Senior Services Delivery: Ethical Issues and Responses

Exemplars in Practice Series

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Editors

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ETHICAL ISSUES AND RESPONSES

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The graying of our population is contributing to unprecedented attention to the care needs of seniors and the mechanisms to deliver necessary community-based services. In 2030, when all of the baby boomers will be 65 and older, nearly one in five U.S. residents is expected to be 65 and older. This age group is projected to increase to 88.5 million in 2050, more than doubling the number in 2008 (38.7 million). Similarly, the 85 and older population is expected to more than triple, from 5.4 million to 19 million between 2008 and 2050 (U.S. Census Bureau, 2008). The care issues are significant for providers from the standpoint of their unique age-driven nature, expansive overall service demand and challenges to ethically-sensitive professional practice.

This edition of the Exemplars in Practice Series focuses on selected aspects of senior service delivery particularly as such efforts pose ethical dilemmas to involved care providers. Our six authors present and discuss a myriad of pertinent issues associated with intervention to the elderly, their families and other involved parties. Reamer articulates a particularly well-constructed and compelling overview of senior service delivery issues, noting the myriad of contemporary ethical challenges facing practitioners and clients. While emphasizing that the expansion of community-based care will require an increased social work labor force in the next decade, Kadushin identifies limited community resources, funding restrictions, service delivery complications and challenges related to management of chronic illnesses as factors contributing to the primacy of ethical dilemmas for community-based practitioners.

Kitchen examines the emerging trend of second, third and fourth generation caregivers parenting children and the profound challenges to grandparents and family systems provoked by biological parents’ inability to parent. She cites the most common cause of this phenomenon as the crack cocaine epidemic and the growing numbers of parents who are seriously ill, in prison or deceased. Regardless of cause, grandparents assuming primary caregiving duties are heralded as the silent saviors of today’s families, but their issues pose fundamental ethical dilemmas.

Thompson expresses concern about increasing numbers of older adults with mental illnesses, noting that seniors experiencing schizophrenia are projected to double over the next twenty-five years and that as high as 80% of long-term nursing home admissions manifest some form of mental disorder. Recognizing that participatory research approaches employing seniors with serious mental illnesses have both successfully impacted the lives of those employed and strengthened services, Thompson goes on to highlight distinct ethical issues that must be acknowledged and addressed when working with people experiencing a serious mental illness. Because motor vehicle injuries are the leading cause of injury-related deaths for 65-74 year olds, Longo promotes the use of social work in a holistic framework for driving cessation decisions. In the context of a hospital-based memory disorder clinic, Shipman underscores the ethical dilemmas that develop when multiples of professionals with differing perspectives and agendas attempt to engage in team decision-making on behalf of clients.

Readers will find our authors propose thought-provoking ideas that challenge our perceptions and practice, with the outcome being one of advancing ethical service to seniors.

William J. Spitzer, Ph.D./DCSW  Karen Neuman, Ph.D.
EDITORS’ NOTE

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**Senior Service Delivery: Ethical Issues and Responses**

**Overall Description:**

This text offers readers a detailed discussion of ethical issues associated with the delivery of services to seniors. It distinguishes concerns of seniors, their families and caregivers, while examining individual professional and community program responses to identified needs.

**Learning Objectives:**

Upon completion of this publication, readers will be able to:

1. Identify and describe the ethical challenges associated with managing risk in social work delivery of senior services.

2. Recognize the ethical dilemmas faced by social workers delivering geriatric care in the community.

3. Understand the concerns and problems grandparents experience when providing caregiving the second time around.

4. Identify significant ethical considerations arising from working with older people living with serious mental illnesses.

5. Describe the concerns faced by social workers when dealing with the vehicle driving capacities of older adults.

6. Distinguish ethical issues prevalent in delivering services in a memory disorder clinic.
Risk Management in Elder Care: Ethical Challenges

Frederic G. Reamer, PhD.

In recent years social workers’ understanding of challenging issues involved in the delivery of social services to seniors has burgeoned. In part this is a result of the widely documented demographic surge in the population of elders and the predictable, dramatic increase in both demand for services among elders and career opportunities for social workers. The seriousness with which the social work profession is expanding its knowledge of elder care is reflected in concerted efforts to educate practitioners about the unique challenges posed by this client population. A key example is the ambitious project sponsored by the Council on Social Work Education Gero-Ed Center (National Center for Gerontological Social Work Education), which is designed to strengthen gerontology-related social work education and competencies throughout the U.S.

Most of the educational and training efforts have focused on strengthening social workers’ clinical skills in their work with elders and practitioners’ understanding of compelling issues related to aging, cultural and social diversity, mental health, family dynamics, spirituality, administration, and policy. Less attention has been paid to a wide range of ethics-related risk-management issues that are germane in elder care. Here are several examples:

Marla N. is an 82-year-old woman who receives home-based services from a local agency. Mrs. N., a widow, struggles with a number of health issues, including signs of early dementia. Mrs. N.’s social worker, Suzanne E., has provided services to Mrs. N. for nearly two years. The two have become quite close; at times Mrs. N. refers to Suzanne as her “pretend daughter.” One day Mrs. N. told Suzanne that she had some gifts for her. Mrs. N. then gave Suzanne two pieces of fine jewelry (a necklace and ring), an expensive sculpture, her theater subscription, and an antique lamp that Suzanne had often admired. Mrs. N. told Suzanne, “I really don’t need these things anymore and I know you’ll love them. I really want you to have them.” Suzanne initially told Mrs. N. that she should not accept the gifts, but Mrs. N. persisted. Eventually Suzanne accepted the gifts. About a month later Mrs. N.’s estranged daughter discovered that her mother had given Suzanne the gifts. The daughter was enraged; she contacted the state social work licensing board and filed a formal complaint against Suzanne.

Edgar R. was a 94-year-old man who was admitted to a nursing home after his recent hospitalization for pneumonia. About one month after his nursing home admission, Mr. R. developed signs of congestive heart failure. The nursing home’s social worker, Darlene M., looked through Mr. R.’s chart to review his advance directive and durable power of attorney for healthcare. Darlene was confused by apparent inconsistencies in the record; apparently Mr. R. had checked options
about his preferences for life-sustaining treatment options (including his wishes concerning artificial ventilation and artificially administered fluids and nutrition) that were contradictory. Shortly thereafter Mr. R. went into a coma. His sole surviving child insisted that the healthcare staff do everything possible to save Mr. R.’s life. However, Darlene felt strongly, based on her conversations with Mr. R. and some of the information on his advance directive, that he did not want life-sustaining treatment.

Alma B. was a 79-year-old woman who lived alone in small, ramshackle home. She received home-health services after her discharge from a hospital following hip surgery. Luis D., the home-care agency’s social worker, visited Miss B. to speak with her about the services he would be able to offer. Miss B. was reluctant to let Luis into her home. Eventually she opened the door. Luis was startled to see the home’s condition. Luis could barely enter the home; he was surrounded by floor-to-ceiling piles of newspapers, magazines, blankets, pillows, clothing, rags, and other objects. Several cats roamed among the piles; the home reeked of cat urine.

Luis D. was concerned about Miss B.’s safety. He conducted a comprehensive assessment and shared his impressions with his clinical supervisor and the agency’s consulting psychiatrist. The agency staffers agreed that Miss B showed clear signs of extreme hoarding behavior and obsessive compulsive disorder. Unfortunately, Miss B. refused Luis’ and the other staffers’ offers of assistance: “This is how I live,” she said. “Just leave me be.” Luis and the agency staffers discussed the risks facing Miss B. but disagreed among themselves with respect to her right to live as she pleases and the agency’s obligation to take steps to protect her.

Clearly, social workers’ principal duty is to protect clients. In some instances, social workers and others may disagree about the most appropriate course of action to protect clients. To what extent should clients’ autonomy and right to self-determination be respected? Are there times when social workers should interfere with clients’ rights in order to protect them from self-harm? Under what circumstances is it appropriate for social workers to disclose confidential information about clients, without their permission, to protect themselves or third parties? Is it permissible for social workers to accept gifts from clients? If so, under what circumstances?

Competent social workers need to know a great deal about the nature of ethical dilemmas in work with elders and ethical decision-making protocols designed to manage risk. In addition to protecting clients – which is always social workers’ principal duty – practitioners should also be aware of risks they incur when they make professional judgments (Healy, 1998; Holstein & Mitzen, 2001; Johnson, 1999; Moody, 1996). In order to protect clients and related third parties, and minimize risk to themselves and their
employers, social workers need to be informed about prevailing standards to prevent ethics complaints and ethics-related lawsuits. Ethics complaints – filed with social work licensing boards or with professional organizations such as the National Association of Social Workers (NASW) – typically allege that social workers violated widely accepted ethical standards in their relationships with clients, colleagues, employers, or other parties. Ethics-related lawsuits typically claim that social workers were negligent, in the strict legal sense, by virtue of their mishandling of some phenomenon, such as the proper management of confidential information or informed consent, maintenance of professional boundaries, use of controversial treatment techniques, conflicts of interest, undue influence, or termination of services (Reamer, 2003, 2006a, 2006b).

The Concept of Risk Management

Social workers expose themselves to risk when they practice in a manner that is inconsistent with prevailing professional standards (Houston-Vega, Nuehring, & Daguyo, 1997; Reamer, 2003; Strom-Gottfried, 2000, 2003). Some ethics complaints arise out of social workers’ mistakes and oversights. Examples include social workers who inadvertently disclose confidential information in a hallway conversation in a nursing home or fail to protect confidential information transmitted via a hospital fax machine or the Internet. Other ethics complaints and lawsuits arise from social workers’ deliberate ethical decisions – for example, when social workers who serve elders disclose confidential information without clients’ consent to protective services officials, or override a hoarding client’s expressed wish to be left alone and right to self-determination. In addition, some complaints and lawsuits are the result of practitioners’ ethical misconduct, for example, when a social worker exploits her or his relationship with a client for the social worker’s own financial or other benefit.

Social workers can be held accountable for negligence and ethical violations in several ways. In addition to filing lawsuits, parties can file ethics complaints with the NASW or with state licensing and regulatory boards. In some instances, social workers are also subjected to review by other professional organizations to which they belong, such as the American Board of Examiners in Clinical Social Work and the Clinical Social Work Association. In exceptional circumstances, criminal charges may be filed against social workers (for example, based on allegations of embezzlement or misappropriation of an elderly client’s funds or fraudulent billing of an insurance company or state funding agency).

Ethics complaints filed against NASW members are processed using a peer review model that includes NASW members and, initially, the National Ethics Committee. If a request for professional review is accepted by the National Ethics Committee, a NASW Chapter Ethics Committee (or the National Ethics Committee in special circumstances) conducts a hearing during which the complainant (the person filing the complaint), the respondent (the person against whom the complaint is filed), and witnesses have an opportunity to testify. After hearing all parties and discussing the testimony, the committee presents a report to elected chapter officers that summarizes its
findings and presents its recommendations. Recommendations may include sanctions or various forms of corrective action, such as suspension from NASW, mandated supervision or consultation, censure in the form of a letter, or instructions to send the complainant a letter of apology. In some cases, the sanction may be publicized through local and national NASW newsletters or newspapers. NASW also offers mediation in some instances in an effort to avoid formal adjudication, particularly involving matters that do not include allegations of extreme misconduct. If complainants and respondents agree to mediate the dispute, NASW will facilitate the mediation.

State legislatures also empower social work licensing boards to process ethics complaints filed against social workers who hold a license. Ordinarily these boards appoint a panel of colleagues to review the complaint and, when warranted, conduct a formal investigation and hearing (some state boards include public members in addition to professional colleagues).

Negligence claims or lawsuits filed against social workers typically allege that social workers engaged in malpractice in that the practitioners failed to adhere to specific standards of care. The standard of care is based on what ordinary, reasonable, and prudent practitioners with the same or similar training would have done under the same or similar circumstances (Madden, 1998; Reamer, 2003; Woody, 1996). Departures from the profession’s standards of care may result from a social worker’s acts of commission or acts of omission. Acts of commission can occur as a result of misfeasance (the commission of a proper act in a wrongful or injurious manner or the improper performance of an act that might have been performed lawfully) or malfeasance (the commission of a wrongful or unlawful act). For example, a social worker who discloses confidential information about an elder inappropriately may be liable for misfeasance. A social worker who exploits an elderly client financially for personal benefit may be liable for malfeasance. An act of omission, or nonfeasance, occurs when a social worker fails to perform certain duties that ought to have been performed. For example, a social worker who fails to obtain an elderly client’s informed consent before releasing sensitive confidential information may be liable for nonfeasance.

Lawsuits and liability claims that allege malpractice are civil suits, in contrast to criminal proceedings. Ordinarily, civil suits are based on tort or contract law, with plaintiffs (the party bringing the lawsuit) seeking some sort of compensation for injuries they claim to have incurred as a result of the practitioner’s negligence. These injuries may be economic (for example, the daughter of an elderly client claims that she was deprived of property that the social worker improperly accepted from her mother); physical (for example, a client who claims that a social worker mistreated him physically); or emotional (for example, depression suffered by a client who did not receive competent care from a practitioner).

As in criminal trials, defendants in civil lawsuits are presumed to be innocent until proved otherwise. In ordinary civil suits, defendants will be found liable for their actions based on the legal standard of preponderance of the evidence, as opposed to the stricter standard of proof beyond a reasonable doubt used in criminal trials. In some civil cases –
for example, those involving contract disputes between a home health agency and a client or the client’s family – the court may expect clear and convincing evidence, a standard of proof that is greater than preponderance of the evidence but less than proof beyond a reasonable doubt.

In general, malpractice occurs when evidence exists that (1) at the time of the alleged malpractice a legal duty existed between the social worker and the client; (2) the social worker was derelict in that duty or breached the duty, either by commission (misfeasance or malfeasance) or omission (nonfeasance); (3) the client suffered some harm or injury; and (4) the harm or injury was directly and proximately caused by the social worker’s dereliction or breach of duty.

In some cases, prevailing standards of care are relatively easy to establish, through citations of the profession’s literature, expert testimony, statutory or regulatory language, or relevant code of ethics standards. Examples include standards concerning sexual relationships with current clients, disclosing confidential information to protect elders who may have been abused or neglected, fraudulent billing, or falsified clinical records. In other cases, however, social workers disagree about standards of care (Austin, Moline, & Williams, 1990; Haas & Malouf, 2005). This may occur in cases involving controversial treatment methods or ambiguous clinical or administrative circumstances (Reamer, 2006a). For example, social workers and others involved in the case of Alma B. (above) may disagree about her right to live in her home given the risky conditions arising from her extreme hoarding behaviors and other mental health issues. Social workers who provide services to elders encounter many situations where thoughtful, reasonable, and principled colleagues disagree about the limits of clients’ right to self-determination, to privacy and confidentiality, to refuse treatment, and so on.

**Key Risks in Social Work**

Social workers’ prevention efforts involving the delivery of services to seniors should focus on a number of risk areas (Reamer, 2001b, 2006b). These include:

*Client rights.* Especially since the 1960s, social workers have developed a keen understanding of a wide range of clients’ rights, many of which were established by legislation or court ruling. These include rights related to confidentiality and privacy, release of information, informed consent, access to services, use of the least restrictive alternative, refusal of treatment, options for alternative services, access to records, termination of services, and grievance procedures.

*Confidentiality, privileged communication, and privacy.* Social workers must understand the nature of clients’ right to confidentiality and exceptions to these rights. More specifically, social workers should have sound policies and procedures in place related to solicitation of private information from elders; disclosure of confidential information to protect clients from self-harm and to protect third parties from harm inflicted by clients; release of confidential information pertaining to alcohol and
substance abuse assessment or treatment; disclosure of information about deceased clients; release of information to guardians or conservators of elderly clients; sharing of confidential information among elders’ family members; disclosure of confidential information to media representatives, law enforcement officials, elder protective service agencies, other social service organizations, and collection agencies; protection of confidential written and electronic records, information transmitted to other parties through the use of computers, electronic mail, fax machines, telephones, and other electronic technology; transfer or disposal of clients’ records; protection of client confidentiality in the event of a social worker’s death, disability, or employment termination; precautions to prevent social workers’ discussion of confidential information in public or semipublic areas such as hospital or nursing home hallways, waiting rooms, elevators, and restaurants; disclosure of confidential information to third-party payers; disclosure of confidential information to consultants; disclosure of confidential information for teaching or training purposes; and protection of confidential and privileged information during legal proceedings (such as probate, guardianship, and conservatorship proceedings and negligence lawsuits).

To protect clients and minimize risk, social workers should discuss with elders and other interested parties (such as guardians) the nature of confidentiality and limitations of clients’ right to confidentiality (Dickson, 1998; Polowy & Gorenberg, 1997). Depending on the setting, these topics can include:

- the importance of confidentiality in the social worker-client relationship (a brief statement of why the social worker treats the subject of confidentiality so seriously);
- laws, ethical standards, and regulations pertaining to confidentiality (relevant federal, state, and local laws and regulations;
- ethical standards in social work); measures the social worker will take to protect clients’ confidentiality (storing records in a secure location, limiting colleagues’ and outside parties’ access to records);
- circumstances in which the social worker would be obligated to disclose confidential information (for example, to comply with mandatory reporting laws related to elder abuse or neglect, to comply with a court order, or to protect a third party from harm or the client from self-injury);
- procedures that will be used to obtain clients’ informed consent for the release of confidential information and any exceptions to this (a summary of the purpose and importance of and the steps involved in informed consent);
- the procedures for sharing information with colleagues for consultation, supervision, and coordination of services (a summary of the roles of consultation and supervision, and coordination of services and why confidential information might be shared);
- access that third-party payers (insurers or healthcare officials) or employers will have to clients’ records (social workers’ policy for sharing information with managed care organizations, insurance companies, insurance company representatives, utilization review personnel, supervisors, and regulatory agencies);
• disclosure of confidential information by telephone, computer, fax machine, email, and the Internet; access to agency facilities and clients by outside parties (for example, people who come to the agency to attend meetings or participate in a tour); and audiotaping and videotaping of clients. Social workers should be aware that different ethnic and cultural groups view the concepts of privacy and confidentiality differently; some people are more likely than others to place a high premium on privacy and confidentiality and to insist on strong protections regarding disclosure (Cortese, 1999).

