe the concern when working with older adults about balancing the principles of autonomy and beneficence.

- **5.** Discuss the prevalence of elder abuse and the cultural issues that are important to consider when determining the severity of elder abuse.
- **6.** In the context of research with older adults, describe proxy consent and the ethical concerns about it.

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