Module # 1: Introduction to Aging
Module # 2: Interdisciplinary Teamwork
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 2: Interdisciplinary Teamwork

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Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

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## Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

### Module # 2: Interdisciplinary Teamwork

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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 2: Interdisciplinary Teamwork

I. Overview

An interdisciplinary healthcare team brings together a group of individuals with diverse training and education to work on an identified task. These healthcare teams can include doctors, dentists, nurse practitioners and registered nurses, occupational therapists, pharmacists, physician assistants, physical therapists, social workers, nutritionists, and clergy. Team members collaborate to address patient problems that are too complex for one discipline, or even many sequential disciplines, to solve. At the most basic level, effective teamwork depends on the ability of members to determine the overall mission, establish shared and explicit goals, and work collaboratively to define and treat patient problems. Ideally, teams can also learn to accept and make use of disciplinary differences, differential amounts and types of power, and overlapping roles to clarify and evaluate the team’s development and effectiveness.¹

II. Learning Objectives

1. Define an interdisciplinary team.
2. Describe the need for interdisciplinary teamwork.
3. Delineate three goals of an interdisciplinary team.
4. Describe two benefits and two problems unique to a team environment.
5. Identify three types of interdisciplinary teams.
6. Identify the various roles of interdisciplinary team members.
III. Defining a Team

The word “team” derives from Old English and is defined as “a group of animals harnessed together to draw some vehicle”. Today, there are many definitions and descriptions of teams, and the team 'concept' is broadly utilized in the corporate world, government agencies, and military organizations. For the purposes of this curriculum, however, we will focus on teams in the healthcare system.

A. **Multidisciplinary vs. Interdisciplinary Teams:** The terms multidisciplinary and interdisciplinary are often confused when referring to team structure and process in the healthcare setting. Members of a multidisciplinary team typically work together in caring for the patient, but only one team member, such as a physician or nurse manager, makes the treatment decisions. On the interdisciplinary team, the decisions are made by the group.

B. **What is an Interdisciplinary Team?** Here are three definitions of the interdisciplinary team that can help frame a discussion on teamwork:

1. "A team is a small number of people with complementary skills who are committed to a common purpose, performance goals, and approach for which they hold themselves mutually accountable."  
2. "The interdisciplinary team is a group of persons who are trained in the use of different tools and concepts among whom there is an organized division of labor around a common problem with each member using his own tools, with continuous intercommunication and re-examination of postulates in terms of the limitations provided by the work of the other members and often with group responsibility for the final product."  
3. "Teamwork can be broadly defined as a mechanism that formalizes joint action towards mutually defined goals."  

C. **Trans-disciplinary Teams:** Recently there has been a growing emphasis on “trans-disciplinary” (or “cross-disciplinary”) teamwork. In these teams, which are rooted in the research and business worlds, members of different disciplines are not only proficient in their own specialties but also, through cross-training and working on the team, become knowledgeable in other specialties as well, making team members' skills overlap. Trans-disciplinary training and teamwork not only allow the provider to see a more complete picture of each patient, but also allow a single provider to assess and, in some cases, treat patients in an area other than his or her own.
IV. The Rationale for Teamwork

A. **The Advantages of Teamwork:** There are many strong reasons for teamwork. Chief among these is the fact that teams are client-centered and helpful in addressing complex health and psychosocial issues such as in geriatric patients and those with life limiting illnesses. However, teamwork does require work and commitment from both the team members and the organization. For example, teams may be personnel and resource intensive, thus requiring commitment from institutional leaders. Furthermore, teamwork calls for tolerance and respect among members. Some health professionals shy away from teams because they have been members of teams which were dysfunctional for a number of reasons, including a lack of leadership, interest, structure, and process.

B. **Better Care for Patients:** Patients who are older or facing life limiting illnesses are best served by interdisciplinary teamwork as described below.

1. **Within Geriatric Care:** Older people are more likely to suffer from complex illnesses, and are thus best served by a team approach. The complexity of formulating a treatment plan entails addressing multiple illnesses, disabilities, medications, and procedures. Because geriatric patient care has often been uncoordinated, treatments may overlap or conflict causing great confusion. Therefore an interdisciplinary team can offer a comprehensive and integrated means of providing effective care.

2. **Within End-of-life and Palliative Care:** Traditionally, care at the end of life was administered solely by a physician. However, patients requiring palliative care generally suffer from an advanced disease in which problems and symptoms are complex and urgent. There are many aspects to palliative care such as pain management, advanced directives, and the alleviation of psychosocial and spiritual distress. Therefore, interdisciplinary care planning and coordination is essential.

V. Goals of the Team

A. **Guidelines:** Team goals will oftentimes vary. However, the following general guidelines will facilitate effective teamwork and maximize patient outcomes.

1. Interdisciplinary team members agree on the mission.

2. The mission of the geriatrics team is viewed as realistic and achievable. If not, team members agree to narrow the mission to a workable size.

3. There is a clear team vision, and the group can progress steadily towards the established goals.

4. The purpose of the meetings, discussions, individual efforts and other
activities is understood to relate to the larger project.\(^6\)

VI. Benefits Unique to a Team Environment

A. Recent studies suggest that both patient and healthcare professionals involved in interdisciplinary teams experience many benefits.

1. The interdisciplinary team will have broadened access to resources – funds, research design development, data collection, computerized data management, statistical consultation and data analysis, grant writing, support staff, sustained communication, and costs of presentations and publication.

2. The accountability that each team member has to one another will increase timely completion of designated tasks and maintain quality standards.

3. Shared responsibility for completion of tasks and preparation of materials for dissemination will enhance the geriatrics team’s level of productivity.\(^7\)

4. Team meetings offer opportunities for informal contacts and feedback among the disciplines concerning patient care that is unrelated to the specific cases scheduled for discussion.

5. The meetings also allow ease of access to each other and reduce time needed for healthcare professionals to connect with each other about patient care.

6. It is highly probable that interdisciplinary geriatrics team care for the elderly will prove to be more cost-effective than traditional medical approaches.\(^8\)

VII. Problems Unique to a Team Environment

A. Culture and philosophy of each discipline: Every discipline has its own culture and philosophy toward geriatric patient care which can create misunderstandings and lack of sympathy by members of one discipline towards the members of another discipline. The culture also results in a specific language or jargon, which may lead to miscommunication. Until the members of the disciplines become familiar with these different nuances of meaning, difficulties may arise in both clinical and educational settings.

B. Varying Qualifications: Required qualifications for healthcare disciplines vary and can range from doctoral or fellow status to bachelor’s degree or para-professional training. The differential status that is assigned by society because of educational attainment can influence how power and leadership are distributed on a team rather than actual knowledge, expertise or familiarity with the specific
patient case.

C. **Scheduling and Time Constraints:** Healthcare professionals may divide their time between various locations. The logistics of bringing the disciplines together for team meetings or even of engaging in telephone contacts can be daunting, especially when the various disciplines tend to follow different scheduling patterns.9

VIII. **Types of Teams**

A. **By composition:** The University of Pennsylvania GITT planning year group identified five types of geriatric interdisciplinary teams based on their professional composition.

1. **The Nurse-Dominated Team:** This team consists of nurse practitioners, geropsychiatric clinical nurse specialist, registered nurses, physical and occupational therapists, speech and language pathologist, social worker, geriatrician, and psychiatrist. It is strongly patient-centered and focused on time-limited intensive rehabilitation of elders.

2. **The Nurse-Physician Team:** This team is composed of geriatricians, two nurse practitioners, and one social worker. It delivers community-based care in the patient’s home and relies heavily on shared roles and informal mechanisms of communication and clinical management.

3. **The Physician-Dominated Team:** This team, which provides interdisciplinary assessment and primary care for older adults, consists of nine physicians, one registered nurse, two nurse practitioners, and one social worker. Patients are assigned to a physician and interact with other team members as appropriate.

4. **The Social Work-Dominated Team:** This team practices in an assisted living facility offering other levels of acute and skilled nursing home care. The team consists of an administrator, assistant administrator, social worker, physicians, nurse manager, and an activity coordinator. The team involves physicians as medical problems arise, but for the most part, social workers manage day-to-day care for these elders experiencing functional losses.

5. **The Consensus Model Team:** This type of team divides the facility into separate units, each of which is led by a nurse practitioner, in consultation with the medical director. It provides roles for a wide range of team members, including registered nurses, social workers, dietary staff, and recreational aides.

B. **By setting:** There are also types of teams based on the location of care and
the awareness that elders are often transferred from setting to setting.  

1. **Hospital-Based Inpatient Team**: Due to specific changes in medical status, patients are frequently admitted directly from the home, doctor's office, or the Emergency Department to a unit within the hospital. This hospital-based inpatient team then provides acute care for the elderly within the hospital setting. Physicians and nurses perform an initial assessment, monitor the patient's health status by making rounds, and collaborate to formulate an effective treatment plan.

2. **Ambulatory Care Team**: The outpatient geriatrics interdisciplinary team is increasingly used for initial assessment and ongoing care coordination. Typically, the interdisciplinary team consists of a physician, nurse and social worker with the "extended team" comprised of representatives from rehabilitation therapy, psychiatry/psychology, nutrition, and pharmacy. A comprehensive initial assessment includes evaluation by each of the three core team members -- physician, nurse practitioner and social worker -- with inclusion of other specialties on an as-needed basis. Some teams may assess patients on a quarterly basis with the team meeting more frequently for clients in acute care. Outpatient teams meet in a variety of ways, including face-to-face meetings, hallway conversations, and telephone consultations and increasingly through virtual means such as e-mail.

3. **Emergency Department Team**: This team, most likely not geriatrics specific, may consist of registered nurses, physicians, and/or surgeons that provide acute care during a medical emergency. Because of the nature of the department, the patient's time with this team is limited. Therefore, it is imperative that the emergency department team ensures that care is properly transferred to a member of the patient's usual interdisciplinary team.

4. **Home Care Team**: This type of geriatrics team may include a social worker, a nurse practitioner, and/or a physician who make regular visits to the patient's residence to assist the patient's with his or her medical problems and to monitor the patient's ability to live at home. Because home care or hospice services enable the patient to remain in a familiar, comfortable environment with some degree of autonomy, this model of care is becoming increasingly popular.

5. **Nursing Home Team**: Because the medical problems of elders are often chronic, complex and sometimes accompanied by limited cognitive capacity, older adults are not always able to continue living at home. When this occurs, the nursing home provides a setting for an interdisciplinary geriatrics team to monitor and treat the chronic illnesses of frail patients on an ongoing basis.
6. **Palliative Care Team**: The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized system for delivering care. Comprehensive palliative care services often require the expertise of various healthcare professionals in order to adequately assess and treat the complex needs of seriously ill patients and their families. Members of a palliative care team may include professionals from nursing, medicine, social work, chaplaincy, nutrition, rehabilitation, pharmacy as well as other disciplines. Trained volunteers are sometimes part of palliative care teams as well. Team leadership, collaboration, coordination and communication are key elements for effective integration of these disciplines and services.12,13,14,15

7. **Community-Based Assessment Teams**: Elderly persons in rural areas are less willing to seek mental healthcare, despite the fact that they have a greater need for the services which may be available to them. Reasons for this behavior include factors associated with rural life, including poorer health status, greater poverty, and lack of specialized providers. One strategy which has been shown to increase the utilization of services in rural areas is a mobile multidisciplinary team of a psychiatrist or psychologist, nurse, and social worker that conduct in-home mental health assessments.16

**IX. Geriatric Care Teams**

A. **Geriatric teams** can be confined to one setting, such as a hospital unit, or span various settings, such as a geriatric consultation team. One of the major challenges in effective teamwork is ensuring successful transitions as the patient moves from setting to setting along the care continuum.

B. **Typical Settings for Geriatrics Teams**: Geriatric teams can be found in a multitude of settings, including just about any facility or agency that provides services for the elderly. Long-term care facilities, inpatient and outpatient mental healthcare agencies, home care agencies and facilities or agencies providing palliative care are all typical settings for Geriatric teams.

C. **Team Members: Professional Roles, Education and Skills**: See attached chart, “Houston Geriatric Interdisciplinary Team Training Manual: Team Members Overview” (See Learning Resource D)

**X. Development of a Team**

A. **It's a Process**: Becoming a team is a process in which missions and tasks are defined and the members define their roles and relationships.
B. Phases of team development:

- Forming - creation stage of the group
- Norming - norms and patterns are worked out
- Storming - tasks and roles are worked out through conflict
- Performing - team working together for improved patient care

For expanded explanation of the above, refer to the handout from the University of Colorado Health Sciences Center's Geriatrics Interdisciplinary Team Training Workbook: “Forming, Storming, Norming, and Performing”17 (See Learning Resource D)

C. Repeating the Process: Each time the team composition changes, the process of team development is repeated. Particular attention must be given to the orientation of new team members.

XI. Different Roles Within a Team

A. Team Functions: Aside from the professional role as described in Section IX above, various team members also fulfill certain informal (but critically important) team functions and responsibilities. The assumption of these responsibilities for the group 'process' ensures that team decision-making, as well as care plan implementation, proceeds smoothly and efficiently. See Table 1: “Functions of Different Roles Within a Team”.

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<tr>
<th>ROLE</th>
<th>RESPONSIBILITIES</th>
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<tr>
<td>Facilitator</td>
<td>Leads the team through the agenda and the consensus making process.</td>
</tr>
<tr>
<td>Recorder</td>
<td>Writes down the team’s decisions. Checks to make sure that what everyone hears is what the team member means.</td>
</tr>
<tr>
<td>Timekeeper</td>
<td>Watches the clock. Informs the team when half of the allotted time has expired, when only five minutes remain, and when time is up.</td>
</tr>
<tr>
<td>Encourager of Individuals</td>
<td>Encourages other members to express their ideas. Asks individuals what they think.</td>
</tr>
<tr>
<td>Initiator</td>
<td>Expresses his or her ideas. Gets the discussion going. Allows others to speak and then initiates again.</td>
</tr>
<tr>
<td>Summarizer</td>
<td>After two or three people have spoken, tries to summarize what has been said thus far. Should be done more than once.</td>
</tr>
<tr>
<td>Elaborator</td>
<td>Elaborates on a point someone else makes. Clarifies the point and adds to it.</td>
</tr>
<tr>
<td>Compromiser</td>
<td>Looks for the common ground between team members who disagree with one another. States the compromise position that</td>
</tr>
<tr>
<td>Role</td>
<td>Description</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Supporter</td>
<td>Shows acceptance and support for ideas and opinions that may differ from the majority.</td>
</tr>
<tr>
<td>Consensus Taker</td>
<td>Listens for the emergence of positions that the whole team can accept. States the position and sees if everyone on the team agrees.</td>
</tr>
<tr>
<td>Gatekeeper</td>
<td>Watches for members who are trying to speak but are cut off by others. Calls on the member to speak. Asks others to wait.</td>
</tr>
<tr>
<td>Encourager of Team</td>
<td>When the team is having difficulty making decisions, expresses his or her belief that a compromise can be found. Gives energy to the team.</td>
</tr>
</tbody>
</table>


XII. Team Leadership

A. Shared Leadership Roles: Although one or more individuals may have a formal designation as group leader or facilitator, teamwork is most effective when all members are willing to share the responsibilities of leadership. Such responsibilities can include:

1. Scheduling, arranging and conducting meetings.
2. Preparing an agenda and ensuring that it is followed during the meeting.
3. Helping to clarify and identify team goals.
4. Identifying common topics and summarizing the ideas discussed to maintain direction of discussion.
5. Encouraging everyone to participate throughout the discussion.
6. Ensuring that all team functions are assigned to various team members.
7. Emphasizing the importance of being open to new and different ideas without becoming immobilized by conflict.
8. Making the group aware of its own resources and how best to use them.
9. Helping the group evaluate its progress and development.

XIII. Team Meeting Process

A. Guide to meeting process: The following 7-step meeting process provides a guideline for facilitating an effective interdisciplinary team meeting with optimal outcomes for the patient:
1. Clarify objectives
2. Review roles
3. Review agenda
4. Work through agenda
5. Plan next steps
6. Evaluate meetings

XIV. Team Communication

A. Importance of effective communication: Particularly in an interdisciplinary setting where team members do not always possess a basic understanding of each other's knowledge, skills and professional and personal values, it is possible that misunderstandings will result.

B. Encouraging and Reinforcing Responses

1. Be succinct and avoid long anecdotes or examples.

2. Make an effort to use positive body language such as head nodding, eye contact, and leaning toward the speaker.

3. In order to show interest, repeat one or two key words from the person's last sentence. This encourages the speaker to continue talking and enhances his or her sense of being heard.

4. To ensure that the message is understood, paraphrase and reflect by repeating a person's statement in his or her own words.

5. Avoid using technical jargon if possible; if a condition is best described in technical terms, however, members should make sure that everyone on the team understands those terms.
XV. References


A Primer for Institutional Leaders. (Center to Advance Palliative Care, Technical Assistance Series). Mount Sinai School of Medicine.


17. Miller, C. L. (1999). Geriatric Interdisciplinary Team Training Workbook. (Sections 1.6-1.9). Available from the University of Colorado Health Science Center on Aging.


Learning Resource A

Material from the John A Hartford Geriatric Interdisciplinary Team Training Program (GITT)

1. GITT Implementation Manual. Hyer, K., Flaherty, E., Fairchild, S., Bottrell, M., & Fulmer, T. This comprehensive manual provides summary information about the National Geriatric Interdisciplinary Team Training Initiative funded by the John A. Hartford Foundation, Inc. Drawing on lessons learned and materials provided by the eight sites, content includes information critical for the development, implementation and evaluation of a successful GITT Training Program. Chapters address such topics as institutional planning, structuring didactic and clinical practicum training, and assessing the effectiveness of GITT training. http://www.gitt.org/products/products.htm

2. GITT Curriculum. Hyer, K., Flaherty, E., Fairchild, S., Bottrell, M., & Fulmer, T. A cross-site curriculum includes six chapters with teaching resources on: teams and teamwork, care planning, ethics and teams, communication and conflict resolution, multiculturalism, and team member roles and responsibilities. More information about this can be found on their web site: http://www.gitt.org/products/products.htm

3. Geriatric Interdisciplinary Team Training: A Curriculum from the Huffington Center on Aging at Baylor College of Medicine: Long, D. & Wilson, N. (Eds.) (2000). This curriculum includes materials in hard copy text format, and floppy disks that contain nine chapters of core geriatric interdisciplinary team topics, along with training resources, a PowerPoint slide floppy disk, a CD-ROM that includes embedded hot links, and video and audio sections covering the nine core geriatric interdisciplinary teams interacting around four different cases. To order or for more information, contact the Huffington Center on Aging through their website: http://www.hcoa.org or by phone: 713-798-5504

4. Geriatric Interdisciplinary Team Managed Care Training of Trainers Program: Kaiser Permanente and the University of California-Los Angeles (1997). This training curriculum was developed to prepare facilitators for team training and includes five content areas: principles of team care, team stages, structure and leadership, information sharing and communication, problem solving, and conflict management and evaluation. A training manual includes student handouts, trainers’ notes and brief team lessons. To order a copy, contact Pamela Jackson-McCall, California Geriatric Education Center, UCLA School of Medicine, 10945 Le Conte Avenue, Suite 2339, Los Angeles, CA 90095-1687.

5. Mount Sinai Geriatric Interdisciplinary Team Training Resource Manual. This 74-page manual provides information on Geriatric Interdisciplinary teamwork for preceptors, faculty, and trainees. It is a compilation of material developed by GITT sites around the country and includes an overview of roles and responsibilities of team members, case studies, exercises, teambuilding games, readings, and web resources. Contact Kristy Kime at 212-241-6353.
6. **Geriatric Interdisciplinary Team Training Workbook.** Miller, C. L., (1999). This workbook consolidates key interdisciplinary health science team principles into five objectives to be practiced and learned in this GITT course. The five learning objectives are: goals and process, roles and responsibilities, structure and process to outcome, client/family’s interests, and verbal and non-verbal behaviors. To order a copy or for more information, contact Ernestine Kotthoff-Burrell at 303-315-8234 or by email at ernestine.kotthoff-burrell@UCHSC.edu

**Learning Resource B**

**Multimedia Learning Resources**

1. **Geriatric Medicine Self-Instruction Modules.** Now in its third edition, this Windows-based CD-ROM contains 17 self-paced multimedia modules on topics important in geriatric care, including HGITT’s interdisciplinary teams. Hot links embedded in text and graphics, plus animation, video, and audio allow the users to progress through the clinical topics at their own pace and “toward” specific material that they wish to access. Modules include learning objectives, self-tests, up-to-date educational content, case studies, patient information materials, and references. This CD was developed by Thomas A. Teasdale, Dr. P.H., through the John A. Hartford Foundation Geriatrics Residency Training Initiative. Dr. Teasdale is an assistant professor in the Department of Medicine at Baylor College of Medicine in Houston and affiliated with Baylor’s Huffington Center on Aging.

   These modules were developed in response to medical residents’ requests for more geriatric content in this program. The modules use an interdisciplinary approach for in-depth study and discussion of the topics by the teams of practitioners and students. Selected titles of modules included in this CD-ROM are: Geriatric Assessment, Falls and Mobility, Hormone Replacement Therapy, Confusion, Involuntary Weight Loss, and Elder Abuse.

   The format used for the modules includes:
   - A case study
   - An interdisciplinary discussion guide
   - Learning assessment questions
   - Articles on the topic from the literature of the primary disciplines

   Currently, production is underway for the fourth edition. More information can be found at [http://www.hcoa.org/hcoa](http://www.hcoa.org/hcoa)

2. **GITT Videos/Scripts.** These video scripts include the text of five 5-minute videotaped geriatric interdisciplinary team meetings developed by the GITT Case Studies Work Group. The scripts are found on the web at [http://www.gitt.org](http://www.gitt.org). Actual videotapes of the meeting are available from the GITT Resource Center at New York University. Each script includes multiple clinicians and a variety of clinical issues and examples of positive and negative team behaviors in the domains of: meeting behavior/style, conflict management, teaching/learning, leadership style, defining the patient/family problems, and recognition of roles of professionals, patient and family. Questions for students to consider are provided after each videotape.
General Teaching Guidelines:
- Identify key issues and questions for trainees to focus on during video viewing
- Show video
- Have students discuss their responses to questions for students in small groups
- Conduct large group discussion with students

3. The Colorado Geriatric Interdisciplinary Team Training (GITT) Project Videotape and Guide. This video presents a case from patient interview through the team meeting used to develop a care plan. The accompanying video guide provides the objectives, learning points, and discussion questions. To order a copy or for more information, contact Ernestine Kotthoff-Burrell at 303-315-8234, or by email at ernestine.kotthoff-burrell@UCHSC.edu

4. GITT Pocket Cards. These downloadable “interdisciplinary team training pocket cards” were developed by GITT Special Interest Groups and designed to help clinicians work in teams. Topics include: 8 Principles of Successful Teamwork, a 7-Step Meeting Process, how to be an effective team member, team dynamics checklist, and guidelines for using different conflict handling styles. These cards are available through the New York University GITT Resource Center at http://www.gitt.org/products.html

5. GITT Nurse Practitioner Clinical Preceptor Guide. This 3-fold clinical preceptor guide was developed by the GITT Nursing Special Interest Group. It describes the role of the preceptor, micro skills for clinical teaching, setting up expectations for student performance, and expected progression of a nurse practitioner student from beginning through advanced. These guides are available through the New York University GITT Resource Center at http://www.gitt.org/products.html

Learning Resource C

Geriatric Training Tools

1. Hospice/Palliative Care Training for Physicians: UNIPACS 1-5: A series of self-study curricula developed by The Academy of Hospice and Palliative Medicine. UNIPAC Five, Caring for the Terminally Ill: Communication and the Physician’s Role on the Interdisciplinary Team has been successfully used in HGITT workshops. For more information, contact Kendall/Hunt at http://www.kendallhunt.com or by calling: 1-800-338-8290

2. Geriatric Syndrome Learning Modules. The Great Lakes GITT Team developed four curriculum modules on the geriatric syndromes (end of life treatment goals, urinary incontinence, delirium, and falls) using an interdisciplinary approach for in-depth study. They are available online at http://www.129.22.12.42/framea.html or by contacting the Great Lakes GITT.
### 3. Geriatrics at Your Fingertips

A small (4”x 6”) portable booklet designed so that practicing clinicians spend a minimum amount of time searching for specific information. It provides assessment instruments, recommended diagnostics tests, and management strategies. Published by the American Geriatrics Society through Kendall/Hunt, more information is found at [http://www.americangeriatrics.org](http://www.americangeriatrics.org) or by calling 1-800-247-4779. It can also be ordered ($9.95) by calling Kendall/Hunt at 1-800-338-8290.

### 4. Core Curriculum in Ethnogeriatrics, 2nd Ed.

This curriculum was developed by the members of the Collaborative on Ethnogeriatric Education. It includes five modules covering culturally appropriate geriatric care: Overview, Patterns of Health Risks, Knowledge, Assessment, and Healthcare interventions. The modules can be downloaded in Adobe Acrobat format from the website: [http://www.stanford.edu/group/ethnoger](http://www.stanford.edu/group/ethnoger)

### Learning Resource D

#### Team Building Resources

1. Houston Geriatric Interdisciplinary Team Training Manual: Team Members Overview*

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<th>Discipline</th>
<th>Practice Roles/ Skills</th>
<th>Education/ Training</th>
<th>Licensure/Credentials</th>
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<tbody>
<tr>
<td>Nurse</td>
<td>Licensed vocational nurse (LVN)- basic nursing skills that are dictated by the facility; and under the supervision of a registered nurse (RN)- associate degree, BS or higher. RN has increased scope of practice, including planning for optimal functioning, coordination of care, teaching, and direct and indirect patient care.</td>
<td>LVN- 1 year of training; RN with associate degree- 2 years of training, usually in a community colleges; BS, RN- 4 years in college: MS/MA, RN- 2 years of graduate specialty study; PhD/DNSc/EdD. RN- 3 to 4 years of doctoral studies.</td>
<td>LVN – exam required for licensing, CE requirements in some states. RN- can be RN; BS, RN; APN; MS, GNP or other specialty RNs; PhD RN: all must pass the national licensure exam and in some states are required to have a prescribed number of CEUs per year. In New York, CEUs are not required.</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>Health assessment, health promotion, histories and physicals in outpatient and acute/home/long-term care settings; order, conduct, and interpret</td>
<td>Master's degree with a defined specialty area such as gerontology (GPN) or a post-master's certificate program.</td>
<td>In addition to RN licensure, NPs pass a National Certification Exam in the appropriate specialty area (e.g. gerontology or family practice). In New York, CEUs are not required.</td>
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<tr>
<td><strong>Physician</strong></td>
<td>Diagnose and treat diseases and injuries, provide preventative care, do routine checkups, prescribe drugs, and perform some surgery.</td>
<td>Physicians complete medical school (4 years) plus 3 to 7 years of graduate medical education. State licensure required for doctor of medicine degree; exam required and possible exams required for specialty areas. CE requirements.</td>
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<tr>
<td><strong>Geriatrician</strong></td>
<td>Physician with special training in the diagnoses, treatment, and prevention of disorders in older people; recognizes aging as a normal process and not a disease.</td>
<td>Completion of medical school, residency training in family medicine and internal medicine, and 1-year fellowship program in geriatric medicine. Completion of fellowship training program and/or passing examination for Certificate of Added Qualifications in Geriatric Medicine (CAQ). Re-certifications by examination required every 6 years.</td>
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<tr>
<td><strong>Physician Assistant</strong></td>
<td>Practice medicine with the supervision of licensed physicians; exercise autonomy in medical decision-making and provide a broad range of diagnostic and therapeutic services; practice is centered on patient care.</td>
<td>Specially designed 2-year PA program located at medical colleges and universities. Most have bachelor's degree and over 4 years of healthcare experience before entering a PA program. State licensure or registration plus certification by NCCPA. Re-certification every 6 years by examination. Requires 100 hours of CME every 2 years.</td>
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<tr>
<td><strong>Social Worker</strong></td>
<td>Assessment of individual and family psychosocial functioning and provision of care to help enhance or restore capacities; this can include locating services or providing counseling.</td>
<td>There is a 4-year college degree (BSW); 2 years of graduate work (MSW), and doctoral degree (PhD); 15 hours of continuing education is required every year. The MSW (for master's level); BSW (BS level); SWA is a social work associate with a combination of education and experience. ACP-signifies licensure for independent clinical practice. In New York, after obtaining the MSW, a social worker may take the state licensing examination and, if</td>
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<td>Psychologist</td>
<td>Assessment, treatment, and management of mental disorders; psychotherapy with individuals, groups, and families.</td>
<td>Graduate training consists of 5 years beyond undergraduate training; most coursework includes gerontology and clinical experience.</td>
<td>PhD or EdD or PsyD are degrees awarded. State licensure; the American Psychological Association has ethics codes as do most states.</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>Medical doctors who treat patients’ mental, emotional, and behavioral symptoms.</td>
<td>Medical school and residency specializing in psychiatry. Residency includes both general residency training and 2 to 3 years in area of specialization (e.g. geriatrics, pediatrics).</td>
<td>State exam to practice medicine; board of Psychiatry and Neurology offers exam for diplomat in psychiatry.</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>Devise and revise a patient’s medication therapy to achieve the optimal regime that suits the individual’s medical and therapeutic needs; information resource for the patient and medical team.</td>
<td>Pharmacists can receive a baccalaureate (B.S.) – 5-year program; or doctorate degree (PharmD). Annual CEUs required range from 10-15 hours.</td>
<td>National exam (NABPLEX); given every quarter; board certifications in specialties available (pharmaco therapy, nuclear pharmacy, nutrition, psychiatric and oncology in near future).</td>
</tr>
<tr>
<td>Speech-Language Pathologist</td>
<td>Assessment and treatment of full range of speech, language, and swallowing disorders; functions within ambulatory or inpatient clinical settings; provides individual or group therapy to maximize individual’s functional communication and swallowing ability.</td>
<td>Masters Degree and completion of 9 month Clinical Fellowship Year (CFY) post-M.A./M.S. required to practice nationwide. Annual CEU’s required.</td>
<td>CCC-SLP (Certificate of Clinical Competence in Speech Language Pathology) awarded by American Speech Language Hearing Association following completion of National Examination (NESA) and CFY. State licensure required in 45 states.</td>
</tr>
<tr>
<td>Audiologist</td>
<td>Identification, assessment, and management of auditory and balance disorders;</td>
<td>Masters Degree and completion of 9 month Clinical Fellowship Year</td>
<td>CCC-A (Certificate of Clinical Competence in Audiology) awarded by American Speech</td>
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<tr>
<td>audiological</td>
<td>rehabilitation; selection, fitting, and dispensing of amplification systems;</td>
<td>(CFY) post-M.A./M.S. required to practice nationwide. Annual CEU’s required.</td>
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<td>consumer education.</td>
<td>Language Hearing Association following completion of National Examination (NESPA) and CFY. State licensure required in 47 states.</td>
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<tr>
<td>Occupational Therapist</td>
<td>One who utilizes therapeutic goal-directed activities to evaluate, prevent, or correct physical, mental, or emotional dysfunction or to maximize function in the life of the individual.</td>
<td>BS or MS in OT with a minimum of 6 months of field work; for OT assistant, an associate degree or OT assistant certificate is required with a minimum of 2 months fieldwork. State exam required for the credential of OTR. (Occupational Therapist Registered). Exam also required for COTA (Certified Occupational Therapy Assistant). These exams are given at least 2 times/year.</td>
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<tr>
<td>Physical Therapist</td>
<td>The evaluation, examination, and utilization of exercises, rehabilitative procedures, massage, manipulations, and physical agents including, but not limited to, mechanical devices, heat, cold, air, light, water, electricity, and sound in the aid of diagnosis or treatment.</td>
<td>Four-year college degree in physical therapy is required to be eligible for the state exam; master’s degree in physical therapy is available; 3 CEUs every 2 years are required. PT is the credential that is used by licensed physical therapists and PTA is the credential for licensed physical therapist assistant. To use either of these titles, one must pass a state exam. CEUs are required for both; titles and licenses must be renewed biennially.</td>
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<tr>
<td>Chaplain</td>
<td>Provide visits and ministry to patients and family.</td>
<td>Master’s degree in theology, plus a minimum of 1 year of clinical supervision, if fully certified. Can work in some settings without being fully certified. Certification is through the Chaplaincy Board of Certification – credentials for this are BCC; however, credentials are not normally used. Most chaplains are ordained ministers, but not all. CEUs required are 50 hours per year.</td>
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<tr>
<td>Dietitian</td>
<td>Evaluate the nutritional status of patients; work with family members and medical team to determine appropriate nutrition goals for patient.</td>
<td>BS degree in food and nutrition and experience are required to be eligible for exam; CEs are required for both the LD (6 clock hours/year) and RD (75 clock hours year RD is the credential for a registered dietitian. For RD, must pass the national exam of the American Dietetic Association; LD is the credential for a licensed dietitian; same exam is required but processing</td>
<td></td>
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<tr>
<td>Client/Patient</td>
<td>Consumer</td>
<td>Provide information necessary for assessment planning of care. Bring their needs and perspectives on illness, treatment and what they view as the major goals of care. Care goals must be endorsed by the client/patient in order to achieve successful adherence to a therapeutic plan.</td>
<td>Illness - Cognitive status – Important to remember that while global decision-making may be diminished, capacity in specific areas can be retained. While unable to manage financial matters, may retain ability to determine end-of-life decisions.</td>
</tr>
<tr>
<td>Family caregiver Spouse/Children</td>
<td>Consumer Advocate for client Provider of direct care</td>
<td>Provide a wealth of information regarding the client/patient - pre-illness functioning, hobbies, interests, and concerns. Offers direct input about ability and willingness to assist in care.</td>
<td>May not have detailed knowledge of disease process or the roles and function of the professionals on the team. May not live close to the client. Family history and/or dynamics may interfere with knowledge of client and ability to participate.</td>
</tr>
<tr>
<td>Caregiver outside family/ Neighbor/ Friend</td>
<td>Advocate for Client Provider of direct care for client</td>
<td>Provide information regarding the client/patient - pre-illness functioning, hobbies, interests, and concerns. Offers direct input about ability and willingness to assist in care.</td>
<td>May not be identified.</td>
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2. The University of Colorado Health Sciences Center's Geriatrics Interdisciplinary Team Training Workbook: “Forming, Storming, Norming, and Performing”

A. Forming: creation of the feeling of being a group through a transition from individual to group member status.

1. Goal of this stage is to reduce ambiguity and discover acceptable interpersonal behaviors and actions of the other group members.