Informed consent. Informed consent is required in a variety of circumstances when working with elders, including release of confidential information, program admission, service delivery and treatment, videotaping, and audiotaping (Berg, et al., 2001). Although various courts, state legislatures, and agencies have somewhat different interpretations and applications of informed consent standards, there is considerable agreement about the key elements that social workers and agencies should incorporate into consent procedures: elders should be given specific details about the purposes of the consent, a verbal explanation, information about their rights to refuse consent and withdraw consent, information about alternative treatment options, and an opportunity to ask questions about the consent process. Social workers who provide elder care need to be assured that clients are competent to provide informed consent (Moody, 1992). Social workers should be aware that different ethnic and cultural groups view the concept of informed consent differently; some people are more likely to defer to professional authority while others may be more insistent on client’s involvement in treatment and other services-related decisions (Cortese, 1999).

Service delivery. Social workers must provide services to elders and represent themselves as competent only within the boundaries of their education, training, license, certification, consultation received, supervised experience, or other relevant professional experience. They should provide services in substantive areas and use practice approaches and techniques that are new to them only after engaging in appropriate study, training, consultation, and supervision from people who are competent in those practice approaches, interventions, and techniques. Social workers who use practice approaches and interventions for which there are no generally recognized standards should obtain appropriate education, training, consultation, and supervision.

Boundary issues, dual relationships, and conflicts of interest. Social workers should establish clear policies, practices, and procedures to ensure proper boundaries in their relationships with current and former clients; relationships with clients’ relatives or acquaintances; relationships with supervisees, trainees, students, and colleagues; physical contact with clients; friendships with current and former clients; encounters with clients in public settings; attending clients’ social, religious, or lifecycle events; gifts to and from clients; performing favors for clients; the delivery of services in clients’ homes; financial conflicts of interest; delivery of services to two or more people who have a relationship with each other (such as elders’ family members); bartering with clients for goods and services; managing relationships in small or rural communities; and self-disclosure to clients (Golden & Sonneborn, 2001; Reamer, 2001a). Social workers who provide
services to elders in their homes face unique challenges because of the informal setting, frequent lack of privacy, and ambiguous boundaries.

**Documentation.** Careful documentation and comprehensive records are necessary to assess elders’ circumstances; plan and deliver services appropriately; facilitate supervision; provide proper accountability to clients, other service providers, funding agencies, insurers, utilization review staff, regulatory agencies, and the courts; evaluate services provided; and ensure continuity in the delivery of future services (Kagle and Kopels, 2008; Reamer, 2005; Wiger, 2005). Thorough documentation also helps to ensure quality care if an elder’s primary social worker becomes unavailable because of illness, incapacitation, vacation, or employment termination. In addition, thorough documentation can help social workers who are named in ethics complaints or lawsuits (for example, when evidence is needed to demonstrate that a social worker obtained an elder’s informed consent before releasing confidential information, assessed for suicide risk properly, consulted with knowledgeable experts about a client’s clinical issues or a potential conflict of interest, consulted the NASW Code of Ethics in order to make a difficult ethical decision, or referred a client to other service providers when services were terminated).

**Defamation of character.** Social workers should ensure that their written and oral communications about elders, their family members, and others are not defamatory. Libel is the written form of defamation of character; slander is the oral form. Defamation occurs when a social worker says or writes something about a client or another party that is untrue, the social worker knew or should have known that the statement was untrue, and the communication caused some injury to the client or third party (for example, the elder was terminated from a day services program because of noncompliant behavior or an elderly client’s adult child’s reputation was damaged because of a social worker’s allegations that the adult child abused the elder).

**Client records.** Social workers should maintain and store records for the number of years required by state statutes or relevant contracts. Practitioners – for example, geriatric care managers – should make special provisions for proper access to their records in the event of their disability, incapacitation, termination of practice, or death. This may include entering into agreements with colleagues who would be willing to assume responsibility for social workers’ records if they are unavailable for any reason.

**Supervision.** In principle, social workers can be named in ethics complaints and lawsuits alleging ethical breaches or negligence by those under their supervision. Social work supervisors should ensure that they meet with supervisees regularly, address appropriate issues (for example, treatment and intervention plans, case recording, correction of errors in all phases of client contact, dual relationships, protection of third parties), and document the supervision provided.

**Consultation and referral.** Social workers who serve elders should be clear about when consultation with colleagues is appropriate and necessary and the procedures they should use to locate competent consultants. Also, social workers have a responsibility to
refer clients to colleagues when social workers do not have the expertise or time to assist clients in need. Practitioners should know when to refer clients to other professionals and how to locate competent colleagues.

_Fraud_. Social workers should have strict procedures in place to prevent fraud related to, for example, documentation in case records, billing for clinical services provided to elders, and employment applications.

_Termination of services_. Social workers expose themselves to risk when they terminate services improperly – for example, when a social worker leaves a home care or hospice agency suddenly without adequately referring a vulnerable elder to another practitioner – or terminates clinical services to a very vulnerable client who has missed appointments or who has not paid an outstanding bill. Practitioners should develop thorough and comprehensive termination protocols to prevent client abandonment.

_Practitioner impairment, misconduct, and incompetence_. A significant percentage of ethics complaints and negligence claims are filed against social workers who meet the definition of impaired professional (impairment that may be due to factors such as substance abuse, mental illness, extraordinary personal stress, or legal difficulties). Social workers should understand the nature of professional impairment and possible causes, be alert to warning signs, and have procedures in place to prevent, identify, and respond appropriately to impairment in their own lives or colleagues’ lives (Reamer, 1992; Strom-Gottfried, 2000, 2003).

In addition, social workers occasionally encounter colleagues who have engaged in ethical misconduct or are incompetent. Examples include social workers who learn that a colleague is exploiting an elder client financially, stealing an elderly client’s narcotic medication, falsifying travel expense vouchers or client records, or providing services outside his or her areas of expertise.

In some instances, social workers can address these situations satisfactorily by approaching their colleague, raising their concerns, and helping the colleague devise an earnest, constructive, and comprehensive plan to stop the unethical behavior, minimize harm to affected parties, seek appropriate supervision and consultation, and develop any necessary competencies. When these measures fail or are not feasible – perhaps because of the seriousness of the ethical misconduct, impairment, or incompetence – social workers must consider “blowing the whistle” on their colleague. Whistle-blowing entails taking action through appropriate channels – such as notifying administrators, supervisors, professional organizations, and licensing and regulatory bodies – in an effort to address the problem. Before deciding to blow the whistle, social workers should carefully consider the severity of the harm and misconduct involved; the quality of the evidence of wrongdoing (one should avoid blowing the whistle without clear and convincing evidence); the effect of the decision on colleagues and one’s agency; the whistle-blower’s motives (that is, whether the whistle-blowing is motivated primarily by a wish for revenge); and the viability of alternative, intermediate courses of action (whether other, less drastic means might address the problem). Social work
administrators need to formulate and enforce agency policies and procedures that support and protect staffers who disclose impairment, misconduct, and incompetence conscientiously and in good faith.

Management practices. Periodically, social work administrators should assess the appropriateness or adequacy of the agency’s risk-management guidelines and ethical standards; ethical decision-making protocols (for example, staffers’ use of supervision and agency-based ethics committees); staff training on risk management; government licenses; the agency’s papers of incorporation and bylaws; the state licenses and current registrations of all professional staff; protocols for emergency action; insurance policies; staff evaluation procedures; and financial management practices (Chase, 2008; Fireman, Dornberg-Lee, & Moss, 2001; Kurzman, 1995).

Implementing a Comprehensive Risk Management Strategy

Social workers who serve elders can prevent ethics complaints and ethics-related lawsuits by conducting a comprehensive ethics audit (Reamer, 2001b). An ethics audit entails thorough examination of major risks associated with one’s practice setting (whether independent or agency-based practice). The audit involves several steps designed to identify ethics-related risks and minimize harm to clients, social workers, and social service agencies: (1) appoint a committee or task force of concerned and informed staff or colleagues; (2) gather the information necessary to assess the level of risk associated with each ethics-related phenomenon (i.e., clients’ rights; confidentiality and privacy; informed consent; service delivery; boundary issues and conflicts of interest; documentation; defamation of character; client records; supervision; staff development and training; consultation; client referral; fraud; termination of services; practitioner impairment, misconduct, or incompetence; management practices) from sources such as agency documents, data gathered from interviews with agency staff, and national accreditation standards; (3) review all available information; (4) determine whether there is no risk, minimal risk, moderate risk, or high risk for each risk area; and (5) prepare an action plan to address each risk area that warrants attention, paying particular attention to the steps required to reduce risk, the resources required, the personnel who will oversee implementation of the action plan, the timetable for completion of the action plan, the indicators of progress toward reducing risk, and plans to monitor implementation of the action plan.

In recent years social workers have learned a great deal about ethical challenges in elder care and paid increased attention to the risk of lawsuits and ethics complaints filed against practitioners and agencies. To minimize these risks, and especially to protect clients, social workers need to understand the nature of professional malpractice and negligence. They also need to be familiar with major risk areas and practical steps they can take to prevent complaints.
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REFERENCES


Ethical Dilemmas in Geriatric Community-Based Care

Goldie Kadushin, Ph.D.

Introduction

Several recent trends have contributed to the transfer of the locus of health care delivery from the acute care setting to community-based care. One factor is the emergence of acute illness with chronic disease as the nation’s leading health care problem. Chronic illness among older adults is long-term, uncertain and requires custodial care that can be provided in the community. A second factor is the concern of policy-makers over rising health care costs, and associated efforts at cost control. This has taken the form of limiting access to and consumption of acute care for Medicare beneficiaries through the implementation of managed care systems that rely on capitated payment to restrict costs. Other changes include the development of technology for procedures that have been transferred out of the hospital to into the community (Egan & Kadushin 2007; Kadushin & Egan, 2008).

The expansion of community-based care will require an increased social work labor force in the next decade, particularly social workers with specialized training in gerontology (Gonyea, Hudson & Curley, 2007; Stone, 2008). However, community-based-care also confronts workers with distinctive ethical problems. Limited community resources, restrictions on the type and amount of care funded, challenges related to chronic and acute illnesses, and third party reimbursement sources are factors that contribute to the primacy of ethical dilemmas for in community-based practitioners (Callopy, Dubler & Zuckerman, 1990; Egan & Kadushin, 1999). An ethical dilemma can be defined as a situation in which the social worker must choose between two competing but contradictory ethical directive or obligations or when every alternative produces undesirable outcomes for one or more individuals (Lowenberg & Dolgoff, & Harrington, 2000).

The emphasis of the chapter is on senior services in community-based care because of the need to provide specialized training and education to this sector of the social work labor force. The most frequently documented ethical dilemmas in the empirical and conceptual social work literature relevant to the delivery of senior care are presented. These include: autonomy vs. beneficence, distributive justice vs. autonomy, and client well being vs. commitment to employer. A final issue discussed here is that of boundary violations. This is not an ethical dilemma but it is an ethical concern for community-based practitioners.
Autonomy vs. Beneficence

Ethical conflicts regarding patient autonomy vs. beneficence are one of the most frequently documented ethical concerns in home care (Egan & Kadushin, 1999; Healy, 1998; Healy, 1999; Healy, 2003; Kadushin & Egan, 2001; Kane & Caplan, 1993). Patient autonomy and self determination are used interchangeably in the literature. A consistent element in both definitions is the element of “control over decision-making” by the client (Healy, 1998). Patient autonomy may present an ethical challenge in community-based care when patients’ decisions potentially place them in unsafe situations. The social workers’ obligation to support patient autonomy is this instance is in conflict with their commitment to protect the welfare of clients or the principle of beneficence, creating an ethical dilemma (Healy, 1998).

The ethical principles of self determination and patient autonomy depend on the clients’ cognitive capacity to make the choice in question (Kane & Caplan, 1993). The evaluation of decision-making capacity is distinguished from the assessment of the client’s global mental competence and mental status. The declaration of a client as mentally competent or incompetent requires a legal decision in court. If a client is found to be incompetent, a guardian or surrogate care providers is delegated to make specific decisions for the client (Levenson, 1990; Tauer, 1993). Decision-making capacity is differentiated from mental status. Mental status refers to psychological and cognitive aspects of mental life (Gallo, Fulmer, Paveza & Reichel, 2003). Cognitive aspects of mental status may refer to functions such as remembering, recalling, and paying attention. Psychological aspects of mental status include psychiatric diagnoses such as anxiety disorders, depression, dementia, Alzheimer’s disease, substance abuse disorders, and schizophrenia and bi-polar disorder.

By contrast, decision-making capacity is concerned with the ability of the individual to make a specific health care decision (Levenson, 1990). Assessment of decision-making capacity is an evaluation of the client’s capacity to understand the facts related to a situation or decision, to rationally consider options and consequence, and to make and communicate a reasoned choice (Tauer, 1993).

Social workers have identified client decision-making capacity as the most significant factor influencing their support of patient self-determination when clients choose to remain in unsafe situations (e.g., clients in abusive relationships or who repeatedly fall or suffer from burns) (Healy, 1998). However, social workers also experience difficulty evaluating decision-making capacity (Healy, 1998; Healy, 1999; Healy 2003). Evaluation of decision-making capacity is influenced by the several considerations. An important issue is separating decisional capacity from executional capacity. Decisional capacity refers to the ability to make a decision; executional capacity refers to the ability to implement the decision through action. A client may not have the ability to implement a decision but may have the capacity to make a decision.
Similarly, a client may need assistance making a decision but may be capable of implementing the decision. Workers should support the self determination or autonomy of both clients with decisional capacity but not executional capacity and clients who need assistance with decisional capacity but can implement their decisions (Callopy, 1988; Naleppa & Reid, 2003). Another consideration is the separation of current performance from the potential for future performance. Clients with reversible or modifiable conditions that influence decisional capacity such as depression or delirium may have the potential capacity for higher decision making capacity after appropriate medical and psychiatric treatment (Levenson, 1990). A final consideration is that not all decisions require the same level of decision-making capacity. A minor decision (e.g., what personal items to take to a nursing home; what to order for lunch) requires a lower level of decision-making capacity than a decision that has wide ranging or serious consequences (e.g., a decision to undergo surgery or a decision to enter a nursing home (Levenson, 1990).

Involvement of clients in decision-making can be evaluated using the following criteria from lowest capacity to highest capacity: the client can provide informed consent, the client can understand the facts of the situation, and repeat them in his/her own words; the client can apply some reasoning ability and their own values and attitudes to make a decision (Levenson, 1990).

Because knowledge of whether a patient’s performance can be improved or reversed is a component of assessing decision-capacity, social workers in community-based care require training to screen clients for treatable cognitive and mental conditions. Social workers who are consistently unsure of their clinical assessments of clients need to advocate for clinical supervision within the agency to help them develop this knowledge (Healy, 2003). For best practice, the establishment of an agency protocol to assess client decision-making capacity that requires a final assessment, incorporating the contributions of a multidisciplinary team is recommended.

However, even if a client is evaluated as having the decisional-capacity to make a specific choice, the duty to the principle of beneficence is given priority over to duty to autonomy if the client’s choice is not voluntary (e.g., the client is a drug addict or is coerced to make a choice by another individual), or if the client is unable or unwilling to address serious threats to personal well-being, such as physical or sexual abuse by others and failure or inability to accept care for basic needs such as essential health care, nutrition, hygiene and warmth. These threats, however, must be presently observable rather than potential future threats to warrant beneficent intervention (Tauer, 1993). A recent concern over the greater possibility of abuse in consumer-directed rather than agency-based care has not been supported by the research (Mathias & Benjamin, 2003).

**Distributive Justice vs. Autonomy**

Clients who received full information about the consequences of a decision, are competent to make this decision and who choose to disregard medical recommendation
raise ethical issues regarding distributive justice vs. autonomy. The ethical principle of distributive justice states that all patients who are accepted by the agency for care, are entitled to appropriate care. Non-compliant patients or patients who refuse care require a larger amount of expenditure of agency resources and time. In some instances it is possible that the care received by these patients deprives other patients of appropriate care. The worker in this situation may need to consult with an ethics committee to make a decision about the future care of the patient (Hogue, 2006).

A related ethical issue arises from the risk management concerns incurred the agency when providers continue to serve non-compliant caregivers and patients. Since it is difficult to differentiate sub-standard care from non-compliance by patients and caregivers, an attorney might make the argument that the agency is liable because it continued to provide services to clients when practitioners knew they were non-compliant (Hogue, 2006). In this situation, the worker is faced with competing duties to uphold their commitment to the employer vs. the obligation to support patient self-determination.

A primary concern in resolving these situations is documentation of all contacts with patients and caregivers in reference to non-compliance, including explicitly describing what was discussed. In addition, the provision of education, information or teaching when needed is ethically required. The worker should also discuss the consequences of compliance and non-compliance and what behaviors are necessary to maintain agency services (Hogue, 2006). In situations that require termination of services because the safety of the patient is at risk, discussion and preparation for termination and referral to appropriate services that are appropriate and can respond in a timely manner to clients’ continuing needs for community support is ethical (Egan & Kadushin, 2007).

Commitment to the Employer vs. Patient Well Being

Conflicts related to the duty to follow the procedures and policies of the employer vs. patient well being arise in community-based care when client needs for services exceed the limits of third party payments (Galambos, 1999; Kadushin & Egan, 2008; National Association of Social Workers, 2000). The dilemma is related to the social workers’ duty to the best interests or well-being of the client, and the simultaneous obligation to practice within agency policies and guidelines, including budget limits.

The implementation of capitated payment systems in home care, and the limited budgets of Medicaid Home and Community Waiver programs and other state funded programs for community-based care are associated with unmet needs for clients with complex chronic-illnesses (Kadushin & Egan, 2006; Schlenkler, Powell & Goodrich, 2005). There is also evidence that cost containment pressures influence decisions of case managers to restrict the resources and time allocated to more expensive, vulnerable clients (Degenholtz, Kane, Kane & Finch, 1999). Additional research suggests that a Medicare capitated payment system for home care that excludes reimbursement to support family caregiving is associated with unmet needs at discharge for caregivers who
are unable to care at discharge when third party funding limits conflict with workers assessments (Kadushin & Egan, 2006). Worker violation of the Code of Ethics, while infrequently reported, is associated with this dilemma (Kadushin & Egan, 2001).

The NASW Code gives priority to the duty to protect client well-being over the duty to adhere to agency policy when these principles conflict. The Code also stipulates that when agency policy interferes with the ethical practice of social work, social workers have a duty to take “reasonable steps” to ensure that the agency policies are consistent with the Code (National Association of Social Workers, 2000). Practitioners can fulfill this duty by advocating for clients with unmet needs. Kane (2004) defines advocacy as going beyond advocacy for a particular benefit or service to a more general stance of being on the side of the client. This type of advocacy is based on an empathic relationship with the client and a belief in fairness, respect and decency and respect for the client.