2. Members get to know each other.
   a. Superficial sharing of name and background information.
   b. Sizing-up -and testing each other.
   c. Categorization of one another, with outside-of-team roles and status determining team roles.
   d. Relationships are guarded- more impersonal than personal.

3. Uncertainty regarding purpose
   a. Attempt is made to define task and methods.
   b. Lofty, abstract discussions of concepts and issues are common.
   c. Discussion of problems related to team function are common.
   d. There may be difficulty in identifying the problems, which are most relevant to the team's purpose.
   e. Complaints about the organization and the barriers to accomplishing tasks begin to surface.

4. Goal formation should be the primary task.
   a. A shared sense of mission is needed to establish the basic conditions required for cooperation, collaboration and interdependent function.
   b. Goals provide a rationale for the team's development.
   c. Goals provide incentive for team members to re-prioritize individual and discipline interests.

5. Conflict is usually neither discussed nor addressed at this stage of development.

B. Storming: Most difficult and conflictual stage. Task and roles begin to be perceived as different and more difficult than members originally anticipated.

1. Goal of this stage is to resolve the internal conflicts and focus on the task at hand.
2. Difficulty in understanding the goals and purpose of the team; attempt to establish common goals.

3. Role overlaps become evident.

4. Concerns about excessive workload.

5. Conflicts are present but are covered up or glossed over.

6. Arguing among members is common, even when they agree on basic issues.
   a. Questioning the wisdom of those who selected this project and appointed the members of the team.
   b. Defensiveness and competition lead to development of factions; sides are chosen.
   c. The implicit or explicit hierarchy, which had developed earlier, is often challenged, which commonly leads to disunity, tension, and jealousy.

C. Norming: The establishment of norms and patterns for regulation of the group process, reconciliation of competing loyalties and responsibilities, and acceptance of roles and team rules.

1. The goal of this stage is to develop cohesiveness and overcome any resistance in an effort of pulling together.

2. Establishing and maintaining ground rules and boundaries.
   a. Attempt to achieve harmony by setting norms-and avoiding conflict.
   b. Determine norms for acceptable group behavior and methods for dealing with group problems.
   c. More friendliness begins to be seen, with members confiding in each other, sharing personal problems, discussing the team's dynamics.

3. Preliminary agreement on shared goals is usually achieved.
   a. A sense of team cohesion develops, with a sense of purpose and common goals.
   b. Decision is made as to what information needs to be gathered.

D. Performing: When a strong sense of group identity and each member's role is developed, useful work can finally be consistently performed.

1. The goal of this stage is to resolve structural issues and generate energy to the task at hand.

2. Focus of group meetings is on problem solving.
   a. Relationships and expectations are finally clear.
   b. Common goals for patient outcomes are agreed upon across disciplines.
   c. A mechanism exists that enables all to contribute and share information essential for effective patient care.
   d. Protocols are established which ensure that care plans are implemented, services are coordinated, and the performance of the team is evaluated.
3. Conflicts begin to be seen as normal and are used as impetus for improvement.
   a. Differences are generally understood and appreciated.
   b. Each member recognizes, accepts, and respects the roles of the others.
   c. Mechanisms for conflict management are in place.

E. **Bringing new team members on board:** (Rubin, et.al, 1975)

1. Invest time in the joining-up process. Don’t expect that a new member can be
   brought up-to-speed immediately. It is not a “one shot” effort but an effort over
   time. Don’t expect too much from the newcomer right away.

2. Orientation is best accomplished through face-to-face interactions between the
   team members and the new member. Written materials alone are an inadequate
   orientation.

3. Orientation should include:
   a. Team goals
   b. Team members and their roles and responsibilities
   c. Team functioning: problem solving, decision making, conflict resolution
   d. Unique aspects of the team

4. If adequate time is not taken to incorporate a new team member, the following
   may occur:
   a. New members will experience considerable confusion and uncertainty about
      the way many of the things which you have learned to take for granted are
      supposed to be done on the team.
   b. Old members will experience disappointment in the new member who does
      not seem “to know anything” and may be hesitant to use the new member’s
      resources.
   c. Morale, satisfaction, and productivity may be reduced.
   d. The new member might quit because he/she never quite felt like he/she
      belonged on the team.

F. **Adjourning:** When either a member leaves the team or the team disbands, the
   termination process is important.

1. Individual leaves
   a. Team and departing member may avoid the difficult and unpleasant work of
      termination.
   b. Depending on the circumstances, the team and the departing member may
      feel anger, disbelief, anxiety, relief, etc.
   c. The team may place subtle pressure on a member not to leave group.
   d. Team may regress to an earlier phase of team development.

2. Team terminates
a. Teams may decide to disband (i.e., conflicts within team) or they may be forced to disband for external reasons (i.e., need no longer exists, funding for group is no longer available).

b. When teams disband, members experience a sense of loss. To deal with feelings of loss and anxiety, team members tend to avoid these feelings in a number of ways: withdrawal, devaluing the importance of the team, anger toward the team leader or other team members, silence and inactivity, and/or leaving the team prematurely.

c. Feelings are expressed as testimonials (i.e., review of team's accomplishments or outstanding contributions of individuals to the team).

d. Team membership is affirmed as a valuable experience.

3. Termination issues that need to be addressed
   a. Review the team's departing members' experience and goals. Verbalize what has been accomplished.
   b. Formally acknowledge the change by allowing team members to say their good-byes and plan for the transition.
   c. Address feelings of loss, anger, or relief rather than avoiding them.
   d. Finish unfinished business with the departing member/the whole team.
   e. Give feedback to each other on what they have learned.
   f. Generalize what has been learned from the team experience so that it can be applied elsewhere.
   g. Notify patients of the team disbanding or change in team composition. Acknowledge loss for patient. Reassure patients that their continued care (by individual providers or the remaining team) is addressed.
Module # 3: Healthy Aging
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 3: Healthy Aging

James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center
Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

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## Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 3: Healthy Aging

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I. Overview

There is no doubt that the elderly population is increasing at a tremendous speed. Therefore, it is crucial that elderly people be proactive in leading healthy and active lifestyles. Such lifestyles may be achieved regardless of where the elderly live, whether it is in an acute, long-term, or community setting. Diet, proper nutrition, routine health examinations, regular socialization, and social support are just some of the ways that aid in improving psychological, physical, and emotional well-being. It is imperative that health care professionals promote wellness among the elderly population and assist patients in improving their overall physical, mental, social, and emotional state. Health care professionals have the ability to make a profound impact on the lives of elderly people by helping them achieve optimal wellness through education, outreach, and support. Family members, caregivers, and friends may also make a positive difference in the lives of the elderly through their assistance and support as well.

II. Learning Objectives

1. Define wellness as it relates to healthy aging.
2. Identify key areas that promote healthy aging among the elderly.
3. Provide a framework for ways in which elderly people may lead healthy lifestyles.

III. Diet And Nutrition

It is no secret that proper diet and nutrition are vital in maintaining a healthy lifestyle. Eating balanced meals, limiting red meat intake, and taking vitamin supplements all lead to healthy aging. There are several ways in which elderly people may improve their health through proper diet and nutrition.
1. Diet

The term diet refers to the actual sum of food that is consumed by a person. Diets among the elderly population may differ tremendously due to varying chronic illnesses or other conditions that require certain types of dietary restrictions. Common diets among the elderly include low-fat, low-calorie, or high-fiber diets among others. Increasing dietary fiber intake by eating an increased number of fruits, vegetables, and grains is a common goal for many people trying to improve their overall health. Research has shown that one’s diet plays a clear role in developing major diseases such as heart disease, diabetes, hypertension, cancer, and stroke. Since heart disease, cancer, and stroke are considered to be three of the four leading causes of death, having a healthy diet will certainly help minimize the risk of such deadly diseases. Elderly people should discuss their diet with their primary care physician or with a registered dietician to ensure that they are following the diet best suited for them. The Journal of Nutrition has published a modified food pyramid that is geared toward people over seventy years of age and is very helpful in breaking down the different types of foods that are necessary for older adult consumption (See Learning Resource A).

2. Nutrition

Nutrition is a process that refers not only to the consumption of food and other nourishing substances but to the subsequent breakdown and extractions of the nutrients contained in such substances that help aid in bodily function. Many elderly people do not have an adequate dietary intake, resulting in nutrient deficiencies. Calcium and iron deficiencies are prevalent among the elderly and may be minimized through regular supplementation. Taking a multivitamin is a great way to supplement a healthy diet and ensure that necessary nutrients are being consumed. Local pharmacies contain a plethora of multivitamins that are geared toward older adults. It is important that elderly people speak with their health care provider to determine which type of multivitamin is best for them. In addition to taking a multivitamin, elderly people should drink large quantities of water to maintain hydration and proper organ function. Elderly individuals should also speak with their health care provider to determine how much water consumption is necessary to improve and maintain their overall health.
IV. Exercise

Sustaining a regular exercise regimen is very important to improve wellness and health among the elderly. Physical activity is so important because it will help maintain mobility, which becomes increasingly difficult as people age. Also, taking part in regular exercise will help eliminate a sedentary lifestyle. This may significantly minimize the risk of developing coronary heart disease as well as reduce the rates of obesity, diabetes, osteoporosis, and hypertension. Some types of physical activities that are most beneficial to older adults include walking, gardening, resistance training, light weights, yoga, tai chi, and other forms of light to moderate exercise. It is important that elderly people work with their health care providers to come up with individually tailored exercise regimens.

V. Preventive Care

The most effective ways that elderly people are able to lead healthy lifestyles and promote healthy aging are to take preventive measures to improve their overall wellness. This may be achieved by doing the following:

1. **Routine Medical Check-ups**
   Too often, people begin to neglect their health as they get older and make fewer visits to their primary care physician. Unfortunately, many people wait until something goes horribly wrong with their health before getting screened for routine check-ups. Having annual cancer screenings and doing annual blood work to check for diabetes, blood sugar, cholesterol, and triglyceride levels may help prevent health problems down the road. Also, having knowledge of medical conditions that exist in one’s immediate family is imperative because it may help determine the risk for developing a particular condition at some point later in life. In addition, knowing the history of illness throughout one’s family may help project life expectancy.

2. **Sleep**
   Sleep is perhaps one of the most overlooked factors that may help increase wellness and improve overall health among the elderly. The reality is that many elderly suffer from insomnia and find themselves having difficulty either falling asleep or remaining asleep. While there is an array of prescription medications that help people with their sleep, there are other natural ways that the elderly may abide by to increase their sleep. This may include following a sleeping schedule, reducing caffeine intake or any other stimulants that may interfere with sleep, and regularly exercising. Speaking with a health
care provider to discuss best sleep strategies is the most effective way to alleviate this problem.

3. Socialization

Research suggests that social engagement and maintaining social connections and activities may help prevent cognitive deterioration in old age and may be associated with better health status in older adults. Thus, baby-boomers as well as current elderly should remain active and involved in the community and amongst peers to the best of their ability. There are several activities that are available to seniors throughout various communities. Health care professionals as well as caregivers, family members, and friends should encourage the elderly to remain active and increase their socialization. For those people living in the community, senior centers offer a vast array of social activities that promote social engagement. For those individuals living in acute or long-term settings, many of the facilities offer several types of social activities as well. Elderly people should feel encouraged to reach out and get involved, and health care professionals should keep abreast of current resources available so that they may refer them to their patients whenever appropriate.

4. Home Safety And Fall Prevention

Home safety is one of the largest concerns among elderly people. This is due to the fact that people want to remain in the home as they age. Therefore, it is crucial to take steps to safeguard the home in order to prevent falls and other injuries, which may result in institutionalization. The following tips may significantly help elderly people reduce the risk of falling in their homes:

- Wear shoes and slippers with non-slip soles. Avoid wearing socks only- they might cause a slip due to their material.
- Use caution if the bathroom floor becomes wet. If the bathroom has handrails, hold onto them when getting up or down. Install non-slip strips in the bathtub.
- Never leave any clothes, magazines, bags, or other objects lying around on the floor.
- Remove or secure any loose rugs or mats.
- Make sure hallways and staircases are well-lit. When walking up or down stairs, hold onto a handrail or use a cane.
5. **Senior Centers**

Elderly people should be aware of local senior centers throughout their communities, as they offer some of the most valuable and current resources. Most senior centers have a wealth of information about issues pertaining to the elderly including retirement, long-term care, prescription drugs, and legal assistance. In addition, many senior centers offer a plethora of activities and events that promote socialization between older adults living in the community. The New York City Housing Authority provides a detailed list of Senior Centers throughout all five boroughs of New York City and is an excellent resource for elderly people as well as health care professionals working with them. Current information is available at

VI. References


Learning Resource A

Modified Food Guide Pyramid For People Over Seventy Years Of Age

* This information may be found at http://jn.nutrition.org/cgi/content/full/129/3/751 as referenced in the Journal of Nutrition. 1999;129:751-753.
Module # 4: Geriatric Syndromes
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 4: Geriatric Syndromes

James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center
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# Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

## Module # 4: Geriatric Syndromes

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I. Overview

Geriatricians use the phrase "geriatric syndrome" to describe the unique features of common health conditions in older people that do not fit into discrete disease categories. These conditions include delirium, falls, incontinence, and frailty. Geriatric syndromes share many common features. They are highly prevalent in older adults, especially frail older people. Their effect on quality of life and disability is substantial. Multiple underlying factors, involving multiple organ systems, tend to contribute to geriatric syndromes. Frequently the primary symptom is not related to the specific pathological condition underlying the change in health status. For example, when an infection involving the urinary tract causes delirium, it is the altered neural function in the form of cognitive and behavioral changes that permits the diagnosis of delirium and determines many functional outcomes. Because these syndromes cross organ systems and transcend discipline-based boundaries, they challenge traditional ways of planning and delivering clinical care.

II. Learning Objectives

1. Describe the prevalence and risk factors associated with falls, gait abnormalities, incontinence, sleep disorders and pressure ulcers in the elderly.

2. Identify the components of evaluation for the above conditions: history and physical examination.

3. Discuss interventions for the above conditions in the elderly.

III. Falls

A. Demographics

1. Falls are the leading cause of accidental death in older adults.
2. Of the fall-related deaths in the US, 70% occur among older adults.

3. In the elderly population, 1 out of every 7 falls results in a fracture.

4. For older adults over the age of 75, who fracture a hip as a result of a fall, half will die within one year of the incident.

5. About one-third of older persons over the age of 65 years living in the community fall each year. The risk for falls increases as the person ages to about 50% of those 80 years and over each year. About 67% of nursing home residents fall each year.

6. Acute care costs related to fractures from falls is estimated at $10 billion annually.

7. An estimated 40% of nursing home admissions are related to falls and instability.

B. Risk Factors

- Cognitive impairment
- Medication
- Impaired mobility / gait / balance
- Fall history
- Acute or chronic illness
- Elimination problems
- Environmental factors
- Sensory deficits
- Alcohol use
- Postural hypotension
- Depression
- Use of assistive devices
- Frailty / deconditioning
- Fear of Falling

C. Risk Factors for Serious Fall Injury

- Older age
- White race
- Decreased bone mineral density
- Decreased body mass index
- Cognitive impairment

D. Protective Factors Against Injury of Fracture

- Estrogen therapy
- Weight gain after age 25
- Walking for exercise
- Adequate dietary calcium intake

E. Evaluation of a Fall
1. History
   a. Activity at the time of the fall
   b. Premonitory symptoms: light-headedness, palpitations, dyspnea, chest pain, vertigo, confusion, incontinence, loss of consciousness, tongue biting
   c. Location of fall
   d. Witnesses to fall
   e. History of previous falls (of same or different character); history of falls may be difficult to elicit
   f. Past medical history
   g. Medications

2. Physical examination
   a. Visual acuity
   b. Cardiovascular system: blood pressure, pulse (supine and standing), arrhythmia, murmur, bruits
   c. Extremities: arthritis, edema, podiatric problems, poorly fitting shoes, ROM strength
   d. Neurologic system: mental status testing, gait and balance assessment, i.e. the timed “up and go” (patient rises from an arm chair, walks 3 meters, and returns to chair—see scoring tables 6), walking, bending, turning, reaching, ascending and descending stairs, standing with eyes closed
   e. (Romberg test), sternal push
   f. Injuries
   g. Use of assistive devices

F. Interventions for Fall Prevention and Minimizing Injury
   (See Table “Treatment of Identified Risk Factors for Fall Injury”)

1. Intrinsic Factors
   a. Review medication regimen (benzodiazepines and drugs causing orthostatic hypotension should be carefully evaluated)
   b. Assess alcohol use (may be difficult to get accurate history)
   c. Assess cognitive abilities
   d. Assess patient mood state (especially for depression)
   e. Provide and maintain assistive devices for sensory deficits (eyeglasses, hearing aids)
   f. Increase strength of the older adult
   g. Evaluate gait and balance — provide restorative therapy/exercises
   h. Assess client use of assistive devices for ambulation (hand rails, canes, walkers)
   i. Evaluate continence needs and establish toileting schedule as appropriate
Module # 4: Geriatric Syndromes

j. Assess patient’s understanding of fall risk and prevention strategies
k. Assess caregiver/surrogate’s understanding of fall risk and prevention strategies

2. Extrinsic Factors

a. Evaluate environment (lighting, loose rugs, slippery or uneven flooring, exposed cords)
b. Evaluate client footwear (stable, proper fitting)
c. Utilize bed-exit alarms as appropriate
d. Shower and toilet grab bars
e. Elevated toilet seats
f. Put frequently used items on lower shelves in home, use grabbing devices
g. Remove clutter

G. Case Analysis: Mr. and Mrs. C’s home:

Mr. and Mrs. C live in a single-family home in the suburbs. Both of them are in their 80s. They have a son and daughter who live within driving distance and visit every week. Mrs. C has osteoarthritis and ambulates with a cane. Mr. C has mild Parkinson’s disease and walks with a mild shuffle.

They have been living in their home for 36 years and in the last 5 years they have not made any repairs. The front stairs are slightly broken and there is no outdoor lighting. Their bathroom is very old with a bathtub, no shower and an old sink and toilet.

They like to have throw rugs throughout the house for their two cats to sleep on. Mrs. C had a fall recently with minimal bruising. She stated at the time, “My cataracts are getting worse,” but has no plans for surgery.

Both take multiple medications and occasionally will “swap” medications for similar complaints. Mr. C has begun using Mrs. C’s glasses because his own are broken. Both have moderate hearing loss but state that it has not adversely affected their lifestyle.


IV. Gait Abnormalities

A. Demographics 7
1. From 8-19% of non-institutionalized older adults have difficulty walking or require the assistance of another person or special equipment to walk.

2. In older adults 85 and older, the incidence of gait abnormality can be as high as 40% in non-institutionalized patients and 60% in nursing-home residents.

B. Evaluation

1. Disordered gait is not an inevitable consequence of aging, but rather a reflection of the increased prevalence and severity of age-associated diseases.

2. The presence of slowed gait speed or deviations in smoothness, symmetry, or synchrony of body movement may indicate that gait is disordered. However, they also may provide the older adult with a safer, independent gait pattern.

3. See the included chart “Gait Disorders Classified by Sensorimotor Level” for the major contributors to abnormal gait. It is likely for more than one disease or impairment to act as a contributor.

4. Standardized assessment tools
   - See the “Tinetti Balance and Gait Evaluation,” included in this Module.
   - See the “Performance-Oriented Mobility Assessment (POMA)” in Module 5: Geriatric Assessment.

C. Treatment

1. The management of gait abnormality includes improvement in functional ability and treatment of specific diseases, however many conditions causing a gait abnormality are only partly treatable.

2. Substantial improvement occurs in the medical treatment of disorders secondary to vitamin B12 and folate deficiency, thyroid disease, knee osteoarthritis, Parkinson’s disease and inflammatory polyneuropathy.

3. Moderate improvement, but with residual disability, can occur after surgical treatment for cervical myelopathy, lumbar stenosis, and normal-pressure hydrocephalus.

V. Urinary Incontinence

A. Definition – an involuntary loss of urine that is objectively demonstrable and leads to a social or hygienic problem
B. Demographics \(^1, 8, 9\)

1. According to the National Institutes of Health (NIH) Consensus Conference, less than half of people with symptoms of incontinence seek treatment.

2. Approximately 15-30% of non-institutionalized older persons are affected by urinary incontinence, including 19% of men and 39% of women. In nursing facilities, 50-70% experience urinary incontinence with 30% of this population also experiencing fecal incontinence.

3. It is about twice as prevalent in older women as in older men.

4. Direct costs of urinary incontinence in community-dwelling older adults are estimated to be over $7 billion annually and $3.3 billion in long-term care nursing facilities.

C. Risk Factors

- Immobility
- Impaired cognition
- Medications
- High-impact physical activities
- Environmental barriers
- Diabetes
- Stroke
- Estrogen depletion
- Pelvic muscle weakness
- Childhood nocturnal enuresis

D. Transient Incontinence

1. DRIP
   - D – Delirium
   - R – (Urinary) Retention or restricted mobility
   - I – (Fecal) Impaction
   - P – Polyuria and pharmaceuticals

E. Established Incontinence \(^8\)

1. **Urge Incontinence**: associated with a strong urge to void. Caused by an overactive detrusor muscle causing excessive involuntary bladder contraction, associated with various neurological conditions including stroke, spinal cord lesions and multiple sclerosis.

2. **Stress Incontinence**: associated with actions that increase intra-abdominal pressure such as coughing, sneezing, bending, lifting, or laughing. The cause is pelvic muscular weakness or urethral hypermobility.
3. **Overflow Incontinence**: occurs when the bladder muscle is overdistended. May present with stress or urge symptoms. The cause is an underactive bladder muscle, or a bladder outlet or urethral obstruction leading to overdistension and overflow.

4. **Functional Incontinence**: occurs when a physical or psychological impairment impedes continence status despite a competent urinary system.

F. Assessment: See included chart “Evaluating Incontinence”

G. Treatment Options

1. A stepped strategy moving from least to more invasive treatments should be used, with behavioral methods tried before medication, and both tried before surgery. 

2. Given the high prevalence of cognitive impairment in patients with incontinence, it is important to note that, according to Flint and Skelly, 55% of ambulatory patients became dry or had a significant improvement in incontinence with an individualized scheduled toileting program.

3. See included chart “Treatment Options for Urinary Incontinence”

H. Case Analysis: Ms. B.

Ms. B is a 76-year-old widow. Her history is significant for diabetes mellitus, coronary artery disease, osteoarthritis and a past history of a total abdominal hysterectomy. She is a five days status post coronary artery bypass. Her postoperative course has been uneventful except for fluid retention as evidenced by pedal edema. Tomorrow she will be discharged to a cardiac short term rehabilitation center. Her baseline ambulatory status is a steady gait with a quad-cane.

Medications include:

- ASA 81 mg PO OD
- Metformin 500 mg PO BID with meals
- Micronase 5 mg PO BID
- Lasinopril 10 mg PO BID
- Lasix 40 mg PO Q 12H
- KCL 20meq PO Q 12H

You are reviewing her discharge instructions. Ms. B asks “Do you think I will still need these diapers when I get home? I never had problems holding my water before.” Use your knowledge of incontinence in the elderly to formulate your response.
VI. Sleep Disorders

A. Demographics

1. Up to 50% of older adults have some kind of sleep complaint, and up to 30% have chronic problems with sleep.

2. Up to half of older adults use some kind of sleeping medicine.

3. Rates of sleep disturbance in long-term care settings are much higher.

B. Normal Age-Related Sleep Changes

1. Aging is associated with decreased sleep continuity. Studies have shown that older individuals have less of a “sleep drive” and spend more time awake at night. Older people are also more sensitive to external factors such as noise, bright light or unfamiliar surroundings.

2. Many older people make up for lost nighttime sleep with daytime sleep. There is increased napping as people age.

3. The time required to fall asleep (sleep latency) increases with age.

4. Older people average an increased number of arousals during sleep.

5. EEG changes: older age reduces the amplitude in the low frequency or NREM sleep. Older individuals appear to have less slow-wave sleep and seem to lose the deepest part of this sleep.

6. Circadian rhythm changes with age. The pineal gland secretion of melatonin diminishes with age. The result of this is less sleep at night and more during the day.

C. Sleep Disturbances:

1. Dyssomnias: disorders of initiating sleep, maintaining sleep and of excessive sleepiness.

2. Parasomnias: disorders that primarily do not cause sleep-related complaints.

3. Disorders associated with medical or psychiatric disorders.
4. Proposed sleep disorders: disorders that continue to be studied to become better defined.

D. Causes

Common causes of sleep disorders may include periodic limb movements, restless legs syndrome, sleep-related breathing disorders such as apneas, illness, pain, nocturia, dementia and alcoholism. Depression is the most significant cause of insomnia.\(^1\)

E. Assessment \(^1\)

1. **Sleep History**: the impact of the sleep complaint on the individual’s daily life.

2. **Medical History**: various medical conditions may contribute to sleep disturbances.

3. **Diet and Drug History**: include prescription and non-prescription medications as well as alcohol, caffeine, and nicotine.

4. **Psychosocial History**: should begin with psychiatric illnesses, such as anxiety, depression and dementia, and then assess social history including grieving the illness or loss of friends and family and translocation.

F. Treatment

1. **Non-Pharmacologic Treatments**

   a. Remove the suspected contributing factors: treat the underlying illness, discontinue or change medication, discontinue alcohol, caffeine or nicotine use.

   b. Change Habits: develop a sleep-preparation routine, use the bedroom for sleep only, develop a sleep story to promote a restful state of mind, reduce daytime napping, and develop a daily exercise routine.

2. **Pharmacologic Treatment**

   a. Only recommended for short-term use in older patients.

   b. Benzodiazepine with a short or intermediate action such as Temazepam (7.5 to 15 mg), with a two-week maximum time period in order to avoid dependence.

   c. Antihistamines are acceptable for occasional use, but lose efficacy quickly.
3. Case Analysis: Ms. R.

Ms. R is a 79-year-old woman who lives with her husband in their own home. She is taking medication for hypertension, but has no other medical problems. She had one daughter who passed away five years ago with lung cancer. Three weeks ago, at her urging, Ms R’s husband participated in a free prostate cancer screening at the local senior center and was diagnosed with the disease. He is scheduled for surgery next week. Over the last several weeks, Ms. R has been seen at the Senior Center, falling asleep in the middle of the morning and again in the afternoon. Many of the seniors have commented that this is not the place to sleep and reported it to the director.

The nurse for the center made a visit one afternoon and interviewed Ms. R about her frequent napping at the center. On assessment, Ms. R stated that she had not been sleeping well at night. She stated that it took her about two hours to fall asleep and then she usually woke up about 2:00AM and stayed up until 5:00AM. She finally manages to fall back to sleep for a few hours, before her husband awakens her at 6:30 AM for morning mass. She admitted that she told her physician and he prescribed her a “little purple pill” but she didn’t want to take it. Further assessment revealed that Ms. R was very upset about her husband’s impending surgery. She cried when she discussed the possibility of losing him and being alone in the world.

On review of the assessment, the nurse found no medical or pharmacological reason for Ms. R’s insomnia. It appeared that her sleep disorder was most likely related to her anxiety over her husband’s impending surgery. The nurse provided Ms. R with education about her husband’s surgery. This helped Ms. R to gain some control over the future events. In addition, the nurse instructed Ms. R to avoid napping during the day and to add a program of physical exercise to her daily routine. Ms. R was assured that the low dose of Halcion prescribed for her was safe for a period of two weeks. The nurse requested the staff and other visitors of the senior center to take frequent opportunities to discuss her feelings of fear and loneliness and scheduled an appointment to come back and reassess Ms. R in two weeks.

When the nurse made her follow-up appointment, Ms. R revealed that her husband was home recovering well from the surgery. She no longer had problems sleeping and had discontinued the sleeping medication two days after her husband’s return.
VII. Pressure Ulcers

A. Epidemiology

1. The prevalence varies widely as a function of care quality, venue, patient population, and the rigor with which pressure ulcers are identified.

2. Prevalence of pressure ulcers in acute care ranges from 3% to 32%, with an overall prevalence of 10%.

3. Prevalence in skilled care and nursing homes is estimated at approximately 23%.

4. Incidence among all elderly people at home is less than 1%; however, among those who receive nursing care in their homes, incidence is 4-5%, with prevalence 10-15%.

B. Risk Assessment

1. Extrinsic Risk Factors: pressure, friction, shear, chemical effects of moisture, urine, and stool.

2. Intrinsic Risk Factors: dermal thickness, subcutaneous adiposity, collagen tensile strength, and skin elasticity all decrease with aging; nutrition and hydration; conditions associated with immobility, impairment of sensation and reduced level of consciousness.

3. Assessment Tool (included): see the “Braden Scale for Predicting Pressure Sore Risk”.

C. Pathophysiology

1. There are four physical factors that can lead to the development of pressure ulcers:

   (a) Pressure – Mild pressure can produce ischemia in tissue after only two hours. This ischemia can then lead to tissue necrosis.
(b) Shear – A shearing force is produced where the skin is against a fixed exterior surface while the subcutaneous tissues are subjected to lateral forces.

(c) Friction – When the skin moves across another surface, abrasions can occur and cause burns.

(d) Moisture – Moisture can lead to tissue maceration. If urinary or fecal incontinence is present, this can add a chemical irritant.

D. Prevention (The National Pressure Ulcer Advisory Panel’s Summary of the AHCPR Clinical Practice Guideline, Pressure Ulcers in Adults: Prediction and Prevention)\textsuperscript{11}

1. Risk Assessment (see above)

2. Skin Care and Early Treatment
   a. Inspect the skin at least daily and document assessment results.
   b. Individualize bathing frequency, use a mild cleansing agent, avoid hot water and excessive friction.
   c. Assess and treat incontinence.
   d. Use moisturizers for dry skin; minimize environmental factors leading to dry skin.
   e. Avoid massage over bony prominences.
   f. Use proper positioning, transferring and turning techniques to minimize skin injury.
   g. Use dry lubricants (cornstarch) or protective coverings to reduce friction injury.
   h. Identify and correct factors compromising protein / calorie intake and consider nutritional supplement / support for nutritionally-compromised persons.
   i. Institute a rehabilitation program to maintain or improve mobility / activity status.
   j. Monitor and document interventions and outcomes.

3. Mechanical Loading and Support Surfaces
   a. Reposition bed-bound persons at least every 2 hours, chair-bound persons every hour.
   b. Use a written repositioning schedule.
   c. Place at-risk persons on a pressure-reducing mattress/chair cushion. Do no use donut-type devices.
   d. Consider postural alignment, distribution of weight, balance and stability, and pressure relief when positioning persons in chairs or wheelchairs.
e. Teach chair-bound persons, who are able, to shift weight every 15 minutes.
f. Use lifting devices to move rather than drag persons during transfers and position changes.
g. Use pillows or foam wedges to keep bony prominences such as knees and ankles from direct contact with each other.
h. Use devices that totally relieve pressure on the heels.
i. Avoid positioning directly on the trochanter when using the side-lying position.
j. Elevate the head of the bed as little and for as short a time as possible.

4. Education

a. Implement educational programs for the prevention of pressure ulcers.
b. Include information on etiology and risk factors, risk assessment tools, skin assessment, support surfaces, skin care, positioning, and documentation.

E. Staging Definitions (National Pressure Ulcer Advisory Panel NPUAP)

1. **Stage I**: A stage I pressure ulcer is an observable pressure-related alteration of intact skin whose indicators, as compared to an adjacent or opposite area on the body, may include changes in one or more of the following: skin temperature (warmth or coolness); tissue consistency (firm or boggy feel); sensation (pain, itching); and color. Specifically, the ulcer appears as a defined area of persistent redness in a lightly pigmented skin, whereas in darker skin tones, the ulcer may appear with persistent red, blue, or purple hues.

2. **Stage II**: Partial thickness skin loss involving epidermis and / or dermis. The ulcer is superficial and presents clinically as an abrasion, blister, or shallow crater.

3. **Stage III**: Full-thickness skin loss involving damage or necrosis of subcutaneous tissue that may extend down to, but not through, underlying fascia. The ulcer presents clinically as a deep crater with or without undermining of adjacent tissue.

4. **Stage IV**: Full-thickness skin loss with extensive destruction, tissue necrosis or damage to muscle, bone or supporting structures (e.g., tendon, joint capsules, etc.).

F. Treatment

1. Assess the whole person, not just the pressure ulcer, including physical health, pain, psychosocial health, and pressure ulcer complications.
2. Attempt to use established measures of wound healing (PUSH) (NPUAP, 1997).

3. Maintain principles of wound care relevant to pressure ulcers:
   a. Debride wound
   b. Clean wound
   c. Use solutions that DON’T kill cells; DON’T use solutions that are cytotoxic i.e. hydrogen peroxide, Dahan’s Solution, or Betadine
   d. Irrigate wound, using minimal force
   e. Cover wound with appropriate dressing

VIII. References


15 Lindgren, M., Unosson, M., Fredrikson, M., Ek, AC. (2004). Immobility--a major risk factor for development of pressure ulcers among adult hospitalized patients: a prospective study. Linkoping, Sweden Department of Medicine and Care, Division of Nursing Science, Faculty of Health Sciences, Linkoping University.


**Learning Resource A**

**Suggested Reading**


**Learning Resource B**

**Tables**

**TABLE 1: THE ABILITY OF “UP & GO” TIME SCORES TO REFLECT BASIC MOBILITY SKILLS**

<table>
<thead>
<tr>
<th>Timed “Up &amp; Go” (Sec)</th>
<th>10-19</th>
<th>20-29</th>
<th>30+</th>
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<tr>
<td>n = 17</td>
<td>n = 15</td>
<td>n = 26</td>
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<th>Chair Transfers</th>
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<tr>
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<td>Self</td>
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<td>Needs Help</td>
<td>0</td>
<td>13</td>
<td>27</td>
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<tr>
<td>Can’t Do</td>
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<tr>
<th>Walking Aid</th>
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<td>6</td>
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<tr>
<td>Cane</td>
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<td>75</td>
<td>48</td>
</tr>
<tr>
<td>Walker</td>
<td>6</td>
<td>0</td>
<td>41</td>
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<tr>
<td>Supervision</td>
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<td>19</td>
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**TABLE 2: THE ABILITY OF “UP & GO” TIME SCORES TO REFLECT EXTENDED MOBILITY SKILLS**

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<th>20-29</th>
<th>30+</th>
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<tbody>
<tr>
<td>n = 17</td>
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<table>
<thead>
<tr>
<th>Tub or shower transfers</th>
<th>%</th>
<th>%</th>
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<tr>
<td>Self</td>
<td>59</td>
<td>60</td>
<td>23</td>
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<tr>
<td>Needs Help</td>
<td>41</td>
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<tr>
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<th>Walk 50 Yards</th>
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<td>Self</td>
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<tr>
<td>Needs Help</td>
<td>18</td>
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<td>50</td>
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<tr>
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<table>
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<tr>
<th>Climbs stairs</th>
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<th>%</th>
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<td>Self</td>
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<td>60</td>
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<tr>
<td>Needs Help</td>
<td>23</td>
<td>40</td>
<td>81</td>
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<tr>
<td>Risk Factor</td>
<td>Medical/Specialty-Intervention</td>
<td>Other Disciplines-Intervention</td>
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</tr>
<tr>
<td>-------------</td>
<td>--------------------------------</td>
<td>--------------------------------</td>
<td></td>
</tr>
<tr>
<td>Balance and gait problems due to neurological disease</td>
<td>Diagnosis and treatment of specific diseases, with neurologic consultation if needed</td>
<td>PT: Balance and gait training; assessment for walking aid OT, N: Environmental safety assessment, especially lighting, adaptive devices</td>
<td></td>
</tr>
<tr>
<td>Musculoskeletal problems Upper or lower extremity weakness, arthritis, deformity</td>
<td>Diagnosis and treatment of specific diseases—orthopedic gait training; or rheumatology consultation if needed</td>
<td>OT, PT: Balance and muscle strengthening exercises; assessment for walking aid</td>
<td></td>
</tr>
<tr>
<td>Foot Problems</td>
<td>Foot Care (nails, bunions, calluses); podiatric or orthopedic consultation if needed</td>
<td>OT, N: Environmental safety assessment; adaptive devices (e.g. raised toilet seats, grab bars in tub); appropriate shoes</td>
<td></td>
</tr>
<tr>
<td>Cognitive Impairment</td>
<td>Evaluation for treatable disease; avoidance of sedating or centrally acting drugs</td>
<td>OT, N, S: Environmental safety assessment, including need for supervision; supervised exercise</td>
<td></td>
</tr>
<tr>
<td>Poor Vision</td>
<td>Ophthalmologic examination; Corrective lenses; surgery</td>
<td>OT, PT: Low vision aids; balance and gait training</td>
<td></td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>Calcium, vitamin D, medication to decrease bone loss</td>
<td>PT: weight-bearing exercise; use of hip padding; balance and gait training OT, N: Environmental safety assessment, especially floor surfaces</td>
<td></td>
</tr>
<tr>
<td>Low body mass index</td>
<td>Medical evaluation for occult disease; depression. Dietary consultation, nutritional supplements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medications</td>
<td>Eliminate unnecessary medications; use lowest effective dose; select shorter-acting agents</td>
<td></td>
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</tr>
</tbody>
</table>
Learning Resource C

Assessment Tools

1. **Tinetti Balance and Gait Evaluation***

BALANCE

*Instructions:* Seat the subject in a hard armless chair. Test the following maneuvers. Select one number that best describes the subject’s performance in each text, and add up the scores at the end.

1. **Sitting balance**
   - Leans or slides in chair = 0
   - Steady, safe = 1

2. **Arising**
   - Unstable without help = 0
   - Able but uses arms to help = 1
   - Able without use of arms = 2

3. **Attempt to arise**
   - Unable without help = 0
   - Able but requires more than one attempt = 1
   - Able to arise with one attempt = 2

4. **Immediate standing balance (first 5 seconds)**
   - Unsteady (staggers, moves fee, marked trunk sway) = 0
   - Steady but uses walker or cane or grabs other objects for support = 1
   - Steady without walker, cane, or other support = 2

5. **Standing balance**
   - Unsteady = 0
   - Steady but wide stance (medial heels more than 4 inches apart) or uses cane, walker, or other support = 1
   - Narrow stance without support = 2

6. **Nudging (with subject’s feet as close together as possible, push lightly on the sternum with palm of hand three times)**
   - Begins to fall = 0
   - Staggers and grabs, but catches self = 1
   - Steady = 2

7. **Eyes closed (at same position as in No. 6)**
   - Unsteady = 0
   - Steady = 1

8. **Turning 360 degrees**
   - Discontinuous steps = 0
   - Continuous steps = 1
   - Unsteady (grabs and stagers) = 0
   - Steady = 1
9. Sitting down
   Unsafe (misjudges distance, falls into chair) = 0
   Uses arms or lacks smooth motion = 1
   Safe, smooth motion = 2

GAIT

Instructions: The subject stands with the examiner, and then walks down the hallway or across the room, first at the usual pace and then back at a rapid but safe pace, using a cane or walker if accustomed to one.

10. Initiation of gait (immediately after being told to go)
    Any hesitancy or several attempts to start = 0
    No hesitancy = 1

11. Step length and height
    Right swing foot:
    Fails to pass left stance foot with step = 0
    Passes left stance foot = 1
    Fails to clear floor completely with step = 0
    Completely clears floor = 1
    Left swing foot:
    Fails to pass right stance foot with step = 0
    Passes right stance foot = 1
    Fails to clear floor completely with step = 0
    Completely clears floor = 1

12. Step symmetry
    Right and left step length unequal = 0
    Right and left step equal = 1

13. Step continuity
    Stopping or discontinuity between steps = 0
    Steps appear continuous = 1

14. Path (observe excursion of either left or right foot over about 10 feet of the course)
    Marked deviation = 0
    Mild to moderate deviation or uses walking aid = 1
    Walks straight without aid = 2

15. Trunk
    Marked sway or uses walking aid = 0
    No sway but flexion of knees or back or spreads arms out while walking = 1
    No sway, flexion, use of arms, or use of walking aid = 2

16. Walking stance
    Heels apart = 0
    Heels almost touching while walking = 1

Balance score ______ / 16
Gait score: ______ / 12
Total score: ______ / 28
## 2. Gait Disorders Classified by Sensorimotor Level*

<table>
<thead>
<tr>
<th>Sensorimotor Level</th>
<th>Condition (pathology, symptoms, signs)</th>
<th>Typical Gait Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peripheral sensory</td>
<td>Sensory ataxia (posterior column, peripheral nerves)</td>
<td>Unsteady uncoordinated</td>
</tr>
<tr>
<td></td>
<td>Vestibular ataxia</td>
<td>Unsteady, weaving (“drunken”)</td>
</tr>
<tr>
<td></td>
<td>Visual ataxia</td>
<td>Tentative, uncertain</td>
</tr>
<tr>
<td>Peripheral motor</td>
<td>Arthritic (antalgic, joint deformity)</td>
<td>Avoids weight bearing on affected side, shortened stance phase</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Painful hip may produce Trendelenburg’s sign (trunk shift over affected side)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Painful knee is flexed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Painful spine produces short, slow steps and decreased lumbar lordosis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other non-antalgic features: contractures, deformity-limited motion, buckling with weight bearing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Kyphosis and ankylosing spondylosis produce stooped posture</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unequal leg length can produce trunk and pelvic motion abnormalities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(including Trendelenburg's sign)</td>
</tr>
<tr>
<td>Myopathic and Neuropathic weakness</td>
<td>Pelvic girdle weakness produces exaggerated lumbar lordosis and lateral trunk flexion (Trendelenburg’s sign and waddling gait)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Proximal motor neuropathy produces waddling gait and foot slap</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Distal motor neuropathy produces distal weakness (especially ankle dorsiflexion or foot drop), which may lead to exaggerated hip flexion or foot lifting (steppage gait) and foot slap</td>
<td></td>
</tr>
<tr>
<td>Middle</td>
<td>Hemiplegia, hemiparesis</td>
<td>Leg swings outward and in semi-circle from hip (circumduction); knee may hyperextend (genu recurvatum), and ankle may</td>
</tr>
<tr>
<td>Spasticity</td>
<td></td>
<td>Excessively plantar flex and invert (talipes equinovarus); with less paresis, some may only lose arm swing and only drag or scrape foot</td>
</tr>
<tr>
<td>Paraplegia,</td>
<td>Both legs circumduct, steps are short shuffling and scraping, and when severe, hip adducts so that knees cross in front of each other (scissoring)</td>
<td></td>
</tr>
<tr>
<td>paraparesis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parkinsonism</td>
<td>Small shuffling steps, hesitation, acceleration (festination), falling forward (propulsion), falling backward (retropulsion), moving the whole body while turning (turning en bloc), absent arm swing</td>
<td></td>
</tr>
<tr>
<td>Cerebellar ataxia</td>
<td>Wide-based with increased trunk sway, irregular stepping, especially on turns</td>
<td></td>
</tr>
<tr>
<td>High</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cautious gait</td>
<td>Fear of falling with appropriate postural responses, normal to widened base, shortened stride, decreased velocity, and en bloc turns</td>
<td></td>
</tr>
<tr>
<td>Frontal-related</td>
<td>Cerebrovascular,</td>
<td>Proposed spectrum ranges from gait ignition failure to frontal gait</td>
</tr>
</tbody>
</table>
normal-pressure disorganization to frontal disequilibrium; may also have cognitive, pyramidal, and urinary disturbances

hydrocephalus

Gait ignition failure: difficulty initiating gait, short shuffling gait, may freeze with diversion of attention or turning

Frontal gait disorder: similar to Parkinson’s disease

Frontal disequilibrium: cannot stand unsupported


3. Evaluating Incontinence

<table>
<thead>
<tr>
<th>Components</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>History</td>
<td>Provider initiation: 50% of affected persons do not report UI; many assume UI is normal</td>
</tr>
<tr>
<td>Specific symptoms</td>
<td>Diagnostic value varies with symptom definition, age and gender, underlying pathology</td>
</tr>
<tr>
<td>Precipitant urgency suggests DO; precipitants include running water, handwashing, cold temperatures, sight of garage or front door</td>
<td></td>
</tr>
<tr>
<td>UI with coughing, laughing, bending, etc.; sensitive for stress UI; delay between maneuver and UI or urge before leakage suggests stress-induced urge UI; leakage with minimal maneuvers or continual urine dripping suggests ISD</td>
<td></td>
</tr>
<tr>
<td>Frequency, nocturia, slow urine stream, hesitancy, interrupted voiding, straining, and terminal dribbling are common with DO, DHIC, BOO, detrusor underactivity, many medical conditions</td>
<td></td>
</tr>
<tr>
<td>Voiding symptom scores (eg, AUA BPH symptom score) useful as severity measure but lack specificity, are not diagnostic</td>
<td></td>
</tr>
<tr>
<td>UI characteristics</td>
<td>Onset, frequency, volume, timing, and precipitants (eg, medications, caffeine, alcohol, physical activity, cough)</td>
</tr>
<tr>
<td>Associated factors</td>
<td>Medical conditions and medications with temporal relation to UI</td>
</tr>
<tr>
<td>Quality of life</td>
<td>Inquire how patient and caregiver are affected, ie, activities of daily living, social, emotional, interpersonal (eg, sexual) relations, self-concept, and general health perception; most bothersome aspect</td>
</tr>
<tr>
<td>Physical examination</td>
<td>Orthostatic vital signs, alertness, cognition, functional status</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>Volume overload, peripheral edema</td>
</tr>
<tr>
<td>Abdomen, rectal</td>
<td>Bladder by palpation (insensitive); rectal masses and impaction</td>
</tr>
<tr>
<td>Back</td>
<td>Dimpling or hair tuft at spine base suggests incomplete spina bifida</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>Mobility and manual dexterity</td>
</tr>
<tr>
<td>Neurologic</td>
<td>Cervical disease suggested by limited lateral rotation and lateral flexion, interossei wasting, and Hoffman’s or Babinski’s sign</td>
</tr>
<tr>
<td>Sacral root integrity: perineal sensation; anal sphincter tone; anal “wink” and bulbocavernosus reflex</td>
<td></td>
</tr>
<tr>
<td>Genitourinary</td>
<td>Men: prostate exam; if uncircumcised, check for phimosis, paraphimosis, and balanitis</td>
</tr>
<tr>
<td>Women: vaginal mucosa for atrophy and pelvic support</td>
<td></td>
</tr>
<tr>
<td>Testing</td>
<td>48-hour record establishes baseline severity; timing and circumstances of UI and continent voids; voided volume; voiding frequency; total day and nocturnal urine output **; UI-associated activities (eg, coffee drinking, exercise). In institutions, staff record patient continence status (dry, damp, soaked) q2h. If nocturnal diuresis, causes (eg, pedal edema, CHF, or alcohol “nightcap”) should be sought; UI occurrence at a typical time of day suggests association with medication, beverages or activity</td>
</tr>
<tr>
<td>Clinical stress test</td>
<td>Best if bladder full, patient relaxes perineum, and single vigorous cough used; specific for stress UI if leakage instantaneous with cough; insensitive if patient cannot cooperate, is inhibited, or if bladder volume low; several-second delay before UI suggests stress-induced DO</td>
</tr>
<tr>
<td>Urine flow rate</td>
<td>Peak flow ≥ 12 mL/sec for voided volume ≥ 200 mL useful for excluding BOO, low flow rate not specific</td>
</tr>
</tbody>
</table>
Postvoiding residual

Done by catheterization or ultrasound; repeated measures possibly needed; PVR, 50 mL can contribute to frequency or nocturia, exacerbate urge and stress UI; PVR, 200 mL suggests detrusor weakness or BOO, and in men hydronephrosis should be excluded (rare in older women)

Laboratory tests

Renal function; glucose, calcium, vitamin B<sub>12</sub> levels, urinalysis and culture; urine cytology and cystoscopy if hematuria or pelvic pain present; PSA in men, if cancer screening appropriate or desirable

** Example: if nocturnal output (volume voided during hours of sleep, plus first morning void) = 800 mL and modal volume voided (proxy for functional bladder volume) = 200 mL, then patient must void 3-4 times per night (800 / 200 = 4).

NOTE: AUA = American Urological Association; BOO = bladder outlet obstruction; BPH = benign prostatic hyperplasia; CHF = congestive heart failure; DHIC = detrusor hyperactivity with impaired contractility; DO = detrusor overactivity; ISD = intrinsic sphincter deficiency; PSA = prostate specific antigen; PVR = postvoiding residual volume; UI = urinary incontinence

### Braden Scale for Predicting Pressure Sore Risk*

<table>
<thead>
<tr>
<th>Article I. SENSORY PERCEPTION</th>
<th>1. Completely Limited: Unresponsive (does not move, flinch, or grasp) the painful stimuli because of diminished level of consciousness or sedation. OR limited ability to feel pain over most of body surface.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. Very Limited: Responds only to painful stimuli. Cannot communicate discomfort except by moaning or restlessness. OR has a sensory impairment that limits the ability to feel pain or discomfort over ½ of the body.</td>
</tr>
<tr>
<td></td>
<td>3. Slightly Limited: Responds to verbal commands, but cannot always communicate discomfort or need to be turned. OR has some sensory impairment that limits ability to feel pain or discomfort in 1 or 2 extremities.</td>
</tr>
<tr>
<td></td>
<td>4. No Impairment Responds to verbal commands. Has no sensory deficit that would limit ability to feel or voice pain or discomfort.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Article II. MOISTURE</th>
<th>1. Constantly Moist: Skin is kept moist almost constantly by perspiration, urine, etc. can be measured every time patient is moved or turned.</th>
</tr>
</thead>
<tbody>
<tr>
<td>degree to which skin is exposed to moisture</td>
<td>2. Very Moist: Skin is often, but not always moist. Linen must be changed at least once a shift.</td>
</tr>
<tr>
<td></td>
<td>3. Occasionally Moist: Skin is occasionally moist, requiring an extra linen change approximately once a day.</td>
</tr>
<tr>
<td></td>
<td>4. Rarely Moist: Skin is usually dry, linen only requires changing at routine intervals.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Article III. ACTIVITY</th>
<th>1. Bedfast: Confined to bed</th>
</tr>
</thead>
<tbody>
<tr>
<td>degree of physical activity</td>
<td>2. Chairfast: Ability to walk severely limited or nonexistent. Cannot bear own weight and / or must be assisted into chair or wheelchair.</td>
</tr>
<tr>
<td></td>
<td>3. Walks Occasionally: Walks occasionally during day, but for very short distances, with or without assistance. Spends majority of each shift in bed or chair.</td>
</tr>
<tr>
<td></td>
<td>4. Walks Frequently: Walks outside the room at least twice a day and inside room at least once every 2 hours during waking hours.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Article IV. MOBILITY</th>
<th>1. Completely Immobile: Does not make even slight changes in body or extremity position without assistance.</th>
</tr>
</thead>
<tbody>
<tr>
<td>ability to change and control body position</td>
<td>2. Very Limited: Makes occasional slight changes in body or extremity position but unable to make frequent or significant changes independently.</td>
</tr>
<tr>
<td></td>
<td>3. Slightly Limited: Makes frequent though slight changes in body or extremity position independently.</td>
</tr>
<tr>
<td></td>
<td>4. No Limitation: Makes major and frequent changes in position without assistance.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Article VI. NUTRITION</th>
<th>1. Very Poor: Never eats a complete meal. Rarely eats more than 1/3 of any food offered. Eats 2 servings or less protein (meat or dairy products) per day. Takes fluids poorly. Does not take a liquid dietary supplement. OR is NPO and / or maintained on clear liquids or IVs for more than 5 days.</th>
</tr>
</thead>
<tbody>
<tr>
<td>usual food intake</td>
<td>2. Probably Inadequate: Rarely eats a complete meal and generally eats only about ½ of any food offered. Protein intake includes only 3 servings of meat or dairy products per day. Occasional may take a dietary supplement. OR receives less than optimum amount of liquid diet or tube feeding.</td>
</tr>
<tr>
<td></td>
<td>3. Adequate: Eats over half of most meals. Eats a total of 4 servings of protein (meat, dairy products) each day. Occasionally will refuse a meal, but will usually take a supplement if offered.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Article VII. FRICTION AND SHEAR</th>
<th>1. Problem: Requires moderate to maximum assistance in moving. Complete lifting without sliding against sheets is impossible. Frequently slides down in bed or chair, requiring frequent repositioning with maximum assistance. Spasticity, contractures, or agitation leads to almost constant friction.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. Potential Problem: Moves feebly or requires minimum assistance. During a move skin probably slides to some extent against sheets, chair, restraints, or other devices. Maintains relatively good position in chair or bed most of the time but occasionally slides down.</td>
</tr>
<tr>
<td></td>
<td>3. No Apparent Problem: Moves in bed and in chair independently and has sufficient muscle strength to lift up completely during move. Maintains good position in bed or chair at all times.</td>
</tr>
</tbody>
</table>

Barbara Braden and Nancy Bergstrom. Copyright, 1988. NOTE: NPO = Nothing by mouth; IV = Intravenously; TPN = Total parenteral nutrition
Module # 6: Geriatric Mental Health
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

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Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

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# Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

## Module # 6: Geriatric Mental Health

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<td>A. The Short Michigan Alcoholism Screening Instrument-Geriatric Version (MAST-G)</td>
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<tr>
<td>B. CAGE Screening Questionnaire</td>
<td></td>
</tr>
<tr>
<td>C. New York State Office of Mental Health (OMH) Geriatric Information and Resources</td>
<td></td>
</tr>
<tr>
<td>D. New York State Office of Mental Health (OMH) 2006 Annual Report</td>
<td></td>
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</table>
I. Overview

There is no question that the elderly population is increasing at a rapid speed due to the aging of the baby boomers. According to the U.S. Bureau of the Census, the population of people aged 65+ in the United States will double from 35-70 million over the next 25 years. In the United States, the percentage of older adults will increase from 13-20% of the population. Over the next quarter century, the number of older adults aged 65+ in New York State will increase over 50% from 2.4 to 3.7 million. By 2015, baby boomers will comprise of 24% of the NYS population. Among the fast growing elderly are minorities, elders living alone, those with chronic illness, and the very old (over 85). These individuals also represent the most vulnerable people in society. As the rate of elderly people continues to skyrocket throughout the country, there is also a growing demand for mental health services that are both easily accessible and culturally competent. Older adults are the most underserved age group with respect to the mental health system. One in five Americans over 65 have a mental health diagnosis, and approximately 50% of older adults with a mental disorder do not receive any treatment.

While there is no formal definition of “mental health”, it is often referred to as a person’s individual emotional and psychological well-being. The World Health Organization (WHO) defines health as a “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” There is no doubt that mental health is incorporated into this definition. Untreated mental illness in older adults results in detrimental consequences including poor health outcomes, high medical co-morbidity, increased disability and mortality, poor quality of life, and higher annual health care costs. Societal stigma about mental illness continues to preclude many older adults from receiving necessary treatment. Therefore, it is crucial that health care professionals educate themselves about mental illness in the elderly and serve as advocates for their patients.
II. Learning Objectives

1. Define mental health as it relates to older adults.
2. Identify prevalence of mental illnesses and substance abuse among the elderly.
3. Discuss barriers to treatment for mental health issues.
4. Identify tools and resources for health care professionals.

III. Older Adults and Mental Illness / Substance Abuse

1. UUMental Illnesses Prevalent Among The Elderly: There are several types of mental disorders that affect the elderly population. In a given one year period, older adults ages 55 and older suffer from the following disorders:  
   - 19.8% suffer from any disorder
   - 11.4% suffer from any anxiety disorder
   - 4.4% suffer from any mood disorder (not including minor depression)
   - 0.6% suffer from schizophrenia
   - 6.6% suffer from severe cognitive impairment (primarily dementia)
   - 25-30% have symptoms of depression

A. Common Disorders Among The Elderly: Some common disorders found within the elderly population include depression, dementia, delirium, anxiety disorder, adjustment disorder, delusional disorder, schizophrenia, obsessive compulsive disorder, bipolar disorder, post-traumatic stress disorder, and substance abuse among others. Physiological problems such as decline in vision and hearing, memory impairment, side effects from medication, and societal factors all contribute to decreased mental health and wellness. While early treatment for such disorders are vital to ensure optimal health, older adults and their family members may be hesitant to discuss any past or present psychological problems due to generational or preconceived stigma, thus making proper diagnosis and subsequent treatment options a tremendous
challenging for health care providers. Untreated mental illness may lead to unnecessary pain, suffering, instability, and even suicide. Therefore, it is imperative that health care providers take part in regular screenings and follow-up with their patients.

B. **Anxiety Disorder**: Anxiety disorders generally involve excessive worry, fear, and apprehension. People who suffer from anxiety disorders tend to experience constant anxiety about habitual events in their daily lives. This is different from *phobias* which are fears of specific activities, situations, or objects. *Panic disorder* is a specific type of anxiety disorder whereby individuals typically experience sudden fear, shortness of breath, and rapid heartbeat.

C. **Mood Disorder**: Mood disorders are often called *affective disorders* because they are characterized by extremes of mood and/or dramatic changes of mood. Examples of mood disorders are mania, depression, and bipolar disorder. *Mania* focuses on abnormally elevated mood, decreased need for sleep, grandiosity, and impulsiveness. *Depression* may include feelings of sadness, worthlessness, hopelessness, changes in sleep patterns, and decreased appetite. *Bipolar disorder* is best described as alternating between extremes of mania and depression.

D. **Schizophrenia**: Symptoms of schizophrenia and other psychotic disorders may include hallucinations, delusions, social withdrawal, disorganized thinking, and diminished emotional responses. Since there are five types of schizophrenia - *paranoid, disorganized, catatonic, undifferentiated, and residual* - people who suffer from this disorder may act quite differently from one another. Untreated schizophrenia may have tremendous adverse impacts on one’s life because perception of reality becomes essentially warped.
E. Cognitive Impairment: Many people suffer from some sort of cognitive impairment as they get older. This may include delirium or dementia. Cognitive impairment involves significant loss of mental functioning. Health care providers often face challenges in treating patients with cognitive impairments, because it may be difficult to decipher normal aging with severe deficits.

F. Depression: Symptoms of depression are often confused with normal aging or dementia. Having a depressive disorder is actually not a natural part of aging. While temporary feelings of grief, sadness, and response to loss are common and expected emotions, feelings that are persistent and interfere with ability to function on a daily basis is not normal. 6 In addition, many older adults who have experienced years of depression (or any other mental illness) throughout adulthood and who have not sought treatment for their condition may appear to have dementia and are consequently misdiagnosed.

2. Substance Abuse Among The Elderly: Alcohol and substance abuse among the elderly population are increasingly growing problems and require close attention. When talking about substance abuse and/or misuse, this may refer to a myriad of things including mood altering drugs, drinking erratically, or unsafe use of medications among others. According to numerous reports by the Journal of the American Medical Association (JAMA): about 50% of individuals with serious mental disorders are also affected by substance abuse; 37% of alcohol abusers and 53% of drug abusers have at least one serious mental illness; and 29% of individuals diagnosed with a mental illness abuse drugs or alcohol. 7 The dangers of drug and alcohol abuse in the elderly are extensive. This is due to the fact that the body changes as it ages, causing slower metabolism, decreased tolerance to alcohol and some medications, and even hypersensitivity.

A. Substance Abuse Screening: Screening for substance abuse among the elderly may be challenging for health care professionals due to the fact that many elderly individuals take
some sort of medication to help manage chronic illnesses. It is crucial that health care providers continuously monitor all medications and their dosage strengths and look for any symptoms of substance abuse. While some individuals may abuse prescribed medications, others may turn to illegal substances. The *Diagnostic and Statistical Manual (DSM-IV)* is a comprehensive manual published by the American Psychiatric Association that helps health care professionals diagnose and treat children and adults with mental health disorders. And since substance abuse and mental health often intertwine, it is vital that health care professionals properly screen for substance abuse. The DSM-IV is an excellent resource that provides specific criteria that helps assist in accurate diagnosis of substance abuse.

**B. Alcohol Abuse Screening:** Alcohol abuse in old age may result from years of drinking in earlier adulthood or may be triggered by social isolation, financial woes, bereavement, role changes, and other challenges that occur during later adulthood. There are several alcohol screening tools available to health care professionals. The *Short Michigan Alcoholism Screening Instrument (MAST-G)* was the first screening instrument developed for the elderly. It is a 24-item tool that helps detect alcohol use in the elderly (See Learning Resource A). Another instrument that is more commonly used to screen for alcohol abuse is the *CAGE Screening Questionnaire*. It is a four-question instrument that gages an individual’s drinking habits. This instrument relies solely on self-report, so it is difficult to determine its validity (See Leaning Resource B).

**3. Addictive Disorders:** Addictive disorders are becoming increasing problems for older adults. These disorders are usually diagnosed as consequences of *drug abuse* or *alcohol abuse*. Typical substances that result in addiction among the elderly
include alcohol, nicotine, caffeine, amphetamines, and sedatives. As people age, most will develop at least one or more chronic illnesses that require daily management. Elderly people may turn to addictive substances as a way to help cope with their chronic conditions. For some elderly, addiction is a lifelong problem, whereas others face problems with addiction in later adulthood.

Another type of addictive disorder most notably found within the elderly population is gambling. Gambling appeals to many people due to its thrill of uncertainty and the possibility of tremendous financial gain. The gambling industry spends exorbitant amounts of money on marketing in attempts to lure people to casinos, sporting events, and other venues that promote such activity. It is not uncommon to find elderly people gambling with their life savings in hopes of increasing their personal wealth.

While addictive disorders are not considered mental illnesses by most mental health professionals, it is very common to find older adults with mental illnesses suffer from addictive disorders as well.

IV. Treatment For Mental Health Services

Elderly people face tremendous barriers when accessing treatment for mental health issues. The primary reason for this is that there are far too few services available. In addition, distant service locations, unaffordable costs of treatment, lack of in-home services, and insufficient bilingual providers all contribute to reasons why so many elderly fail to seek treatment. Furthermore, there is minimal outreach and public education available for elders about this topic, thus making treatment options seem unrealistic and impractical. Lastly, many elderly individuals are unaware of the specialized health care professionals who have training in Geriatrics and who are able to provide better care and treatment.