Research indicates that social workers in community-based care can serve as effective advocates for their clients by developing relationships with administrators who control budget allocations. Administrators who are part of a worker’s informal network of allies may be more responsive to worker advocacy and willing to circumvent formal bureaucratic channels to provide necessary resources (Egan & Kadushin, 2004). Workers can also advocate for system change by revising agency policy. An example might be the development of an agency fund to cover cases requiring complex social and emotional care. These funds could then be used in cases that meet criteria developed by practitioners and administrators. Another mechanism might be the establishment of administrative teams of supervisors, administrators and practitioners who meet periodically to review service delivery, quality care, and consumer feedback. These teams could review and revise procedures as needed (Galambos, 1999).

The role of the social worker as an advocate in changing social policy is another approach to these ethical dilemmas. This advocacy is fueled by the many recent demographic and social changes that have consequences for family caregivers and chronically ill dependent older adults. The primary source of support for older chronically ill and/or disabled individuals is unpaid family care. The increased population of older chronically-ill community-dwelling seniors, the participation of women, the traditional caregivers, in the labor force; the geographic dispersion of the family; the growth in non-traditional and immigrant families; and the transfer of high-tech medical care from hospital to home are developments that intensify caregiving demands (Lee & Rock, 2005; Levine, 2008).

Though there are some positive consequences of family caregiving, caregiving is also associated with adverse health mental health social interpersonal and financial consequences (Kadushin & Egan, 2008). Long-term care policies reflect the assumption that the government should intervene to provide resources only after family caregiving capacity has been exhausted. Family caregivers are thus not recognized as clients in their own right and there is no requirement for providers to perform an assessment of the caregivers’ situation and needs and address these needs (Levine, 2008).
This situation, an increasing need for social workers and other community-based geriatric providers to support family caregivers and older clients coupled with restricted reimbursement to provide psychosocial community-based care, is likely to result in future ethical conflicts for workers and unmet needs among families and clients who need long-term care. Advocacy by social workers to change long-term policy at both the Federal and state levels is a comprehensive approach to preventing these ethical issues (Lee & Rock, 2005; Levine, 2008). Finally, clients who have the ability can be trained by workers to develop skills and knowledge to become their own advocates by knowing their rights and responsibilities, learning how to press for those rights and make life choices (Kane, 2004).

**Boundary Violations and Crossings**

The following discussion of boundary issues addresses only the worker and the client. Boundary issues occur when social workers are in situations that pose a potential conflict of interest in the form of dual or multiple relationships (Reamer, 2003). Dual or multiple relationships can be identified when the worker engages with clients in more than one relationship such as professional and sexual, professional and business, or professional and social (Reamer, 2003).

Boundary violations should be distinguished from boundary crossings. Boundary violations occur when a worker is involved in a dual relationship with a client that has the effect of exploiting, manipulating, deceiving or coercing the client. Boundary violations involve a conflict of interest that harms the client. For example, a socially isolated worker who develops a friendship with a client is in a situation in which personal interests clash with professional duties. Boundary violations may also involve “undue influence.” Undue influence occurs when the worker uses his or her authority to exploit or take advantage of the client. All of these issues—conflicts of interests, dual relationships, and undue influence are prohibited by the Code of Ethics (National Association of Social Workers, 2000; Reamer, 2003).

Boundary crossings are defined as situations in which the worker is involved in a dual relationship with a client that is not intentionally exploitive, manipulative, deceptive or coercive. For example, a home health social work who is restrained in the use self-disclosure or a home care worker who is a member of the same religious group as a client’s daughter is generally not harming a client and may to some extent be helping the client by encouraging exploration of a difficult topic in the fist example, and by “normalizing” the relationship in the second example (Reamer, 2003, 1998).

“Gray areas” can also be identified in distinguishing between a situation that is a boundary violation and a situation that is a boundary crossing (Reamer, 1998). Clients who come to see a worker in an agency are likely to regard the worker as an employee of that organization. The waiting area and the office itself convey to the client that the worker is a professional working for an agency. When social workers visit clients at home their professional role is less formally circumscribed. The informality of the home
setting, and the potential of the client and worker to assume complementary roles as “host(ess)” and “guest” may blur the boundaries between friendship and professionalism. For example, the client as host(ess) may offer the worker something to eat or drink. On one hand, accepting the invitation may help the client feel more “connected” and is therefore not harmful, but on the other hand it may be misinterpreted as extending the professional into a personal relationship (Naleppa & Hash, 2001). Another example, of a “gray area” in home visiting is gift giving. Gift giving has been reported to be more frequent in home-based than in agency-based practice. This may be related to the greater possibility of blurred professional boundaries in home visiting (Naleppa & Hash, 2001). Whether the worker who accepts a gift from a client is involved in a boundary violation or a boundary crossing may depend on the situation, the type of gift, and how the worker manages the situation (Naleppa & Hash, 2001; Reamer 2003).

Some situations in home health visiting however clearly represent potential boundary violations. For example, situations in which a client asks the worker to stop by the store to buy a gallon of milk on the way to visit or asks the worker to stay until the client’s best friend comes over create the potential for a blurring of the professional and personal relationship, and by definition suggests a dual relationship (Naleppa & Hash, 2001; Reamer, 2003). Another area in which there is a clear potential for boundary violations in home visiting are sexual advances. Respondents in home-based practice perceived the occurrence of these problems as more frequent in the home than in the agency. For example, some clients have been documented engaged in exhibiting sexually provocative or inappropriate gestures (Naleppa & Hash, 2001). The worker is presented in these situations with the potential for a professional relationship to become an intimate relationship, which is obviously unethical given the criteria for boundary violations discussed above.

How does the worker decide how to manage situations in which boundary violations, boundary crossings or “gray areas” that do not clearly fall into either category arise? Reamer (2003, 2001) recommends that workers develop a clear definition of what constitutes an ethical and an unethical relationship. A dual relationship is unethical if it interferes with the worker’s professional discretion; interferes with the worker’s impartial judgment; exploits clients for the worker’s personal gain and/or harms clients.

Cultural issues are also a consideration in deciding whether a relationship is a dual relationship in home visiting. In some cultures, there is great significance associated with “breaking bread” with the practitioner. Clients in these cultures may be reluctant to trust a practitioner who refuses an invitation to share a meal (Reamer, 2001). The response of the worker in these situations is constrained by the requirement to draw clear professional boundaries, while at the same time not exhibiting a lack of respect for cultural norms (Naleppa & Hash, 2001; Reamer, 2003; Wasik & Bryant, 2001). Accepting an offer of crackers and a non-alcoholic beverage may maintain clear professional boundaries without violating cultural values (Reamer, 2003). The Code of Ethics does address these issues in stating that when “dual or multiple relationships are unavoidable, social workers should take steps to protect clients and are responsible for
setting clear, appropriate, and culturally sensitive boundaries (National Association of Social Workers, 2000; Reamer, 2003).

A risk management protocol proposed to manage boundary issues proposed by Reamer (2003) identifies the following criteria. The workers should be alert to potential or actual conflicts of interest in their relationship with clients and indicators of situations that may signal a boundary problem. For example, a community social worker should be aware of situations in which they treat a client as “special”, self-disclose intimate, personal details of their lives, or do favors for the client. When a worker recognizes that boundaries have been violated, they should consult appropriate agency personnel such as supervisors and administrators and also discuss the situation with the client. The worker is then advised to design a plan to remedy the boundary violation to protect the client to the greatest extent possible. Documentation of all discussions, consultations, supervision and any other steps taken to address the problem is essential for risk management. The worker is finally advised to monitor the implementation of the plan, possibly by phone, to evaluate whether the remedy minimized or reduced the boundary violation (Reamer, 2003).

Summary

Four ethical conflicts in community-based social work practice with seniors were discussed. The first ethical issue, the conflict between patient autonomy or self determination and beneficence, occurs when older adult clients make decisions that endanger their safety and welfare. Because ethically the principle of self determination is dependent on client decision-making capacity, workers require knowledge and skill to accurately assess decision-making capacity in collaboration with other disciplines. The second dilemma described the conflict regarding social justice vs. autonomy and discussed the workers obligation to clients who are non-compliant with medical recommendations as opposed to other clients requiring long-term care services. The third ethical issue, the conflict between the duty to protect client well being and the duty to adhere to agency policies and procedures, may arise when third party payments limits fail to provide sufficient resources to meet the needs of frail chronically ill older adult clients and their caregivers. Social workers can address these conflicts through advocacy with the client, in the agency and at the wider system level of social policy. Finally, situations in home care that present the potential for boundary violations, boundary crossings, and gray areas that do not fall into either category were discussed. Guidelines for distinguishing ethical from unethical relationships were presented and a risk management protocol was outlined.

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Grandparent Caregiving
Unplanned Parenting: The Second Time Around

Alice Kitchen, LCSW, MPA

Overview

Grandparents and relatives have historically cared for their grandchildren in time of crisis, marital discord, military duty, incarceration, or institutionalization. Often these care-giving periods were time limited: the marital discord was resolved, or the parent returned from military duty or prison. Today’s relative caregivers often become the sole caregivers for grandchildren or their relatives. Grandparents who are solely responsible for their grandchildren have been heralded as silent saviors of the family. (Creighton, 1991)

Unplanned parenthood the second time around presents challenges rarely experienced the first time around. The growing population of second, third and fourth generation caregivers parenting children is the result of a number of social factors. The most common causes of the phenomenon are the crack cocaine epidemic, which started in the 1980s, and growing numbers of parents who are seriously mentally ill, in prison, or deceased.

This chapter focuses on this emerging trend and its impact on social work practice in healthcare settings. The social, emotional, financial, environmental and intergenerational factors that influence this phenomenon will be identified as well as the challenges to family systems provoked by the biological parents’ inability to parent. Typical ethical dilemmas faced by caregivers and their families will be considered with implications for social work practice. Insights on this population were garnered during twelve years of working with the grandparent/caregiver population and their support groups in a Midwest urban and suburban area. The population is largely African and Anglo American grandparents and caregivers as they are the ones that have surfaced in our setting.

Demographics

According to the 2006 U.S. Census Bureau (American Community Survey), there are 4.7 million children are living in 2.5 million grandparents’ or other relatives’ households. This number should not be confused with the 3.9 million multigenerational family households - families in which grandparents and two or more generations of descendents live under the same roof.

From 1990 to 2000, a 30% increase occurred in the number of children living with grandparents in the parenting role, thus leading to the U.S. Census Bureau’s decision to track this trend in recent years. Geographic and cultural variations are associated with
this evolving social trend. The largest ethnic grouping in the general population is Caucasian at 53% followed by African American at 28%, and Hispanic at 22%. “Proportionately, however, African Americans (4.3%) and Hispanics (2.9%) are more likely to be caring for grandchildren than are Caucasians (1%)” (Hayslip and Kaminski, 2005). American Latino custodial grandparents are more likely to co-parent with an adult child other than the grandchild’s parent (Burnette, 1999). Hispanics and African Americans are more likely than Caucasian Americans to co-parent with one of their grandchild’s parents, “consistent with an emphasis on the family as an ongoing entity, and expectations of intergeneration assistance for the former two groups” (Hayslip et al., 2005).

The children in care range in age from infants to seventeen. Of these, 46.9% are under 6 years of age, 29.1% are between 6-to-11 years of age, and 24% are 11-to-17 years of age. The percent of grandchildren with a disability is 9.9%. The average family income is $49,427 per household. Thirty-nine percent of these grandchildren lived in households receiving social security income, cash public assistance, or food stamps. Of this number, 21.5% lived below the poverty level in the last 12 months and 78.5% had income at or below the poverty level during the past 12 months.

Personal observation and experience with the Hispanic culture suggests that although Hispanic grandchildren may live with their grandparents, the biological parents may still live in the same household. In Anglo and African American cultures, the biological parent tends not to be in the home. Other variations are related to differential rates of incarceration or to the type of drug that results in the biological parent’s inability to parent.

This generation of caregivers faces many challenges. Social workers in hospitals, public health settings, substance abuse prevention/treatment programs, corrections, and mental health settings will likely experience these newly configured families.

Social and Emotional factors

Grandparents who serve as parents to their grandchildren fill extended family roles that are not well understood. One approach to increased understanding is based on knowing the developmental needs and life-stages perspectives of each generation. (Goodman and Silverstein, 2001)

Many caregivers face the dilemma of wanting their child to be present in their biological child’s life and in their lives. . . . They desperately want the child to have a nuclear family. . . . It is not a style of grand parenting freely chosen; rather, it is a style adopted under duress. They fear the return of the parent and the disruption to the life of the child. Their fear and ambivalence stem from three concerns. They worry that the parent may not be able to care for their grandchild. They fear that the parent may take the grandchild for a few months and may find once again
that he or she cannot function as a parent disrupting the child’s life even more, and the emotional ties they have to their grandchild (Cherlin and Furstenberg, 1992, page 129).

As one grandparent put it so aptly, “In the beginning, I was a babysitter and a helper as any grandmother would if she could. However, my life was turned upside down because of my daughter for various reasons; she was not there for her children. She was more like a visitor than a mother. I loved my grandchildren very much, but I wanted to be a ‘grandmother’ not a full time mother.” (Craig, 1997, p.2)

Such unplanned parenting often occurs in a toxic social environment according to James Garbarino. In Raising Children in a Socially Toxic Environment (1999), he writes: “Grandmothers described themselves as parenting in a ‘whole new world’ that is toxic to their grandchildren’s healthy development” (Preface). Evidence that the environment is damaging to their grandchildren is seen in the negative influences of the media, drugs, alcohol, liberal attitudes toward sex, peer pressure, crime, violence, and a lack of healthy well balanced peers.

Many factors are operating simultaneously when grandparents become parents again. Everyone has to change; interactions change permanently. Emotional needs of grandchildren and grandparents change. Roles change. Grandparents no longer have the luxury merely to enjoy and spoil their grandchildren which is the “fun part” of that stage in life. Transition and redefinition of family boundaries become imperative (Mayer, 2002).

According to Hetherington, Stanley-Hagan and Anderson (1989), despite initial distress, most children adapt to living in their new environment within two or three years if the new situation is not compounded by continued or additional adversity. If the adversity persists, symptoms of distress may include aggressive, noncompliant, acting-out behavior, or the child or children may experience academic or other school-related difficulties or disruption in relationships with peers. This study found that children ultimately adapt better to a well-functioning family (grandparents included) than to a conflict ridden family of origin.

Thus, grandparents or other relatives should be helped as far as possible to know when a new environment is in the child’s best interest. Craig (1997) quotes one grandmother’s questions at the onset of this critical decision:

Here are some questions I asked myself on my journey to guardianship; what had I done to get my grandchildren into this mess? Why am I now a full time “Mom”? Did I try to get my daughter some help for her problems? Did I have to call the police on my daughter and wind up in Family Court? Would the Court do something to help my daughter? How would the children deal with all of this? What help was available for grandparents seeking guardianship? (p.2)
The child welfare system views grandparents and relative caregivers as a constructive substitute for placement in child custody cases. Permanency planning is the foundation of the Adoption and Safe Families Act of 1997 (AFSA). For the child welfare system grandparents and relatives are usually the first line of consideration in temporary placement after an assessment. Placement with relative caregivers will likely continue as a response to the philosophy of permanency planning and the mandates of the Adoption Assistance and Child Welfare Act of 1980 (AACWA; Public Law 96-272). Placement with relatives is not a given, however. Child protection workers may fear that the relatives will quickly hand the child back to the biological parent. When that fear is not warranted, relative caregiving can result in keeping the child within the family of origin. Kinship care is a structured part of the child welfare system in many states. Oversight provided by the state can be similar to the foster care system with all the safeguards and education required by the state. Subsidies vary depending on the program the caregiver chooses. The options range from official foster parenting to kinship programs with some financial support and subsidy for the child without state oversight.

Harrison, Kelley, Richman, and Vittimberga (2000) studied parental stress in grandparents versus parenting children with behavior problems. They concluded that when grandparents were responsible for the caregiving of their clinic-referred grandchildren, they reported lower levels of stress than both single and married parents. On the other hand, a study by Ehrle and Day (1994) found no significant differences between guardian grandparents and nonguardian grandparents on family adjustment. Grandparents grieve over the loss or incapacitation of their child as well as cope with the grandchild’s adjustment reactions to parental loss.” (p.68)

Family systems theorists view emotional closeness as a central construct when assessing family cohesion and considering family alliances (Moos, 1990). These studies suggest that training and practice approaches need to be cognizant of the relationship between generations. The assumption that the mother is the invisible connection should be reevaluated in these disrupted families

To be effective, practitioners must understand the developmental levels of all three generations and the interplay between them. Child care and the child’s educational and health needs, emotional wellness, and physical capacity must be addressed and will challenge the new family structure. Practitioners can assist by helping the family find child care and by making sure the child has a primary care physician, up-to-date immunizations, and is scheduled for Early Periodic Screening, and Diagnosis and Treatment (EPSDT). Special needs children require extra attention to connect them to all the resources they will need to function in the community.

Intergenerational caregiver roles are not well understood; however, some studies have researched the emotional bonds from the perspective of the link between grandparent/relative caregiver, the biological parent, and the child (Hayslip and Kaminski 2005, Craig, 1997, and Dolbin-MacNab, 2006). The circumstances under which grandparents become involved in raising grandchildren provide an important window into intergenerational relations in the United States at the end of the 20th Century.
Understanding the situation in which a sense of family obligation overrides the usual norm of noninterference provides useful information to social workers about how caregivers perceive their responsibilities for helping those in another generation (Pebley and Rudkin, 1999, page 219).

Many new and unfamiliar tasks accompany the newly accepted parenting role. The processes for selecting a school and enrolling the child often differ from the way caregivers placed their own children in school. After school programs may be more structured, neighborhood activities may need more scrutiny, and transportation to extracurricular events will present new challenges for caregivers.

Social workers will need to find ways to connect caregivers to learning opportunities that can enhance their parenting skills. This task may be awkward as most caregivers think they know how to parent and to suggest otherwise is to question their competence. One way to avoid resistance is to define these sessions as ways to build new skills for new times (Hayslip & Kaminski, 2005). Such opportunities will offer ways to help caregivers reflect on the parenting experience and think objectively about areas in which they could try new methods or relax their current way of parenting.

To provide such guidance effectively, social workers will need to know the caregiver in the context of the family. According to Finn and Jacobson (2003), there are three approaches to assessing individuals within familiar communal and historical contexts. Social workers have developed these tools to assess the person in the environment and the ecosystem around them.

- **Ecomap**: This tool visually illustrates persons in their environment and relationships, the flow of everyday resources, and the nature of the relationship. The value of this tool lies in its depiction of where strengths lie, thus guiding the social worker toward an intervention plan.

- **Genogram**: The benefit of this tool is its anthropological approach which borrows from kinship studies and their intergenerational focus on family relationships. Social workers can take information from the genogram to facilitate discussion about family history, patterns, struggles, and sources of strength.

- **Social Network Map**: This tool attends to family structure and the functions of their relationships. The social worker can gain useful information using this tool to identify stressors, strains, and resources in the family environment. The process of using this tool helps the social worker identify relationships that are important in various family members’ lives.
Financial Factors

Financial needs also take their toll on income-strapped caregivers. The grandparenting stage in life is not typically the time of high work productivity and increased income. For many in this population cohort a pension or Social Security is the only income they have. Social workers can help these caregivers explore the value of seeking public support for the grandchildren by way of a subsidy available through the state child welfare system and Medicaid coverage.

Today, because of earlier pregnancies and increased longevity, grandparents, come in a wider age range than in the past. Thus, their needs vary: many will be caught in a balancing act to keep a job while simultaneously managing their new parenting activities. They must find child friendly housing, maintain their own physical health, deal with medical appointments, and handle transportation to after school activities. At the same time, they must manage their finances, keep a social life to maintain balance, and have time to themselves – as they would in a more typical family cycle.

Grandparent caregivers represent many life stages: from finding and keeping a job to going through retirement, disability, reduced energy, divorce, widowhood, and loss. This generation of caregivers also faces the unique task of planning for the future caregiver of their grandchild in their absence. No wonder that many feel that this course is not the way it was supposed to be. Grandparents are not supposed to outlive their children, let alone their grandchildren. The traditional life course of the family is drastically altered.

Legal Factors

Deciding whether to seek legal custody is a major ethical dilemma facing grandparents or other relative caregivers. The grandparent or relative who has the child living in his or her home is considered the custodial caregiver.

Connecting grandparent caregivers to legal resources is advisable, not only to help the caregiver plan for the child’s care in the event of the caregiver’s death but also and more immediately to secure all the proper consents for such tasks as enrolling children in school, getting health insurance, immunizations, and consenting to medical treatment.

Custodial grandparents agonize over the decision to obtain a legal relationship with their grandchildren. Custodial grandparents do not usually seek this relationship but “offer” to provide care when the grandchild’s home becomes unlivable. When the home situation becomes intolerable because of the mother’s emotional, mental, drug, and alcohol problems, Cherlin and Furstenberg (1992) claim that grandparents see themselves as protectors of the family, bulwarks against the forces of separation, divorce, drugs, and crime. The offer to provide care results from fear that the child will be placed in foster care. Typically neither white nor black grandparents want their grandchildren in foster care.
Ethical Challenges

Parenting grandchildren is fraught with ethical dilemmas for both caregivers and their social workers. For example, it is not uncommon for grandparent caregivers to be ambivalent about their own child’s role in the life of their grandchild. They may have decided or accepted the role of being the sole caregiver but hope that their child will “get his or her act together” and come back into the life of the child.

It is in these trying times that the social worker can be most helpful sorting out the best interest of the child and the grandparents’ ability to provide that care. If the social worker’s primary client is the biological nonparenting parent he or she still needs to keep the best interest of the child in the forefront. In a case in which the child is in an abusive or neglectful situation regardless of whether it is in the home of the grandparent or the biological parent, it is the duty of the social worker as a mandated reporter to call this situation to the attention of the child protection system. Social workers are required by law to report signs of abuse and neglect and they to share this role with their clients. This role supersedes the client relationship.

The following questions pose some of the commonly experienced challenges faced by grandparents and relative caregivers. The proposed responses to these challenges are practice based.

Do I/we really want to do this?

Ambivalence is a common emotion at the beginning of this challenge, which represents a first stage in deciding to take on the parenting role. Feeling compelled and repelled at the same time is an exceedingly uncomfortable position to be in. Potential caregivers are often thrust into the decision-making process with little time to think about all the consequences of their decision. In some cases, children are simply dropped off for the night, but the son or daughter does not return for days, and then only to repeat this pattern time and again. The decision is forced on the reluctant caregiver.

The social worker’s assessment is key to resolving this dilemma. Many models exist. The ethnogram on the caregiver and family system can be particularly valuable with this population. The use of an ecogram or an ethnogram (Finn and Jacobson, 2003) can give the social worker insight into areas to probe and ways to offer supportive counseling to the grandparent who must make the decision. The caregiver’s strengths need to be identified, recognized, and affirmed. These strengths are the foundation on which a parenting plan can be shaped.

Ability and willingness are essential factors in the decision to parent grandchildren. Just as all parents are not automatically endowed with innate parenting skills, being a grandparent does not guarantee that one is able to or skilled at nurturing a child.
Can I really do this financially, emotionally, and physically?

In the child welfare system, grandparents or relatives are evaluated for their ability to provide a supportive home environment for these children. State workers do not assume that because they are grandparents or relatives, they automatically meet court criteria. The potential ability of these related caregivers to protect the child from the harm that brought them into the child protection system in the first place will be the pivotal factor in the state workers’ recommendation to the judge.

Caregivers who decide consciously or unconsciously by default to parent their grandchildren are today’s heroes. They keep the children connected to a family they know and spare them the trauma of separation. Children often cling to the known because it is known, even if that parent treats them poorly, ignores them, or even abuses them. In some cases, grandparents are a welcome relief from that neglect. However, the hope that their parents will come back and love them can linger on for years.

Children who are placed by the court in relative caregiver homes can come under supervision of the state agency. This supervision includes a home visit, a determination that the caregiver is fit to care for the child and that the home meets the child’s basic needs for safety, privacy, and space. Many families decide to care for their relative’s children precisely because they want to keep them in the family and not be separated by geography or cultural differences.

Because this growing social phenomenon has become so visible and works such a hardship on caregivers, it has come to the attention of legislators in many states. Legislators have been pressed to provide a subsidy for each child in the caregiver’s home, financial support for the caregivers, access to Temporary Assistance for Needy Families (TANF), to Medicaid, and food stamps for the children. Legislation has moved the age bar up and down depending on the state and the advocacy efforts. The demographics show this caregiver population is increasingly under 65 years of age.

Do I want to participate in the state agency kinship programs?

Many caregivers struggle with this dilemma for years. The choice is between having financial support, healthcare, and a clothing allowance for the grandchild or going it alone with the caregiver’s own income or lack thereof being one’s sole resource. This agonizing decision impacts the autonomy of the caregiver: for some, it adds to their strength; for others, it feels like becoming a foster parent to their grandchild. For still others, the choice to seek custody is fraught with guilt, feelings of disloyalty, and betrayal of the family norms.

Kinship care usually requires some oversight by the child protection program staff. It also requires training and a choice to participate in various supportive services. The agency may have access to counseling, medical care, or therapies not covered by healthcare providers, tutoring, or tuition allowance. Social workers can be instrumental in helping care givers determine which direction is best for them and their extended family.
Can I change my mind?

Whether a grandparent is young or old, healthy or frail, financially secure or poor, the decision to accept a grandchild or a family member’s child is nearly always difficult. It is a decision that is also hard to take back without further consequences to themselves or the children.

Social workers can help caregivers, as they struggle to make this decision. They can also help caregivers reaffirm their decision along the way, or help them find other caregiving solutions for their grandchildren if that is their choice. An ongoing relationship with the caregiver makes this dialogue more natural and comfortable. Grandparent support services exist in many communities. They serve a vital role in helping caregivers meet these challenges and give them emotional support along with way. Child welfare agencies, both public and private, are good places to start. Generations United, Grandparents as Parents (GAP), National Coalition of Grandparents (NCOG), Brookdale Foundation and some Area on Aging (AOA) offices often have information on these resources.

Should I seek legal guardianship?

A frequent topic in support groups is “Should I seek guardianship of my grandchild?” Indeed, this dilemma often causes caregivers the most agony. Child welfare workers and social workers with intergenerational experience have an advantage here. The following questions suggest the many challenges embedded in this dilemma:

1. Why would I put a barrier between me and my child’s ability to return to parent their child?
2. Will my child get angry with me and lash out?
3. Am I giving up on my child when I take the step to take their right to their child away from them?
4. If I have custody of my grandchild does that mean that parental rights are severed?
5. Is adoption the better solution?
6. Can the guardianship be “undone” if my child gets her/his act together?
7. Do I really want to be fully responsible for my grandchild? I’ve already done this once before.
8. Can I afford a lawyer to get the guardianship process completed?
9. What if the judge does not grant me guardianship because my child shows up at the court and pleads for their child?

Again, support groups represent a valuable service to caregivers considering guardianship. They provide peer feedback and tough love that would not always be accepted from an outsider, social worker, counselor or family member (Brungardt, 1997).
How do I plan for the children when I am no longer able or alive?

The first step to planning for the future is to make the decision on guardianship. If legal guardianship is planned or achieved, then completing a formal Last Will can provide a legal written document to ensure the custody of the children. The Will needs to address questions of financial support if such questions existed prior to the death of the caregiver and will persist into the future. If the grandparent has a subsidy, he or she should research whether the subsidy is transferable upon death. This information can be a critical factor for the formulation of subsequent permanency planning. A family law professional will know the components that need to be in such a Will. Difficult questions related to the potential return of the child to the biological parents should also be addressed to avoid subjecting the child to the same circumstances that precipitated the child moving in with the grandparent.

How do I deal with the embarrassment of raising a child whose parent is such a disappointment to me?

A first step for the caregiver dealing with this difficult dilemma is to acknowledge this feeling and not run away from it. Social workers can help caregivers explore this feeling and prevent it from paralyzing them. Reflecting on the wide range of parental experience can be quite useful in helping the caregivers become aware that parenthood comes with no guarantees. Wonderful parents can produce troubled children, and inept parents can produce a resilient child who excels beyond belief.

Intellectual discussion is just that: it comforts some people some of the time but does not erase these powerful emotions. Reality therapy would suggest acknowledging the feelings of disappointment and self-doubt, but would also focus on resolving the issue – either by choosing to accept the parenting role with added insight or by choosing not to parent the child. The second option may produce guilt if the grandparent or other relative walks away from the situation too abruptly. A better way to handle the choice not to parent is to encourage the person to engage in the placement decision that will be made by others.

How do I meet the children’s educational development and emotional needs?

Caregivers are often focused on providing for the basic needs of the child. They must also comfort the child even as they are changing from a grandparenting role to a parenting role, and they must build that relationship, set expectations, and deal with behavioral problems. Enrolling a grandchild in a school may not be as easy as it was the first time around. Parents have choices about the schools their children will attend and transportation to these schools may present obstacles if the schools do not provide transportation.

School social workers and school nurses can be a major asset at this time. They can also connect the child to a healthcare provider to get the necessary immunizations required by the school prior to enrollment. If the grandparent works, these practitioners
can help them know how other working parents deal with getting to parent teacher conferences. The very reasons that resulted in the child being cared for by a relative may have a noticeable or dramatic impact on the child’s ability to learn. Again, school social workers can be key to helping both parties through this transition.

**How do I parent this generation’s children when my child didn’t manage to become a caring parent?**

If grandparents are apprehensive, it may be that they believe that they were not ideal parents to their own children. Then the task for social workers will be to help them explore and analyze those feelings. Insights gained from a structured approach to this question can help the caregiver decide if parenting again is the right decision for him or her.

Other caregivers may come to this impasse with insight gained through painful experience, having grown in their ability to manage their lives and be self-sufficient. Their use of resources such as counseling, education, and support groups, have given them the maturity to take on the parenting role a second time around with added insight. They may be helpful mentors to new grandparents in this role. Lingering doubts about one’s parenting ability are unlikely to evaporate during the caregiving process. Any disruptive outburst may cause these emotions to resurface. Social workers have a key role in helping these caregivers assess their skills and strengths and use this self-awareness to guide them day-to-day.

**Is there help out there for caregivers like me?**

For those who choose to parent again, support groups exist in many communities. In addition, national networks listed in the appendix to this article can guide caregivers to the nearest support group in the caregivers’ local communities.

Resources vary by community. The quality of the support depends on the group members’ experience and their ability to share that experience in a positive manner. The value of each group is clearly in their common experience, which gives them a creditability that cannot be disputed. Self-help support groups are not to be confused with therapeutic support groups facilitated by social workers, psychologists, and mental health professionals. Nevertheless, caregiver support groups can benefit from having social workers available onsite to ensure that individual members and children in need of therapeutic interventions have access to the counseling they need. The social worker with intergenerational experience has the advance of knowing both the aging and the pediatric populations (*Brungardt, 1997*).

Another challenge for grandparents and relative caregivers is that they may have a perception that the social worker has no similar experience and therefore cannot be helpful to them. This perception may be further compounded if the social worker is very young or of the opposite sex. This challenge should be acknowledged and resolved as soon as possible.
Other resources for caregivers can be found through the many area offices of aging located throughout the United States and typically found embedded in county government structures. School social workers are also a rich resource for caregivers and will help their grandchildren adjust to the classroom and academic obstacles.

In sum, the following questions reprise the ethical challenges facing grandparents and other relative caregivers:

1. How do I live with the embarrassment/disappointment in my child?
2. What should I do when my child neglects, mistreats and/or abandons their children?
3. What did I do wrong in my parenting?
4. How do I get used to my ambivalence/resentment about having this choice forced upon me?
5. What can I do when I can’t manage my grandchild’s behavior?
6. Should I get an attorney and expose my whole family to a fight in court to get custody of my grandchildren and chance alienating my biological child forever?

**Common Ethical Challenges for Social Workers in Caregiver Settings**

Social workers too, face challenges that are unique to the intergenerational experience. A social worker may have the grandparent as the first client and then his or her daughter or son may resurface and generate confusion in the home. Who then is the social worker’s first client and primary duty? The NASW Code of Ethics, in the section on Social Workers Ethical Responsibilities to the Clients 1.01 on Commitment to the Client, distinguishes the ranking of roles. First, the primary (or first) client is the one the social worker attends to promote his or her well-being. The absent parent’s rights are to be acknowledged and the grandparent needs to be counseled to clarify in his or her own mind what relationship they want to have to their grandchild.

The following abbreviated case studies illustrate the challenges that social workers may experience in working with grandparent or other relative caregivers. In each case, knowledge of the ethical principles guiding social work and healthcare practice can guide the social worker’s effort to help their clients make responsible decisions about parenting a second time (Beauchamp and Childress, 2001). The principle of respect for autonomy, for example, can help social workers recognize the dignity and worth of all persons involved in the child’s care and trust their desire to do the right thing for their children and grandchildren. The principles of beneficence and nonmaleficence can help practitioners guard against acting in a paternalistic manner. These principles also promote a better attempt to balance the risks and benefits involved in a particular course of action – especially one that that may be recommended by some parties involved in the case and disputed by others. Likewise, justice, the principle of treating like cases the same, can reinforce practitioners regard for all parties even as they work to ensure the best interest of the child. Ethics committees in healthcare institutions
are often a resource in this area. Social workers will also benefit from sharing such case studies during in service trainings or informally, for example, over a brown bag lunch.

1. Faced with grandparent caregivers and a daughter who is struggling to get her children back, who is the social worker working for or with? Is the primary client the grandparent, the biological parent, or the child?

   **Case Example**
   Mabel and her husband have taken care of her two grandchildren since the youngest was two years old. Five years later her absent daughter shows up to take her children back. She claims she is drug free. The social worker from the drug treatment program vouches for her sobriety. Taking that information into consideration the social worker has two basic principles to add to the equation: the core value of holding a nonjudgmental attitude and the belief in the ability of the individual to make behavioral changes in life. However, the child’s best interest is at stake.

   Although there are several conflicting and competing factors going on in this situation, the social worker need not feel divided. Reflection on the “best interest of the child” and on the capacity of both parties to shape a realistic gradual plan is the goal. But if the re-entry of the parent becomes a tug of war, the social worker needs to drop the shared decision making process and focus solely on the best interest of the child.

2. The grandmother hopes her son will return home sober and will take his children with him. She knows he does not have adequate housing and has not been sober long, but she wants to be free of his kids. What is the social worker’s role in this situation?

   **Case Example**
   Edith has cared for her son Jackson’s four children off and on for two years. In the last year, Jackson did not come to her home to see his child at all. Edith, however, is growing weary of the responsibility for his children. She has arthritis and at 72 years of age has limited energy. Keeping up with her grandson’s schooling, parent/teacher visits, homework assignments, and ball games is very demanding as she does not drive. The apartment Edith lives in does not allow children and the neighbors’ continue to ask the manager to tell her to make a choice: the grandkids or the apartment.

   She does not want State Child Protection workers to take her grandchildren away from her or her son. All she has heard about “the State” is that they come in and take your children away and you never see them again. Edith is not aware of the “Kinship Provider Program.”
3. The social worker is concerned that a grandmother caregiver has an alcohol problem. Her son abandoned his children. This grandmother is barely capable of caring for herself let alone her grandchildren. On several occasions the social worker has pondered whether she ought to consider this case one that should be hotlined to Child Protective Services (CPS). She fears it may get worse. What should she do?

Case Example
Lucille raised her son by herself all the while struggling with alcoholism. Her son Stanley was sexually active at a young age. He became a father when he was only 15 years-old. Stanley’s girlfriend, the mother of Samantha, left Stanley almost as soon as the baby was born and has not been seen again. Lucille didn’t consciously choose to parent Samantha but as her son and his daughter lived in her home, she became the primary caregiver. Stanley’s bipolar diagnosis coupled with his struggle with crack cocaine caused him to leave the home. Now Samantha is often left unattended while Lucille is drunk. There is no other family in the surrounding area, no aunts, uncles, brothers or sisters.

4. The hospital social worker thinks she should contact CPS because the grandparent caregiver is blind and her granddaughter came to the hospital with a broken leg. The social worker could not fathom how this 93-year-old frail woman could provide the follow up medical care for this granddaughter and her siblings. The hospital social worker and the support group family advocate are at odds. How should the situation be reconciled?

Case Example
Mrs. Jones took over the care of her two granddaughters when her daughter was institutionalized. She attends the support group and the activities planned by the group. She and her granddaughters are always impeccably dressed. The girls help her navigate her way around and they travel by cab or with the help of other family members. When the oldest granddaughter fell and broke her leg at school she was taken to the hospital. There the social worker did a cursory assessment and decided to hotline the child given that the grandparent may not be able to care for the child post discharge. However, the grandparent’s support group facilitator heard of the child’s hospitalization and contacted the social worker, then took Mrs. Jones to visit her granddaughter.