1. **Types of Health Care Professionals:** Geriatricians are physicians who specialize in the diagnosis and treatment of diseases and problems specific to older adults. Ideally, a geriatrician should serve as an elderly person’s primary care provider. This will enable the physician to provide specific comprehensive assessments
and screenings which will help when referring patients to seek appropriate treatment for mental health services or issues of substance abuse. Although several hospital outpatient clinics have at least one geriatrician working as part of the staff, there is a significant shortage of this specialty. In addition to geriatricians, geriatric psychiatrists are medical doctors who have special training in the diagnosis and treatment of mental disorders that occur in older adults. Both geriatricians and geriatric psychiatrists work in a variety of settings including offices, hospitals, outpatient clinics, long-term care facilities, and independent or assisted living facilities. Also, many allied health professionals such as social workers and nurses are beginning to receive additional formal training in geriatrics and gerontology in order to better understand the needs of older patients. All health care professionals working with the elderly population should be knowledgeable about local resources available so that they may help educate patients and their families about seeking the most effective and appropriate treatments.

2. **Barriers to Access Services:** Elderly people are faced with several barriers when trying to access viable mental health services. This becomes increasingly prevalent when speaking about minority elders, particularly African Americans and Hispanic elderly. These include barriers at a systematic, agency, and individual level. 8 By examining each type of barrier, health care providers are able to better understand why so many elderly do not receive necessary treatment.

   A. **System Level Barriers:** This refers to the macro, systematic level of care. There is no question that the health care “system” is broken and has several gaps in patient care. Many elderly people and their families find it terribly difficult to navigate the health care system. This is due to lack of clarity surrounding treatment and accessibility to care. There are separate funding sources for the elderly and for mental health services which makes treatment viability rather confusing. Medicare reimbursement for mental health services are significantly lower than physical health services. Prescription drug coverage for certain
medications continues to be one of the largest problems facing Medicare beneficiaries. For elderly individuals covered under managed care plans, there may be a number of restrictions on treatments that are covered. For those individuals who have low incomes but who do not qualify for Medicaid and other income tested programs, ability to pay for necessary medications and treatments become virtually impossible.

B. **Agency Level Barriers:** Barriers at an agency level include stereotypes of older adults as poor candidates for mental health services; health care provider attitudes that depression and anxiety are simply “normal” aspects of aging; and insufficient agency resources to manage elderly patients who suffer from complex co-morbidity. The number of agencies that provide services to treat mental health issues are generally lower in rural areas than in suburban and urban areas, making it increasingly difficult for some elderly to access care. In addition, the homebound and frail elderly are far less likely to receive treatment because of their inability to travel to an outside agency. Also, there is a tremendous shortage of community-based services that offer specialized treatment for mental health issues.

C. **Individual Level Barriers:** There are several individual barriers that preclude the elderly from accessing treatment for mental health issues. Varying generational ideologies about seeking treatment for mental health issues is among the top reasons for not getting treatment. The current elderly population comes from a generation where getting treatment for such conditions is shunned and stigmatized.

V. **Tools For Health Care Professionals**

With the increasing number of elderly people in need of mental health services, there is much that health care professionals can do in order to help better serve this population. Staying abreast of current research, assessment tools, and local resources are all ways in which health care professionals are able to better understand the most prevalent conditions that affect the elderly. Also, advocating for increased monetary allocations for mental health
services and education may help push city and state agencies to provide more comprehensive and easily accessible treatment options to elderly patients.

1. **Screening Tools:** There are several tools that may assist health care professionals to screen for alcohol abuse in the elderly (See Learning Resource A and B). Utilizing a valid screening tool is essential for accurate diagnosis. Tools to screen for depression and other mental health disorders are also widespread and are readily available online and within research databases. Health care professionals should follow the procedures and guidelines set forth in their respective agencies on screening for disorders among the elderly.

2. **Local Resources:** In the state of New York, there is a plethora of resources that enable health care professionals to educate themselves about topics in mental health as well as provide patients and their families with valuable information about symptoms, diagnosis, and treatment. The New York State Office of Mental Health (OMH) has compiled a comprehensive list of Geriatric Information and Resources (See Learning Resource C) that directs individuals to appropriate agencies and organizations for assistance and services.

3. **Legislation:** It is imperative that health care professionals are aware of any legislative changes made to health care services. This is especially important when funding is being cut to any major services or programs throughout a service area. In order to make effective policies about health care, policy makers must be able to truly understand the population for which it is trying to protect. Therefore, health care professionals should have knowledge of current trends and practices in place. In August of 2005, the state of New York enacted the Geriatric Mental Health Act to address the mental health needs of NY residents (See Learning Resource D). This report presents a comprehensive framework on mental health issues and is greatly beneficial for health care professionals working in the field of mental health. More recently, the federal government passed legislation in October 2008 requiring insurance companies to treat mental health equally with physical illnesses when insurance policy coverage includes both types of benefits. This legislation came as part of the $700 billion economic bailout and is a huge triumph for mental health advocates across the country.
VI. References


The Short Michigan Alcoholism Screening Instrument- Geriatric Version (MAST-G)

The Short Michigan Alcoholism Screening Instrument- Geriatric Version (MAST-G) was the first screening instrument developed for the elderly. It is a 24-item tool that helps detect alcohol use in the elderly.


© The Regents of the University of Michigan, 1991.

<table>
<thead>
<tr>
<th>Michigan Alcoholism Screening Test - Geriatric Version (MAST-G)</th>
</tr>
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<tbody>
<tr>
<td>1. After drinking have you ever noticed an increase in your heart rate or beating in your chest?</td>
</tr>
<tr>
<td>2. When talking with others, do you ever underestimate how much you actually drink?</td>
</tr>
<tr>
<td>3. Does alcohol make you sleepy so that you often fall asleep in your chair?</td>
</tr>
<tr>
<td>4. After a few drinks, have you sometimes not eaten or been able to skip a meal because you didn't feel hungry?</td>
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<tr>
<td>5. Does having a few drinks help decrease your shakiness or tremors?</td>
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<tr>
<td><strong>6.</strong> Does alcohol sometimes make it hard for you to remember parts of the day or night?</td>
</tr>
<tr>
<td><strong>7.</strong> Do you have rules for yourself that you won't drink before a certain time of the day?</td>
</tr>
<tr>
<td><strong>8.</strong> Have you lost interest in hobbies or activities you used to enjoy?</td>
</tr>
<tr>
<td><strong>9.</strong> When you wake up in the morning, do you ever have trouble remembering part of the night before?</td>
</tr>
<tr>
<td><strong>10.</strong> Does having a drink help you sleep?</td>
</tr>
<tr>
<td><strong>11.</strong> Do you hide your alcohol bottles from family members?</td>
</tr>
<tr>
<td><strong>12.</strong> After a social gathering, have you ever felt embarrassed because you drank too much?</td>
</tr>
<tr>
<td><strong>13.</strong> Have you ever been concerned that drinking might be harmful to your health?</td>
</tr>
<tr>
<td><strong>14.</strong> Do you like to end an evening with a nightcap?</td>
</tr>
<tr>
<td><strong>15.</strong> Did you find your drinking increased after someone close to you died?</td>
</tr>
<tr>
<td><strong>16.</strong> In general, would you prefer to have a few drinks at home rather than go out to social events?</td>
</tr>
<tr>
<td>Question</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>17. Are you drinking more now than in the past?</td>
</tr>
<tr>
<td>18. Do you usually take a drink to relax or calm your nerves?</td>
</tr>
<tr>
<td>19. Do you drink to take your mind off your problems?</td>
</tr>
<tr>
<td>20. Have you ever increased your drinking after experiencing a loss in your life?</td>
</tr>
<tr>
<td>21. Do you sometimes drive when you have had too much to drink?</td>
</tr>
<tr>
<td>22. Has a doctor or nurse ever said they were worried or concerned about your drinking?</td>
</tr>
<tr>
<td>23. Have you ever made rules to manage your drinking?</td>
</tr>
<tr>
<td>24. When you feel lonely, does having a drink help?</td>
</tr>
</tbody>
</table>
Learning Resource B

CAGE Screening Questionnaire

The CAGE Questionnaire is a commonly used four-question instrument that gauges an individual’s drinking habits. Since this instrument relies solely on self-report, it is difficult to determine its validity. “Yes” responses to any of the four questions should result in further evaluation.

1. Have you ever felt you should *cut down* on your drinking?
2. Have people *annoyed* you by criticizing your drinking?
3. Have you ever felt bad or *guilty* about your drinking?
4. Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover (*eye opener*)?
Learning Resource C

New York State Office of Mental Health (OMH)
Geriatric Information and Resources

*This information has been taken from the New York State Office of Mental Health website. For more information, please visit:
http://www.omh.state.ny.us/omhweb/geriatric/resources.html.

Geriatric Information and Resources

General

- **Blueprint for Change: Achieving Integrated Health Care for an Aging Population** - A report developed by the American Psychological Association outlines the challenges and benefits of building interdisciplinary teams to address the specific health care needs of older people.
  http://www.apa.org/pi/aging/blueprint.html
- **CornellCares.com** - Innovative yet sensible practice tools, information, and resources to make geriatric mental health and psychosocial assessments and interventions easier and more effective for all health care and social service practitioners.
  http://www.cornellcares.com
- **Geriatric Mental Health Alliance of New York** - Advocating for changes in mental health practice and policy to improve current mental health services for older adults.
  http://www.mhawestchester.org/advocates/geriatrichome.asp
- **Geriatric Mental Health Foundation** - Mental health information for older adults and their families; find a geriatric psychiatrist; news of Foundation programs and events.
  http://www.gmhfonline.org/gmhf
- **National Council on Aging** - Improving the lives of older Americans through advocacy, programs and research.
  http://www.ncoa.org
• **National Institute on Aging** - Leading the federal effort on research. Information on publications and clinical trials.  

• **New York City Department for the Aging** - Strengthening and improving services for seniors in New York City.  

• **Older Americans Substance Abuse and Mental Health Technical Assistance Center** -  
  National repository to disseminate information, training, and direct assistance in the prevention and early intervention of substance abuse and mental health problems.  
  [http://www.samhsa.gov/olderAdultsTAC](http://www.samhsa.gov/olderAdultsTAC)

• **Surgeon General's Report on Older Adults and Mental Health**  

### Caregivers

• **AARP Caregiving** - Provides information and supports for caregivers.  
  [http://www.aarp.org/family/caregiving](http://www.aarp.org/family/caregiving)

• **Caregiver Information** - Ask Medicare's information site to help caregivers navigate the Medicare system.  
  [http://www.medicare.gov/Caregivers](http://www.medicare.gov/Caregivers)

• **Caregiver Stress Quiz** - Quiz to determine if you're feeling stressed or strained.  
  [http://assets.aarp.org/external_sites/caregiving/homeCare/managing_the_stress_quiz.html](http://assets.aarp.org/external_sites/caregiving/homeCare/managing_the_stress_quiz.html)

• **Family Caregiver Workshops** - On-going series of workshops sponsored by the NYC Chapter of the Alzheimer's Association.  
  [http://www.alzny.org/meetings/familycaregiverworkshop.asp](http://www.alzny.org/meetings/familycaregiverworkshop.asp)

• **Family Caregivers of Vets** - List and descriptions of resources and supports for veterans and their caregivers.  
Chemical Dependence

- **OASAS and New York's Seniors** - Presentation on Working with Aging Client Populations: Preventing, Identifying and Treating Alcohol & Substance Abuse and Supporting Recovery.
  http://www.oasas.state.ny.us/admed/documents/seniors.ppt
- **OASAS Seniors and Health** - Provides seniors, their families and friends, professionals, and other caregivers with information about the risks and harmful effects that older adults face regarding their use of alcohol, medications and other drugs.
  http://www.oasas.state.ny.us/prevention/senior/index.cfm
- **The Elderly and Alcohol** - Various articles and studies on alcohol abuse and the elderly found on About.com.
  http://alcoholism.about.com/od/elder/Elderly_and_Alcohol.htm

Community Resources

- **Eldercare Locator** - The first step to finding resources for older adults in any U.S. community. A public service of the U.S. Administration on Aging.
  http://www.eldercare.gov/Eldercare/Public/Home.asp
- **NY Connects – Choices for Long-term Care** - Provides county level, consumer-centered access points to information and assistance for all individuals in need of long term care services.
  http://www.nyconnects.org
- **NYS Senior Citizen's Resource Guide** - NYS Office for the Aging guide to resource topics and links of interest to seniors.

Depression

- **Mental Health America's Factsheet on Depression in Older Adults**
  http://www.mentalhealthamerica.net/go/information/get-info/depression/depression-in-older-adults/depression-in-older-adults
• **National Institute on Aging: Age Page on Depression** - Overview of depression.

• **National Institute of Mental Health's Depression Page** - Information on depression: causes, symptoms and treatment.
  http://nihseniorhealth.gov/depression/toc.html

**Long-Term Care**

• **Frequently Asked Questions on Long-term Care** by planaheadny.
  http://planaheadny.com/faq.htm

• **NYS Partnership for Long-term Care** - A unique program combining long-term care insurance and Medicaid Extended Coverage that helps New Yorkers finance long-term care without impoverishing themselves.
  http://www.nyspltc.org

**Mental Health Publications**

• **Anxiety Disorders** - A booklet to help you identify symptoms and causes of anxiety disorders. It will also explain how to obtain treatment and suggest ways to make such treatment more effective.
  http://www.omh.state.ny.us/omhweb/booklets/AnxietyDisorders.htm

• **Bipolar Disorders** - A booklet that will help you identify symptoms and causes of bipolar disorder, also know as manic-depression.
  http://www.omh.state.ny.us/omhweb/booklets/Bipolar.htm

• **Depression** - A booklet that will help you identify symptoms and causes of depression.
  http://www.omh.state.ny.us/omhweb/booklets/depression.htm

• **Grief Counseling Resource Guide** - A manual developed as a guide for those who encounter individuals reacting to trauma related grief reactions in the course of their outreach work.
  http://www.omh.state.ny.us/omhweb/grief
VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 6: Geriatric Mental Health

- **Medications** - A booklet to help people with mental illness and their families understand how and why medications can be used as part of the treatment of mental health problems.
  http://www.omh.state.ny.us/omhweb/booklets/medications.htm

- **Post-Traumatic Stress Disorder (PTSD)** - This booklet examines the signs, symptoms and steps you can take to treat PTSD.
  http://www.omh.state.ny.us/omhweb/booklets/ptsd.htm

- **Schizophrenia** - A booklet that will help you identify symptoms, causes and treatment options for schizophrenia.
  http://www.omh.state.ny.us/omhweb/booklets/schizophrenia.htm

- **SPEAK Kits** - Suicide Prevention Education and Awareness Kits offered by the NYS Office of Mental Health.
  http://www.omh.state.ny.us/omhweb/speak/speakelderly.htm

**Prescription Drug Program**

- **Elderly Pharmaceutical Insurance Coverage (EPIC) Program** - New York State program that helps seniors pay for their prescription drugs.
  http://www.health.state.ny.us/health_care/epic/index.htm

- **Health Insurance Information, Counseling & Assistance (HIICAP)** - New York State program that offers assistance to seniors with regards to health insurance.
  http://hiicap.state.ny.us

- **Medicare** - Official U.S. Government site for people with Medicare.
  http://www.medicare.gov/default.asp

- **Medicare Part D** - OMH site offering a quick reference guide to Medicare Part D.
  http://www.omh.state.ny.us/omhweb/medicare

**Suicide Prevention**

- **American Foundation for Suicide Prevention** - organization providing groundbreaking research, new educational campaigns, innovative demonstration programs, and critical policy work to reduce loss of life from suicide.
NYS Office of Mental Health Suicide Prevention - Quick reference guide to information, trainings, and events.
http://www.omh.state.ny.us/omhweb/suicide_prevention

Research Article by Dr. Yeates Conwell, University of Rochester School of Medicine Center for the Study and Prevention of Suicide - Suicide and the Elderly.
http://www.omh.state.ny.us/omhweb/savinglives/Volume2/elders.html

SPEAK Kits - Suicide Prevention Education and Awareness Kits offered by the NYS Office of Mental Health.
http://www.omh.state.ny.us/omhweb/speak/speakelderly.htm

Veterans

After Deployment - A mental wellness resource for service members, veterans, and military families.
http://www.afterdeployment.org

Family Caregivers of Vets - List and descriptions of resources and supports for veterans and their caregivers.
http://www.aarp.org/family/caregiving/articles/iraq_vets_resources.html

Military Personnel & Their Families - NYS Office of Mental Health offers information and referral services for service members, their families, and veterans during deployment, reintegration, and post-deployment periods.
http://www.omh.state.ny.us/omhweb/military

U.S. Department of Veteran's Affairs: Office of Geriatrics and Extended Care - Advances quality care for aging and chronically ill veterans by providing policy direction for the development, coordination, and integration of geriatrics and long-term care clinical programs.
http://www1.va.gov/geriatricsshg
Wellness

- **International Longevity Center: Sleep and Healthy Aging** - A Project that advances the awareness and understanding among health professionals and the public of the importance of sleep in older adults.

- **NYS Adult Immunization Campaign** - Locate a local flu clinic.
  [http://www.flu.state.ny.us](http://www.flu.state.ny.us)

- **NYS Office for the Aging Health Index** - Offers information on aging well.
  [http://www.aging.ny.gov/Health/Index.cfm](http://www.aging.ny.gov/Health/Index.cfm)
Learning Resource D

New York State Office of Mental Health (OMH) 2006 Annual Report

*This information has been taken from the New York State Office of Mental Health website. For more information, please visit:


2006 Annual Report

On August 23, 2005 New York State enacted the Geriatric Mental Health Act. Effective April 1, 2006, this law authorized the establishment of an Interagency Geriatric Mental Health Planning Council, a geriatric service demonstration program, and a requirement for an annual report to the Governor and the Legislature with a long-term plan regarding the geriatric mental health needs of the residents of New York. This is the initial report to the Governor and Legislature of New York State.

The projected growth of the older adult population in New York State will increase the number of adults 65 and older who have mental disorders by 56 percent in 2030 (see Table 1). This dramatic increase raises concerns about the ability of health, mental health, and aging services to provide adequate access to services that respond to the unique needs of older adults in a coordinated way. The projected growth of cultural minorities in the older adult population, the projected decrease in the proportion of working age adults, and the fact that fewer than 25 percent of older adults with mental disorders currently receive treatment from mental health professionals, present additional challenges.
As part of the growing attention and interest at all levels of government to advance geriatric mental health care, New York State enacted the Geriatric Mental Health Act on August 23, 2005. The law, which took effect on April 1, 2006, authorized the establishment of (1) an Interagency Geriatric Mental Health Planning Council, (2) a geriatric service demonstration program, and (3) a requirement for an annual report to the Governor and the Legislature.

**Interagency Geriatric Mental Health Planning Council**

**Description**

The Interagency Geriatric Mental Health Planning Council consists of 15 members, as follows:

- The Commissioner of Mental Health, co-chair of the Council;
- The Director of the State Office for the Aging, co-chair of the Council;
- One member representing the Office of Alcoholism and Substance Abuse Services;
- One member representing the Office of Mental Retardation and Developmental Disabilities;
- One member representing the Commission on Quality of Care and Advocacy for Persons with Disabilities;
- One member representing the Department of Health;
- One member representing the Education Department and the Board of Regents;
- One member representing the Office of Children and Family Services;
- One member representing the Office of Temporary and Disability Assistance;
- Two members appointed by the Governor;
- Two members appointed by the Temporary President of the Senate; and
- Two members appointed by the Speaker of the Assembly.
The Council is to meet at least four times per calendar year to develop recommendations to be submitted to the Commissioner of the Office of Mental Health (OMH) and the Director of the State Office for the Aging (NYSOFA) regarding geriatric mental health needs.

Work Completed in 2006

- Fourteen members of the Council were appointed prior to its first meeting. The final appointment was still pending clearance.
- The Council met four times during 2006.
- To make recommendations regarding priority areas to be addressed in the context of the demonstration projects, the Council formed three workgroups: (1) Integration, which focused on community integration and integration of services; (2) Screening, Assessment, and Treatment; and (3) Workforce Development, Staff Training, and Information Clearinghouse. Workgroup reports were presented to the Commissioner of OMH and the Director of NYSOFA at the Council’s September 29, 2006 meeting.

Geriatric Service Demonstration Program

Description

To support the provision of mental health services to the elderly, the Geriatric Mental Health Act called for OMH to establish a geriatric service demonstration program to provide grants, within appropriations, to providers of mental health care to the elderly. The program is administered by OMH in cooperation with NYSOFA.

Grants may be awarded for purposes which may include one or more of the following:

- **Community integration** - programs which enable older adults with mental disabilities to age in the community and prevent the unnecessary use of institutional care;
- **Improved quality of treatment** - programs for older adults which improve the quality of mental health care in the community;
- **Integration of services** - programs which integrate mental health and aging services with alcohol, drug, health and other support services;
- **Workforce** - programs which make more efficient use of mental health and health professionals by developing alternative service roles for paraprofessionals and volunteers, including peers, and programs that are more effective in recruitment and retention of bi-lingual, bi-cultural or culturally competent staff;
- **Family support** - programs which provide support for family caregivers, to include the provision of care to older adults by younger family members and by older adults to younger family members;
- **Finance** - programs which have developed and implemented innovative financing methodologies to support the delivery of best practices;
- **Specialized populations** - programs which concentrate on outreach to, engagement of, and effective treatment of cultural minorities;
• Information clearinghouse - programs which compile, distribute and make available information on clinical developments, program innovations and policy developments which improve the care to older adults with mental disabilities; and

• Staff training - programs which offer on-going training initiatives including improved clinical and cultural skills, evidence-based geriatric mental health skills, and the identification and management of mental, behavioral and substance abuse disorders among older adults.

Work Completed in 2006

• Recommendations developed by three Council workgroups regarding priority areas to be addressed in the context of the demonstration projects were utilized in developing two Requests for Proposals (RFPs) to invite eligible applicants to submit proposals for establishing demonstration projects.

• The RFPs, one to establish a Gatekeeper Program and the other to establish a Physical Health – Mental Health Integration Program, were developed by OMH in consultation with NYSOFA and released on December 11, 2006. The target population is older adults 65 years old and older whose independence, tenure, or survival in the community is in jeopardy because of a behavioral health problem. A joint review process by OMH and NYSOFA will be used to select successful grant recipients, with contracts expected to be awarded in early 2007.

Recommendations to Improve Mental Health Services for Older Adults

Description

The Commissioner of OMH and the Director of NYSOFA are to jointly report to the Governor, the Temporary President of the Senate, and the Speaker of the Assembly no later than March 1, 2007, and annually thereafter, with a long-term plan regarding the geriatric mental health needs of the residents of the State and recommendations to address those needs. Recommendations may include those of the Interagency Geriatric Mental Health Planning Council.

Improving Services for Older Adults

In keeping with OMH’s Statewide Comprehensive Plan for Mental Health Services 2006-2010, the overall planning goal is to improve services for older adults, identifying needs and formulating recommendations to address those needs. The focus of this first annual report is on services/programs that enable older adults with behavioral health problems to age in the community and prevent the unnecessary use of institutional care. The recommendations below are based on the work of the Council’s three workgroups, and were later endorsed by the Council. It is recognized that its recommendation are extensive, and many are of a complex nature, therefore, as part of the council’s ongoing efforts, these recommendation will be discussed in greater detail, with the goal of identifying short term versus long term recommendations, and prioritizing items within those categories.
Improving the Availability and Quality of Mental Health Treatment

To address the need to improve the quality of mental health treatment available for older adults, priorities include the early identification of mental health issues, screening, assessment, and – acknowledging the importance of research and translating research into practice – the application of evidence-based and promising practices through interdisciplinary team work.

Recommendations:

- Detect mental disorders and intervene with services before mental health problems become severe and jeopardize community tenure.
- Establish community gatekeeper programs to proactively identify at-risk older adults in the community who are not connected to the service delivery system. (Gatekeepers are non-traditional referral sources who come into contact with older adults through their everyday work activities.)
- Utilize the PHQ-9 screening tool for depression. With items that follow the DSM-IV depression category, this tool includes nine criteria assessing clinical depression and has been used in multiple community settings, though most commonly in primary care. Advantages include rapid administration and easy scoring algorithm. It can be administered by a health or mental health professional and by other non-medical personnel with some training.
- Identify and utilize screening tools for other mental health conditions.
- Provide or make available a more detailed assessment of late life depression and intervention plans for older individuals who are screened for mental health needs.
- Utilize interdisciplinary team work for effective mental health care management and service delivery in settings where older adults reside (i.e., community urban-rural healthcare settings such as home care and primary care, senior housing, nursing homes, assisted living, and retirement communities).
- Utilize effective evidence-based interventions for late life psychiatric illnesses, such as major depression, minor depression, sub-threshold depression, and generalized anxiety disorders. Evidence-based interventions may include medication or psychosocial interventions or their combination, such as antidepressant medication (SSRIs, SNRIs), problem solving therapy, cognitive behavioral therapy, and interpersonal therapy.
- Though further evaluation of their effectiveness is needed, consider promising interventions for late life depression for their potential innovation, feasibility, and ability to replicate. Promising interventions include friendly visiting such as might be provided in a naturally occurring retirement community, telephone support, physical activity/exercise, and supportive psychotherapy.

Services Integration

More than half of older adults who receive mental health care receive such services from their primary care physician (see Table 2), the advantages of primary care for older adults
including convenience and coordination of mental and medical disorders. However, no one service system is equipped to address all of the needs of older adults with mental illness. Improving services coordination and collaboration between and among mental health and physical health providers is a priority.

Recommendations:

- Integrate mental health screening and assessment with physical health care, i.e., primary, specialty, and home health care.
- Screening and referral for assessment, treatment, and support services should be available in locations such as senior apartments, assisted living, retirement communities, naturally occurring retirement communities (vertical or horizontal) and meals on wheels.
- Examine models of integrated physical and mental health care for opportunities to improve care. Models of integrated physical and mental health care are varied and include co-located primary and mental health care, integrated teams of primary and mental health professionals, care management (including peer medical care management), training for primary care providers, and telepsychiatric support for primary care providers and specialists.

Integrated physical and mental health care is all the more important given a 2006 technical report from the National Association of State Mental Health Program Directors that concluded that people with serious mental illness served by public mental health systems died, on average, 25 years earlier than the general population.

- Address the mental health needs of older adults with chronic disease. The unmet mental health needs of this population is a complicating factor in chronic disease management.
• Integrate services for older adults with co-occurring mental health, substance abuse, and chronic illness.

• Integrate mental health and aging services to expand mental health education, on-site screening, referral, and on-site treatment. Aging services programs which offer such opportunities include case management (such as expanded in-home services for the elderly), senior centers, naturally occurring retirement community – supportive service programs (NORC-SSPs), and social adult day care.

• Connect older adults diagnosed with serious mental illness with day programs that integrate health and mental health services using various models, such as wellness programs; primary health care in psychiatric rehabilitation, personalized recovery-oriented services programs, and continuing day treatment programs; adult medical day care and social adult day care adapted to meet mental or behavioral needs; and new models integrating psychiatric rehabilitation approaches with adult medical day care.

• Support recipient wellness self-management practices that help individuals with mental illness cope more effectively and manage their symptoms, prevent relapse, reduce stress, strengthen social relationships, and support their own recovery.

• Include the mental health needs of older adults in discussions of long-term care reform, such as mega waiver, nursing home diversion and transition waiver, and single point of entry for long-term care services.

**Community Integration**

Reflecting the focus of this annual report, the need to create services that assist older adults lead lives of dignity in the community in both rural and urban settings is a major priority. The importance of services and programs enabling older adults with behavioral health problems to age in their communities and prevent the unnecessary use of institutional care must be considered.

**Recommendations:**

• Adapt mental health service delivery strategies to accommodate the unique challenges of providing such services to older adults in rural and urban settings. In a rural environment, resource options are limited and individuals are more self-reliant and less likely to seek help, except perhaps from their primary care physician. In urban areas, more options are available although there may not be the sense of community otherwise found in rural areas.

• Address the need for accessible transportation.

• Utilize new models such as telehealth and in-home screening, assessment, and treatment to increase the individual attention to personal health, mental health, and medication that is so important for service delivery to older adults. These models exist in New York State, particularly in home health care, naturally occurring retirement communities, and meals on wheels programs.

• Develop housing options that are accessible to people with mental and/or physical disabilities – “smart home” technology, for example, and other state of the art
options that provide “falls prevention” construction, and ADL and other supports, but also allow independence.

- Adapt community-based psychiatric rehabilitation models for individuals with serious and persistent mental illness to the developmental needs of older adults.
- Make available legal services in order to prevent eviction, obtain government entitlements, obtain home health services, and provide assistance with financial management.
- Make available the humane, end-of-life care needed to make continuing contact with community-based caregivers possible.
- Develop a public awareness and education initiative addressing stigma.

Family Support

Family caregiving is a critical ingredient of community integration that itself requires care and support. The importance of providing respite and culturally competent psychoeducation and support for family caregivers in a variety of roles needs to be addressed.

Recommendations:

- Provide family support for aging family members caring for younger family members with mental disabilities, for younger family members caring for older adults with physical and/or mental disorders, and for spouses, siblings, and children of older adults with mental disorders.
- Provide culturally competent family support for minority communities. This is particularly important because many of these communities rarely place family members in institutions.
- Assess caregiver needs during home visits. Caregivers typically have psychoeducation needs and might benefit from educational offerings regarding older adults similar to those designed for providers. Local Area Agencies on Aging operate caregiver resource centers across the State.
- Address the need for respite care to benefit both caregivers and those they care for.

Staff/Caregiver Training and Workforce Development

An investment in staff/caregiver training and workforce development (see Table 3) related to helping individuals with geriatric mental health needs is required to implement the priorities included in this report. These recommendations include providing staff/caregiver education on basic skills and evidence-based practices for older adults with mental illness, assessing training needs, incorporating cultural competency, and providing competency-based skills training for identified staff and non-staff caregivers.
Recommendations:

- Address provider need for education related to screening, making referrals, and otherwise assisting or treating the target populations in health (e.g., primary care, home healthcare, community healthcare), general mental health, and social services (e.g., senior services), settings.
- Provide training in late life depression management for those who administer depression screening instruments to older adults. This is very important as the manner and methods employed to administer an instrument have significance on the validity of the screening results.
- Assist primary care physicians increase their knowledge of geriatric mental health.
- Support the effective integration of mental health and aging services by providing adequate training regarding mental health for aging services providers.
- Provide ongoing training and supervision for community agencies on the implementation of specific evidence-based interventions and practices.
- Incorporate cultural competency, awareness, and sensitivity for a diverse and often specialized aging population in developing training or workforce development initiatives.
- Conduct a geriatric mental health training needs assessment for identified staff and non-staff caregivers (such as family members, friends, clergy, and volunteers) in identified treatment, residential, or other settings. Starting with basics, access and/or develop competency-based core training materials on geriatric mental health skills that can be tailored to the training needs of identified staff and non-staff caregivers.
- Work with professional education programs on curricula development related to geriatric mental health.
- Create incentives, such as loan forgiveness programs, for people to enter the workforce to help individuals with geriatric mental health needs.
- Develop new workforce roles for paraprofessionals and peers, especially older adults.
- Recruit and retain bilingual, bicultural providers and professional interpreters.
Finance

Ongoing financial support and the development of fiscally viable program models is a critical ingredient in the creation of both core and innovative geriatric mental health services and programs that enable older adults with behavioral health problems to age in the community.

Recommendations:

- The financing mechanisms and fiscal viability of services and programs developed for older adults must be considered so that models can be replicated and sustained either by existing systems and resources, or through innovative financing models.
- Develop a cross-agency study group to explore financing models that support evidence-based practices, best practices, and innovation; promote integration; provide parity; and/or create incentives to enhance the workforce.
Module # 7: Comprehensive Geriatric Assessment
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 7: Comprehensive Geriatric Assessment

James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

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# Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

## Module # 7: Comprehensive Geriatric Assessment

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I. Overview

As patients age, functional impairments (cognitive, physical, psychological and social) can have a profound effect on their ability to maintain their health and to live independently in the community. Many of these impairments can be treated simply and inexpensively if they are identified early. Others require more extensive evaluation and management. In the outpatient setting, the Comprehensive Geriatric Assessment is an important tool that can identify a broad range of these functional impairments and their interaction with patients’ underlying medical problems, home environments and social support systems, allowing for early intervention and treatment.

In the inpatient setting, the elderly face an additional set of challenges often termed the “hazards of hospitalization” that include prolonged bed rest, tethering, functional incontinence, unfamiliar environments, falls, and pressure ulcers. These can lead to further functional decline, worsening of chronic illnesses and poor response to treatment for patients’ presenting medical problems. The Comprehensive Geriatric Assessment is an important tool for addressing the full spectrum of issues confronting hospitalized older patients with the ultimate goals of treating acute illnesses while maintaining function, and return to independent living in the community.