5. The aunt inherited the care of her sister’s three children when their mother died of AIDS. She lives on Social Security. The three children were able to get Social Security Income (SSI) thanks to the hospital social worker, but their aunt’s subsidized housing development does not allow children to live with them. In the meantime, however, she has two teenage boys and a preteen girl living in a one-bedroom apartment. What can the social worker recommend in this case?
Case Example

Roberta just inherited her sister’s children. She raised her own four children and has seven grandchildren of her own. Parenting a second time was not in her retirement plan and certainly not within her budget. Her public housing development has given her notice that she is in violation of her lease. Roberta asks the housing development staff to put her on the waiting list for family developments. They agreed to do this. Her neighbors are not happy about living next to teenage boys. The youth do not like living in a senior citizen high rise. Roberta has heard about the state agency kinship care program. She is not sure she wants the state in her business but financial support makes this attractive.

Conclusion

Unplanned parenthood the second time around is not a new phenomenon, but given the current social and political environment (substance abuse, incarceration patterns, mental health challenges, and teenage pregnancy), these new custodial arrangements have increased dramatically. The impact on the child welfare system and on caregivers presents significant opportunities for social workers in health care to strengthen their practice skills to the specific tasks faced by these populations.

Efforts to understand the root causes of this phenomenon and the search for practical solutions entail more questions than are answered here. Social workers in health care have a narrow window in responding to this growing trend. The question is not whether the trend is good or bad – that question is irrelevant. The crucial question is how to help practitioners understand these intergenerational patterns, adjust their practice to affirm the strengths of this skipped generation, and provide experience and support to push the dynamics toward the best interests of the child and caregiver.

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REFERENCES


Transitions Towards Recovery: Ethical Considerations in Working With Older People Living With a Serious Mental Illness

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Introduction

The focus of this article on the ethics involved in working with older people living with a serious mental illness (SMI) is timely for social work practitioners and leaders in the health care sector. In the United States, social workers are the largest provider of mental health services. Social workers provide more services than all other mental health care providers combined (NASW, 2002). Given the demographics of the aging North American population, the need for ethically sensitive social work practice with older adults experiencing mental illness is increasing significantly.

In the United States, Canada and other G8 / Organisation for Economic Co-operation and Development countries, the fastest growing age group is senior citizens, particularly people over the age of 80 years (McClowskey, 2005). In 2000, an estimated two percent of the population in the United States was age 85 or older. The percentage is expected to be five percent before mid-century (Lindsay, 1999). The life expectancy of a North American woman is on average five years longer than that of a North American man (World Health Organization, 2008). An estimated 70% of North Americans over the age of 85 years are women (Lindsay, 1999). As a larger proportion of North Americans survive to old ages, the ability of older citizens to function independently in the community has become an important public health issue (Guralnik, Fried & Salive, 1996).

Increasing numbers of older people with mental illnesses are expected in the coming decades due to the large size of the aging “baby boomer” cohort coming into their retirement years. An estimated 20% of people over the age of 65 years suffer mild to severe depression. The rate ranges from 5-10% of seniors in the community and 30 to 40% of seniors in institutions (Canadian Coalition for Seniors Mental Health, 2004; Health Canada, 2002a). Due to the overall aging of the North American population, the population of older adults with schizophrenia is expected to double over the next twenty five years (Bartel, Levine & Shea, 1999).

Mental disorders are reported to be as high as 80 percent amongst admissions into long-term nursing homes in the US (Rovner, German, Broadhead, Morriss, Brandt, Blaustein & Folstein, 1990; Whyte, 2004). In a study of 454 admissions, the most common mental disorders were dementia syndromes at 67.4% and affective (mood

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1 The author gratefully acknowledges the editing input of Nicole Chovil, PhD, Jayne Whyte, B.A.(Psychology) and Kay Davidson, DSW.
2 The G8 Countries include: Germany, France, the United Kingdom, Italy, Japan, the United States of America and Canada (OECD, 2005).
disorders at 10% (Rovner et al, 1990). Of the patients with dementia, 40% are dually diagnosed with psychiatric syndromes such as delusions or depression and require more restraints and medications. This sub-population of nursing home patients was reported as consuming the greatest amount of nursing time (Rovner et al., 1990).³

This chapter reports the results of the Weyburn Research Project. In each phase of the research, opportunities occurred to reflect upon the meaning of ethically competent research and social work practice with older adults living with a SMI. The following sections detail the ethical considerations that arose throughout the project. Ethical challenges arose early in the project and included the recruitment phase and the process of changing the research question and focus. Additionally, it was critical at points of the inquiry – when individuals experienced health problems requiring hospitalization – to focus on prioritizing the wellbeing of co-researchers over the project goals. In every instance, resolutions to the ethical considerations that arose throughout the study were achieved through focusing on the premises of the ethical approval process and the social work code of ethics. As this chapter stresses, the participatory research method used in the study provided a solid framework for completing this ethically sensitive initiative.

From the spring of 2006 until the end of 2007, the author led a Participatory Action Research (PAR) project in Weyburn, Saskatchewan, Canada. The initial research question was: How can families impacted by a SMI best prepare for the future well being of an older adult with a SMI beyond the death of a caregiving parent? The PAR process began by recruiting nine co-researchers, themselves older adults with a SMI.⁴ The first phase of the research involved the co-research group taking ownership of the research project by amending the original research questions and re-focusing the research topic, developing a research instrument and interviewing community members who are also older adults living with a SMI. The PAR journey offered a transformative experience for each of the nine co-researchers as well as the principal researcher.

**Health Needs of Older Adults**

The needs of older people living with a SMI are the same as the basic factors that promote the health, dignity and wellbeing of all older people. Aging individuals in North America commonly experience multiple losses such as the loss of meaningful work, death of relatives and friends and an overall decline level of health. The most basic necessities of life required for older citizens to enjoy a decent level of well being include adequate income; food and shelter; safety and security; access to a health care; transportation and human contact through individual relationships and community engagement (Whyte, 2004; World Health Organization, 2001).

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³ The relationship between mental illness in adult life and the risk of developing dementia as an older person is unclear. Some research indicates that experiencing a mental illness as an adult increases the risk of dementia in old age while other studies reveal no evidence of association (Cooper and Holmes, 1998).

⁴ The research was approved by the Conjoint Faculties Research Ethics Board, University of Calgary, Canada.
The poverty rate of disabled adults is double the overall poverty rate (StatsRRTC, 2006; Mink & O’Connor, 2004; Canadian Council on Social Development, 2000). In 2006, the poverty rate of working-age people without disabilities in the US was 9.2 and 25.3 percent for working-age people with disabilities (StatsRRTC, 2006). People with a mental disability have the highest rate of poverty amongst the identified types of disabilities (32.5 percent of compared to 23.3 percent for people with a sensory disability) (StatsRRTC, 2006). Moreover, old age is also a risk factor for being poor and unattached individuals are particularly at risk. The national rate of poverty amongst unattached adults in Canada is 35 percent (Hunter, Douglas & Pederson, 2008). Twice as many elderly disabled people are poor compared to non-disabled elderly citizens, 11.4% compared to 6.5% respectively (Mink & O’Connor, 2004). In general, older women are more at risk of old-age poverty than men given that women live longer and have lower earning opportunities throughout their lifetimes (Nelson & Robinson, 1999).

People living in chronic poverty face daily challenges around housing, nutrition, transportation, access to health care, isolation and community engagement (Whyte, 2004). Increasingly, across North America, particularly in urban centers, there is a lack of affordable and supportive housing services for low income people (Rude & Thompson, 2001). Canadians are experiencing unprecedented homelessness (Laird, 2007). Untreated mental illness is estimated to be the leading cause of homelessness in the United States.

Health and overall wellbeing are severely compromised in older citizens who face chronic poverty (Whyte, 2004). It may be difficult for poor seniors with a SMI to access basic health care, more so in the United States than in Canada, which has a national, universal medi-care system. The continuum of quality, appropriate health care, including alternatives to the medical model, required to support the well being of senior citizens can be expensive. The global rise in food and transportation costs and dramatic shifts in housing markets increase difficulties for older people with mental illnesses. Housing and food costs make it more difficult for older adults to enjoy sources of social and personal well being such as active lifelong learning, safety and security, acceptance and social support.

Older people with a SMI face challenges related to living with at least one disability and may have experienced high levels of stigma and discrimination when younger. Long-term marginalization, a limited learning history, the lifelong stress of being disabled, the side effects of long-term psychoactive pharmaceutical use and cognitive impairments place older adults with a SMI at risk for a poor quality of life.

Both aging and mental illness increase the potential that persons will not be valued as full citizens and may limit rehabilitative, vocational and cognitive abilities. The combination of limited or negative social experience places people at a high risk of co-morbidity, poly-pharmacy, depression and suicide (Whyte, 2004; Thompson, 2003). It is critical for clinicians to recognize that the deaths of 10% - 15% of adults diagnosed with schizophrenia are classified as suicide (Pinihahana, Happel, & Keks, 2003).
Developing sensitivity towards the risk factors people with a SMI experience was significant in the participatory research project described below.

**Definitions**

Some of the acronyms and terms used in this chapter are as follows. ‘SMI’ stands for *serious mental illness*, and refers to DSM IV diagnoses of chronic, debilitating and disabling conditions which can involve psychotic episodes (*American Psychiatric Association, 2000*). This category includes schizophrenia and related spectrum disorders (e.g. schizo-affective disorder), clinical depression and bi-polar depression. The term *disabling* is assigned to an illness which causes significant disruption to one’s life and lifestyle (e.g. loss of housing, employment, relationships). The term *persons with mental illnesses* is used periodically in the article to refer more broadly to persons with mental illnesses and includes people living with a SMI as well as individuals with other DSM IV disorders such as personality and anxiety disorders. An estimated 50% of persons with mental illnesses are also affected by substance abuse (*Kirby & Keon, 2006; Health Canada, 2002a*). The term *concurrent disorder* is used to describe an individual who is affected by licit or illicit substances and a mental illness at the same time (*Health Canada, 2002b*). The term *older adult* is used to describe a citizen who is over the 55 years of age. The term *elderly* is used to refer to a person who is 65 years of age or older.

The concept of *recovery* is used in this paper is adapted from recovery as it is defined in the psychosocial rehabilitation field (*Davidson, 2003*). The recovery model is becoming a guiding vision for service practice within mental health systems around the world (*Davidson, 2008; Piat, 2008*). For people living with a SMI, the model promotes recovery through self-determination and self-expression of an individual’s self-understanding of the factors that improve their lives rather than the curative medical orientation.

**Ethical Considerations of the Weyburn Research Project**

People who live with a SMI are marginalized in contemporary culture and thus are considered, from a research ethics perspective, as being a vulnerable population for the conduct of academic research. The codes of ethics governing North American social workers provide a starting point for conducting research that respects the dignity and worth of all humans (*National Association of Social Work, 2006; Canadian Association of Social Work, 2005*). Moreover, social workers focus on social justice, professional integrity and competence (*National Association of Social Work, 2006; Canadian Association of Social Work, 2005*). These principles are aligned with the criteria of conducting research with people who experience a mental illness. Best practices in psychiatric research involve ensuring informed consent, reinforcing voluntary participation and being sensitive to the impact of the research on participants (*Roberts, Warner, Brody, Roberts, Lauriello & Lyketsos, 2002; Roberts, Warner & Brody, 2000*). Ensuring truly informed consent is especially important when working with middle-aged
and elderly patients with psychiatric disorders who may experience impaired decision-making capacities (Dunn, Lindamer, Palmer, Golshan, Schneiderman & Jeste, 2002).

Since the ethics of psychiatric research are controversial, this research focused on strengthening informed consent with older people who live with a SMI (Dunn et al, 2002). The consent process was designed to ensure authentic consent through substantial discussion of the expectations, the potential for harm and the incentives for participation. Potential participants were given consent forms to read over a period of several weeks. The recruitment process also involved discussing the influence of relationships with clinicians and family members upon participatory decisions (Roberts et al, 2002). As a consequence of frank discussions about involvement in the project, only half of the people who came to the recruitment meetings became research participants. Another factor that contributed to the ethical sensitivity in recruiting and retaining participants for the project was the participatory nature of the study. Participatory Action Research, or PAR, provides an opportunity to do research ‘with’ rather than ‘on’ people. PAR emphasizes working with community groups as researchers. In PAR, all of the research participants are seen as both co-researchers and co-subjects (Heron & Reason, 2004).

PAR assumes that the experts are the people who live the experiences that are being studied and that knowledge is produced through the active engagement and interaction of members of the research group (Falls-Borda & Rahman, 1991). PAR is about understanding reality and taking action to transform reality (Reason & Bradbury, 2004). The focus in PAR is to be part of the change and movement towards tangibly improving the quality of life for individuals and communities. PAR focuses on having an effect and emphasizing possibilities not prediction (Heron & Reason, 2004; Park, 2004).

PAR is participative and experiential, representing a shift from theory-driven to context-driven research (Falls-Borda & Rahman, 1991). A social justice orientation is pivotal in PAR (Freire, 1970) with the explicit aim of bringing about a more just society in which no group or class of people suffers from deprivation of essentials such as food, clothing and shelter and in which all enjoy basic human freedoms and dignity (Park, 2004). Ideally, PAR produces new knowledge and is transformative in some way for the participants (Heron, 1998). The four basic themes in PAR are: (1) empowerment of participants; (2) collaboration through participation; (3) the acquisition of knowledge and (4) social change (Heron and Reason, 2004; Heron, 1998).

Historically, much medical and psychological research involving people who experience a SMI and their caregiving family members has not tangibly improved participant wellbeing. There is a high level of concern for patients’ rights and ethical standards when conducting research with people who live with a SMI (Mills, 2006; Levine, 1999). Issues of honesty, informed consent, safety and patient benefit are of the utmost importance when working with marginalized and vulnerable people. In light of the sensitive nature of the topic area, the ultimate concern throughout all phases of the

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5 “Participant Validity” is important in PAR as it is expected that improved participant wellbeing will occur as an outcome of a properly conducted participatory inquiry (Reason and Bradbury, 2004; Smith, et al, 1997).
research project was for the well-being of the participants. PAR emphasizes paramount responsibility to the participants and in the case of conflict of interest, puts the participants’ well being first (Smith, Willms & Johnson, 1997). It is incumbent upon a PAR practitioner to do everything possible to protect the holistic well-being and dignity of participants throughout all phases of the research process (Park, 2004; Smith et al, 1997). People with a SMI who participate in empowerment-oriented research report the experience of participating in PAR to be positive (Reeve, Cornell, D’Costa, Janzen & Ochocha, 2002; Ochocha, Janzen & Nelson, 2002; Fossey, Epstein, Findlay, Plant & Harvey, 2002). The encouraging and positive experiences of co-researchers, or consumer researchers, emphasizes how important the PAR concepts of sharing knowledge, power and positive feedback are in working with people who have psychiatric illnesses (Reeve, et al., 2002; Ochocha, et al, 2002; Fossey, et al., 2002).

For full disclosure, the participant recruitment phase stressed to potential participants that considerable time and energy is required as part of a PAR project. An authentic commitment from participants (who are referred to as co-researchers) was established through trust-building experiences, the research team began to work together for shared social transformation goals. For the year of the study, the co-research group met for half a day twice a month with individual work between meetings totaling about 12 hours of work each month (including the twice-monthly meetings).

Other specific ethical considerations related to age and to risk of psychosis. Some potential participants were older adults who may have spent a considerable portion of their lives in institutionalized care and for whom the brainstorming, group work and community-based action that would evolve throughout the project might not be appropriate. Another significant ethical consideration in doing research with older people living with a SMI is sensitivity to the clinical wellbeing of each co-researcher. The participants involved in this project were in various stages of recovery. A criterion for being in the study was that co-researchers knew how to access mental health services, a working relationship with mental health practitioners. It was ethically critical that the co-researchers have other resources than the principal researcher, should they experience distress as a consequence of the topics explored in the research. Two of the co-researchers were hospitalized during the study. In one instance the hospitalization was due to a physiological, medical situation. The other co-researcher required acute inpatient care on more than one occasion. Since the co-researcher was already engaged with the mental health system, timely and appropriate care was available in the community. The co-researchers and principal researcher were accommodating and supportive to the individual experiencing a decompensation in functioning. There were no negative ethical implications for the individual, the other co-researchers or the project as a consequence of the acute health care needs of researchers that arose throughout the project.

An ethical imperative dominating the entire research project was the reality that the vast majority of adults with a SMI experience chronic poverty and are dependent on social assistance. All of the nine co-researchers in the Weyburn Research Project rely on either provincial or federal government transfer payments. The co-researchers were paid
an honorarium for participating in meetings and for work completed outside the meetings. It is ethically important to pay people who live in poverty for research projects and the reality of paying participants poses challenges.

PAR has ethical specificities that may not be seen in other types of research. For example, the model recognizes the challenges around voluntary participation with people who live in poverty. Although participants signed a consent form stating that one can withdraw from the research at any time, it is important to recognize that people may feel that it is not possible to leave the project because of the cooperative and collaborative spirit of PAR (Speziale & Carpenter, 2003). An astute practitioner should be aware of possible dilemmas by regularly reviewing participants’ agreements (Speziale and Carpenter, 2003). Munhall (2001) describes this as process consent, allowing all participants to renegotiate aspects of the informed consent based on the evolving nature of the project. An established method for overcoming ethical challenges related to PAR research involves informing all research participants about potential ethical issues before, during and after the study (Speziale & Carpenter, 2003).

The ethical considerations provided a structure for framing principled and ethical research (McIntyre, 2008). Considerations include engaging participants in all aspects of the project and reducing barriers between co-researchers and practitioners. The knowledge transfer component of PAR encourages practitioners to share knowledge and co-researchers to learn about appropriate research methods (McIntyre, 2008). PAR practitioners appreciate the capacity for individuals to work together to effect change. Other ethical considerations include taking every precaution to protect the confidentiality of participants as well as receiving the consent of co-researchers before publishing research data (McIntyre, 2008). For the psychological well-being of the co-researchers, a criterion for inclusion in the project was that participants lived independently of family caregivers. The research topic – the advanced aging and death of parents – is difficult for most adults to explore. Only adults not living with or dependent on aging parents were included to reduce the potential for causing undue stress on any participants. This decision presented one of the most substantial ethical challenges of the project. A primary ethical consideration in PAR is the need for practitioners to be flexible and unattached to the original research goals (McIntyre, 2008). Practitioners are required to be “trustworthy; scrupulous in their efforts to give primacy to participants’ goals; responsible for the well-being of all involved; fair, just, and willing to relinquish their agendas if they conflict with participants’ desires” (McIntyre, 2008, p. 12).