Ideally, an interdisciplinary geriatrics team is available to perform the CGA. A physician, nurse practitioner or physician’s assistant needs to perform the medical history and physical exam components of the CGA. The remainder of the CGA’s domains can be assessed by other members of the team.

II. Learning Objectives

1. Briefly describe the goals and domains of a functional geriatric assessment.
2. Know when and where a general geriatric assessment should be conducted.
3. Understand the risk posed to elderly patients by the ‘hazards of hospitalization’.
III. Inpatient Comprehensive Geriatric Assessment

The current CGA used on the inpatient service at the Bronx VA assesses 18 different areas of function. The outpatient CGA assesses 17. (Delirium is omitted.) The following is an annotated outline of the inpatient CGA based on the *Geriatrics Review Syllabus, Sixth Edition* and *2006-2007 Geriatrics at your Fingertips.*

A. Delirium is the most common hazard of hospitalization in older adults, and is defined as an acute disorder of attention and cognition.

1. Frequently under-recognized in the hospitalized patient
   a) Missed more often by physicians than by nurse
   b) Requires formal assessment – Confusion Assessment Method (CAM)

A. Can lead to poor clinical outcomes
   a) Increased risk of death
   b) Prolonged hospital stay
   c) Nursing home placement
   d) Poor functional recovery

B. Risk factors for developing delirium
   a) Dementia
   b) Advanced age
   c) Sleep deprivation
   d) Immobility
   e) Dehydration
   f) Pain
   g) Sensory deficit

C. Causes of delirium – many are reversible or treatable
   a) Medications
   b) Infections
   c) Metabolic abnormalities
   d) Cardiovascular problems
   e) Neurological problems
   f) Fecal impaction
   g) Urinary retention
   h) Postoperative state
   i) Sleep deprivation

B. Dementia: Memory impairment combined with sufficient loss of other cognitive function to interfere with daily living.

1. Can lead to:
   a) Loss of independence
   b) Care giving expenses
   c) Falls
   d) Accidents
2. Prevalence increases with age

3. Most (60-70%) dementias in the US are due to Alzheimer’s Disease

4. A small percentage of dementias have a reversible cause
   a) Vitamin B12 deficiency
   b. Thyroid disease
   c) Depression
   d) Neuro-syphilis

5. Both history from family or caregivers, and formal assessment essential for diagnosis
   a) Mini-Cog (Clock drawing test and three item recall)
   b) Mini Mental State Exam (MMSE)
   c) Animal naming test
   d) Formal neuro-psych testing
   e) Early treatment can improve quality of life and maximize function while allowing patient and family establish goals of care and plan for the future

C. Depression

1) Major Depression, while somewhat less frequent among the elderly than among the middle-aged, is under diagnosed.

2) Depressive symptoms that do not meet DSM-IV criteria for Major Depression are common among the elderly.

3) Presenting symptoms are more frequently anhedonia and somatic complaints such as lack of energy, which patients may fail to mention to health care providers thinking they are just part of older age.

4) Untreated Major Depression or depressive symptoms can lead to
   a) Worsening of underlying medical illness, especially cardiac disease
   b) Loss of physical function
   c) Pseudo-dementia
   d) Suicide
   e) Death

5) It is important to screen elderly patients for depression using a standardized instrument such as the Geriatric Depression Scale (GDS) which comes in 5, 15 and 30 question versions and the Patient Health Questionnaire (PHQ-9)
D. Gait and Balance

1) A variety of factors contribute to gait and balance abnormalities as patients age
   a) Decreased muscle mass and strength
   b) Injuries
   c) Arthritis
   d) Neuropathies
   e) Neurologic illness
   f) Sensory deficits
      i. Visual
      ii. Proprioceptive
      iii. Vestibular
   g) Medications

2) Alterations in gait and balance can lead to falls

3) There are effective interventions to improve gait and balance
   a) Physical therapy
   b) Occupational therapy
   c) Assistive devices
   d) Treatment of underlying medical illness
   e) Adjustment of medications

4) It is important to screen elderly patients for gait and balance problems using a standardized instrument such as the Performance-Oriented Mobility Assessment (POMA)

E. Falls

1) Can lead to significant morbidity and loss of independence

2) Etiology is multi-factorial
   a) Intrinsic
      i. Poor balance
      ii. Weakness
      iii. Gait abnormalities
      iv. Chronic illness
      v. Dementia
      vi. Sensory Deficits
   b) Extrinsic – Poly-pharmacy
   c) Environmental
      i. Clutter
      ii. Rugs
      iii. Poor lighting
      iv. Uneven surfaces
v. Lack of appropriate safety devices such as grab bars in the bathroom

3) It is important to take a careful history of falls over the last year, and to screen for risk factors.

F. Hearing
1) Hearing loss is common as people age.

2) Screening can be performed with a whisper test.

3) Hearing loss can lead to
   a) Social isolation
   b) Decreased mobility
   c) Loss of self esteem
   d) Anger
   e) Difficulties in participating in medical encounters
   f) Decreased quality of life

4) There are effective methods to improve hearing and communication
   a) Hearing aids
   b) Personal amplification devices
   c) Adaptive equipment
   d) Communication Enhancement Strategies

G. Vision
1) Visual impairment is common as patients age

2) Visual impairment can lead to
   a) Falls
   b) Motor vehicle accidents
   c) Decrease quality of life
   d) Decreased ability to perform ADLs and IADLs
   e) Decreased functional independence

3) Some causes of visual impairment are easily and effectively treated
   a) Refractive error
   b) Cataracts

4) Others require more extensive work-up and treatment
   a) Glaucoma
   b) Macular degeneration
   c) Diabetic retinopathy

5) All benefit from early identification and intervention.
6) Screening with a Snellen chart is quick and easy.

7) All elderly patients should have yearly ophthalmologic screening for glaucoma.

H. Activities of Daily Living (ADLs)
   1) Difficulties in performing these basic activities can stem from physical and/or cognitive deficits.

   2) The incidence of ADL impairment increases with age.

   3) Screening for ADL impairment should be part of a comprehensive geriatric assessment.

   4) In the hospitalized patient, it is important to ascertain his or her pre-hospitalization functional level as this will help establish reasonable rehabilitation goals.

   5) Use a screening tool that assesses
      a) Toileting
      b) Feeding
      c) Dressing
      d) Grooming
      e) Ambulation
      f) Bathing

I. Instrumental Activities of Daily Living (IADLs)
   1) Difficulties in performing these complex activities of daily living can arise from physical deficits but more often arise from cognitive deficits.

   2) The incidence of IADL impairment increases with age.

   3) Screening for IADL impairment should be part of a comprehensive geriatric assessment.

   4) In the hospitalized patient, it is important to ascertain his or her pre-hospitalization functional level as this will help establish reasonable rehabilitation goals.

   5) Use a screening tool that assesses
      a) Telephone use
      b) Shopping
      c) Food preparation
      d) Housekeeping
      e) Laundry
J. Pain

1) Pain is common among the elderly yet often goes undiagnosed or undertreated.

2) Untreated pain can lead to
   a) Deficits in ADLs
   b) Depression
   c) Decreased cognitive function
   d) Sleep disorders
   e) Decreased appetite
   f) Social isolation

3) Thorough assessment should include
   a) Character
   b) Onset
   c) Duration
   d) Location
   e) Severity
   f) Relieving factors
   g) Exacerbating factors
   h) Physical examination

K. Medications

1) Elderly patients often take multiple prescription and over the counter medications.

2) Elderly patients often have multiple co-morbidities.

3) Elderly patients often have multiple health care providers at multiple institutions.

4) There are physiologic changes in the elderly that can affect drug metabolism.

5) Physical, cognitive and psycho-social functional impairments may prevent patients from taking medications as prescribed.

6) There can be complex interactions among the patient’s medications, co-morbidities, physiologic changes, substance use and even food that can have deleterious effects for patients’ health.
7) It is essential to have a complete list of all prescription and over the counter medications including vitamins and supplements.

8) Every effort should be made to simplify patients’ regimens and to provide the necessary aids for proper administration.

L. Nutrition
1) Both weight loss and obesity can be problems in old age.

2) Weigh loss and weight gain can be symptoms of some underlying illness and can exacerbate others.

3) Obtain a history from the patient or care giver about weight changes, medications and diet.

4) Measure current weight and compare to prior weights.

5) Assess for risk factors for poor nutritional status.
   a) Substance abuse
   b) Dementia
   c) Decreased exercise
   d) Depression
   e) Functional deficits
   f) Limited education
   g) Limited mobility
   h) Medical problems, chronic illness
   i) Medications
   j) Poor dentition
   k) Restricted diet
   l) Social Isolation

M. Dentition
1) Almost 50% of Americans over 85 are edentulous.

2) Many elderly Americans do not seek treatment for periodontal disease, caries, missing teeth and other areas of oral health because of the costs associated with dental care, which are not covered by Medicare.

3) Broken or missing teeth and poor oral hygiene can lead to
   a) Poor nutrition
   b) Difficulties in speech and communication
   c) Social isolation
   d) Poor self image

4) Evaluation of dentition and oral health is an important part of the Comprehensive Geriatric Assessment.
N. Urinary Incontinence

1) Urinary incontinence is not a normal aspect of aging.

2) Risk factors for UI include
   a) Advanced age
   b) Parity
   c) Delirium
   d) Dementia
   e) Depression
   f) TIA and stroke
   g) Heart failure
   h) Constipation
   i) Fecal incontinence
   j) Obesity
   k) Cough
   l) COPD
   m) Chronic cough
   n) DM
   o) Impaired mobility
   p) Impaired ADLs
   q) Medications

3) Urinary incontinence can lead to
   a) Cellulitis
   b) Pressure ulcers
   c) UTIs
   d) Sleep deprivation
   e) Social withdrawal
   f) Falls and fractures
   g) Depression
   h) Sexual dysfunction

4) Patients often fail to complain to their health care providers about UI because
   a) They assume it’s a normal part of aging
   b) They are embarrassed

5) Many factors leading to UI can be corrected or improved, leading to improve function and quality of life

6) It is important to ask all elderly patients about UI and the risk factors that can lead to UI.

O. Bowel Function

1) Constipation is a source of discomfort for many elderly patients.
2) Untreated, constipation can lead to
   a) Urinary tract infection
   b) Delirium
   c) Pain
   d) Urinary incontinence

3) Fecal incontinence is less common but can be very distressing

4) As with urinary incontinence, patients are often reluctant to discuss bowel problems with their health care providers. It is therefore the health care provider’s responsibility to ask.

P. Social Situation and Support
1) With impairments in physical and cognitive function, older patients are more in need of community and family supports than younger patients.

2) It is important to screen patients for both current support systems and finances and to assess for future needs.

Q. Substance Use
1) Alcohol is the most common drug of abuse in older patients.

2) Substance abuse can lead to
   a) Poor control of medical problems
   b) Depression
   c) Family discord
   d) Social isolation
   e) Homelessness

3) It is important to screen for use of alcohol, illicit drugs and improper use of prescription drugs.

R. Healthcare Proxy/Advance Directives - Every visit to a health care provider is an opportunity to discuss patient wishes regarding health care proxy and advance directives.
Module # 8: Depression, Dementia & Delirium
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

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# Module #8: Depression, Dementia & Delirium

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I. Overview

Depression, dementia, and delirium are the three most prevalent mental disorders in the elderly. While depression and dementia are prevalent in the community, hospitals, and nursing homes, delirium is seen most often in acute care hospitals. Dementia is defined by a chronic loss of intellectual or cognitive function of sufficient severity to interfere with social or occupational function. Delirium is an acute disturbance of consciousness marked by an attention deficit and a change in cognitive function. Depression is an affective disorder evidenced by a dysphoric mood, but the most pervasive symptom is a loss of ability to enjoy usual activities. It is important to recognize that these syndromes are not mutually exclusive, as dementia frequently co-exists with delirium and depression. Furthermore, physical diagnoses, such as chronic obstructive lung disease, congestive heart failure, stroke, and endocrine disorders, are frequently associated with depressive symptoms. Given this, a comprehensive evaluation is mandatory.

II. Learning Objectives

1. Define the prevalence and symptoms of depression in the older population.
2. List depression assessment tools for use in the elderly.
3. Describe methods for managing depression in late life.
4. Describe the prevalence and symptoms of delirium in the older population.
5. Provide an overview of the assessment and treatment of delirium in older adults.
6. Define the prevalence and symptoms of dementia in the elderly.

III. Depression

A. Prevalence

1. In The Older Population
A. Depression is significantly under-diagnosed and undertreated in older adults. Older adults and health care professionals may attribute symptoms of depression to old age or other physical conditions.

B. The prevalence of major depression in the general older population is 1.4% in women and 0.4% in men, with an overall prevalence of 1%. However, 17-37% of the older medical population suffers from depression, with 30% of these patients suffering from major depression.

C. Major depressive disorders occur less often in older adults compared to younger adults; however, older adults suffer from psychotic (delusional) depression more frequently.

D. The highest rate of completed suicide of any age, gender, or ethnic group is among older white men. The risk of suicide is 50% higher in older adults than the rate for younger people.

2. In the Seriously Ill

   A. 25-77% of seriously ill patients experience intense feelings of sadness and anxiety accompanied by depressive symptoms, which persist for longer than a few weeks.

B. Symptoms

   1. Clinical Manifestations Of Depression In Older Adults

      A. Mood

         • Depressed, irritable, or anxious (may deny sad mood and complain of pain or somatic distress)
         • Crying spells (or complaining of inability to cry or experience emotion)
         • Persistent for more than 14 days

      B. Associated Psychological Symptoms

         • Reduction in gratification, loss of interest in usual activities, loss of attachments, social withdrawal
         • Lack of self-confidence, low self-esteem, self reproach
         • Poor concentration and memory
         • Difficulty making decisions
         • Negative expectations, hopelessness, helplessness, increased dependency
         • Recurrent thoughts of death
         • Suicidal thoughts

      C. Somatic Manifestations
• Anorexia and weight loss
• Insomnia – early morning awakening
• Psychomotor retardation
• Agitation – common symptoms in an older person

D. **Psychotic Symptoms**

- Delusions of worthlessness and sinfulness
- Delusions of ill health
- Delusions of poverty. Evaluate delusions as 30% of elderly women already are at the poverty level.
- Depressive hallucination in the auditory, visual, and olfactory spheres (rarely)

2. Clinical Manifestations in the Seriously Ill

A. While in the general population somatic symptoms are important when making a diagnosis of depression, these symptoms are invariably present in patients with advanced illness. Therefore, psychological and cognitive symptoms are the most important signs.

B. The most reliable symptoms of major depression in the seriously ill include persistent dysphoria, anhedonia (loss of pleasure), feelings of helplessness, hopelessness, worthlessness, and loss of self-esteem.

C. Other symptoms include excessive guilt, pervasive despair, bothersome ruminations about death, and thoughts of suicide.

C. **Assessment Tools**

1. Geriatric Depression Scale (GDS)
2. Cornell Depression Scale (CDS)

D. **Management**

1. Pharmacologic

   A. In Older Adults

   - Principal regarding dosages in older adults – Start Low Go Slow
   - Carefully monitor for side effects (e.g. falls, anorexia)

   B. Choosing an Antidepressant: (see Table below and list of antidepressants to avoid)

      i. First-line Therapy: Consider an SSRI for most older adults, especially those with heart conduction defects or ischemic heart disease; prostatic hyperplasia; uncontrolled glaucoma.
ii. Second-line Therapy: Consider venlafaxine, mirtazapine, or bupropion.

iii. Third-line Therapy: Consider nortriptyline or desipramine for patients with severe melancholic depression.

IV. Antidepressants Used With Older Adults

<table>
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<tr>
<th>Class, Drug</th>
<th>Initial Dosage</th>
<th>Usual Dosage</th>
<th>Formulations</th>
<th>Comments (Metabolism, Excretion)</th>
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<tr>
<td><strong>Selective Serotonin-Reuptake Inhibitors</strong></td>
<td></td>
<td></td>
<td></td>
<td>Class adverse events (EPS, hyponatremia) (L, K [10%])</td>
</tr>
<tr>
<td>Citalopram <em>(Celexa)</em></td>
<td>10–20 mg qam</td>
<td>20–30 mg/d</td>
<td>T: 20, 40, 60; S: 5 mg/10 mL</td>
<td></td>
</tr>
<tr>
<td>Escitalopram <em>(Lexapro)</em></td>
<td>10 mg/d</td>
<td>10 mg/d</td>
<td>T: 10, 20</td>
<td></td>
</tr>
<tr>
<td>Fluoxetine <em>(Prozac)</em></td>
<td>5 mg qam</td>
<td>5–60 mg/d</td>
<td>T: 10; C: 10, 20, 40; S: 20 mg/5 mL; C: SR 90 (weekly dose)</td>
<td>Long half-lives of parent and active metabolite may allow for less frequent dosing; may cause more insomnia than other SSRIs; CYP2D6, -2C9, -3A4 inhibitor (L)</td>
</tr>
<tr>
<td>Fluvoxamine <em>(Luvox)</em></td>
<td>25 mg qhs</td>
<td>100–300 mg/d</td>
<td>T: 25, 50, 100</td>
<td>Not approved as an antidepressant in US; CYP1A2, -3A4 inhibitor (L)</td>
</tr>
<tr>
<td>Paroxetine <em>(Paxil)</em></td>
<td>5 mg</td>
<td>10–40 mg/d</td>
<td>T: 10, 20, 30, 40</td>
<td>Helpful if anxiety symptoms are prominent; increased risk of withdrawal symptoms (dizziness); CYP2D6 inhibitor (L)</td>
</tr>
<tr>
<td><em>(Paxil CR)</em></td>
<td>12.5 mg/d</td>
<td>—</td>
<td>T: ER 12.5, 25, 37.5; S: 10 mg/5 mL</td>
<td>Increase by 12.5 mg/d no faster than 1/wk (L)</td>
</tr>
<tr>
<td>Sertraline <em>(Zoloft)</em></td>
<td>25 mg qam</td>
<td>50–200 mg/d</td>
<td>T: 25, 50, 100; S: 20 mg/mL</td>
<td>(L)</td>
</tr>
<tr>
<td><strong>Additional Medications</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bupropion <em>(Wellbutrin, Zyban)</em></td>
<td>37.5–50 mg bid</td>
<td>75–150 mg bid</td>
<td>T: 75, 100, SR 100, 150</td>
<td>Consider for SSRI, TCA nonresponders; safe in HF; may be stimulating; can lower seizure threshold (L)</td>
</tr>
<tr>
<td>Duloxetine <em>(Cymbalta)</em></td>
<td>20 mg qd</td>
<td>20–30 mg bid</td>
<td>C: 20, 30, 60</td>
<td>Most common side effects: nausea, dry mouth, constipation, diarrhea, urinary hesitancy (L)</td>
</tr>
<tr>
<td>Methylphenidate <em>(Ritalin)</em></td>
<td>2.5–5 mg at 7 AM and noon</td>
<td>5–10 mg at 7 AM and noon</td>
<td>T: 5, 10, 20</td>
<td>Short-term treatment of depression or apathy in physically ill older adults; used as an adjunct (L)</td>
</tr>
<tr>
<td>Mirtazapine <em>(Remeron)</em></td>
<td>15 mg qhs</td>
<td>15–45 mg/d</td>
<td>T: 15, 30, 45</td>
<td>May increase appetite; sedating; oral disintegrating tab (SolTab) available (L)</td>
</tr>
<tr>
<td>Trazodone <em>(Desyrel)</em></td>
<td>25 mg qhs</td>
<td>75–600 mg/d</td>
<td>T: 50, 100, 150, 300</td>
<td>Sedation may limit dose; may be used as a hypnotic; ventricular irritability; priapism in men (L)</td>
</tr>
<tr>
<td>Venlafaxine <em>(Effexor)</em></td>
<td>25–50 mg bid</td>
<td>75–225 mg/d</td>
<td>T: 25, 37.5, 50, 75, 100</td>
<td>Low anticholinergic activity; minimal sedation and hypotension; may increase BP and QTc; may be useful when somatic pain present; EPS, withdrawal symptoms, hyponatremia (L)</td>
</tr>
<tr>
<td><em>(Effexor XR)</em></td>
<td>75 mg qam</td>
<td>75–225 mg/d</td>
<td>C: 37.5, 75, 150</td>
<td>Same as above</td>
</tr>
<tr>
<td><strong>Tricyclic Antidepressants</strong></td>
<td></td>
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</tr>
</tbody>
</table>

VSN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 8: Depression, Dementia & Delirium
Desipramine (Norpramin)  10–25 mg qhs  50–150 mg/d  T: 10, 25, 50, 75, 100, 150  Therapeutic serum level >115 ng/mL (L)

Nortriptyline (Aventyl, Pamelor)  10–25 mg qhs  75–150 mg/d  C: 10, 25, 50, 75; S: 10 mg/5 mL  Therapeutic window (50–150 ng/mL) (L)

**Monoamine Oxidase Inhibitors**  
- **Isocarboxazid (Marplan)**  
  10 mg bid–tid  10 mg tid  T: 10
- **Phenelzine (Nardil)**  
  15 mg qd  15–60 mg/d  T: 15
- **Tranylcypromine (Parnate)**  
  10 mg bid  20–40 mg/d  T: 10

**V. Antidepressants To Avoid With Older Adults**

- **Amitriptyline** (e.g., Elavil): anticholinergic, sedating, hypotensive
- **Amoxapine** (Asendin): anticholinergic, sedating, hypotensive; also associated with EPS, tardive dyskinesia, and neuroleptic malignant syndrome
- **Doxepin** (e.g., Sinequan): anticholinergic, sedating, hypotensive
- **Imipramine** (Tofranil): anticholinergic, sedating, hypotensive
- **Maprotiline** (Ludiomil): seizures, rashes
- **Protriptyline** (Vivactil): very anticholinergic; can be stimulating
- **St. John's wort**: decreases effects of digoxin and CYP3A4 substrates; efficacy questioned
- **Trimipramine** (Surmontil): anticholinergic, sedating, hypotensive

**C. In Seriously Ill Patients**

i. **Psychostimulants**: rapid-acting psychostimulant is the best choice when reversal of depression is an immediate short-term goal. Adverse effects are minimal and they can be used alone or in combination with other antidepressants; not to be used in patients with cardiac disease.

ii. **Selective Serotonin Reuptake Inhibitors (SSRIs)**: usually begin to act within 2 to 4 weeks, are highly effective (70%), once-daily dosing is possible, and cause less constipation, sedation, and dry mouth than the tricyclic antidepressants, though nausea may be worse.

iii. **Tricyclic Antidepressants**: tricyclic antidepressants may take 3 to 6 weeks to have an effect and are not recommended.
as a first-line therapy. Anticholinergic adverse effects and cardiac conduction delays are seen frequently.

iv. Just as with older patients – “Start Low Go Slow”

2. Electroconvulsive Therapy: treatment of choice for older persons with severe depression; improvement rate in older persons who do not respond to antidepressant drugs is 80% (same as in younger persons).

3. Psychotherapy:
   
   A. **In Older Adults**: especially effective in preventing relapses of episodic depression (30% relapse rate of depression in older adults); however, the practitioner must take into consideration that older adults may have negative attitudes towards psychotherapy. For mild to moderate depression, can be in combination with pharmacotherapy: cognitive-behavioral therapy, interpersonal therapy, and problem solving therapy.

   B. **In the Seriously Ill**: may help put perceptions, expectations, needs, fears, and fantasies about his or her illness and death into a different perspective. Relaxation, meditation, guided imagery, or self-hypnosis can also be introduced.

VI. Case Analysis: Ms. G *

Ms. G is a 75 year-old female living alone in her apartment in New York City. Her husband died suddenly two years ago of a heart attack. Their two children are alive and living out-of-state. Both of her sons maintain weekly phone contact with Ms. G and visit usually once a year. Ms. G has been doing well until about 6 weeks ago when she fell in her apartment and sustained bruises but did not require a hospital visit. Since then, she has been preoccupied with her failing eyesight and decreased ambulation. She does not go shopping as often, stating she doesn’t enjoy going out anymore and feels “very sad and teary”. Ms. G states that her shopping needs are less, since she is not as hungry as she used to be and “besides I’m getting too old to cook for one person only”.

Focus Questions:

1. What risk factors might account for Ms. G’s symptoms of depression?

2. What are Ms. G’s depressive symptoms?

3. What might be some treatment strategies for Ms. G?

VII. Delirium

A. Prevalence

Delirium or acute confusional states occur in 30% of older persons during medical hospitalization and occur 10%-50% during surgical hospitalization. Most at risk are those with dementia and those of advanced age, comorbid physical problems, especially sleep deprivation, immobility, dehydration, pain, and sensory impairment.

B. DSM-I Criteria Used to Identify Delirium

1. Disturbance of consciousness (i.e., reduced clarity of awareness of the environment) with reduced ability to focus, or shift attention;
2. Change in cognition (such as memory deficit, disorientation, language disturbance) or the development of a perceptual disturbance that is not better accounted for by a preexisting, established, or evolving dementia;
3. Disturbance that develops over a short period of time (usually hours to days) and tends to fluctuate over the course of the day;
4. Evidence from the history, physical examination, or laboratory findings that the disturbance is caused by the direct physiologic consequences of a specific medical condition, substance intoxication, substance withdrawal, multiple causes, causes not otherwise specified, insufficient evidence to establish a specific cause, or from other reasons, such as sensory deprivation.

C. Symptoms

- Abrupt precise onset with identifiable date
- Acute illness, generally days to weeks, rarely more than 1 month
- Usually reversible, often completely
- Disorientation early
- Variability from moment to moment, hour to hour, throughout the day
- Prominent physiological changes
- Clouded, altered, and changing level of consciousness (alert→lethargy)
- Strikingly short attention span
- Disturbed sleep-wake cycle with hour-to-hour variation
- Marked psychomotor changes (hyperactive or hypoactive)
D. **Assessment**

1. Obtain a comprehensive history, including ADLs and IADLs, alcohol use, baseline cognitive function, and time course of changes in consciousness.

2. Physical examination (there may be more than one problem).

3. Review of all current medications, both over-the-counter and prescription.

4. Evaluate basic laboratory studies (complete blood count, serum electrolytes and urinalysis).

5. Consider further testing on basis of results of laboratory studies and response to initial therapy (chest radiography, cultures, drug levels, serum B12, thyroid function tests, pulse oximetry, electrocardiogram, brain imaging, lumbar puncture, electroencephalogram).

E. **Treatment**

1. Identify and treat the underlying cause.

2. Provide supportive and restorative care: improve orientation, decrease sensory overload or deprivation, provide reassurance, provide a quiet room, and follow fixed daily schedules.

3. Treat behavioral symptoms that may result. Haloperidol sedates and treats hallucinations, paranoia, and delusions. Benzodiazepines are an alternative when sedation is the primary desired effect.

4. If psychotic symptoms are severe, frightening, or may effect safety, use antipsychotic.

6. Olanzapine, quetiapine, and risperidone are first choice because of fewer adverse events (TD extremely high in older adults taking typical antipsychotics).

7. Failure to treat delays recovery and can worsen the older person’s health and function.
VIII. Representative Medications For Treatment Of Psychosis

<table>
<thead>
<tr>
<th>Class, Agent</th>
<th>Dosage*</th>
<th>Formulations</th>
<th>Comments (Metabolism)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atypical Antipsychotics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aripiprazole</td>
<td>10–15 (1)</td>
<td>T: 10, 15, 20, 30</td>
<td>Sedation; wait 2 wk between dosage changes (CYP2D6, 3A4) (L)</td>
</tr>
<tr>
<td>Clozapine</td>
<td>25–150 (1)</td>
<td>T: 25, 100</td>
<td>May be useful for parkinsonism and TD; sedation, orthostasis, anticholinergic effects, agranulocytosis, weight gain; high risk of diabetes mellitus and dyslipidemia (L)</td>
</tr>
<tr>
<td>Olanzapine</td>
<td>2.5–10 (1)</td>
<td>T: 2.5, 5, 7.5, 10, 15, 20; disintegrating tab: 5, 10, 15, 20</td>
<td>Sedation, anticholinergic effects at high doses, high risk of weight gain, hyperglycemia, diabetes mellitus, risk of cerebrovascular adverse events; dose-related EPS (L)</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>25–800 (1–2)</td>
<td>T: 25, 100, 200, 300</td>
<td>Sedation, orthostasis, no dose-related EPS; intermediate risk of diabetes mellitus and dyslipidemia; limited geriatric data (L, K)</td>
</tr>
<tr>
<td>Risperidone</td>
<td>0.5–1 (1–2)</td>
<td>T: 0.25, 0.5, 1, 2, 3, 4 scored; S: 1 mg/mL; IM long-acting: 25, 37.5, and 50 mg/2 mL</td>
<td>Orthostasis, dose-related EPS; caution in patients at risk of stroke, risk of cerebrovascular adverse events, intermediate risk of diabetes mellitus and dyslipidemia; IM not for acute treatment; do not exceed 6 mg (L, K)</td>
</tr>
<tr>
<td>Low Potency</td>
<td></td>
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<td></td>
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<tr>
<td>Thioridazine</td>
<td>25–200 (1–3)</td>
<td>T: 10, 15, 25, 50, 100, 150, 200; S: 30 mg/mL</td>
<td>Anticholinergic effects, orthostasis, QTc prolongation, sedation, TD; for acute use only (L, K)</td>
</tr>
<tr>
<td>Intermediate Potency</td>
<td></td>
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<tr>
<td>Loxapine</td>
<td>2.5–20 (1–3)</td>
<td>C: 5, 10, 25, 50; S: 25 mg/mL</td>
<td>Anticholinergic effects, orthostasis, sedation, TD; for acute use only (L, K)</td>
</tr>
<tr>
<td>High Potency</td>
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<tr>
<td>Haloperidol</td>
<td>0.5–2 (1–3); depot 100–200 mg IM q 4 wk</td>
<td>T: 0.5, 1, 2, 5, 10, 20; S: conc 2 mg/mL; Inj</td>
<td>EPS, TD; for acute use only (L, K)</td>
</tr>
</tbody>
</table>

\( \checkmark = \) preferred for treating older adults but does not imply lower risk; mortality may be increased in patients with dementia.

* Total mg/d (frequency/d).

IX. Terminal Delirium

Common in patients with advanced illnesses who are nearing death. Presents as day-night reversal and is complex; therefore, it is difficult to assess and manage. When patients who are dying experience agitation, restlessness, moaning, and/or groaning due to terminal delirium, it is usually irreversible. Management is focused on symptomatic control and relief of patient and family. Benzodiazepines or sedating neuroleptics are most effective.
X. Case Analysis: Mr. T *

Mr. T is a 70 year-old male admitted to the orthopedic unit in a large urban hospital. Mr. T fractured his right ankle in a golf outing and had an open reduction with internal fixation this morning. As you take report at 3:00PM, the day shift charge nurse tells you that Mr. T is insisting on going home and keeps getting out of bed. Multiple attempts to explain that he is unable to walk safely in the cast have not convinced him and he is now yelling, disturbing other patients on the floor.

Focus Questions:

1. Given the above information, you suspect that Mr. T’s condition is caused by
   a) post-operative infection
   b) dementia
   c) delirium
   d) depression

2. Delirium:
   a) is self-limiting and requires no intervention
   b) usually has no identifiable cause
   c) requires acute assessment
   d) should be treated symptomatically

3. The causes of delirium include
   a) infection
   b) hypoxia
   c) medications
   d) all of the above

4. Some strategies to assist in caring for Mr. T would include
   a) reality orientation offered in a calm, nonjudgmental manner
   b) calling family to visit patient
   c) telling him to relax and his ankle will heal
   d) a & b only

XI. Dementia

A. Prevalence

Dementia, defined as a syndrome of persistent cognitive impairment in adults, occurs in 5% to 15% of older persons, with prevalence rates doubling every 5 years between the ages of 65 and 85. Twenty-five to thirty percent (25% – 30%) of persons age 85 and over have dementia. It has been estimated that by the year 2050, there will be over 13 million persons with dementia in the US and 114 million worldwide.