In PAR, the co-research group repeatedly moves through a four phase research cycle. Phase 1 involves the researchers agreeing on an area for inquiry, identifying some initial research propositions and agreeing on a set of procedures for observing and recording their own and others’ behaviour. In Phase 2 the co-researchers begin to initiate the agreed action and to observe and record their own and others’ behaviour. Phase 3 is when the co-researchers become fully immersed in conducting the research. Phase 4 is about reflection; the researchers revisit their original research propositions and analyze the material they have collected. When appropriate, the final phase involves presenting the results to community and scholarly groups (Heron & Reason, 2004; Heron, 1996).
Research Findings

Nine middle-aged and older co-researchers who live with a SMI were engaged as co-researchers. Seven have a schizophrenia spectrum disorder while two live with concurrent disorders or dual diagnoses involving depression. The participants ranged in age from 48 – 67. During the 16-month inquiry the co-researchers went through the four phase research cycle a total of ten times, outlined in Table 1.

Before the first research cycle began, ethical considerations arose regarding the configuration of the co-research group. A total of 18 adults came to the two recruitment meetings in the fall of 2006. Some decided not to participate after hearing details of the research (a diagnosis of a SMI, not dependent on or living with parents, over the age of 40 and a resident of the Weyburn area).

An ethical difficulty arose with two individuals who did not meet the criteria and were enthusiastic about being part of the project. The difficult choice of excluding them was helped by the three committee ethical approval process at the University of Calgary. The ethical dilemmas around the formation of the research group were soundly articulated in my ethics application. Resolving the dilemmas involved returning to the ethics application and related literature. Numerous ethical considerations arose as the project unfolded, most significantly in the first cycle. The first research cycle involved each co-researcher providing written answers to an agreed-upon, semi-structured interview guide that focused on the impact of living with a SMI and coping strategies.

An ethical consideration began to arise as the co-research group began to take ownership of the research process and questions. The original parental-focused topic about how to support families in planning for the future was not of interest to eight of the nine co-researchers, since only adults who live independently of their family were included. The author learned to be part of a truly participatory process in which the co-researchers took ownership in cycle one of PAR. An enthusiastic co-research group arrived at a new research question that every member was keenly interested in: What factors support the wellbeing and recovery of older adults living with a SMI?

The co-research group further defined the topic of inquiry to focus on three main areas: (1) the impact of living with a SMI; (2) the importance of supports such as friends, family and mental health practitioners and (3) factors that support well-being and recovery. The co-researchers created and piloted a semi-structured, qualitative interview guide and each interviewed one older adult living with a SMI. In total, eighteen adults living with a SMI participated in the study – nine co-researchers and nine interviewees. The nine interviewees also shared in a roundtable discussion. The research results were disseminated to the community during the final cycles.

The interviewees and co-researchers concluded that the most significant factor that supports the wellbeing and recovery of an older person living with a SMI is paid employment. Extra income mitigates the harsh consequences of chronic poverty. While volunteering and community involvement in civil society organizations such as a church
or a charity is helpful, earning money to supplement social assistance improves the quality of life of older adults with a SMI more. Other tangibly useful influences include supportive involvement with community-based organizations. Coping strategies such as creating art, enjoying music, exercising, writing and watching television were commonly cited as positively influencing wellbeing and recovery. Participants reported enjoying positive support through relationships with friends and family members; friendships were reported to be generally more supportive than family relationships. Governmental services such as financial assistance, access to physical health care and mental health services were important factors for all participants. Most had been hospitalized in a psychiatric ward at some point in their lives due to an acute psychotic phase. The experience of being hospitalized was reported as primarily positive. One person reported the experience to be neutral, described as both positive and negative. No one reported that hospitalization was entirely negative.

The findings of the Weyburn study, that work itself supports recovery, are aligned with Davidson (2003) a leader in the North American recovery movement impacting the mental health field. Davidson’s (2008) position is that recovery is best supported by helping adults with a SMI engage in meaningful, paid employment. Even if the symptoms of a SMI are not fully controlled, Davidson argues (2008) that individuals should be supported in pursuing paid work. Not only does paid employment expand engagement within the community, but earning extra income can also help an individual to pursue meaningful hobbies and activities that support their wellbeing and overall capacity to cope.

Policy Implications

Policy recommendations result from the research questions: what factors best support the wellbeing and recovery of older adults with a SMI? While the research was conducted in Canada, the following broadly-based policy recommendations are offered within a North American context. Substantial differences between the delivery of mental health services in Canada and the United States are most notably, that all Canadians have access to federally- and provincially-funded hospital and physician services. Nevertheless, there are substantial similarities between the lives of older American and Canadian citizens who live with a SMI. In both the United States and Canada, mental health services are scarce, difficult to access and focused on physicians and hospitals. Both offer a limited patchwork of mental health services available to low income residents. Moreover, chronic poverty is placing an increasing number of senior citizens in precarious positions in terms of housing and food. It is important to focus on reducing the depth of poverty and increase the quality of life experienced by older adults with a SMI. Strategies proposed include supporting part-time paid employment, providing adequate housing and community-based acute and crisis intervention services.

The co-researchers and interviewees of this research highlighted their most helpful resource as paid employment. While all participants rely on government transfer payments as a main source of income, they benefit from the ability to earn some money
each month. Since participants reported that the stigma of being poor is worse than the stigma of having a mental illness, money directed at stigma-reduction initiatives could be better spent by tangibly supporting the income security of people with a SMI who are living in poverty. As the participants uniformly stated, being less poor can reduce the experience of stigmatization. Social assistance programs for older disabled adults that allow assistance and pension recipients to earn a discretionary income mitigate the damaging consequences of chronic poverty.

For the nine co-researchers, this project was a job. Throughout the project the principal researcher was aware that some co-researchers may not have taken on the role without being paid. Each of the nine individuals became fully engaged in the project. The group was capable, hard working and reliable. When they agreed to engage in small group or individual actions or reflections outside of the larger group, the research goals were met. Moreover, when participants engaged in brainstorming or focus group scenarios, thoughts flowed freely and the capacity of the group to collectively create new knowledge more than exceeded expectations. Co-researchers reported they coped the best with their illness and related symptoms when the group was fully engaged in its processes. Working in an environment where all voices are heard and where power is authentically shared is a highly effective method for supporting the recovery of people who experience a SMI.

Given the depth of poverty that older adults with a SMI endure, supporting income security and suitable welfare models that allow people to earn more income through paid work is the most meaningful policy and practice reform. In other countries, such as Australia and the United Kingdom, people who use mental health services are routinely employed within the system to involve people with mental illnesses in the evaluation, design and delivery of mental health programs (Mills, 2006; Kelly and Simpson, 2001). The physician- and hospital-based mental health models in Canada and the US both fall far short of meeting the needs of older adults with a SMI. The well being and recovery of older adults with a SMI can be supported by evolving our expensive and ineffective, hospital-based mental health model into the community so that individuals and community-based organizations can provide housing, employment coaching and other basic supports to older citizens living with a SMI. The mental heath system could benefit from the wisdom that long-standing recipients of mental health services accrue over the decades by learning constructive (and observing destructive) coping strategies. Including people with mental illnesses in program development and delivery would both create employment and strengthen mental health policies and programs.

The wellbeing of older citizens with a SMI could be supported by expanding home-care and community-based care services. Home care could also include home intervention to assist and support people in crisis and resources (Whyte, 2004). Some older people with a SMI experience a lessening of symptoms with age (Nasar, 1998). The 18 participants reported that older people benefit from the experience of living with a SMI over a long period of time and being aware of the factors that help or hinder their
wellbeing. They noted that older people with a SMI have often developed coping mechanisms over the decades that help lessen instances of acute psychosis.

In light of the shortage of physicians in general and psychiatrists specifically, it is possible for teams of mental health practitioners to provide home-based and community-based care to older citizens with a SMI. While a physician/psychiatrist is pivotal to the treatment team, given the exclusive jurisdiction of doctors to prescribe psychoactive pharmaceuticals, other practitioners are eminently qualified to support the wellbeing and recovery of older citizens. Pharmacists and nurses (nurse practitioners, psychiatric nurses and licensed practical nurses) are trained in administering and monitoring medications. Psychologists and social workers are qualified to provide psycho-social therapy to people with mental illnesses. Occupational therapists and social workers are capable of tangibly improving the quality of life of individuals with a SMI by supporting day-to-day realities such as securing and retaining adequate housing, job coaching, community involvement and other problem solving. Para-professionals in community-based organizations that support people with mental illnesses can provide a variety of job coaching and other opportunities. Most significantly, evidence solidly indicates that support groups run by persons with mental illnesses, self-described as “consumer / survivor” groups, tangibly support recovery (Piat, 2008; Davidson, 2007; Cook & Jonikas, 2002).

Summary

This chapter highlighted some of the ethical issues that arose when conducting research with older adults living with a SMI. The academic ethical approval process provided a solid framework for resolving each scenario. The ethics literature about conducting research with people living with a SMI and the ethics approval process helped on the occasions when a co-researcher required hospitalization during the research project (Dunn et al, 2002; Roberts et al, 2002)

Given the participatory nature of this research, it was possible throughout the project to remain true to the ethical values of social work, including acting with integrity, competence, in the spirit of service and social justice, treating all humans with dignity and respect while valuing all human relationships and all human beings (National Association of Social Workers, 2006; Canadian Association of Social Workers, 2005). The ethical values underpinning the practice of social work are grounded in a set of social values congruent with the philosophy of PAR. Specifically, the participatory nature of this study was aligned with social work ethics related to power, reciprocity and contextual relevance (Shaw, 2003). The context-driven focus of PAR is aligned with the person-in-environment orientation of social work. However, as this chapter highlights, beyond the codes of social work practice, research with people living with a SMI requires extra ethical considerations. For both practice and research, it is important for practitioners and leaders to be sensitive to the unique needs of older residents with a SMI and to be involved in participatory processes, authentically and inclusively sharing power and decision making processes. Working ethically with older people with a SMI is as much a human rights movement as it is about clinical effectiveness (Davidson, 2008).
PAR offers social workers a research model that allows professionals to support the wellbeing and recovery of older citizens living with a serious mental illness (Lacasse & Gommery, 2003).

Despite the wide-spread poverty that older people with a SMI endure, there is hope for improvement. The recovery model sweeping the North American mental health system offers a more optimistic future for people with a SMI with its focus on improving overall quality of life. In general, society is more accepting of the full citizenship of people living with disabilities compared to previous decades (Whyte, 2004). Canada is the only nation in the G8 without a national mental health plan. However, in 2007, the Government of Canada established the Canadian Mental Health Commission, as the outcome of a half-decade of solid public policy research and development by members of the Senate of Canada (Kirby & Keon, 2004; 2005). In committee was formed following a publication entitled Out of the shadows at last: Transforming mental health, mental illness and addiction services in Canada (Kirby & Keon, 2006). The goal of the federally-funded commission is to establish an integrated mental health system with people living with mental illness at its centre (Kirby & Keon, 2004). The committee is positioned to be a catalyst for the reform of mental health policies and improvements in service delivery across Canada.

There is also hope also for improved services in the United States for persons with mental illnesses. July 2008 saw the House and Senate successfully override the President’s veto of legislation (HR 6331) making critical reforms to the Medicare program for beneficiaries living with mental illness (National Alliance for the Mentally Ill, 2008). HR 6331 includes critical provisions including: parity for cost sharing for outpatient mental health services; statutory authority under Part D drug benefit for the Centers for Medicare and Medicaid Services to ensure broad coverage on drug formularies for psycho-active pharmaceuticals. HR 6331 also includes changes to eligibility for the Part D Low-Income Subsidy program to increase the amount of allowable resources and in-kind support (National Association for the Mentally Ill, 2008).

Recent mental health sector initiatives in the United States and Canada represent significant steps towards supporting the recovery of older adults with a SMI. This research highlights that clinical and social work interventions are limited by the depth of poverty that people who live with a SMI commonly experience. In light of the current era of food and housing insecurity, it is essential that social workers work towards mitigating the impact of the chronic poverty that older adults with a SMI face. Social work has a significant role to play in responding to the current meta-ethical realities of facing the North American mental health sector.

One of the most significant clinical and operational shifts that social work practitioners can make is to respond to the challenging ethics of working with older adults living with a SMI by adopting participatory models. Participatory approaches that employ people with a SMI in research as well as in developing, evaluating and delivering programs have both successfully impacted the lives of those employed and strengthened
services. The power-sharing focus of the participatory project described in this chapter was transformational for the nine co-researchers and the principal researcher.

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Driving and Older Adults

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Overview

Issues related to older adults and driving are expected to become more prevalent with the aging of society. While many older adults are capable drivers, diseases that commonly occur with advanced age can affect driving abilities. Chronic medical conditions that cause subtle and progressive visual, motor and perceptual changes challenge professionals to determine when it is no longer safe to drive. A holistic framework is necessary to consider the psychological, social, functional, ethical, and legal issues involved in driving cessation decisions. Social workers who possess skills to assess driving fitness in the context of a comprehensive psychosocial, cognitive and functional assessment are needed. Advanced assessment and counseling skills, a thorough knowledge of systems and resources, and advocacy for assessable transportation are unique contributions that social workers bring to the table. Social workers who possess expertise in senior driving issues will be prepared to help the older adults and families they serve and be a valued member of the interdisciplinary team.

Older Adult Accident and Fatality Statistics

It is a common assumption that older drivers are not good drivers. When statistics evaluating overall accident risk are considered, however, older adults are actually involved in fewer accidents then younger cohorts. People aged 65 and older represent 14% of licensed drivers but are involved in 8% of accidents. Comparatively, drivers between the age of 16 and 29 comprise 13% of licensed drivers and are involved in 33% of accidents (The Hartford/MIT AgeLab, 2005).

The Hartford’s Corporate Gerontology Group and MIT Age Lab found two-thirds of older drivers modify their driving to prolong their driving years. They try to avoid high-risk situations such as rush hour, highways, and nighttime driving. They tend to drive less and primarily in local areas. Unfortunately, some of these modifications put older drivers at increased risk since more accidents occur for people of all ages at intersections that are more prevalent on local roadways. Older adults also have more difficulty following traffic signs, turning left, and determining the right of way. These difficulties contribute to higher accident rates per mile as well (Wang, C., Koslinski, C., Schwartzberg, J. and Shanklin, A., 2003). It has been suggested when accidents per mile data are examined, the accident risk of low-mileage drivers such as older adults is exaggerated (Janke, 1991).

Regardless of how accident risk data is interpreted, motor vehicle injuries are the leading cause of injury-related deaths for 65-74 year olds and are the second leading
cause of death after falls for those aged 75-84 year olds (Wang, C., Koslinski, C., Schwartzberg, J. and Shanklin, A., 2003). Older adults have less ability to survive trauma and have increased incidents of post-traumatic complications that result in death (U.S Department of Transportation, 1997).

**Emotional and Interpersonal Issues with Driving Cessation**

Emotional and social issues related to driving privilege play a significant role in an older adult’s decision to continue, modify, or retire from driving. In U.S. society, driving is very important. To be able to go where one wants to go when one chooses provides a sense of freedom. Driving represents autonomy, independence, and self-sufficiency, which are values deeply engrained in our culture.

Driving or riding in an automobile is the preferred choice for older adults. Research suggests most older adults have no experience with public transportation and may not be aware of local resources if they are available (Kostyniuk, L. and Shope, J., 2003). Since they are more likely to turn to family and friends, it is common for older adults to worry they will be a burden to others if they stop driving. This awareness leads to reluctance to give up driving even when it is no longer safe to drive. If the older adult does limit or give up driving, there is often hesitation to ask for or accept help. Trips may be limited to essential places, such as the doctor’s office, since many older adults do not want to be a “bother.” Caregivers often struggle to provide the time and transportation to meet basic needs and may be unable to offer additional transportation for social needs (Gardezi et al., 2006).

The privacy of the older adult is also impacted when all activities require someone else to be involved for transportation. The older adult who has always managed doctor visits and finances independently may not welcome the involvement of family or friends in personal business.

Social interactions and connection to the community are greatly decreased when one can no longer drive. Having the ability to get in the car to connect with others spontaneously is lost. People who drive can decide to make a quick trip to the store, meet someone for lunch, or go to a religious service when they feel the need to be socially connected. Outings become less frequent when it is necessary to plan ahead and rely on others for transportation.

There are also interpersonal implications when one retires from driving. Transportation is connected to how we control the structure of the day. Depending on someone else for a ride can be a source of interpersonal conflict. Differences in time management and punctuality can be an issue. Older adults with functional and cognitive limitations often make errands a slow process, and this can further cause frustration for caregivers who are already overwhelmed.
Differences in driving styles can also contribute to problems. Factors such as how fast one drives, how much distance there is between vehicles, and how one uses signaling are variable. These discrepancies can lead to conflict between elderly passengers and drivers. It is not surprising given the value placed on driving in our society that research has found negative outcomes associated with driving cessation for older adults. Researchers have found that former drivers report higher levels of depressive symptoms in studies when other factors such as health status and cognitive function are controlled (Ragland, D., Satiriano, W. & MacLeod, K, 2005).

Assessing Driving Competency: An Interdisciplinary Approach

The involvement of professionals is often required to determine the competency of older adult drivers and to help patients and families make the decision whether it is necessary to retire from driving. Yet the assessment of older adult’s driving fitness is still an evolving field. Professionals do not easily make the decision to recommend driving cessation. It is difficult to know when the safety risk of driving is greater than the negative consequences of driving cessation. There is not one measure that predicts with certainty whether a person will be safe on the road. A thorough interdisciplinary assessment including physiological evaluation, driving history, cognitive testing, simulated driving evaluations, on-the-road testing and State Department of Motor Vehicles (DMV) license renewal procedures can assist to determine driving competency.

The Role of the Physician

Diseases that affect sensory, motor or cognitive function all have the potential to cause functional driving impairment. Normal age-related changes in vision, reflexes, and reaction time could also impact driving ability (American Medical Association, 2007). Since health problems, medication usages, and cognitive changes occur often in older age, the physician has the opportunity to play an integral role in the driving fitness assessment and to provide recommendations regarding driving restriction and cessation.