B. Symptoms

- Gradual onset that cannot be dated
- Chronic illness, characteristically progressing over years. Diagnosis based on at least six months of confusion
- Generally irreversible, often chronically progressive
- Disorientation later in the illness, often after months or years
- Much more stable day-to-day (unless delirium develops)
- Less prominent physiological changes than delirium
- Consciousness not clouded until terminal (alert but confused and disoriented)
- Attention span not characteristically reduced
- Disturbed sleep-wake cycle with day-night reversal
- Psychomotor changes characteristically late (unless depression develops)
- Depression can affect performance on mental status tests and should be considered when cognitive impairment is suspected. As discussed by Gallo and Wittink:

  “The person with the appearance of cognitive impairment secondary to depression remains oriented and with coaxing can perform cognitive tests. Clues that dementia may be secondary to depression include recent onset and rapid progression, a family history of depressive disorders, a personal history of affective disorders, and onset of the disorder after the age of 60 years.”
C. Assessment

1. Use a screen for cognitive status in older adults such as the Folstein Mini-Mental Status Exam (MMSE).

2. A complete dementia evaluation should include the following.20
   - Medical and social history
   - Complete psychiatric and medical evaluation including neurological and mental state examination
   - Laboratory tests of blood and cerebrospinal fluid
   - Brain imaging
   - Evaluation of activities of daily living (ADLs)
   - Social investigations
   - Summary evaluation and planning for the future

3. Advantages of Early Diagnosis in Dementing Conditions
   - Provide a diagnostic answer and education for the patient and or family
   - Relieve the fear of an irreversible or progressive disease
   - Treat the underlying disease
   - Initiate prevention and/or rehabilitation strategies
   - Treat behavioral and cognitive symptoms
   - Plan legal and financial future while patient is still competent
   - Initiate management strategies that will postpone dependence and institutionalization

D. Clinical Features Distinguishing Alzheimer’s Disease & Other Types of Dementia

Types of Dementia

- Alzheimer’s Disease: Memory, language, visual-spatial disturbances, indifference, delusions, agitation
- Frontotemporal dementia: Personality change, executive dysfunction, hypeorality, relative preservation of visual-spatial skills
- Lewy body dementia: visual hallucinations, delusions, EPS, fluctuating mental status, sensitivity to antipsychotic meds
- Vascular dementia: abrupt onset, stepwise deterioration, prominent aphasia, motor signs
- Mild Cognitive Impairment: memory loss, delayed paragraph recall,
no functional impairment, normal ADL, mild executive dysfunction

E. Progression of Alzheimer’s Disease

1. Early, Mild Impairment (yr 1–3 from onset of symptoms)  MMSE: 22–28
   - Disoriented to date
   - Naming difficulties (anomia)
   - Recent recall problems
   - Mild difficulty copying figures
   - Decreased insight
   - Social withdrawal
   - Irritability, mood change
   - Problems managing finances

2. Middle, Moderate Impairment (yr 2–8)  MMSE: 10–21
   - Disoriented to date, place
   - Comprehension difficulties (aphasia)
   - Impaired new learning
   - Getting lost in familiar areas
   - Impaired calculating skills
   - Delusions, agitation, aggression
   - Not cooking, shopping, banking
   - Restless, anxious, depressed
   - Problems with dressing, grooming

3. Late, Severe Impairment (yr 6–12)  MMSE: 0–9
   - Nearly unintelligible verbal output
   - Remote memory gone
   - Unable to copy or write
   - No longer grooming or dressing
   - Incontinent
   - Motor or verbal agitation
F. Treatment

1. Non-pharmacologic

   a. Use personal history, life experiences, and habits as a basis for self-care and leisure activities.

   b. Maintain a familiar and comfortable routine that alternates activity with rest to avoid fatigue and dysfunction.

   c. Promote independence, autonomy, and self-directed meaningful activities by cueing the person to do as much for him/herself as possible and providing a safe, secure setting.

   d. Modify the physical environment to reduce misinterpretation of real-life object or events.

XII. Pharmacological Treatment Of Cognitive Dysfunction

• Patients with a diagnosis of mild or moderate AD should receive a cholinesterase inhibitor that will increase level of acetylcholine in brain (see table).

   • Controlled data show modest symptomatic benefit for cognition, mood, behavioral symptoms, and daily function of cholinergic drugs compared with placebo for 1 yr, and open trials demonstrate benefit for 3 yr.

   • Only 10%–25% of patients taking cholinesterase inhibitors show clinical improvement, but 80% have less rapid decline.

   • Initial studies show benefits of these drugs for patients with dementia associated with Parkinson's disease, Lewy body dementia, and vascular dementia.

   • Cholinesterase inhibitors have not been convincingly demonstrated to slow progression of mild cognitive impairment to dementia.

   • Cholinesterase inhibitors may attenuate non-cognitive symptoms and delay nursing-home placement.

   • To evaluate response:

     • Elicit caregiver observations of patient's behavior (alertness, initiative) and follow functional status (ADL and IADL).

     • Follow cognitive status (e.g., improved or stabilized) by caregiver's report or serial ratings of cognition (e.g., MMSE).

   • Memantine (Namenda) demonstrated modest efficacy compared with placebo in moderate to severe AD as monotherapy and when combined with donepezil (Aricept).

   • Vitamin E at 1000 IU bid found to delay functional decline in AD (caution in those with cardiovascular disease because ≥400 IU may increase mortality).

   • Ginkgo biloba is not generally recommended because clinical trial results are not yet definitive, and preparations vary because such nutriceuticals are not regulated by the FDA.

   • Postmenopausal hormone therapy in older women may increase risk of developing AD.

### Cognitive Enhancers

<table>
<thead>
<tr>
<th>Drug</th>
<th>Formulations</th>
<th>Dosing (Metabolism)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donepezil (Aricept)*</td>
<td>T: 5, 10; ODT: 5, 10,**</td>
<td>Start at 5 mg qd, increase to 10 mg qd after 1 mo (CYP2D6, 3A4) (L)</td>
</tr>
</tbody>
</table>
XIII. Case Analysis: Ms. D *

Ms. D is a 98 year-old female in a skilled nursing facility with a diagnosis of Alzheimer’s disease. Ms. D comes to the nursing station and appears very upset. She tells you that she is looking for her mother and asks you to help her. You start walking with Ms. D. Which of the following strategies would be helpful in assisting Ms. D?

True or False:

1. Telling her that her mother died a long time ago.
2. Reassuring her that everything is OK and that you will help her.
3. Attempting to distract/redirect her into a pleasurable activity (eating, singing).
4. Using reality orientation hoping to reverse her cognitive losses.
5. Asking her to help you with a small talk and later you will look for her mother together.

More True or False Questions:

1. Cognitive losses related to Alzheimer’s disease are irreversible.
2. Although pharmacologic agents may be helpful (in the presence of disturbing delusions, hallucinations), behavioral approaches to treatment are first-line in treating dementia.
3. Promoting dependence (with feeding, dressing, toileting) is advantageous for persons with dementia.
4. Compensating for sensory impairments (glasses, hearing aids) may help minimize disturbing illusions / delusions.
XIV. General Guidelines For Differentiating Depression, Delirium, and Dementia

Often depression, delirium, and dementia can coexist. In such cases, delirium should be assessed and treated first, depression second, and dementia third.

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Depression</th>
<th>Delirium</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Onset</td>
<td>Weeks</td>
<td>Short/rapid, Abrupt, Hours/days</td>
<td>Months to years</td>
</tr>
<tr>
<td>Duration</td>
<td>3 to 6 months, may be chronic</td>
<td>Days to 3 weeks</td>
<td>5 to 15 years</td>
</tr>
<tr>
<td>Initial presentation</td>
<td>Flat affect, Hypochondrias, Focus on symptoms, Apathy, Little effort given to perform tasks</td>
<td>Disorientation, Clouded consciousness, Fluctuated moods, Disordered thoughts, Fails to understand tasks</td>
<td>Vague symptoms, Loss of intellect, Denies/conceals symptoms, Easily distracted, Great effort to perform tasks</td>
</tr>
<tr>
<td>Recent memory</td>
<td>Normal or recent/ past both altered</td>
<td>Patchy, Remote intact</td>
<td>Impaired, Concrete thinking</td>
</tr>
<tr>
<td>Intellect</td>
<td>Slowed, may be unwilling to respond</td>
<td>Impaired</td>
<td>Impaired, Bad/ inappropriate decisions, Denies problem</td>
</tr>
<tr>
<td>Judgment</td>
<td>Poor judgment, Many “don’t know” answers</td>
<td>Impaired, Difficulty separating facts &amp; hallucinations</td>
<td>Impaired, Bad/ inappropriate decisions, Denies problem</td>
</tr>
<tr>
<td>Diurnal Pattern</td>
<td>Worse in morning, Sleep impaired</td>
<td>Day drowsiness, Nighttime hallucinations, Insomnia, Nightmares</td>
<td>Worse in evening, “Sundowning,” Reversed sleep</td>
</tr>
<tr>
<td>Attention Affect</td>
<td>Withdrawn, Constricted, Apathy, Hopeless, Distressed</td>
<td>Labile, Variable, Fear/panic, Euphoria, Disturbed</td>
<td>Easily distracted, Shallow, Labile, Inappropriate anxiety, Depression, Susicious</td>
</tr>
<tr>
<td>Orientation</td>
<td>Intact</td>
<td>Disoriented, but usually not to person, Periods of lucidity</td>
<td>Disoriented</td>
</tr>
<tr>
<td>Level of consciousness</td>
<td>Intact</td>
<td>Disturbed</td>
<td>Intact</td>
</tr>
<tr>
<td>Psychotic symptoms</td>
<td>Delusions</td>
<td>Delusions</td>
<td>Late delusion, Hallucinations</td>
</tr>
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Module # 9: Advance Directives
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 9: Advance Directives

James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

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# Module # 9: Advance Directives

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A. Case Studies
   # 1: Mr. Lewis
   # 2: Mrs. Rodriquez (with case analysis)
B. Template For Ethics Case Analysis
C. Your Life/Your Choices: Choosing A Spokesperson
D. Instructions And Definitions For VA Advance Directives
E. VA Advance Directive: Durable Power Of Attorney For Health Care And Living Will
I. Overview

The delivery of ethical patient care is a goal of all health care providers, but this objective can be more challenging when the patient is older with an array of conditions and diseases. An interdisciplinary health care team may have an advantage in dealing with these issues because of the multiple perspectives brought to bear in case discussion. However, a possible disadvantage to the resolution of ethical issues in a team context is a tendency for “groupthink”, with the strongest team members dominating the discussion. Advance care planning is an ongoing process that offers the patient the opportunity to have a dialog with his or her family members and physician regarding the choices for care at the end of life. During this process, the patient's questions, fears and values are explored. As the important issues are uncovered, the information can be translated into a plan of action, called the advance directive. Ultimately, advance care planning is designed to clarify the patient's questions, fears and values, and thus improve the patient's well-being by reducing the frequency and magnitude of over treatment and under treatment as defined by the patient.

II. Learning Objectives

1. Define and describe ethical principles within a health care setting.
2. Compare personal values and professional codes of ethics.
3. Describe a seven-step process for ethical decision-making.
4. Delineate the role of the health care team in ethical decision-making.
5. Define Advance Care Planning.
6. Describe the benefits and barriers to Advanced Care Planning and Directives.
7. Describe the purpose and health care responsibilities related to the Patient Self-Determination Act.
8. Discuss informed consent, including definition, importance, related procedures, and influence of age.
9. Identify the legal consensus on treatment limitations.
10. Discuss the issue of physician-assisted suicide.
11. Discuss medical futility.
III. Definitions

The following two definitions are important for an understanding of ethics in health care:

A. **Ethics** can be defined as declarations of what is right or wrong and what ought to be. Ethics is a specialized area of philosophy with origins dating back to ancient Greece. The ethical principles enunciated by Hippocrates still serve as the underpinnings of many of today’s ethical issues. In an ethical decision making process, one asks in a systematic way, “what do dignity and respect demand in terms of response from others”? Following are some questions that may follow from this initial question:

1. Do our values, behaviors, and character traits pass the test of further examination when measured against this standard?
2. Which values, duties, and other guidelines are the most important in situations where conflicts arise?
3. When situations present uncertainty, what aspects of present moralities will most reliably guide individuals on a path of survival?

B. **Ethical dilemma** can be defined as 1) a difficult problem seemingly incapable of a satisfactory solution, or 2) a situation involving choice between equally unsatisfactory alternatives. This is not to suggest that all dilemmas in life are ethical in nature; rather, that ethical dilemmas arise when moral claims conflict with each other.

IV. Ethical Principles Within Health Care

A. **Autonomy**: the right to self-determination, independence, and freedom. Involves the provider’s willingness to respect a patient’s right to make decisions about and for him or herself, even if the provider does not agree with the patient’s decision.

B. **Justice**: the obligation to be fair to all people, regardless of race, sex, marital status, medical diagnosis, social standing, economic level, or religious belief. It is sometimes expanded to include equal access to health care for all.

C. **Beneficence**: requires that providers do good for patients under their care. Good care requires that the provider understand the patient from a holistic perspective that includes the patient’s beliefs, feelings, and wishes as well as those of the patient’s family and significant others. Involves acting in ways that demonstrate caring; listening, empathizing, supporting, and nurturing.

D. **Nonmaleficence**: requirement that providers do not harm their patients and opposite of beneficence. Also requires that providers protect those individuals from harm if they cannot protect themselves.
E. **Veracity**: “truthfulness” requires that providers not intentionally deceive or mislead patients. Based on mutual trust and respect for human dignity. As with other rights and obligations, there are limitations to this principle; an example would be a situation where telling the patient the truth would seriously harm or produce greater illness or go against the cultural mores of the patient.

V. Framework For Ethical Analysis

There are several frameworks to analyze an ethical dilemma in a health care setting. (Refer to Figure 1, a modified case analysis structure originally developed by Jonsen, Siegler, and Winslade.) This framework is useful when discussing a particular case in a health care team setting.

VI. Personal Values vs. Professional Code Of Ethics

A. Personal values are generally derived from society. Providers need to know the patient’s values about life, health, illness and death. Some important ethical issues include:

1. Individual’s right to make decisions for self
2. Euthanasia (active and passive)
3. Blood transfusions
4. AIDS/HIV
5. Withholding fluids and nutrition
6. Cultural differences
7. Spiritual and religious differences

B. Professional Values are often a reflection and expansion of personal values. They may come from ethic codes, healthcare experiences, teachers, and peers.

C. A Code of Ethics is a formal statement that sets standards of ethical behavior for a group of people. Professional societies have developed codes of ethics for their members. It reflects the groups’ moral judgments over time and serves as a standard for their professional actions. Please go to the following sites to review professional codes of ethics:

1. National Association of Social Workers
2. American Pharmacists Association
   [http://www.aphanet.org/AM/Template.cfm?Section=Pharmacy_Practice_Resources&Template=/CM/HTMLDisplay.cfm&ContentID=2903](http://www.aphanet.org/AM/Template.cfm?Section=Pharmacy_Practice_Resources&Template=/CM/HTMLDisplay.cfm&ContentID=2903)
3. American Nursing Association
   [http://www.nursingworld.org/ethics/chcode.htm](http://www.nursingworld.org/ethics/chcode.htm)
4. American Medical Association
VII. When The Provider Cannot Support The Patient’s Decision

A. Typically occurs when goals are unreasonable or illegal.

B. Provider must set limits on what he or she will do without implying abandonment or destroying the relationship with the family.

C. Provider should make the conflict explicit and offer to help find an alternate solution.

VIII. Overview Of Advance Care Planning

A. Advance Care Planning is the process of planning for future medical care, particularly for the event when the patient is unable to make his or her own decisions. It also involves the patient deciding and designating whom they would like to make those decisions on their behalf in the event they cannot make them for themselves.

B. Advance care planning involves decision making and the communication of those decisions between the person and their family, friends, physicians and other health care providers that ensure that patient’s choices are known, preferably long before a crisis situation or when they can no longer communicate their wishes. The process helps patients identify and clarify their personal values and goals about health, medical treatment, and how, where, and with whom they want to live the end of their lives and puts in place concrete arrangements for services.

IX. Definitions

A. The living will (or "medical directive" or "declaration" or "directive to physicians") is a written instruction spelling out any treatments you want or don't want if you are unable to speak for yourself and terminally ill or permanently unconscious. A living will says in effect, "Whoever is deciding, please follow these instructions!" On its own, a living will is very limited—it usually applies only to end-of-life decisions, and standard instructions tend to be general.

B. A health care power of attorney (or health care "proxy," or "medical power of attorney") is a document that appoints someone of your choosing to be your authorized "agent". You can give your agent as much or as little authority as you wish to make health care decisions. The decisions are not limited to just end-of-life decisions. Appointing an agent provides someone with authority to weigh all the medical facts and circumstances and interpret your wishes accordingly. A health care power of attorney is broader and more flexible than the living will.
C. A comprehensive **Health Care Advance Directive** combines the living will and the health care power of attorney into one document. In addition, you may include any other directions, including organ donation or where and how you prefer to be cared for. Because it is more comprehensive and more flexible than the other tools, it is the preferred legal tool.

X. Why Have Advance Care Planning?

A. States have laws supporting the appointment of a health care proxy.

B. All states but New York and Michigan have a living will statute, but these documents are still recognized as a matter of practice in those states.

C. The Patient Self-Determination Act (1990) requires all health care facilities that receive Medicare payments inform patients of their rights to complete advance directives under their state law.

   1. Insurance companies and regulatory agencies see advance directives as quality indicators.
   2. We will all die someday from a variety of disease for which there is a wide spectrum of treatments.
   3. Many of us will achieve advanced age and mental incapacity, where others will be deciding medical treatments for us.

D. Benefits and Barriers to Advanced Care Planning and Directives

A. Benefits

   1. Advance Directives allow the individuals to exercise control over their bodies and direct health care in the event that they will lack decision-making capacity at the time a medical decision needs to be made. Older adults are more likely to develop impaired decision-making capacity than are younger people. 13

   2. When patients communicate these wishes ahead of time, it decreases the chance of conflict in future decision making, decreases the potential for ethical dilemmas, and takes the burden of the family and healthcare team when the patient can no longer communicate for him/herself. The sense of control and peace of mind that this process fosters in the patient and the reduction in anxiety of proxy decision-makers are important benefits.

B. Barriers

   1. Vague language.
   2. They do not guide treatment decisions by physicians - (SUPPORT Study).
3. Surrogate decision makers often unaware of patient wishes, or unwilling to support them.
4. Physicians do not bring them up, and patients feel it is the physician’s responsibility to do so.
5. Physicians have difficulty with truth-telling and breaking bad news.
6. Physicians want to maintain “hope”.
7. Problems with prognostication.
8. Anticipated disagreement between physician and patient or family over appropriateness of specific treatments.
10. Medical-legal concern
11. Physicians feeling advance directives not appropriate for healthy patients.
12. Time.

XI. Preparing A Living Will

- Prepared while the patient has decisional capacity.
- Describes the patient's preferences in the event they become incapable of making decisions or communicating decisions.
- Usually describes what type of life prolonging procedures the patient would or would not want and circumstances under which they would want these procedures carried out, withheld, or withdrawn.
- Documentation of living will - Copy should be in patient's home, physician's record, hospital record, outpatient record and with surrogate/proxy.
- Variations exist by state so professionals must be familiar with state laws.

XII. Patient Self-Determination Act

A. The Federal Patient Self-Determination Act (PSDA): (enacted by Congress in 1991) creates obligations for health care facilities participating in the Medicaid and Medicare program to: 1) ask patients whether they have an advance directive and to record this information in the medical record; 2) to honor advance directives; 3) to educate patients about advance directives; and 4) to conduct community education.

B. The Patient Self-Determination Act requires providers to tell patients what their state provides in the form of an advance directive, and hospitals are required to inform patients of their right to accept or refuse medical treatment and to make advance directives. The Act is intended to protect the views and choices of patients when they become incapacitated to make decisions.
XIII. Informed Consent

A. Definition

Informed consent is a legal doctrine requiring the disclosure of information about a proposed treatment before obtaining consent for its performance. Informed consent involves providing factual information, including the benefits and burdens of an action, and determining a person’s understanding of that information. After being given information, a person is thought to be able to give informed consent if they can: a) evidence a choice; b) understand and appreciate the issues; c) rationally manipulate information; and d) make a stable and coherent decision. 17

B. The Importance of Informed Consent

Many patients and families who are facing treatment withdrawal may have not been fully informed of the risks and benefits of the therapy at the time it was begun, nor, often are they told that treatment could be withdrawn if no longer effective. Patients and families who refuse further treatment should be told the consequences of the discontinuation of treatment.

C. Procedures of Informed Consent 18

1. The informed consent process is one of discussion and shared decision making.

2. It is ideally woven into regular clinical interaction.

3. The health care provider should bring news and information to the patient about his or her disease and its management in as timely and sensitive a fashion as possible.

4. Age Changes Which May Influence Informed Consent in Older Adults 19

   a. Sensory deficits in hearing and vision.

   b. Adult learning needs for both written and verbal information presented slowly with opportunities to repeat and clarify content.

   c. Values and beliefs about making health care choices (i.e., “let the doctor decide”).

   d. Decision-making capacity that fluctuates or is diminished.
XIV. The Steps Of Advance Care Planning


A. Preparing for the Discussion

1. Discussions can never be all-inclusive.

2. Discussion should be directed toward expected clinical situations whenever possible.

3. Appointment of a surrogate is an important first step for both patients with and without identifiable risk factors for specific treatment issues.

4. Discussion must address patient values - prolong life or comfort care.

5. Discussions should take place over time, whenever possible.

6. Information should be presented in a thorough and unbiased fashion.

7. The physician needs to recognize that some patients do not want to have these discussions - may or may not be based in culture - need to ask.

8. Must address medical uncertainty - concept of time-limited trials.

9. Directives must be well documented and available.

10. The possibility that the patient may change his or her mind must be anticipated, and wishes periodically reviewed, as long as the patient retains decisional capacity.
B. Introducing the Topic

1. Be straightforward and routine: whenever possible, routinely initiate the advance care planning process with every adult patient, regardless of age or current state of health.

2. Determine patient familiarity: some patients may already have advance directives. If this is the case, review the documents and amend if appropriate.

3. Explain the process: before beginning, explain the goals and the process. Literature or validated worksheets may be helpful.

4. Determine the patient’s comfort level: be aware of the patient’s comfort level during the introduction of the topic. If a patient does not seem comfortable, be supportive and provide information, but do not force the conversation.

5. Identify a proxy: ask the patient to identify a possible proxy decision-maker who might act on his or her behalf, to be involved in subsequent conversations.

C. Surrogate Issues

1. Surrogates should be chosen who are familiar with and willing to support the patient’s wishes and values.

2. Surrogates must be decisional capacity.

3. Directives should address if surrogate has discretion to override previously stated wishes.

4. Surrogates must be informed and reachable.

D. Engage in Structured Discussions

1. Proxy decision-maker(s) should be present: potential proxy-decision maker should be present at the discussions and planning so that he or she can have a thorough and explicit understanding of the patient’s wishes.

2. Describe scenarios and options for care: this will provide insight as to scenarios that might arise and the types of decisions that proxies most commonly face.
3. Elicit patient’s values and goals: this can be done by asking about past experiences and describing possible scenarios.

4. Specific issues that ought to be discussed include: the patient’s choice of a spokesperson; beliefs; health conditions; life-sustaining treatments; vision of a good death; organ donation; and funeral arrangements.

5. Use a worksheet: worksheet should include a range of potential scenarios that patients should consider. It should elicit the patient’s values and goals related to health and medical care in general terms and should include the most common life-threatening interventions.

E. Treatments to be Covered in Discussion

1. Resuscitation
2. Mechanical breathing (intubation)
3. Surgery
4. Chemotherapy
5. Dialysis
6. Blood transfusion
7. Artificial nutrition and hydration
8. Diagnostic tests
9. Antibiotics
10. Pain medication

F. Document Patient Preferences

1. Formalize the directives: check for inconsistencies and misunderstandings. Have the patient sign the directives.

2. Enter directives into the medical record: directives should be formally documented into the patient’s medical record.

3. Recommend statutory documents: One or more statutory documents that comply with state statutes can be completed for added protection.

4. Distribute the directive: the records should be available wherever the patient may receive care.

G. Review and Update the Directive

1. Follow up periodically.
2. Note major life events: such as illness, marriage, birth of a child, which may affect a person’s attitude.

3. Discuss changes: ensure patient, provider, and proxy understand the new wishes.

4. Document changes: documents should be updated and shared appropriately.

H. Apply Prior Directives to Actual Circumstances

1. Determine the patient’s capacity to make decisions
   a. **Decision-making capacity** is a clinical determination as to whether a person possesses a set of values and goals, the ability to communicate and understand information, and the ability to reason and deliberate about their choices.
   
   b. **Competency**: a legal determination (by a judge) as to qualified to give testimony or execute legal documents (in the law with regard to health care decisions there is no definitive test for competency).

   c. Questions for Determining Decisional Capacity
      - Can the person make and express personal preferences at all?
      - Can the person give reasons for the alternative selected?
      - Are the supporting reasons rational, in the sense that the patient begins with a factually plausible premise and reasons logically from that premise to the result?
      - Does the person in fact comprehend the implications?

   d. Because a substantial number of older adults have altered decision-making capacity, it is an issue every time an older adult is asked to consent to treatment or execute a Health Care Proxy or living will.

   e. Cognitive impairment does not automatically constitute decisional incapacity. Widely used tests of mental status assessment (e.g., Mini-Mental Status Assessment of MMSE) are NOT good measure of an individual’s ability to make health care decisions.
2. Read the advance directive: never assume its content.

3. Interpret the advance directive: should be interpreted in view of the clinical facts of the case. No matter how thorough they are, advance directives cannot anticipate all possible circumstances.

4. Consult with the proxy: whenever significant interpretation is necessary.

5. Use ethics committee: for cases in which disagreements cannot be resolved.

6. Carry out the treatment plan.

(Refer to Figure 3, “Instructions and Definitions for VA Advanced Directives)

XV. Legal Consensus On Treatment Limitation

A. Patients May Refuse Unwanted Treatment: Patients with decision-making capacity may refuse unwanted medical treatment, even if this may result in their death.  

B. Surrogate Decision-Making: Patients who lack capacity to make the decisions at hand have the same rights as those who have capacity. Authorized surrogate decision-makers may make decisions to limit treatment.

C. Sustaining medical treatment is considered neither homicide nor suicide. There are no limitations on the type of treatment that may be withheld or withdrawn. This may arise more frequently with older adults where the potential benefits of a treatment are unclear.

D. Legally (and ethically) there is no difference between never starting therapy and discontinuing therapy.

1. State laws can vary from the prevailing legal consensus on end-of-life care (e.g., in the degree of certainty that a surrogate should have about a patient’s wishes).

XVI. Issue Of Physician-Assisted Suicide

A. In 1997, the US Supreme Court held that there is no federal Constitutional right to assisted suicide. In doing so, it reaffirmed the distinction between withholding or withdrawing life-sustaining treatment and assisted suicide. Some professionals do have difficulty distinguishing professionally sanctioned end of life interventions from those that are not. This is partially
due to imprecisely defined or understood terms used in end of life interventions. For purposes of clarification, the use of the following definitions are recommended:

1. Assistance in dying: is an act that directly and intentionally brings about the death of a capable adult who voluntarily requests such assistance to end suffering.

2. Suicide: is the act of taking one’s own life, and the act of doing so was decriminalized in 1961.

3. Assisted Suicide: is the provision of the means to end life, such as through the prescription for a lethal amount of drug, the lethal drug itself, or other measures) to an adult who is capable of ending life, with knowledge of that person’s intentions.

4. Voluntary Active Euthanasia: is a deliberate and intentional act that causes death, often by lethal injection, at the voluntary request of an adult who is capable of causing his or her own death.

5. Non-voluntary Euthanasia: is the deliberate and intentional act that causes the death of a person who is incapable of expressing his or her own wishes about dying.

6. Involuntary Euthanasia: is the direct and intentional killing of a competent person who explicitly refuses receiving euthanasia.

B. Provision of medication with the intent to produce death is considered to be assisting suicide.

C. All states except Oregon, which has developed a state statutory right, have laws that make assisting a suicide by anyone a criminal offense. In the first and second year after the physician assisted suicide (PAS) law was passed in Oregon, 16 and 27 terminally ill patients, respectively, ingested lethal amounts of drugs. According to preliminary information, the reasons these individuals gave for requesting PAS was loss of personal autonomy and control of body functions, inability to participate in activities of daily living that made life enjoyable, and desire to control the manner of dying. The experience of unmanaged pain was not a factor.
XVII. Medical Futility

A. There are times when there are conflicts regarding belief of the beneficial nature of a treatment. These situations are referred to as "medical futility" and are common reasons for ethics consults or ethics committee presentations. These conflicts often involve failure in communication or misunderstandings over prognosis or benefits versus burden of treatment options. There are also important cultural and religious influences in these matters.

B. By asking the fundamental question, "Who are we doing this for?" many futile interventions can be avoided. The answer should be guided by the patient's values. Often, interventions (e.g. daily weights, mobilizing patients, continuing dietary supplements) may become questions to involving futility.

C. Many institutions have developed futility policies and have advocated the use of prognostic data to assist in determining when a treatment is futile. Such efforts alone rarely solve the fundamental disagreements about quality of life, meaning and decision making authority.
XVIII. References


(Module 4). Available from the American Association of Colleges of Nursing: www.aacn.nche.edu/elnec


Learning Resource A

Case Studies

Case # 1: Mr. Lewis*

Mr. Lewis, age 71, has been a patient in the hospital for three weeks after suffering a very severe stroke. He has a tracheostomy (not ventilator dependent) and rarely leaves his bed. He has several infections that respond well to therapy. He communicates by whispering and writing. Many staff members observe that Mr. Lewis seems depressed. He has never been treated for clinical depression. His spouse of nearly 50 years, Mrs. Lewis, visits him faithfully during hospitalization. She feeds him his lunch and dinner by spoon. She is a much-admired visitor and brings gifts for the staff. She is a “lovely woman, truly devoted to her husband,” in the words of the staff social worker.

Mr. Lewis was offered an opportunity to complete an advance directive. He chose to fill out only a durable power of attorney for health care (health care proxy). He named his wife as his surrogate decision-maker should he lose decisional capacity. Mr. Lewis’s health care proxy was filed in his chart. In a subsequent discussion with his physician, he requested that no cardiopulmonary resuscitation be attempted were he to suffer an arrest. The Do Not Resuscitate order was also appropriately charted.

Later, however, Mr. Lewis told his primary nurse “when the time comes, I don’t want one of them feeding tubes. I would rather starve to death.” The nurse reported this statement to the physician. The physician brought up the matter the next day with both Mr. Lewis and his wife. This time Mr. Lewis said nothing. His wife stated, “Well, you know, his mind wanders sometimes. I know that he would not want to die without food or water.” Later, outside of the patient’s room, she told the nurse and doctor, “I don’t really care what he says. He doesn’t know what he wants. I could never let him die that way. We would both go straight to hell. If he does have another stroke, I will become the decision-maker. So it really doesn’t matter anyhow.”

Focus Questions:

1. What are some ethical issues introduced in this case study?
2. Who could be involved in assisting in this situation?
3. How would you plan care for Mr. Lewis based on the information outlined here?
4. What are any thoughts/feelings that you have about this care situation?

Case # 2: Mrs. Rodríguez

Mrs. Rodríguez, a 79 year old widow with a history of diabetes mellitus, breast cancer, poor vision and gait instability, lived in a senior housing facility in the inner city. Eight months prior to her death she was diagnosed with a recurrence of her breast cancer. This time the cancer was found to be widely metastasized. She was advised by her primary care physician that there was no hope of cure. She continued to live in the senior housing facility. Soon thereafter her health began to decline.

Three months after being diagnosed with the recurrence of breast cancer, Mrs. Rodríguez fell at home. She was taken to the emergency room by her daughter-in-law, and was subsequently hospitalized at an academic medical center with a fractured arm. Due to Mrs. Rodríguez’s decline in functional status, the medical center’s inpatient social worker recommended that Mrs. Rodríguez be aced in a nursing home. The patient and her close confidant, a local pastor, were very clearly against her being placed in a nursing home. A nurse who had become quite close to Mrs. Rodríguez during her inpatient stay also tried to advocate on Mrs. Rodríguez’ behalf against nursing home placement in heated discussions with the inpatient social worker, but was unsuccessful in her efforts. Based on the evaluation of the inpatient social worker, the social worker at Mrs. Rodríguez’ senior housing facility steadfastly refused to allow Mrs. Rodríguez to return to her home, citing liability restrictions of the housing facility.

Mrs. Rodríguez was sent to a nursing home to convalesce while efforts continued on the part of the pastor to get her adequate home attendant services so that she could be returned to the senior housing facility. The nursing home’s chief geriatrician as well as its social worker took up the cause at the pastor’s behest. Medicare personnel would only approve nine hours of home attendant services, however, and neither the staff of the nursing home nor the senior housing social worker would accept this as adequate for her care.

An interdisciplinary meeting was held at the nursing home. The senior housing social worker, the pastor, the patient’s daughter-in-law, and the nursing home’s geriatrician and social worker were in attendance. This pastor, the nursing home’s social worker, and the patient’s daughter-in-law continued to press for discharge to the senior housing facility in keeping with the patient’s wishes, while the housing facility’s social worker reluctantly continued to deny permission. It was noted at this meeting that Mrs. Rodríguez had become much more withdrawn and depressed at the nursing home. At the end of this meeting the nursing home social worker promised to push Medicare for round the clock home attendance care for the patient, which the senior facility social worker reluctantly agreed would be adequate for her return. Mrs. Rodríguez also signed a health care proxy form naming her daughter-in-law as proxy. Four days prior to Mrs. Rodríguez’s death she was approved for 24-hour home attendant care. She was transferred to the senior housing facility where she died in her sleep soon after.
Mrs. Rodriguez Case Analysis

A. Patient and Family Preferences

The patient desires to be returned to their apartment in senior housing. She appears to have capacity to make this decision as she is allowed to sign a health care proxy form, and the inpatient nurse’s notes indicate that she is “alert and oriented x 3.” The patient’s daughter-in-law and pastor want Mrs. Rodriguez to be allowed to return to her apartment.

The foremost ethical issue in Mrs. Rodriguez’ case is the conflict between autonomy and beneficence: the desire to respect the patient’s wishes and right to self-determination balanced with the desire for health professionals to act in what they perceive to be the patient’s best interest. Here, several of Mrs. Rodriguez’ healthcare providers emphasize finding the optimal care setting for the preservation of her life, giving the issue of beneficence more primacy than the started desire of both Mrs. Rodriguez and her confidants to have her back in her home. Ethically, patients should be considered to have the capacity to make their own decisions unless there is a compelling reason to question their decision-making ability.

In this case the patient appears to have the capacity to make her own decisions, as evidenced by the fact that she is alert and oriented and retains the legal right to assign her own proxy. Her confidants also agree with the patients choices. Nevertheless, Mrs. Rodriguez is kept out of her home until four days prior to her death. A better compromise between autonomy and beneficence might have been worked out had round-the-clock home attendant care been readily available.

B. Quality of Life Issues

Mrs. Rodriguez will be unable to return to normal life in the senior center housing facility without round-the-clock care; however, the patient still desires this opinion over life in a nursing home.

C. Contextual Factors: Teams and Transitions

See next page
Parties involved with the care of Mrs. Rodriguez:
Primary care physician
Family: Mrs. Rodriguez’s daughter-in-law and pastor
Inpatient social worker, Inpatient nurse
Senior housing social worker
Nursing home: geriatrician, social worker, nurses
Medical personnel

Collegiality. Another facet of team dynamics that can complicate decision-making is that of colleagues waiting to respect each other’s decisions. In order for a team to function effectively it is necessary for team members to behave toward each other in a manner that is consistent with how the team members behave toward the patient – ideally, by respecting autonomy. A premium is placed on colleagues respecting each other’s autonomy and decision making capacity: just as patients with capacity must be permitted to make poor choices. Thus the desire not to affect the group dynamic of a team adversely may prevent team members from confronting each other when they encounter what appear to be poor judgment calls by their colleagues. This may be the case with the senior housing facility social worker, who appears to lack sufficient knowledge about the importance of respecting patient autonomy. Other members of the team, had they felt comfortable educating the social worker in this regard, may have been able to convince her that transfer back to the adult home was indeed appropriate. When team members do not know each other very well, which is often the case of multiple-institutional teamwork, there is a greater reluctance to disagree with a colleague.

Legal implications. Team effectiveness can be comprised by influences entirely outside their control. One example is the senior housing social worker’s refusal to permit re-entry into the housing. Her hands were in fact tied by her duty to heed regulations of the housing facility. Here it could be argued that the senior housing social worker – or those who initially determined the housing policies – are violating Mrs. Rodriguez’ right to autonomy. This argument must be weighed against the legal liability of the housing facility should Mrs. Rodriguez have an accident upon her return or cause accidental injury to others through fire, etc. An ethical dilemma arising during Mrs. Rodriguez’ transitions is whether persons living in a housing facility have less right to autonomy that persons living in a private home; i.e., a conflict between patient autonomy and housing facility liabilities.
From the point of view of clients in need of long-term care most likely for the rest of their lives but wishing to live at home as long as possible, as in Mrs. Rodriguez’ case, a single agency responsible for providing all care and assuming complete accountability is preferable to the patient being shuttled from setting to setting. A model of care such as PACE’s may have prevented unnecessary hospitalization and avoided this particular ethical dilemma from arising.

**Allocation of Resources.** Another contextual feature of this case is Medicare’s unwillingness to provide more hours of daily home attendant care makes what could have been a logical team compromise – for Mrs. Rodriguez to remain at home with extended home attendance – an impossibility. Medicare personnel, presumable for cost control reasons, block the way for this compromise by only approving nine hours of daily home care. Medicare regulations and personal play an important role in this case, yet no Medicare representatives are part of the team. Managed care administration may very often play a central role in a team’s decisions without actually being a physical part of the team. This can engender frustration from care providers, patients, and family members alike. Here again, a mega-team model is instructive, where those parties responsible for making cost-decisions are actively involved in team decisions for each patient. In the case that follows, how the PACE accomplishes this goal will be discussed.

**Team composition.** Team composition is blurry. There are several care providers, but it is not clear if there are teams at all. Certainly the provision of care is not coordinated. The patient’s primary care physician who originally diagnosed the cancer is not actively involved throughout the transitions. The health care providers at the hospital, including the hospital’s inpatient nurse and social worker, do not play an active role once the patient make a transition beyond the hospital doors. Yet the inpatient social worker’s evaluation of the patient has such primacy that it continues to directly affect the patient by forming the basis on which Mrs. Rodriguez is prevented from returning home.

The patient might better have been served had members of the hospital involved Mrs. Rodriguez’s care – or at the very least the inpatient social worker – stayed involved in the case until its resolution. It is not known, however, what other burdens these providers faced and whether continuing involvement was even a possibility given other time and staffing constraints at the hospital. The interdisciplinary meeting involving professionals from the nursing home and senior housing facility as well as the patient’s confidants is an attempt on the part of these providers to function as a single team. In fact this meeting did serve to accomplish the patient’s goal, albeit too late to be of benefit to her.

**Team management.** Even if all the various health professionals involved in this case are regarded as functioning as a single “mega-team”, lack of clear team management still obscures what should be the central role of the patient being able to make her own choices about living arrangements. Until the last days of the patient’s life when she signs a proxy form, no one on this “team” appears to take responsibility for ensuring that an assessment of the patient’s decision-making capacity is carried out in an explicit manner such that the entire team is aware of whether or not the patient is able to make her own decisions. Without a person with the needed combination of awareness of the importance of patient
autonomy and the power to return her to her apartment, several members of the team appear to operate under the assumption that the patient lacks decisional capacity.

The de facto leader in coordinating the team’s decisions could be viewed as the senior housing social worker in that she is able to block transfer of Mrs. Rodriguez, or as the pastor in that he is consistently involved throughout the various transactions. A case manager is badly need here, whether it be the patient’s primary car provider, someone from the hospital who had the patient’s trust, such as the inpatient nurse, or any of the other professionals involved in Mrs. Rodriguez’ care, preferably one upstream in the transition process.

Role of Family and Confidants on Team. The Pastor and the daughter-in-law both have the desire to follow the patients wishes, but they are powerless to convince the senior housing social worker who doe not place as great an emphasis on the patient’s decisional capacity. Here the role of the family on the team and what level of involvement in decision-making should be afforded the family members and patient confidants is another central team issue.
Learning Resource B

Template For Ethics Case Analysis

1. Gather the Clinical Information
   a. What is the patient’s medical problem? History? Diagnosis? Prognosis?
   c. What are the goals of the treatment and care?
   d. What are the probabilities of success?
   e. What are the plans in case of therapeutic failure?
   f. In sum, will medical and nursing care benefit the patient and harm be avoided?

2. Identify Patient and Family Preferences
   a. What has the patient expressed about preferences for treatment?
   b. Has the patient been informed of benefits and risks, understood, and given consent?
   c. Is the patient mentally capable and legally competent? What is evidence of incapacity?
   d. Has the patient expressed prior preferences (e.g. advance directives)?
   e. How does the patient want to include family or friends in the decision-making process?
   f. If the patient is incapacitated, who is the appropriate surrogate? Is the surrogate using appropriate standards?
   g. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?
   h. Are there family issues that might influence treatment decisions?
   i. In sum, is the patient’s right to choose being respected to the extent possible in ethics and law?

3. Evaluate Quality-of-Life Issues
   a. What are the prospects, with or without treatment, for the patient to return to a normal life?
   b. What biases might prejudice provider evaluations of the patient’s quality of life (i.e., is the patient’s or family’s definition of quality of life or the provider’s definition used?)
   c. What physical, mental, and social deficits is the patient likely to experience if treatment succeeds?
   d. Is the patient’s present or future condition such that, if it continues, he or she might judge life undesirable?
   e. Is there any plan and rationale to forgo treatment?
   f. What are the plans for comfort and palliative care?

4. Consider Contextual Factors
   a. Are there provider (physician, nurse, etc.) issues that might influence
treatment decisions?
b. Are there financial and economic factors?
c. Are there religious or cultural factors?
d. Is there any justification for breaching confidentiality?
e. Are there resource allocation problems?
f. What are the legal implications of treatment decisions?
g. Is clinical research or teaching involved?
h. Is there any provider or institutional conflict of interest?

5. Resolve the Ethical Issues and Create the Plan

6. Implement the Plan

7. Evaluate the Plan

Learning Resource C

**Your Life/Your Choices: Choosing A Spokesperson**

**Who should speak for me?**

**Instructions**  This exercise will help you choose the best spokesperson for you. On the top of each column, write in the names of one or more people you're considering to be your spokesperson. Place a check mark (✓) in the column for that person if the following statements are true. The first two statements must be true for your spokesperson to have legal authority to represent you. You should weigh how important the other attributes are to you in deciding your first choice.

<table>
<thead>
<tr>
<th><strong>Meets the legal criteria in my state for durable power of attorney for health care</strong> (see the instructions in the back pocket).</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Would be willing to speak on my behalf.</strong></td>
</tr>
<tr>
<td>Would be able to act on my wishes and separate her/his own feelings from mine.</td>
</tr>
<tr>
<td>Lives close by or could travel to be at my side if needed.</td>
</tr>
<tr>
<td>Knows me well and understands what’s important to me.</td>
</tr>
<tr>
<td>Could handle the responsibility.</td>
</tr>
<tr>
<td>Will talk with me now about sensitive issues and will listen to my wishes.</td>
</tr>
<tr>
<td>Will be available in the future if needed.</td>
</tr>
<tr>
<td>Would be able to handle conflicting opinions between family members, friends, and/or medical personnel.</td>
</tr>
</tbody>
</table>
**What makes your life worth living?**

**Instructions** This exercise will help you think about how you would feel about your life if each factor **by itself** described you.

<table>
<thead>
<tr>
<th>Difficult, but acceptable</th>
<th>Worth living, but barely</th>
<th>Not worth living</th>
<th>Can’t answer now</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I can no longer walk but get around in a wheelchair.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. I can no longer get outside - I spend all day at home.</td>
<td></td>
<td></td>
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<tr>
<td>c. I can no longer contribute to my family’s well being.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. I am in severe pain most of the time.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. I have severe discomfort most of the time (such as nausea, diarrhea, or shortness of breath.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. I rely on a feeding tube to keep me alive.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. I rely on a kidney dialysis machine to keep me alive.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. I rely on a breathing machine to keep me alive.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. I need someone to help take care of me all of the time.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j. I can no longer control my bladder.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>k. I can no longer control my bowels.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>l. I live in a nursing home.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>m. I can no longer think clearly - I am confused all of the time.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n. I can no longer recognize family/friends.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>o. I can no longer talk and be understood by others.</td>
<td></td>
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<tr>
<td>p. My situation causes severe emotional burden for my family (such as feeling worried or stressed all the time).</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>q. I am a severe financial burden on my family.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>r. I cannot seem to “shake the blues”.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>s. Other (write in):</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
Instructions. To help others make sense out of your answers, think about the following questions and be sure to explain your answers to your loved ones and health care providers. If you checked “worth living, but just barely” for more than one factor, would a combination of these factors make your life “not worth living?” If so, which factors? If you checked “not worth living,” does this mean that you would rather die than be kept alive?

If you checked “can’t answer now,” what information or people do you need to help you decide?

Your Beliefs and Values

In

Instructions. Circle yes, not sure or no to indicate whether you agree with each statement. If you do not agree with the “always” statements, this could mean that you agree with these statements some of the time, but not always. You can use the space at the bottom of the page to explain and clarify your beliefs.

Personal and spiritual beliefs.

Many people have special personal or spiritual beliefs that they want respected in decision making about life-sustaining treatments? What are yours?

I believe that it is always wrong to withhold (not start) treatments that could keep me alive. Yes Not sure No

I believe that it is always wrong to withdraw (stop) treatments that could keep me alive after they’ve been started. Yes Not sure No

I believe it is wrong to withhold (not provide) nutrition and fluids given through tubes, even if I am terminally ill or in a permanent coma. Yes Not sure No

I do not wish to receive a blood transfusion or any blood products, such as plasma or red blood cells. Yes Not sure No

I would like to have my pastor, priest, rabbi, or other spiritual advisor consulted regarding any difficult health care decision that must be made on my behalf. (write in name) _____________________________ Yes Not sure No

I believe in other forms of treatment, such as healing through prayer, acupuncture, or herbal remedies. I want the following treatments included in my care: Yes Not sure No
I believe that controlling pain is very important, even if the pain medications might hasten my death. 

I believe that my loved ones should take their own interests into consideration, as well as mine, when making health care decisions on my behalf.

I believe that it is acceptable to consider financial burden of treatment on my loved ones when making health care decisions on my behalf.

I believe that my loved ones should follow my directions as closely as possible.

Additional beliefs and/or explanations for my beliefs: 
______________________________________________________________________
______________________________________________________________________

Hope for recovery

People have different feelings about hope that influence what health care they want. What are your feelings about hope?

*Imagine that you are very sick and have been told that you will very likely die soon.*

I would want all possible treatment, even though my doctors don’t think they will help me, because I would hope for a miracle cure that would prolong my life.

*Imagine that you have been in a coma for three weeks. The doctors think that the chance that you will ever return to your previous state of health is very small.*

I would want to be kept alive indefinitely because I would still hope for a new medical development that would help me to recover.

Weighing pros and cons of treatment for different chances of recovery

People evaluate the pros and cons of medical treatments in very personal ways. This explains why some people choose a treatment and others reject it. A big question is, how
much would you be willing to endure if the chance of regaining your current health was high? What if the chance was low? Answer the questions below to carefully evaluate your own willingness to take such risks.

*Imagine that you are seriously ill. The doctors are recommending treatment for your illness, but the treatments have very severe side effects, such as severe pain, nausea, vomiting, or weakness that could last for 2-3 months.*

I would be willing to endure severe side effects if the chance that I would regain my current health was:

- high (over 80%) Yes Not sure No
- moderate (50%) Yes Not sure No
- low (20%) Yes Not sure No
- very low (less than 2%) Yes Not sure No


**How would you like to spend your last days?**

Many people have strong opinions about what would be important to them at the very end of their lives. For some, they want to express things they would like to have happen. Others want to be sure that certain things they dislike or fear will be avoided. What are some of the things that you would hope for that could make your last weeks, days, or hours the most peaceful?

**Instructions.** For each row, check (✓) one answer to express how important these issues would be to you if you were dying.

<table>
<thead>
<tr>
<th>Issues</th>
<th>Not Important</th>
<th>Moderately Important</th>
<th>Very Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Avoiding pain and suffering, even if it means that I might not live as long.</td>
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<tr>
<td>b. Being alert, even if it means I might be in pain.</td>
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<tr>
<td>c. Being around my family and close friends.</td>
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<tr>
<td>d. Being able to feel someone touching</td>
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<tr>
<td><strong>VISN 3 Geriatric Research, Education &amp; Clinical Center (GRECC)</strong></td>
<td>Geriatrics, Palliative Care &amp; Interprofessional Teamwork Curriculum</td>
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<tr>
<td><strong>Module # 9: Advance Directives</strong></td>
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<tr>
<td>me.</td>
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<tr>
<td>e. Having religious or spiritual advisors at my side when I die.</td>
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<tr>
<td>f. Being able to tell my life story and leave good memories for others.</td>
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<tr>
<td>g. Reconciling differences and saying “good-bye” to my family and friends.</td>
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<tr>
<td>h. Being at home when I die.</td>
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</tr>
<tr>
<td>j. Being kept alive long enough for my family to get to my bedside to see me before I die, even if I’m unconscious.</td>
<td></td>
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</tr>
<tr>
<td>k. What are your biggest hopes about the end of your life?</td>
<td></td>
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<tr>
<td></td>
<td></td>
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<tr>
<td>l. What are your biggest fears about the end of your life?</td>
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<tr>
<td><strong>Other related matters</strong></td>
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<tr>
<td>The topics that have been covered up to this point have related to decisions about your health care in the event you could not speak for yourself. Your decisions about the next topics would go into effect after your death. We include them here because they are related issues that you may want to communicate to others.</td>
<td></td>
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<tr>
<td><strong>Organ donation and autopsy</strong></td>
<td>Sometimes after death, organs and tissues can be used to help other people who need them. Family members must give consent to transplant your organs. You can help them make this decision by letting them know how you feel about this. After an autopsy, the body can be shown and buried.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Instructions.</strong> Circle one word to express how you feel. I want to donate any viable organs/tissues.</td>
<td>Yes Not sure No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If yes, have you filled out an organ donor card? Have you told your family?</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>I consent to the use of all or part of my body for medical research.</td>
<td>Yes Not sure No</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>If yes, do you have a preference for a research institution? Have you told your family?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I permit an autopsy.</td>
<td>Yes Not sure No</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Burial arrangements.
People often leave instructions about what they want done with their bodies after they die. Some want to be buried in a particular place, perhaps in a cemetery with other family. Other people would prefer to be cremated and have their ashes put or scattered in a special place. You can indicate your preferences by answering the questions below.

I would prefer to be: (circle one) Buried Cremated No preference

I would like my remains to be placed: _______________________________________

Other preferences: ______________________________________________________
_____________________________________________________________________

Funeral or memorial services
People have different ideas about funerals and memorial services. These services are often very comforting to family and friends as they celebrate and honor the life of their loved one. Services also can make a statement about one’s religious faith. Write in below any thoughts about a funeral or memorial service such as where it should be held, songs or readings to be included, where donations should be sent, information for an obituary notice, or other wishes.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Learning Resource D

Instructions And Definitions For VA Advance Directives

The new advance directive form 10-0137 expands veterans’ opportunity to express their wishes about end-of-life care and is structured to prompt veterans to give careful consideration to the care they would like to receive in different clinical circumstances. The form also encourages veterans to provide guidance for decision makers to help ensure that the treatment preferences they set out in their advance directive are appropriately interpreted.

The National Center for Ethics in Health Care anticipates that the new form will prompt veterans to ask more questions of their practitioners and that it will generate productive discussions and a better understanding of patients’ wishes regarding care at the end of life. Practitioners looking for a guide to help veterans complete the new advance directive may wish to refer to “Your Life, Your Choices” (http://vaww.ethics.va.gov/pubs/ylyc.pdf). This PDF booklet offers a step-by-step discussion guide to end-of-life planning that veterans can use on their own or together with a health care practitioner. An interactive version of “Your Life, Your Choices” will be available through the MyHealthVet portal in the future.

This combined Durable Power of Attorney for Health Care and Living Will permits you to specify certain treatment you may or may not want. With this form, you can:
   a. Appoint someone to make health care decisions for you if, in the future you become unable to make those decisions for yourself and/or
   b. Indicate what medical treatments(s) you do or do not want if in the future you are unable to make your wishes known.

2. Instructions:
   a. Read each section carefully.
   b. Talk to the person(s) you plan to appoint to make sure that they understand your wishes, and are willing to take the responsibility.
   c. Place the initials of your name in the blank before those choices you want to make under part 1 and 2 of VA Form 10-0137.
   d. Add any special instructions in the blank spaces provided. If you need more space for additional comments, you may use a separate sheet of paper; but you must indicate on the form that there are additional pages to your advance directive.
e. Sign the form and have it witnessed.
f. Keep the original for yourself.
g. Give a copy of this entire form to all of the following people: your doctor or your nurse, the person you appoint to make your health care decisions for you, your family, and anyone else who might be involved in your care.
h. Remember that you may change or cancel this document at any time.

3. Definitions (Words you need to know.)
   a. **Advance Directive:** A written document that tells what you want or do not want, if you become unable to make your wishes about health care treatments known.
   b. **Artificial Nutrition and Hydration:** When synthetic food (or nutrients) and water are fed to you through a tube inserted through your nose into your stomach or into the intestine directly or into a vein.
   c. **Comfort Care:** Care that helps to keep you comfortable but does not cure your disease. Bathing, turning, pain medication, keeping your lips and mouth moist and pain medications are examples of comfort care.
   d. **Cardiopulmonary Resuscitation (CPR):** Treatment to try and restart a person’s breathing or heartbeat. CPS may be done by breathing into your mouth, pushing on your chest, by putting a tube through your mouth or nose into your throat, administering medication, giving electric shock to your chest, or by other means.
   e. **Durable Power of Attorney for Health Care:** A document that appoints a specific individual to make health care decisions for you if you become unable to make those decisions for yourself.
   f. **Life-sustaining Treatment:** Any medical treatment that is used to delay the moment of death. A breathing machine (ventilator), CPR, and artificial nutrition and hydration are examples of life-sustaining treatments.
   g. **Living Will:** Instructions you have made in advance that tell what medical treatment you do or do not want if you become unable to make your wishes known.
   h. **Permanent Vegetative State:** When a person is unconscious with no hope of regaining consciousness even with medical treatment. The body may move and eyes may be open, but as far as anyone can tell, the person can’t think or communicate.
   i. **Surrogate Decision-maker:** This is an individual, organization or other body authorized to make health care decisions for you if you are unable to do so yourself.
YOUR RIGHTS REGARDING ADVANCE DIRECTIVES

Advance Directives. Advance directives are legal forms that state your preferences about future health care. If you become too ill to make decisions about your care, an advance directive can help your doctors and family members understand what you want. It is up to you to decide if you want an advance directive. Your decision must not affect your access to health care or other VHA services. There are two types of advance directives. In the Department of Veterans Affairs (VA), the two types are in one form. You may complete neither, one, or both of the following: Durable Power of Attorney for Health Care. In this type of advance directive, you name a person as your Health Care Agent who is to make health care decisions for you if you are notable to do so. Your Health Care Agent is the first person your health care team contacts for decisions about your care. Living Will. In this type of advance directive, you state your preferences about treatments you want, or don't want, in different situations when you cannot make treatment decisions yourself. A living will helps your Health Care Agent or others know what treatments you would choose. Your Rights: 1. You have the right to accept or refuse any medical treatment. 2. You have the right to complete a durable power of attorney for health care. 3. You have the right to complete a living will. Your Responsibilities: 1. If you have an advance directive, it's important to give the Veterans Health Administration (VHA) a copy for your health record. 2. If you'd like more information about advance directives, or help filling out the forms, please call to schedule an appointment.

VA FORM

10-0137A

DEC 2006

WHAT YOU SHOULD KNOW ABOUT ADVANCE DIRECTIVES

As a VA patient you have a say in the health care you receive. When you are ill, your doctor should explain what treatments there are for your illness so that you can decide which one is best for you. But if you were too ill to understand your treatment choices or to tell your doctor what treatment you want:

- Who would you want to make decisions for you?
- What type of health care would you want?
- What health care wouldn’t you want?
Questions like these may be hard to think about, but they’re important. That’s why VA wants you to know about a legal form you can complete. It’s called an advance directive.

**What is an advance directive?**
An advance directive is a legal form that helps your doctors and family members understand your wishes about health care. It can help them decide about treatments if you are too ill to decide for yourself. For example, if you are unconscious or too weak to talk. There are two types of advance directives: durable power of attorney for health care and living will.

**What is a durable power of attorney for health care?**
This form lets you name the person you trust to make health care decisions for you if you can’t make them yourself—your “health care agent.” He or she will have the legal right to make health care decisions for you. You can choose any adult to be your agent. It’s best to choose someone you trust, who knows you well and who knows your values. You should make sure the person is willing to serve as your agent. If you don’t choose an agent, your doctor will choose someone to make decisions for you in the following order: legal guardian (if you have one), spouse, adult child, parent, sibling, grandparent, grandchild, or a close friend. Your health care team, or a court, will make decisions for you in accordance with VA policy if none of the above is available.

**What is a living will?**
A living will is a legal form that states what kinds of treatments you would or wouldn’t want if you become ill and can’t decide for yourself. It can help your health care agent and your doctor make decisions the way you want them to. Writing down what kind of treatment you would or wouldn’t want can help make it easier for those who are asked to make decisions for you. Talk with your family, your health care agent, and your doctor about your wishes so they won’t have to wonder what you want and if they’re doing the right thing. If you don’t have a living will, decisions will be made for you based on what is known about you in general and about your values. That’s why it’s important to discuss your wishes with your loved ones, your doctors, and your health care team.

**Must my health care agent always follow my living will?**
Most of the time, yes. Your health care agent should try to respect your wishes. But it can be hard to imagine future health and say just what treatment you would want at that time, so sometimes your agent may have to interpret your wishes. In a VA advance directive, you can say if you want your agent to do just what your living will says, or if they may make the decision they think is best for you at that time, even if it isn’t what you said you would want.
Should I have an advance directive?
Yes, it’s a good idea to have one. An advance directive helps protect your right to make your own choices. It helps make sure people respect your values and wishes if you can’t speak for yourself. Your advance directive is used only when you aren’t able to make decisions yourself.

How do I complete an advance directive?
Fill out VA Form 10-0137, “VA Advance Directive: Durable Power of Attorney and Living Will.” Or use any valid state advance directive form. Talk to a health care professional at your local VA health care facility. This might be a social worker or your primary care doctor. Or talk to your spiritual advisor or attorney. Your VA health care team can make your advance directive part of your medical record.

Do I need to fill out a durable power of attorney and a living will?
No. Even though the VA form contains both, it’s up to you whether you complete the durable power of attorney for health care, the living will, or both.

Can I change my advance directive?
Yes, you may change or cancel your advance directive at any time. In fact, you should review your advance directive periodically, especially if there is a change in your health, to make sure it’s up to date. If you change it, be sure to tell your health care team and have them put it in your health record. Share your new directive with your family members and other loved ones.

Other resources for advance directives:
Your Life, Your Choices has exercises to help you think about important questions. It’s available on MyHealthVet at http://www.myhealth.va.gov.

VA Form 10-0137B
DEC 2006
Learning Resource E

VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

This advance directive form is an official document where you can write down your preferences about your medical care. If some day you become unable to make health care decisions for yourself, this advance directive can help guide the people who will make decisions for you. You can use this form to name specific people to make health care decisions for you and/or to describe your preferences about how you want to be treated. When you complete this form, it is important that you also talk to your doctor, your family, or others who may be involved in decisions about your care, to make sure they understand what you meant when you filled out this form. A health care professional can help you with this form and can answer any questions you might have. If more space is needed for any part of this form, you may attach additional pages. Be sure to initial and date every page that you attach.

PART I: PERSONAL INFORMATION

SOCIAL SECURITY NUMBER

NAME (Last, First, Middle)

STREET ADDRESS

CITY, STATE AND ZIP CODE

HOME PHONE WITH AREA CODE

WORK PHONE WITH AREA CODE

MOBILE PHONE WITH AREA CODE

Privacy Act Information and Paperwork Reduction Act Notice

The information requested on this form is solicited under the authority of 38.C.F.R. §17.32. It is being collected to document your preferences about your medical care in the event you are no longer able to express these preferences. The information you provide may be disclosed outside the VA as permitted by law; possible disclosures include those described in the "routine uses" identified in the VA system of records 24VA19, Patient Medical Record-VA, published in the Federal Register in accordance with the Privacy Act of 1974. This is also available in the Compilation of Privacy Act Issuances via online GPO access at
http://www.gpoaccess.gov/privacyact/index.html. Completion of this form is voluntary; however, without this information VA health care providers may have less information about your preferences. Failure to furnish the information will have no adverse effect on any other benefits which you may be entitled to receive. The Paperwork Reduction Act of 1995 requires us to notify you that this information collection is in accordance with the clearance requirements of section 3507 of this Act. The public reporting burden for this collection of information is estimated to average 30 minutes, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. No person will be penalized for failing to furnish this information if it does not display a currently valid OMB control number.

VA FORMDEC 2006 (RS)

10-0137

Page 1 of 6

VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (Last, First, Middle)

SOCIAL SECURITY NUMBER

PART II: DURABLE POWER OF ATTORNEY FOR HEALTH CARE

This section of the advance directive form is called a Durable Power of Attorney for Health Care. This section of the form allows you to appoint a specific person to make health care decisions for you in case you become unable to make decisions for yourself. This person will be called your Health Care Agent. Your Health Care Agent should be someone you trust, who knows you well, and is familiar with your values and beliefs. If you become too ill to make decisions for yourself, your Health Care Agent will have the authority to make all health care decisions for you, including decisions to admit you to and discharge you from any hospital or other health care institution. Your Health Care Agent can also decide to start or stop any type of clinical treatment, and can access your personal health information, including information from your medical records. NOTE: Information about whether you have been tested for HIV or treated for AIDS, sickle cell anemia, substance abuse or alcoholism cannot be shared with your Health Care Agent unless you give special written consent. Ask your VA health care provider for the form you must sign (VAForm 10-5345) if you wish to give permission for VA to share this information with your Health Care Agent.
A - HEALTH CARE AGENT

Initial the box next to your choice. *Choose only one.*

Initials

I do not wish to designate a Health Care Agent at this time. (Skip this section and go to Part III, page 3.)

Initials

I appoint the person named below to make decisions about my health care if there ever comes time when I cannot make those decisions.

Name *(Last, First, Middle)*

Relationship

Street Address

City, State and Zip Code

Work Phone with Area Code

Mobile Phone with Area Code

Home Phone with Area Code

B - ALTERNATE HEALTH CARE AGENT

Complete this section if you want to appoint a second person to make health care decisions for you in case the first person you appointed is unavailable.

Initials

If the person named above cannot or will not make decisions for me, I appoint the person named below to act as my Health Care Agent.

Name *(Last, First, Middle)*

Relationship

Street Address

City, State and Zip Code
VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (Last, First, Middle)

SOCIAL SECURITY NUMBER

PART III: LIVING WILL

This section of the advance directive form is called a Living Will. This section of the form allows you to write down how you want to be treated in case you become unable to make decisions for yourself. Its purpose is to inform the people who will be making decisions about your care.

A - SPECIFIC PREFERENCES ABOUT LIFE-SUSTAINING TREATMENTS

This section gives you a place to indicate your preferences about life-sustaining treatments in particular situations. Some examples of life-sustaining treatments are CPR (cardiopulmonary resuscitation), breathing machine (mechanical ventilation), kidney dialysis, feeding tubes (artificial nutrition and hydration), and medicines to fight infection (antibiotics). Think about each situation described on the left and ask yourself, “In that situation, would I want to have life-sustaining treatments?” Place your initials in the box that best describes your treatment preference. You may complete some, all, or none of this section. Choose only one box for each statement.

Yes. I would want to have life-sustaining treatments.

It would depend on the circumstances.

No. I would not want to have life-sustaining treatments.