Many older adults respect the advice of their physician when driving restrictions are indicated. Families often turn to the physician for recommendations about driving because it can be very difficult to initiate these discussions. Focus groups conducted with older adults who had stopped driving found the advice of family members alone had limited influence. Most group participant’s agreed that if their doctor also advised them to stop driving, they would (Wang, C., Koslinski, C., Schwartzberg, J. and Shanklin, A., 2003). Some physicians find this discussion to be very difficult because they understand the value driving holds for their patient and do not want to harm the patient or physician/patient relationship. Geriatricians, physicians with specialized training in treating older adults, are experienced and skilled in facilitating difficult discussions regarding driving cessation and play a vital role in the driving cessation decision.
Physicians generally follow standard guidelines to provide restrictions to patients after acute medical problems. Chronic medical problems that cause episodic or progressive changes over the course of the disease make the decision to restrict driving more complex. Conditions including cardiovascular disease, metabolic disorders such as diabetes and hypothyroidism, musculoskeletal disabilities including arthritis and foot abnormalities, neurologic diseases, polypharmacy, psychiatric illness, respiratory disease, substance abuse and visual disorders can all potentially impact driving (Wang, C., Koslinski, C., Schwartzberg, J., and Shanklin, A., 2003).

As the population ages, dementia and driving issues are expected to increase. Alzheimer’s disease, which is the most common of cognitive disorders, is a chronic and progressive illness posing unique challenges. It is estimated there are currently 5.1 million people living with Alzheimer’s disease. The risk of developing Alzheimer’s disease increases with age. Almost half of people aged 85 or older have the disease (The Hartford/MIT AgeLab, 2005).

Research indicates drivers with dementia are at risk for unsafe driving and accidents (Alder et al, 2006). Dementia affects memory as well as many other cognitive domains required in driving. Cognitive functions including learning and recalling new information, selective and divided attention, visual-spatial abilities, and executive skills such as decision making, judgment and multi-tasking are frequently impaired in people with dementia. Early in the disease, driving skills may remain intact. As the disease progresses, driving will become unsafe.

While many people over estimate their driving ability, dementia further clouds self-assessment. Particularly when the frontal lobe of the brain is affected, judgment and insight tend to be impaired. Researchers found older adults with dementia minimize driving complexity and often lack of insight into driving difficulties (Brown et al, 2005). Older adults with dementia cannot be expected to make appropriate decisions to retire from driving in a timely manner (Adler et al, 2005). Family members and professionals who work with older adults with dementia are challenged to recognize when driving is no longer safe and facilitate driving retirement.

**The Social Work Role**

The opportunity for social workers to contribute to the assessment process of older adult driving fitness is great, but underutilized. Social workers have unique training to assess the person in the context of their environment. Advanced skills are necessary to complete a comprehensive evaluation that assesses the psychosocial, cognitive, functional, and physical factors involved.

- **Functional Assessment**

Social workers working in many settings evaluate patient’s functional abilities. Completing a thorough functional history including questions related to driving is
important information to gather when working with older adults. It is natural for older adults to minimize driving difficulties if driving privilege appears threatened. People with cognitive deficits may be unable to be forthright regarding driving due to lack of insight or memory impairment. When compiling this history the social worker should obtain input from the older adult’s significant supports including family or friends. Being aware of the emotional factors tied to driving such as autonomy and independence and potential defensiveness that may surround questions related to driving makes social workers ideal candidates for assessing these issues. Obtaining a thorough functional history including questions related to activities of daily living (ADLs) and instrumental activities of daily living (IADLs), makes questions related to driving less threatening.

A thorough driving history involves asking several questions of the older adult and obtaining collateral information from someone who have information about the patient’s current driving abilities. Ideally, the older adult and family members should meet separately with the social worker to obtain accurate information. Questions related to accidents or near accidents, unexplained dents or scratches on the car, tickets, incidents of getting lost or difficulty with directions and driving safety are standard. Inquiring how the older driver handles lane position, intersection decisions, lane changes and compliance with the speed limit will provide insight into a driver’s abilities. Asking family members if they feel safe riding as a passenger with the older adult, including an open-ended follow up question of why or why not can provide insight into driving safety.

- Psychological Assessment/Counseling

It is important to assess the older adult driver’s emotional state to determine whether there are incidents of anger, frustration or anxiety while driving. Behavioral changes may be the result of a cognitive and/or psychiatric disorder that affects mood and judgment. Physical or cognitive issues that make driving more difficult can also contribute to increased anxiety and irritability on the road. When the older adult driver is exhibiting behavioral changes, safety is likely comprised.

Encouraging dialogue about pre-planning for driving cessation including exploration of anticipatory loss may ease the transition to driving retirement. Helping the older adult verbalize what driving symbolizes to them, including self-sufficiency, independence and control, is a starting point for later discussion about transportation needs and options. Since retirement from driving is a process, discussion should be ongoing. Older adults want to make decisions regarding driving and should be included in the decision making process (Bauer et al., 2003). Being actively involved allows older adults to have a sense of control over driving decisions and eases the transition to driving retirement.

- Social Assessment/Resources

Determining how the older adult relies on driving to do daily activities is necessary to assessment and future planning. Exploring where, when and why the older adult drives provides insight into self-modifications that have already occurred due to
driving issues and how driving cessation will affect daily life in the future. Information obtained about driving patterns also assists in planning for alternative transportation resources.

Since the majority of older adults get rides from others once they stop driving, informal support options need to be explored. Helping patients’ examine potential supports, personal feelings about needing help from others and interpersonal dynamics prepares the older adult for utilizing informal supports in the future. Facilitating a discussion between the older adult and his support persons allows potential issues to be openly addressed. Many older adults are not aware of community resources and do not have experience using alternative forms of transportation, making exploration of transportation resources essential (Kostyniuk and Shope, 2003). If the older adult has cognitive or functional limitations, standard forms of public transportation may not be accessible. Information gained in assessment will assist in the referral to appropriate transportation alternatives.

There are clinical situations when sufficient alternative transportation resources are not available due to lack of informal and formal social support options. When adequate transportation alternatives are not available, social and basic needs will not be met for the older adult who retires from driving. It is important to assess social support availability because the unsafe older adult may continue to drive if he or she sees no other option. The social worker will need to assist older adults lacking social supports plan for future driving retirement by considering alternative living environments that can meet basic, social and transportation needs. On the macro level, there is a role for social workers to create programs and advocate for accessible transportation so older adults are not forced to consider relocation.

• Cognitive Evaluation/Cognitive Testing

Many neuropsychological tests have been studied in relation to driving abilities. The American Medical Association (AMA) has recommended the Clock Drawing Test and Trail Making Test Part B. Both the Clock Drawing Test and Trail Making Test Part B require attention, executive function, memory and visual-spatial skills, abilities required in driving. Poor scores on these tests have been correlated with increased crash rates, impaired performance in driving simulations and on the road tests in older adults with dementia (Carr, 2006).

The Clock Drawing and Trail Making Part B tests can easily be administered and interpreted in the office setting by allied health professionals, including social workers as a part of a thorough psychosocial, cognitive and functional assessment. The American Medical Association web site offers instruction and scoring information (Wang, C., Koslinski, C., Schwartzberg, J. and Shanklin, A., 2003). The Clock Drawing and Trail Making Part B tests are helpful tools to be used as part of a comprehensive assessment to assess driving fitness. Patients and families, as well as the professional interdisciplinary team, find concrete and objective data from cognitive testing helpful in making decisions regarding driving when used in conjunction with a thorough history and physical.
The Role of the Occupation Therapist/Driver Rehabilitation Specialist

A referral to a driver rehabilitation specialist (DRS) may be needed to further assess driver safety in situations when the doctor and social worker’s assessment is inconclusive regarding an older adult’s driving capability. DRSs are often occupational therapists that are based in hospital or rehabilitation centers and have additional training and certification in driver assessment and rehabilitation. Older adults will often be receptive to this service when it is offered in a medical setting by a professional whose services are among covered insurance benefits.

Driver rehabilitation specialists contribute to the assessment process by evaluating the older adult’s ability to drive by obtaining a thorough medical and driving history and testing vision, reaction time, range of motion, strength, coordination and sensation, and cognition. Simulated driving is often part of the assessment (Stutts and Wilkins, 2003).

Following the evaluation, recommendations are given to the older adult, discussed with the family and forwarded to the referring professional. These recommendations may include continued driving with or without adaptive equipment, driving limitations based on time of day or geographical location, referral to a remedial driving course for driver retraining or suggest driving cessation until the patient has an on the road test or evaluation by the Secretary of State. The driver rehabilitation specialist does not have the right to revoke a person’s driving privilege and often can make suggestions to prolong the older adult’s driving years.

Sometimes a rehabilitation specialist assessment will not be an option if the older adult does not have insurance that covers the evaluation, cannot afford the evaluation, does not wish to have the evaluation or if the service is not accessible in the community the older adult resides. When pre-driving screening services are available and accessible, they can be quite helpful in situations when the physician and social worker need more information to make a recommendation about driving.

On the Road Driving Evaluations

Many communities have private companies that will provide on the road evaluations for older adults for a fee. They employ driver rehabilitation specialists, including occupational therapists or people from diverse backgrounds such as driver education. These resources can be found by contacting social workers who work specifically with older adults, occupational therapy departments based in your local hospital or rehabilitation center or The Association for Driver Rehabilitation Specialists online directory at www.driver-ed.org or www.ADED.net. (Wang, C., Koslinski, C., Schwartzberg, J. and Shanklin, A., 2003).

These companies often come to the client so the driving evaluation occurs in a familiar area. Companies may allow the older adult to use a personal vehicle or can require the use of the company car that provides the assessor with an emergency brake.
While evaluations by driver rehabilitation specialists including hospital based occupational therapists and through private companies that provide on the road testing is beneficial, it is not always a viable option. These services are not available in all communities. When they are available, cost can be prohibitive. Not all insurances cover the hospital based occupational therapy evaluation and none cover the on-the-road evaluation through private companies.

**The Secretary of State**

The State Department of Motor Vehicles (DMV) is the only agency with the right to revoke a person’s driving privilege. Assessment of driving fitness varies greatly from state to state. Few have age-related restrictions though some states have shortened licensing periods, require in person renewal, a test of knowledge of traffic rules, or specialized evaluations such as vision tests for older adults (Adler, 2007). If the DMV suspects a person may not be safe to drive based on red flags identified during the in-person renewal process or a history of driving violations, they may require applicants to have a physical or mental evaluation or retake vision, written and/or road tests (Insurance Institute for Highway Safety, Highway Loss Data Institute, 2007).

The DMV relies heavily on professionals to assess and identify drivers who are a safety risk. Six states (California, Delaware, Nevada, New Jersey, Oregon and Pennsylvania) require health care professionals to report people they suspect may be unsafe drivers. The state of California is the only state requiring physicians to report patients with a dementia diagnosis, regardless of the stage of disease (Adler, G., 2007). Other states encourage community members and professionals to alert the DMV of potential safety issues (Berkowitz et al, 2007).

When a family member or allied professional alerts the Secretary of State to potential safety issues by completing a Request for Driving Evaluation form, the person will receive notification of an anonymous tip. They will be asked to sign a release of information allowing the DMV to obtain information from the physician. If the person refuses to sign the release, driving privilege is revoked. If the release is signed and the physician provides recommendations regarding driving, the DMV typically follows the doctor’s recommendations. The physician can recommend driving without restriction, driving with specific restrictions, having periodic re-evaluation, suspending driving, or taking an on-the-road evaluation. The Secretary of State can provide an on-the-road evaluation at no cost to the older adult to assist in their determination if it is recommended. Following the DMV determination, the older adult receives written communication notifying them whether they can continue to drive, to drive with restrictions or whether the license is revoked. Involvement of the Secretary of State is very troubling to the older adult but may be necessary if all other measures fail to remove an unsafe driver from the road.
Ethical Issues

Driving and older adults raise many ethical issues for professionals. Clients trust that social workers have their best interests at heart. The majority of older adults view the right to drive to be in their best interests. Driving allows independence, self-determination and autonomy, values social workers recognize to be essential for well-being. When patients share their concerns about driving, they expect empathy and support.

Central to the therapeutic relationship is confidentiality. All clients should be informed at that beginning of treatment that confidentiality cannot be legally maintained when there is a risk to the safety of the client or others. Typically these risks are explained in the context of suicide or homicide. Rarely do older adults or their families envision that confidentiality may be broken by a referral to the Secretary of State due to unsafe driving.

Objective data supporting driving concerns and recommendations for driving retirement should be shared openly with clients. Practitioners may counsel unsafe older drivers to come to the decision to retire from driving because of the risks. Older adults who make the decision to stop driving voluntarily maintain a sense of control and self-determination. Exploration of other transportation alternatives can help people be hopeful about maintaining a meaningful life-style through the use of services and social supports.

The Hartford/MIT studies found many older adults prefer discussions about potential driving cessation occur with people who have insight into their driving abilities and have their best interests at heart. When patients allow professionals to talk with their family or support persons, loved ones may be able to provide emotional and transportation support and influence the older adult’s decision not to drive. Coaching caregivers on strategies to discuss driving cessation may make communication less difficult. If the older adult has not signed the Health Insurance Portability and Accountability Act of 1996 (HIPPA) paperwork and does not want his or her family involved, the client’s confidentiality must be protected.

Denial regarding driving ability deficits and/or lack of insight due to cognitive disorders may impair the older adult’s decision-making capacity. When clients decide to continue driving despite evidence that it is not safe to do so, professionals face an ethical dilemma. Professionals need to be knowledgeable about state DMV requirements since they vary greatly state to state. The Physician’s Guide to Assessing and Counseling Older Drivers provides a summary of each state’s mandates for professional reporting to the DMV (Wang, C., Koslinski, C., Schwartzberg, J., and Shanklin, A., 2003). If the professional is required to notify the DMV, then he or she must do so despite a breach of confidentiality. In states such as Michigan where the professional is not mandated to report, the decision is more difficult. If disclosure to the DMV is necessary to protect the client and the community based on competent clinical judgment, then it is ethically appropriate to inform even in the absence of a legal responsibility to do so.
While in many states the professional can choose to make an anonymous referral to the DMV, he or she must consider whether it is ethical to withhold this information from the patient. The National Association of Social Workers takes the stance that social workers are ethically bound to inform clients when they do not keep information confidential out of necessity to “prevent serious, foreseeable and imminent harm.” Given the trust invested in the therapeutic relationship, it is best to be honest when a referral to the DWV is warranted. When social workers do report, they should provide the least amount of information necessary to preserve confidentiality to the highest degree possible.

Organizations that employ social workers may have their own policies that guide decisions about notifying the Secretary of State. Ethics committees in the workplace and professional associations may be a source of consultation and support in situations when it is not clear if a referral to the Secretary of State is indicated.

Social workers have an ethical responsibility to challenge systems when they are not responsive to the needs of the clients we serve. If unsafe older adults are to retire from driving, resources must be available to help them meet their basic and social needs through accessible, affordable and safe transportation. Many communities lack even minimal transportation options, particularly in rural areas. Clinicians are encouraged to seek opportunities for collaboration with government and community organizations to assist in the planning process to develop acceptable transportation options (Bauer, M., Rottunda, S., and Adler, G., 2003).

Summary

Health problems more common in older age often impacts driving abilities. It can be difficult to determine whether the older adult with limitations is safe to remain behind the wheel. Older adults with driving impairments may be reluctant to retire from driving due to the autonomy and independence driving represents. Social workers who are skilled in completing a thorough psycho-social, cognitive and functional assessment, that possess advanced counseling skills and awareness of community resources are needed to help older adults make safe driving decisions. Knowledge of the ethical and legal issues involved in driving cessation further prepares social workers to work with older adults and their families in clinical practice.

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Clinical Practice in a Memory Disorder Clinic: Ethical and Legal Issues

Judy Shipman, LCSW

Overview

The state of Florida has a large and growing older adult population. According to the Florida Department of Elder Affairs, people over the age of 60 make up 22.7 percent of the State population. Florida ranks first nationally in the number of older adults (those over the age of 60) and fourth in the nation of adults over the age of 85. The impact of this demographic is significant because adults who are over the age of 85 are most at risk for debilitating illnesses (Florida Department of Elder Affairs, 2006, p. 3). Age is also the greatest risk factor for Alzheimer’s disease. According to a 2008 report by the Alzheimer’s Association, one in eight individuals over 65 and nearly half over 85 are affected by this disease (Alzheimer’s Association, 2008, p.9).

The Alzheimer’s Association report projects that Florida will have 450,000 residents age 65+ with Alzheimer’s disease (AD) by 2010, a 25% increase from 2000. The only state projected to have a greater number of persons with AD is California, whose projected 480,000 people with AD in 2010 represents an increase of 9% (Alzheimer’s Association, 2008, p.19).

In 1985 the Florida Legislature established the Alzheimer’s disease Initiative (ADI) as a way to address the needs of some of these elderly and their caregivers. “The ADI is one of the most comprehensive programs in the nation addressing Alzheimer’s disease and related dementia” (Florida Department of Elder Affairs, 2007, p.3). The Memory Disorder Clinics (MDCs) are important components of the ADI. Currently Florida has 15 state designated MDCs, 13 of which receive state funding. Clinics are directed to pursue three goals:

- Encourage early diagnosis and treatment through screenings and medical evaluations;
- Provide education, resources and information to professionals, caregivers and the general public;
- Pursue basic medical and applied research to discover the causes and improve the understanding of these disease (Florida Department of Elder Affairs, 2008b).

The MDC at Tallahassee Memorial Hospital was founded as a state designated center in July, 1998. During the first year the clinic was open, 56 people were evaluated. During the fiscal year which ended on June 20, 2008, 332 people were seen. Even though Tallahassee is one of the younger areas of the state demographically, continued growth is expected as the population ages.
The treatment team includes a neurologist/medical director, a neuropsychologist, pharmacists, social workers and an administrative assistant. Of these, only the administrative assistant and one of the social workers, who also serves as Clinic Coordinator, are full time employees. The Tallahassee MDC currently conducts patient evaluations three days per week. Evaluation includes visits with the appropriate medical professionals. Neurological assessment is performed to rule out other conditions that can cause memory loss, such as stroke or seizures. The neuropsychologist administers a battery of cognitive tests to determine areas of strength and weakness in functioning. Since many seniors are prescribed multiple medications by multiple physicians, a pharmacy evaluation can focus on medications that may be cognitively impairing and problematic medication interactions. The social worker meets with family members to assess their situation, resources and coping skills. Weekly multidisciplinary case staffing and discussion lead to diagnosis and the creation of a detailed summary report and recommendations which are given to the patient, his/her family and the referring physician. The evaluation includes an exit conference at which results and recommendations are presented to the family for review. Potential ethical and legal concerns may arise at any point in this evaluation process and influence practice decisions.

The Tallahassee MDC is one of only two clinics in the state that employs a master’s level social worker as Clinic Coordinator. We also have a half-time master’s level social worker to assist with assessment and counseling. In addition we benefit from the placement of social work interns from Florida State University for most of the academic year. The breadth and depth of social work skill available to the Tallahassee MDC are invaluable when ethical and legal issues arise.

Ethical Base for Practice

There is no single accepted definition of clinical ethics. The Social Work Dictionary defines ethics as “a system of moral principles and perceptions about right versus wrong and the resulting philosophy of conduct that is practiced by an individual, group, profession or culture” (Barker, 1995, p.124). Ahronheim, Moreno and Zukerman (2000) note three commonly cited principles that underlie ethical decision making: patient self determination (autonomy), justice, and beneficence. Self-determination, or autonomy, asserts that the patient is the ultimate authority on what is best for his or her well-being. Beauchamp and Childress (2001) further define the principle as respect for autonomy asserting that respect involves respectful action not just a respectful attitude. The professional obligations that flow from autonomy include truth telling, respect for privacy, protecting confidential information, obtaining consent for interventions with patients, and when asked, helping others make important decisions. Beneficence instructs the clinician to act in the patient’s best interest by protecting and defending their rights, helping people with disabilities and rescuing people in danger. The principle of justice mandates equal treatment to all members of society, including those who are most disadvantaged, and a fair distribution and purposeful stewardship of healthcare resources.
These principles are echoed in the Social Work Code of Ethics. The Code defines the purpose of the profession particularly its duty to vulnerable populations. The Preamble states, “The mission of the social work profession is rooted in a set of core values. These core values, embraced by social workers throughout the profession's history, are the foundation of social work's unique purpose and perspective:

- service
- social justice
- dignity and worth of the person
- importance of human relationships
- integrity
- competence (NASW, 1999)

From these values a set of ethical principles guides practice standards. These standards include duties and obligations to clients, colleagues and practice settings as professionals, the profession and the broader society.

Standard 1.02 specifically addresses the issue of self determination. “Social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals. Social workers may limit clients' right to self-determination when, in the social workers' professional judgment, clients' actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others” (NASW, 1999)

Standard 2.03, Interdisciplinary Collaboration, is particularly applicable to the Memory Disorder Model: “(a) Social workers who are members of an interdisciplinary team should participate in and contribute to decisions that affect the well-being of clients by drawing on the perspectives, values, and experiences of the social work profession. Professional and ethical obligations of the interdisciplinary team as a whole and of its individual members should be clearly established.” Team collaboration and mutual respect are essential to arriving at an appropriate diagnosis and treatment plan. This enables the social worker to have the best possible information with which to assist the family with coping skills and future planning. In additions the skills of the social worker are essential to the rest of the treatment team in providing appropriate communication counseling and resource acquisition. As the population ages, the responsibility of social workers to the broader society, will mandate increased services to this vulnerable population.

The principles of beneficence, autonomy, and social justice are equally congruent with the Social Work Code. Problems and ethical issues arise when these obligations conflict with each other. Abramson (1989) describes circumstances when paternalistic beneficence guides ethical decision making when the client’s choice may place them in danger. The intent is to protect the client but the effect is to violate the client’s wishes. Social justice would direct the clinician to develop a contextual framework to guide decisions that limit the client’s autonomy to assure transparency and equal application. Much of the research and study of the interface between ethical issues and geriatrics
focuses on end-of-life issues, such as the role of advance directives in decision making. Ethical problems can also arise when dealing with a generally healthy adult who is suffering from cognitive decline. For example the adult may wish to make a decision that may not be in his/her best interest. Family members and medical professionals (including social workers) may want to enforce decisions that are at odds with the patient’s wishes but may be seen as being for his/her benefit. Which standard then takes precedence? As might be expected, the answer often is neither clear nor simple.

The Code of Ethics does provide some guidance but a model for ethical decision making inclusive of the context of the dilemma, professional literature, ethical principles and perspectives, legal and regulatory mandates, the values of all parties, and a review of the available options for resolution is a more effective approach to ethical problem solving than reliance of the Code of Ethics alone (Joseph, 1983).

The Alzheimer Society of Canada, which in 1997 released a series of ethical guidelines, defines an ethical dilemma as a situation in which:

- one is unsure of what to do;
- two or more values may be in conflict
- some harm may be caused no matter what one does

The values underlying these guidelines are again familiar to social workers and congruent with the code of ethics: respect for the dignity of the person, compassion, concern, integrity and competency (effective, appropriate services). The website (www.alzheimer.ca) includes sections on driving, living alone, decision making, quality of life, participation in research, genetic testing, restraints, intimacy and sexuality, and tracking devices.

In 1995 the Center for Biomedical Ethics at Case Western Reserve University School of Medicine developed “Fairhill Guidelines on Ethics of the Care of People with Alzheimer’s Disease (Post and Whitehouse, 1995). This document, according to a summary published in the Journal of the American Geriatrics Society includes the issues of truth-telling and diagnosis, driving privileges, respecting choice (autonomy, capacity and competence), problems of behavioral control, issues related to death and dying and quality of life.

Many of these issues and concerns are part of the daily experience in the course of a MDC evaluation.

**Truth Telling: Communicating the diagnosis**

**Case example:** A 70 year old man comes to the MDC for a baseline diagnosis and is found to have normal memory for age. He returns every two years. On his third visit, testing indicates the beginnings of cognitive decline. The man comes to the clinic without a family member and the social worker knows from previous visits that he and his wife do
not get along well. In addition, at each visit, he describes in detail how he will kill himself (he has been saving medications) if the diagnosis of Alzheimer’s is ever made.

The ethical decision making process begins with decisions by the team and family regarding sharing the diagnosis. It is still impossible to make an absolute diagnosis of Alzheimer’s disease before autopsy. It remains a “rule out” diagnosis, a presumptive diagnosis of “possible” or “probable” Alzheimer’s after other causes for the symptoms have been ruled out. Many people are afraid of the word “Alzheimer’s” and the mental pictures it evokes. It is common to hear something like, “my mother doesn’t have Alzheimer’s disease; she just has dementia.” In fact, dementia is an “umbrella” term encompassing many types of conditions, of which Alzheimer’s is by far the most common.

In the culture of western medicine, we believe that people have the right to know their diagnosis and prognosis in order to make the most informed choices. However, many family members come into the MDC asking specifically that the word “Alzheimer’s” not be mentioned. Often, the patient has had prior experience with the disease and its most difficult aspects, such as in taking care of a parent or spouse. One has to wonder, however, whether the patient or the caregiver is the one who needs protection from the diagnosis. It is always critical, of course, to be aware of cultural considerations in communicating a diagnosis. Not all cultures adhere to the western dictum that the patient must be told, and for some cultures, this is quite inappropriate (Galanti, p.143).

The team may experience ethical distress when asked not to meet their obligation to tell the truth to protect the patient from unnecessary distress. The team will work with the family to frame the discussion to meet the patient’s request for information while protecting the patient. Respect for the family’s perspective further the treatment bond between the team and the family in meeting the patient’s care needs.

Communicating a diagnosis should be completed in a quiet place by a caring professional, with significant time allowed for questions and discussion. And the insight of the patient should never be underestimated. It is not unusual for a professional to try to soften the diagnosis using terms such as “memory problems” or “dementia” and to have the patient look directly at him/her and ask, “Do I have Alzheimer’s disease?” While one can fall back on the fact that we can not know for sure, honesty is surely the best policy in such a case. On the other hand, families sometimes demand that the patient be told the diagnosis in the belief that he/she will be more reasonable if aware of the condition. This rarely works. Even if there is an initial understanding, the combination of memory loss and lack of insight usually make such a tactic useless and unnecessarily harsh.
**Driving**

**Case Example:** Patient is told by the neurologist and again at exit conference that he should not be driving. He does not agree. A few days later his daughter calls to report that he continues to drive; she wants to know what the MDC can do to stop him.

Whether a person should drive is one of the most difficult topics discussed at a MDC. At the Tallahassee MDC which serves nine very rural counties in addition to the Tallahassee/Leon County area, the discussion is intensified, because for many of our patients there are simply no good alternatives to driving. Besides the symbolic meaning in our culture where a car equals independence, as a practical matter not having a car can mean not being able to leave home.

To further complicate the issue, a diagnosis of Alzheimer’s disease does not necessarily mean that a person is not competent to safely drive a car. Driving is a complex skill, and for most of us it is a skill embedded in our long term memory. Alzheimer’s disease first attacks the short term memory; for otherwise healthy adults driving may still be safe for a time. However, eventually the disease of Alzheimer’s will make driving unsafe.

In these cases the principles of autonomy and beneficence collide, and responsibility to others plays a part as well. In particular, the social worker has a dual obligation to promote the patient’s interests while protecting the common good of society. Ahronheim (2000) includes the principle of nonmaleficence (doing no harm) as part of beneficence. By restricting the patient’s driving privileges the team protects the interests of society at large. The patient’s decision to continue driving may very well put them as well as others at significant risk.

Reactions to a recommendation to stop driving vary greatly. Some patients have already made a decision to stop, perhaps following an accident or an incident of becoming confused or lost. Other patients simply refuse, sometime quite vehemently. Family reactions vary as well, from a desire that the MDC somehow enforce the directive to a desire to keep their loved one independent by allowing them to drive perhaps within a restricted area.

There are, in fact, several actions that can be taken. First, if the person is still able to drive, conversation about what will happen when they are no longer able is critical. Most helpful is a formal driving evaluation by a certified Occupational Therapist who can further clarify the situation; however these are not always available.

Written directives are often helpful since the patient may truly not remember being told that driving is unsafe. Many physicians will write “no driving” on a prescription form, which can be used as a reminder. The written MDC report can also be used for this purpose. The state of Florida Department of Highway Safety website includes a downloadable anonymous reporting form to report concerns and trigger further evaluation.
No matter how skilled the professionals are, much of the burden for stopping the patient from driving will fall on the caregiver. They are encouraged to shift “blame” to the professionals, but they are the ones on the front lines. Suggestions may include removing keys or removing or disabling the car. It is important to remember that persons with dementia may be quite capable of calling a locksmith or even buying another car. It is critical that every effort be made to enable the person with dementia to get where they need to go – church, senior center, club meetings, outings with friends – to maintain quality of life.

**Autonomy and choice**

This principle is at the crux of many practical and ethical dilemmas facing professional and family caregivers. Kitwood (1997) asserts “men and women who have dementia have emerged from the places where they were hidden away; they have walked on to the stage of history and begun to be regarded as persons in the full sense” (p.133). One can only hope that this is true, and that we never deny the person with dementia his/her personhood. “People with dementia should be allowed to exercise their remaining capacities for specific tasks and choices; denying these choices challenges their independence and dignity” (Post and Whitehouse, 1995, p.3). However, as the Canadian Guidelines state, “a diagnosis of Alzheimer's disease, in itself, does not mean that a person is immediately incapable of making decisions. However, as the disease progresses, a person's decision-making abilities will change.” (Alzheimer's Society of Canada website).

The concept of a person with a diagnosis of AD or dementia making informed decisions is a surprising one for many who do not realize the variations of impairment at different stages of the disease. Particularly in the early stage of the disease, although impairments in short term memory are present, many choices can still be made. Although a person may not be able to make sophisticated financial decisions or even manage their checkbook, they may still be able to name a Power of Attorney or make the decisions needed for a Living Will. Indeed, it is at this stage when such choices and documentation should be completed, if this has not been done previously, to avoid the conflict and confusion that may arise later.

This said it is often extremely difficult to determine what choices a person is safely able to make. Should they remain at home, living alone? Should they drive? What level of supervision is necessary? What about spending money? What about intimate relationships, sex or marriage? The dilemma is complicated by the inability of the patient to recognize their own limitations, which is characteristic of the disease. Thus, attempts by caring professionals or loving family members to limit freedom and activities are frequently seen as unnecessary, even cruel. Since suspicion and paranoia are also common symptoms, caregivers will not be thanked and may suffer anger and even verbal or physical abuse in response to their attempted interventions.

The question of capacity often leads to issues of guardianship. If advance care decisions are not made early in the dementia process, the family may be faced with the
need to take legal action assume guardianship. In Florida, a three person examining committee is appointed to advise the Court on the person’s abilities. Such decisions are not made in the MDC, although the MDC report is often submitted as part of the process.

**Behavioral Control**

**Living alone**

**Case example:** A woman is brought to the MDC by her daughter. The daughter has been living with her mother, but is planning to move to NYC in two weeks to start a graduate program. The plan is for the mother to continue to live at home, alone. She is still driving. Examination indicates that the mother is entering middle stage dementia, probably AD. Alternatives suggested to daughter include an assisted living facility or hiring a case manager. Daughter rejects all suggestions.

Safety is a primary concern for a person with Alzheimer’s disease, and living alone certainly does pose risks. On the other hand, many people in the earlier stages of the disease do best in familiar surroundings and with a well-known routine. This is why sometimes the disease is not diagnosed until people are removed from their environment, perhaps during a trip or a hospitalization. So again, a diagnosis does not indicate a clear direction.

Evaluation of supports and safety concerns can help with decision making. Clinic staff tries to determine the level of support from family and community. How often are family and friends coming to visit? Is there a regular check such as Meals on Wheels? The belief is that the more eyes on the situation, the better. As for safety, indicators such as forgetting to turn off appliances such as the stove may be a warning sign. Forgetting to take medication or not taking it correctly is another concern. Perhaps the person is forgetting to pay bills – has the power or the phone ever been shut off? People who live alone may also be targets for unscrupulous salesmen or may open the door to a stranger when it is not safe to do so.

Adjustments can be made to keep the person in the home as long as possible, ranging from a pill box organized by a family member to a personal caregiver. However at some point, living alone will no longer be possible. The sooner the family starts to discuss and plan for this eventuality, the less likely it is that decisions will have to be made at a time of crisis.

The case cited above was the subject of intense discussion. After the daughter left, the woman returned for a follow up appointment with no idea why she was there and no memory of past visits. At this time the decision was made to call in a report of elder neglect. Although the investigation did not lead to any changes, (the woman was not judged to be at imminent risk), staff agreed that this action was warranted.
Personal life, intimacy and sexuality

Case example: A patient was brought in by her daughter with whom she was living. She was diagnosed with probable Alzheimer’s disease, early stage. Several weeks later the daughter called to say that her mother was planning to marry a man she had met at the local Senior Center. The daughter did not feel that this was in her mother’s best interest; she felt that the man was after her mother’s money and would not take good care of her. She asked how to stop this marriage from taking place.

When is it appropriate to extend control into the most private aspects of life? This is a difficult topic for many, especially for adult children. In this case, the clinic social worker did not have enough information to accurately evaluate the merits of this situation, other than knowing that the disease does affect decision making and judgment. However, a diagnosis of probable Alzheimer’s disease does not automatically affect legal capacity or rights. The daughter was advised to seek legal assistance.

Financial affairs

Case example: A prominent and quite wealthy member of the community has been diagnosed with Parkinson’s disease and Lewy Body Dementia. He never completed a Power of Attorney and now there is disagreement about who should be in charge of his affairs – his (second) wife or his children. The children wish to prove he was not competent when he married her.

Issues of money and financial control emerge frequently. Many families are genuinely concerned and wish to preserve resources to ensure good future care. At other times, relatives may have different motives. For whatever reason, family members may ask the MDC to make a determination as to whether the patient is competent to handle financial affairs. Again, an adult is presumed to have capacity until determined otherwise, and this is a legal determination. While memory may be a component of capacity, it is not the only component. Capacity is a determination best left to trained evaluators and the legal system.

Quality of life.

As Alzheimer’s disease progresses, a person loses many of the skills and abilities that considered important to quality of life. “All those who participate in the lives of people with Alzheimer’s disease should know or learn that, despite changes and loss of abilities, people with Alzheimer's disease are able to find pleasure and experience satisfaction. The disease does not remove a person's ability to appreciate, respond to and experience feelings such as anger, fear, joy, love or sadness. Recognizing an individual's abilities, interests and life-long skills helps to maintain and enhance that person's quality of life.” (Alzheimer’s Society of Canada website). It is part of the job of a MDC to educate family and professional caregivers on the ability as well as the disability of the person with AD. Professional staff works with family members to plan for a good quality of life for the patient.
At the same time, the quality of life of the caregiver cannot be ignored. Caregivers commonly neglect their own health and wellbeing. According to the Family Caregiver Alliance, a “substantial body of research shows that family members who provide care to individuals with chronic or disabling conditions are themselves at risk. Emotional, mental, and physical health problems arise from complex caregiving situations and the strains of caring for frail or disabled relatives.” (Family Caregiver Alliance website).

Thus, maintaining caregiver wellbeing is essential to maintaining patient well being. This can bring the wishes of the patient and the needs of the caregiver into opposition. The caregiver may have promised never to place the parent or spouse into a nursing home and then may find that promise to be untenable when that person becomes belligerent, or incontinent. Caring and professional staff can help negotiate between the differing wants and needs of the patient and the caregiver, attempting to find a “good enough” solution.

Autonomy, beneficence, safety and quality of life are all important considerations when working with patients with AD and their caregivers. And, as indicated, these important values are sometimes in conflict. Although not all of Florida’s MDCs employ social workers, it would seem that the profession is an ideal one to help negotiate between these values and concerns. Working with patients and families, assessing and accessing strengths, support systems, community resources, taking time to learn family and cultural values, is the best way to ensure an acceptable, ethical outcome.

Death and dying

While most patients who are seen at a Memory Disorder Clinic are in relatively good health, the issue of advance planning is frequently addressed. When the diagnosis is made in the earlier stages of the disease the patient is still able to understand advance directive options and their purpose and to plan accordingly. It becomes the responsibility of the social worker to educate the patient and family about options and planning tools and to refer to legal counsel when appropriate (Alzheimer’s Association – South Central Wisconsin, 2002).

Conclusion

Alzheimer’s disease and other conditions affecting the cognitive and functional abilities of older adults represent potential threats to emotional well-being, safety, physical health and quality of life for the patient and any involved caregivers and/or family members. The increase in numbers of such circumstances makes effective intervention crucial, not just for the affected patients and their families, but for communities at large. The Memory Disorder Clinic at Tallahassee Memorial Hospital offers a treatment team
approach to address such circumstances and provides insight into how professionals can collaborate effectively and ethically with older adults with Alzheimer’s or related health concerns.

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