If I am unconscious, in a coma, or in a persistent vegetative state and there is little or no chance of recovery
Initials

Initials

Initials

If I have permanent severe brain damage (for example, severe dementia) that makes me unable to recognize my family or friends

Initials

Initials

Initials

If I have a permanent condition that makes me completely dependent on others for my daily needs (for example, eating, bathing, toileting)

Initials

Initials

Initials

If I am confined to bed and need a breathing machine for the rest of my life

Initials

Initials

Initials

If I have pain or other severe symptoms that cannot be relieved

Initials

Initials

Initials

If I have a condition that will cause me to die very soon, even with life-sustaining treatments

Initials

Initials

Initials
VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (Last, First, Middle)

SOCIAL SECURITY NUMBER

PART III: LIVING WILL (Cont'd)

B - ADDITIONAL PREFERENCES

You may use this space to write any other preferences about your health care that are important to you and that are not described elsewhere in this document. This may include general preferences about how you would like to be cared for, or specific requests. For example, you might have clear opinions about whether you would want a particular treatment (for example, a feeding tube or blood transfusions). You might want to comment on treatment of pain, or whether you would want life-sustaining treatments on a trial basis. Or you might want to write about your preferences regarding treatment of mental illness.

C - HOW STRICTLY YOU WANT YOUR PREFERENCES FOLLOWED

Initial the box next to the statement that reflects how strictly you want your preferences to be followed. Choose only one.

Initials

I want my preferences, expressed above in this Living Will, to serve as a general guide. I understand that in some situations the person making decisions for me may decide something different from the preferences I express above, if they think it is in my best interest.

Initials

I want my preferences, expressed above in this Living Will, to be followed strictly, even if the person who is making decisions for me thinks this is not in my best interest.

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NAME (Last, First, Middle)

SOCIAL SECURITY NUMBER

PART IV: SIGNATURES

A - YOUR SIGNATURE

By my signature below, I certify that this form accurately describes my preferences.

SIGNATURE

DATE

B - WITNESSES' SIGNATURES

Two people must witness your signature. *VA employees of the Chaplain Service, Psychology Service, Social Work Service, or non clinical employees (e.g., Medical Administration Service, Voluntary Service or Environmental Management Service) may serve as witnesses. Other individuals employed by your VA facility may not sign as witnesses to the advance directive unless they are your family members.*

Witness #1

I personally witnessed the signing of this advance directive. I am not appointed as Health Care Agent in this advance directive. I am not financially responsible for the care of the person making this advance directive. To the best of my knowledge, I am not named in the person's will.

Date

SIGNATURE

Name (Printed or Typed)

Street Address

City, State and Zip Code

Witness #2
I personally witnessed the signing of this advance directive. I am not appointed as Health Care Agent in this advance directive. I am not financially responsible for the care of the person making this advance directive. To the best of my knowledge, I am not named in the person's will.

SIGNATURE

Date

Name (Printed or Typed)

Street Address

City, State and Zip Code

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VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (Last, First, Middle)

SOCIAL SECURITY NUMBER

PART V: SIGNATURE AND SEAL OF NOTARY PUBLIC (Optional)

This VA Advance Directive form does not have to be notarized to be valid in VA facilities. However, you may need to have this document notarized for it to be recognized outside the VA health care setting. Space for a Notary's signature and seal is included below.

On this day of, in the year of, personally appeared before me known by me to be the person who completed this document and acknowledged it as their free act and deed. IN WITNESS WHEREOF, I have set my hand and affixed my official seal in the County of, State of, on the date written above. Notary Public Commission Expires.

[SEAL]

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Module # 10: Introduction to Palliative & Hospice Care
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James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

This interdisciplinary curriculum is geared to allied health students and may be reproduced and used with attribution.
# Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 10: Introduction to Palliative & Hospice Care

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I. Overview

While over 2 million deaths are expected annually in the United States, millions more people are living, often for many years, with chronic diseases and other serious illnesses that significantly affect their quality of life and ability to function. Most older adults will develop one or more chronic illnesses with which they may live for many years, often with physical and psychological symptom distress and progressive functional dependence and frailty. It is widely acknowledged that the care of these individuals is in need of improvement. There is now abundant evidence that the quality of life during these advanced stages of disease is often poor, characterized by inadequately treated physical, psychosocial, and spiritual distress; fragmented care systems, poor communication between health care providers, patients and families, and enormous strain on family caregiver and support systems.

Despite these demographic trends pointing to the critical need for services in palliative care for the older population, this is an area with a significant lack of training and education. This module addresses this need with an introduction to several key practices and principles of palliative care.

II. Learning Objectives

1. Discuss the demographics related to dying in America.
2. Discuss the results of the SUPPORT study and implications for palliative care.
3. Conceptualize a good death.
4. Identify the goals of palliative care.
5. Articulate the goals, precepts, and importance of the National Consensus Project Guidelines.
6. Discuss the palliative care domains identified by the National Consensus Project Guidelines.
7. Identify the expected outcomes of the National Consensus Project Guidelines.
8. Describe the criteria for JCAHO certification in palliative care.
9. Identify the site of delivery for palliative care.
10. Discuss barriers to end-of-life care.
11. Discuss Hospice care, including the benefits, barriers, standards, and Hospice eligibility under Medicare.
12. Discuss the role of members of the interdisciplinary palliative care team and the value of an interdisciplinary approach.
13. Identify the factors that signal the need for a palliative care consult.
14. Discuss causes of inadequate pain management and principles.
15. Assess the spiritual/cultural needs of patients and families in palliative care.
16. Discuss critical aspects related to the care of the dying.

III. Demographics Of Dying In The U.S. ¹

A. The Current State of Dying

1. Americans are living longer than ever before.

2. The life expectancy at age 65 is 18.1 years. The life expectancy of those aged 85 is 6.5 years.

3. Women in both age groups tend to live longer than men. The life expectancy of a woman age 65 is 19.4 years, 3 years higher than the 16.4 years expected for a man. At 85, women have a life expectancy of 6.9 years, while men have a life expectancy of 5.7 years.

4. The two leading causes of death among those over 65 are heart disease and malignant neoplasms.

5. Chronic illnesses plague those over age 65. Over 30% report suffering from heart disease, 50% suffer from hypertension, and 21% suffer from some form of cancer.


B. Sites of Death ²

1. Hospitals  56%
2. Nursing homes 19%
3. Home  21%
4. Other  4%

IV. The SUPPORT Study: Evidence Of The Need For Palliative Care

A. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT): a multicenter controlled trial to improve the care of 9,000 patients with life-threatening illnesses. The study was funded by RWJ. Phase I was “How people die in hospitals” and Phase II, “RCT of nurse-based intervention.” 2,500 subjects were in each group. The median age of the patients (total patients in study: 9,105) was 65, with 56% on Medicare, 44% were female. 

1. Phase I of SUPPORT was to determine objective measures of quality of death: presence and timing of written DNR, MD awareness of DNR preferences, number of “undesirable” days, pain levels, and costs of care. Phase I found the following:
• 46% of DNR orders were written within the last 2 days of life, suggesting little advance planning in terminal illness.

• Physicians did not always understand their patients. For example, 53% of physicians did not understand that a patient wanted to avoid CPR.

• 38% of patients experienced 10 or more days in the ICU, in a coma, or on a ventilator.

• Half of patients (50%) experienced moderate or severe pain at least ½ of the time within their last few days.

• Seriously-ill patients’ families were impacted as:

  Needed large amount of family caregiving 34%
  Lost most family savings 31%
  Lost major source of income 29%
  Major life change for family member 20%
  Other family illness from stress 12%
  At least one of the above 55%

2. Phase II of SUPPORT, conducted from 1992-1994, demonstrated the need for hospitals and health systems to pursue a higher standard for end-of-life care— a standard that includes helping patients learn how to live well while dying; focusing on the patient and family, not just the disease; and working with the patient and family to create a plan for dying.

V. A Good Death

A. Criteria for a Good Death

1. Relatively free of pain
2. Suffering kept to a minimum
3. Social and emotional needs are met
4. Maintaining independence and function
5. Resolving personal and social conflicts
6. Free to choose and relinquish control over various aspects of life

B. Goals of care

1. Treat the disease
2. Prolong the patient’s life while managing symptoms
3. Restore or maintain function
4. Maintain quality of life
5. Preserve control
6. Comfort and support the patient and family
7. Avoid needless suffering in order to permit experiences that will have positive meaning.

C. Goals May Change Near the End of Life

1. Some goals may take priority over others.
2. The shift in the focus of care is:
   • gradual
   • an expected part of the continuum of medical care
3. Review goals with any change in:
   • health/functional status (e.g. advancing illness)
   • setting of care
   • treatment preferences

VI. National Consensus Project Guidelines For Quality Palliative Care

A. Goal of Palliative Care

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients of all ages and their families experiencing advanced chronic or life-threatening illnesses in all health care settings. 5

B. Precepts Regarding Palliative Care

1. Palliative care is offered from the time of diagnosis with serious, chronic, debilitating, or life-threatening illness through the full course of illness and into the bereavement period for families.
2. Palliative care is holistic care that focuses on the physical, psychosocial, cultural, and spiritual needs of patients and their families.
3. Palliative Care ensures:
   a. Physical comfort through state-of-the-art, comprehensive management of pain and symptoms.
   b. Practical needs are addressed and coordinated.
   c. Psychosocial and spiritual distress is managed.
   d. Patients and families receive the information needed to understand their condition and treatment options.
   e. Patient and family values and decisions are respected and honored.
   f. Coordination of care and communication across health care settings.
   g. Patient and family are prepared for the dying process and death as possible, when it is anticipated.
   h. Hospice options are explored.
   i. Opportunities are available for growth and resolution.
   j. Bereavement support is available. 5
C. Palliative Care Continuum

1. Palliative care can be delivered concurrently with life prolonging care or as the main focus of care.

2. Close coordination and partnership between palliative care and hospice programs are critical to achieving continuity of palliative care throughout the illness/dying trajectory and across the continuum of care settings.

3. Palliative Care is both a general approach to patient care routinely integrated with disease-modifying therapies, as well as a growing practice specialty for highly trained specialist physicians, nurses, social workers, chaplains, and others who typically work on interdisciplinary palliative care teams.

D. The Importance of Palliative Care

1. There is an overall aging of the population with an increase in chronic debilitating or life-threatening conditions. The nation is about to experience a great demographic shock. Between 2010 and 2030 the 65+ population will rise over 70 percent.

2. Palliative Care involves persons of any age with acute, serious, chronic, or life-threatening illness and a broad range of diagnostic categories.

3. Patients are suffering needlessly.

4. Patients need support in navigating the health system.

5. Policy makers need effective solutions.

6. Health care settings are challenged to deliver efficient and effective management of long-term advanced illness.

7. Clinicians need support and expertise for treating this growing population.

E. The Relationship Between Hospice and Palliative Care

1. Hospice has created “gold standard” of care.

2. Hospices are successfully expanding services to provide palliative care to patients in a variety of settings earlier in the course of illness.

3. Leading hospitals and long-term care facilities have started palliative care programs.

4. Hospital-hospice partnerships are being created.

5. Palliative care represents the success of the hospice movement in influencing the rest of the health care system.

1. To create a set of voluntary clinical practice guidelines to promote consistent high quality palliative care.
2. To guide the development and structure of new and existing palliative care programs.
3. Establish accepted definitions, essential elements, and best practices for palliative care.
4. Foster continuity of care across health care settings.

G. National Consensus Project Goals

1. Stimulate and guide the development of new and existing palliative care programs across care settings.
2. Promote care of consistent, high quality.
3. In the absence of organized palliative care programs or specialists, guide clinicians to incorporate vital aspects of palliative care into their practice to improve care for their sickest patients over the course of their illnesses.
4. Build national consensus concerning the definition, essential elements, and best practices of palliative care through an open and inclusive process that includes the array of professionals, providers, and consumers involved in and affected by palliative care.
5. Broadly disseminate the clinical practice guidelines to enable existing and future programs to better define their program organization, resource requirements, and performance measures.
6. Foster continuity of palliative care by expansion of access to care and coordination across settings through hospice and other care management programs.
7. Promote recognition, stable reimbursement structures, and accreditation initiatives.

H. The National Consensus Project Process

1. Resulted from a national leadership conference in December 2001 initiated by the Center to Advance Palliative Care.
2. Created a national consensus process for creating and disseminating a consensus document with potential endorsement of both the palliative and hospice communities and those involved with policy, regulatory, and fiscal management of health care.
3. Created a process that was inclusive, interdisciplinary, transparent, and meaningful to those who will be affected.

The National Consensus Project Membership:

a. Steering Committee – 20 members develop draft document
b. Advisory Committee – 100 nationally recognized leaders across a variety of health care settings review and revise
c. Liaison Organizations – 50 organizations with major responsibility for health care of patients with life-threatening illness endorse and disseminate the standards

4. Created an NCP grant proposal and raised $200,000 from a range of sources to support the administrative requirements.

5. Secured professional and fiscal commitments from the consortium organizations.

6. Maintained regulation communication between the steering committee, NCP advisory committee, and potential funders.

7. Developed the National Clinical Practice Guidelines based on scientific evidence, clinical experience, and expert opinion.

8. Created a communication plan in collaboration with a professional relations firm and disseminated the guidelines in April 2005.

I. National Consensus Project Assumptions

1. The guidelines represent goals that palliative care programs should strive to attain as opposed to minimal practices.

2. Health care quality standards will be followed such as safety, effective leadership, medical record keeping, and error reduction.

3. The guidelines assume codes of ethics.

4. The guidelines will evolve as professional practice, the evidence-base, and health care system change over time.

5. Guidelines are peer-defined; established through a consensus process with a broad range of palliative care professionals.

6. Specialty care involves professionals with palliative care qualifications through professional credentials and programmatic accreditation.

7. Continuing professional education.

8. Applicability of guidelines to promote integration and application of the principles, philosophy, and practices of palliative care across the continuum of care and health care settings. 

J. The 8 Clinical Practice Domains for Palliative Care

Domain 1: Structure and Process of Care

1. Plan of care is based on a comprehensive interdisciplinary assessment of patient and family.

2. Addresses both identified and expressed needs of patient and family.

3. An interdisciplinary team provides services consistent with the plan of care.

4. Team is committed to quality improvement.

5. Support for education and training of professionals.

6. Emotional impact of work on team members is addressed.

7. Team has relationship with hospices.

8. The physical environment is considered in providing care.
Domain 2: Physical

1. Pain, other symptoms, and treatment side effects are managed using best practices.
2. Team documents and communicates treatment alternatives, permitting patient/family to make informed choices.
3. Family is educated and supported to provide safe/appropriate comfort measures to patient.

Domain 3: Psychological and Psychiatric

1. Psychological and psychiatric issues are assessed and managed based on best available evidence.
2. Team employs pharmacologic, non-pharmacologic, and complementary therapies as appropriate.
3. Grief and bereavement program is available to patients and families.

Domain 4: Social

1. Assessment (e.g. Family structure, relationships, medical decision making, finances, sexuality, caregiver availability, access to medications, and equipment).
2. Individualized, comprehensive care plan alleviates caregiver burden and promotes well-being.

Domain 5: Spiritual, Religious and Existential

1. Assesses and addresses spiritual concerns.
2. Recognizes and respects religious beliefs - provides religious support.
3. Makes connections with community and spiritual/religious groups or individuals as desired by patient/family.

Domain 6: Cultural

1. Assesses and aims to meet the culture-specific needs of patients and families.
2. Respects and accommodates range of language, dietary, habitual, and ritual practices of patients and families.
3. Team has access to/uses translation resources.
4. Recruitment and hiring practices reflect cultural diversity of community.

Domain 7: The Imminently Dying Patient

1. Team recognizes imminence of death and provides appropriate care to patient/families.
2. As patients decline, team introduces hospice referral option.
3. Team educates family on signs/symptoms of approaching death in a developmentally, age, and culturally appropriate manner.

Domain 8: Ethics and Law

1. Patient’s goals, preferences, and choices are respected and form basis for plan of care.
2. Team is aware of and addresses complex ethical issues.
3. Team is knowledgeable about relevant federal and state statutes and regulations.

K. Expected Outcomes of the National Clinical Practice Guidelines

A. Hospitals will:

1. Develop quality programs;
2. Have increased efficiency: appropriate use of resources, decreased hospital and ICU stays, lower costs;
3. Better clinical outcomes: relieves pain and distressing symptoms in all stages of treatment;
4. Strengthened patient satisfaction: patients get comfort care without forgoing other treatment;
5. Improved staff retention and morale: supports doctors/nurses in care of complex patients;
6. Meet JCAHO Hospital Accreditation Standards.

B. Nursing Homes will:

1. Develop roadmaps for caring for patients with chronic illness;
2. Have improved patient outcomes in accord with regulations;
3. Will meet patient and family needs;
4. Strengthen patient satisfaction: patients get comfort care without forgoing other treatment;
5. Improve staff retention and morale: supports doctors/nurses in care of complex patients.

C. Health Care Professionals will:

1. Provide optimal, evidence-based care to the most complex, sick patients without significant workload burden.

D. Policymakers will:

1. Be able to strengthen a health system that serves our sickest patients;
2. More appropriately use of financial resources to improve care while lowering costs;
3. Ensure that all patients and their families, your constituents, receive a uniform and appropriate level of care.

E. Patients and the Public will

1. Receive expert pain and/or symptom relief and end needless suffering;
2. Understand their right to the best quality care;
3. Receive assistance in navigating the medical system and choosing health care providers.

L. JCAHO Certification in Palliative Care

1. Palliative Care Program Certification is a two-year award.
2. Successful programs will be acknowledged on the JCAHO website.
3. Palliative Care Certification can be achieved with or without concomitant JCAHO Accreditation.
4. Accreditation is an organization wide award.
5. Certification for Palliative Care is special recognition of excellence in the provision of palliative care services.

VII. Delivery Of Palliative Care

A. Hospital-Based

1. Primary care
2. Consultation
3. Inpatient Unit

B. Nursing Home

C. Hospice

1. Home hospice
2. Hospital inpatient
3. Hospice inpatient

VIII. Barriers To End-Of-Life Care

A. Areas in which barriers usually reside include institutional culture, structures, policies, regulations, reimbursements, and individual attitudes.

B. Frequently, neither the public nor health care providers acknowledge that end-of-life care is important. It is often introduced too late to be effective, and funding is frequently inadequate to deliver quality palliative care.

C. Fears of addiction, exaggerated risks of adverse effects, and restrictive legislation have resulted in inadequate control of symptoms.
D. Discomfort with communicating bad news and prognosis, lack of skill to assist patients and families to negotiate clear goals of care and treatment priorities, and lack of understanding of patients’ rights to decline or withdraw treatment have led to frequent misunderstanding and excessive futile intervention.

E. Personal fears, fantasies, worries, and lack of confidence have prompted many physicians to avoid dealing with patients who are dying.

IX. Hospice

A. What is Hospice?

1. A reimbursement benefit for patients who have a limited prognosis or life expectancy.
2. Primarily community-based
3. Care for severely ill patients and their families
4. Team of professionals and trained volunteers
5. Focus is on care, not cure
6. Goals:
   - Relief of pain and other symptoms
   - Psychosocial support

B. In order to be most effective, hospice strives to administer care to all patients with any life-threatening diagnosis at any time during their illness when they need symptom control or have supportive care needs and are prepared to accept care.

C. As of 1995, about 17% of patients died while under hospice care.

D. The term “hospice” can refer to any one of the following, which often times is a source of confusion:

1. A site of care for the dying
2. An organization that provides care in a variety of settings but is usually focused on the patient’s home. Hospice agencies started in the US in the late 1970s in order to help families care for patients with advanced life-threatening illnesses.
3. An approach to care that is integrated across all health care settings and practices.
4. A benefit available to Medicare beneficiaries and subject to the rules and regulations promulgated by HCFA to govern that federal program.

E. Hospice care provides:

1. Patient control over decisions about care
2. Family involvement
3. Specialized services
Pharmaceuticals and home supplies/equipment
• Pastoral support
• Grief counseling
• Volunteer support
4. Option for patient to die at home

F. Conditions for Hospice Eligibility under Medicare:
1. Limited life expectancy (generally 6 months or less)- certified by physician.
2. Patient chooses hospice benefits rather than standard Medicare (patient may choose to stop hospice care and revert to cure-oriented care at any time).
3. Care provided by Medicare-certified hospice program.
4. A physician to direct care.
5. Available/able/willing caregiver at home.

G. The standards by which hospice are regulated may also be useful when applied to palliative care. Palliative care:
1. Attempts to expand rather than limit access to and delivery of care.
2. Provides patients and their families with adequate information. They should be able to make informed choices and participate in choice of settings and interventions.
3. Along with the communities, hospitals and physicians develop programs to provide patients and their families with symptom management, mental and spiritual health, and social support.
4. Provides grief and bereavement support for the family.
5. Provides continuity between care settings. Sometimes transfer is deemed necessary and continuity of providers between settings should be available.
6. Ensures that incoming professionals are well educated in their roles in palliative care by means of evaluation, research, and education.

X. Comparison Of Hospice And Palliative Care

<table>
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<tr>
<th><strong>Hospice</strong></th>
<th><strong>Palliative Care</strong></th>
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<tbody>
<tr>
<td>▪ Prognosis of 6 months or less</td>
<td>▪ Any time during illness</td>
</tr>
<tr>
<td>▪ Focus on comfort care</td>
<td>▪ May be combined with curative care</td>
</tr>
<tr>
<td>▪ Medicare hospice benefits</td>
<td>▪ Interdisciplinary care</td>
</tr>
<tr>
<td>▪ Volunteers integral and required aspect of the program</td>
<td>▪ Independent of payer</td>
</tr>
<tr>
<td>▪ Interdisciplinary care</td>
<td></td>
</tr>
</tbody>
</table>
XI. Interdisciplinary Teams In Palliative Care

A. The Interdisciplinary Team members may consist of the following disciplines:

1. **Physician**: hospice and primary care attending.

2. **Nurse**: coordination drives most patient services and care such as assessment, evaluate needs for supplies and equipment, therapy, counseling, and spiritual and emotional dimensions of quality of life.

3. **Social Worker**: review plan of care with team and initial psychosocial assessment. Identify problem list; role in bereavement process.

4. **Counselor/Clergy**: focus on spiritual concerns, grief, and loss.

5. **Volunteers**: hands of care-work in office, public relations, and fundraising.

6. **Home Health Aide**: provides physical care.

B. Factors that may signal the need for a team approach:

1. The presence of advancing disease not responding to disease-directed therapies.

2. Poorly controlled or multiple symptoms.


4. Increasing debility or need for nursing care.

5. Increasing distress-difficulty coping physically, emotionally, or financially.

6. Caregiver burden increased by poor control of symptoms, need for frequent medications, physical strain, interrupted sleep, confinement, and isolation.

XII. Identification Of Holistic Aspects Of Palliative Care

A. Need for Pain Assessment and Management

1. Research indicates that under treatment of pain:

   a. For 597 ambulatory cancer patients, pain was greatest in women from age 63-69 and in men age 70-90. ⁹

   b. For minority patients with cancer, Hispanics reported greatest pain (72%); blacks were second highest (59%), whites were the lowest (49%). ¹⁰
c. Of ambulatory NYC AIDS patients, approximately 84% expressed need vs. approximately 49% expressed by patients with cancer.  

2. Causes of Inadequate Pain Management \(^{12}\)

a. Clinician-related factors:

- Lack of pain assessment skills
- Lack of knowledge of pain management
- Inappropriate avoidance of opioid
- Overestimation of risk of addiction
- Overestimation of risk of tolerance
- Concern about managing side effects
- Concern about regulation of controlled drugs

b. Patient-related factors:

- Problems reporting pain due to desire to focus on cure, stoicism, desire to please staff, fear of suppressing pain
- Reluctance to take opioid due to fear of addiction, fear of tolerance, fear of side effects
- Poor compliance

c. Health system factors:

- Focus on life prolongation and cure
- Low priority given to pain/symptom control
- Unavailability of opioids
- Lack of access to palliative care expertise
- Inadequate insurance coverage

3. Pain Assessment Principles \(^{13}\)

a. Ask the patient and believe his/her complaint.

b. Develop a systematic approach to assessment using a validated pain scale and including:

- Pain history (location, duration, intensity, quality, relieving/exacerbating factors, associated factors (i.e. nausea, weakness), changes in functional status, and the meaning of pain.
- Physical examination, including neurological exam if indicated.
- Diagnostic procedures depending on goals of care.
c. Reassess frequently

B. Addressing Religious/Spiritual Needs

1. Religiosity refers to the beliefs and practices of different religious faiths and an acceptance of their traditions.

2. Spirituality is a broader concept than religiosity. It refers to:
   - the energy in the deepest core of the individual.
   - an integrating life force within that allows us to transcend our physical being.
   - whoever or whatever gives ultimate meaning and purpose in one’s life.
   - the sense of connectedness with self, others, nature, and an ultimate being.

3. Spirituality may be understood as non-material or metaphysical, hence pertaining to sacred things or the soul, or more broadly, the intellectual and moral aspects of life. Religion provides a set of core beliefs about life events and establishes an ethical foundation for clinical decision making.

4. Okon identified themes of an existentially/spiritually focused history as:
   - Meaning
   - Hopes, identity, continuity
   - Legacy
   - Trust, support, and caring relationships
   - Life review: Experience of pain and forgiveness or estrangement and reconciliation
   - Resilience and self-efficacy

5. Tasks of religion and spirituality:
   - Confront one’s finitude and vulnerability.
   - Uncover meaning, value, and dignity in illness and death.
   - Develop meaning, purpose, and connectedness to others.
   - Seek faith, hope, love, and forgiveness in the midst of fear and despair.
   - Engender serenity and transcendence, thereby buffering stress.

6. Spiritual Needs of the Ill and Dying
   a. The search for meaning of life and purpose of one’s own existence through a review of life and its goals, values, and experiences.
   b. The need to die appropriately or meaningfully in a way that is consistent with our self-identity.
   c. Assurance that our life in some way will continue. Symbolic immortality through our children, creative works, theology, eternal nature, or community.
7. Spiritual History addresses the following questions:17
   F: **Faith** – does religion or spirituality play an important part in your life? Do you consider yourself a religious or spiritual person?
   I: **Influence** – How does your religious faith or spirituality influence the way you think about your health or the way that you care for yourself?
   C: **Community** – Are you a part of a religious or spiritual community?
   A: **Address** – Would you like me to address your religious or spiritual issues or concerns with you?

8. Symptoms of Spiritual Pain:14
   a. Sorrow and grief
   b. Isolation of self and others
   c. Meaninglessness and emptiness
   d. Fear and avoidance of the future
   e. Hopelessness and despair
   f. Anger and bitterness towards God

9. Connecting Spirituality with Patients by:17
   W: **Welcome** – demonstrate acceptance and invite the patient to discuss issues of faith and belief.
   E: **Encouragement** – to continue healthy religious beliefs and practices.
   B: **Blessing** – express words of blessing in a faith sensitive manner such as “Blessings to you.”

10. Implications for Caregivers Regarding Spiritual Care:
    - Explore their concerns in a non-judgmental and non-threatening way.
    - Enable the dying to strengthen their own meanings of death.
    - Support individuals’ needs for rituals (i.e. confession or communion, prayer, etc.).

11. Accommodating Cultural Diversity:14
    a. Know your own attitudes, beliefs, values, and cultural practices.
    b. Listen for language patterns.
    c. Gather information about distinctive practices, rituals, beliefs, and assumptions.
    d. Find out who makes the decisions.
    e. Identify their time orientation.
    f. Ask “What can I do for you today?”

C. Care of the Dying

1. Developmental Tasks of Dying:16
   a. Experience love of self and others
   b. The completion of relationships
   c. The acceptance of finality of one’s life
   d. The achievement of a new sense of self despite physical demise
2. Guidelines for Communicating with a Dying Patient:
   a. Deliver and interpret the technical information given to the patient – check out the patient’s perceptions of what is being told.
   b. Facilitate meaningful discussions and ask questions to determine if they understand in a climate that is supportive.
   c. Encourage patients and families to discuss alternatives and their consequences.
   d. Recognize the values of the patient and family.
   e. Do not undermine the patient’s right to determine his own fate.

3. Guidelines for Counseling:
   a. Ensure that patient has as much control as possible – it is the patient’s life and death even if we disagree.
   b. Provide a working team to provide a holistic plan of care.
   c. Normalize feelings without minimizing them.
   d. Ask what questions are on the patient’s mind.
   e. Help patient communicate clearly and know what the patient is really asking by requesting clarification and use of reflection.
   f. Acknowledge the difficulties of terminal illness – but do not confront the patient.
   g. Make sure you are talking about the same issue.
   h. Recognize the incongruities between your verbal and non-verbal communication.
   i. Capitalize on the times the patient is willing to talk.

4. Completing Relationships
   The need to say:
   - I forgive you
   - Forgive me – I’m sorry
   - Thank you
   - I love you
   - Goodbye

5. Active Presence-ing
   a. Staying with a dying patient – saying whenever you do die I am going to miss you. You really are a privilege to know. Is there anything else that you need or want?
   b. Telling the person how much he/she is loved and how much he/she will be missed and to journey on knowing that he/she will always be loved.
XIII. Conclusion

“If medicine takes aim at death prevention, rather than at health and relief of suffering, if it regards every death as premature, as a failure of today’s medicine – but avoidable by tomorrow’s – then it is tacitly asserting that its true goal is bodily immortality . . . Physicians [and other health professionals] should try to keep their eyes on the main business, restoring and correcting what can be corrected and restored, always acknowledging that death will and must come, that health is a mortal good, and that as embodied beings we are fragile beings that must stop sooner or later, medicine or no medicine.” 21
XIV. References


XV. Learning Resources


Byock I. Dying Well ; Riverhead Trade; March 1998.


This session was devoted to student group presentations.
Module # 12: Intergenerational and Family Issues
Geriatrics, Palliative Care and 
Interprofessional Teamwork 
Curriculum

Module # 12: Intergenerational and Family Issues

James J. Peters VA Bronx Medical Center 
Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine 
Brookdale Department of Geriatrics and Adult Development

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Module # 12: Intergenerational and Family Issues

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I. Overview

Dealing with the aging process within a family is a complicated matter. As the older adult transitions to a state of dependence, the balance and the functionality of the family is disrupted. Roles must be re-examined and changed while unresolved issues re-emerge. This is a stressful time for all concerned, and those families who do not have a history of cohesiveness and compatibility will not be able to unite to benefit the aging relative. This module examines family systems theory and presents strategies to help families overcome the challenges associated with the complex role of caring for an older adult.

II. Learning Objectives

1. Define family.
2. Recognize culturally supported notions of the role of family with older adult members.
3. Review the stages of the family life cycle and define the family system from a multigenerational context.
4. Complete and analyze a genogram to understand multigenerational relationships and patterns of communication.
5. Understand the components of a family assessment and methods of collecting data within a family meeting.

III. The Family

A. General Definition: Those who consider themselves economically and emotionally related to each other by blood, marriage, or commitment; Those who are tied together through their common biological, legal, cultural, and emotional history and their implied future together; The primary and almost always the most powerful system to which humans belong.

1. Nuclear Family: a married/committed pair with dependent
children and an independent household, bound to outside kin by voluntary ties of affection or duty

2. Extended Family/Modified Extended Family: all of those related to one another by blood or marriage

3. Support System: a group of individuals who join together to give support and assistance to each other, sometimes for a specific purpose

B. Family Life Cycle Theory

1. Developed after WWII when families were larger and fewer divorces
2. Traditional, idealized
3. Attention now to transitions vs. stages
4. Developmental tasks and needs of each generation are no longer complementary
5. Tension between older adult and adult children
6. Sandwich generation/women in the middle
7. Role of female as the caregiver

IV. Culturally Supported Notions Of Family

A. Adult Children
   1. Duty to one’s parents
   2. Can never do enough
   3. Indebted for the gift of life

B. Older Adult
   1. Irreplaceable losses
   2. Guilt over dependence on children
   3. Fear of alienating children if needy

C. Relationship Myths
   1. Adult children neglect and abandon older parents
   2. Solidarity, support, and affection between parent and child

D. Aging Parents
   1. 70% of people enter mid adulthood with 2 living parents (1993)
   2. Approximately 50% of older people have daily contact with their children
   3. Nearly 80% see an adult child at least once per week
   4. More than 75% talk on the phone at least weekly
   5. 91% feel close to their mothers
   6. 87% feel close to their fathers
V. Family Systems Perspective

- Family is an emotional unit
- Change or stress affecting one affects all
- Repeating interaction patterns
- Family interactions and relationships tend to be highly reciprocal and patterned – creating difficulty in reorganization
- Individual symptoms have a function
- Loss of control, loss of continuity, loss of defined roles, loss of significant relationships, and loss of sense of purpose
- Adaptation to changing circumstances (i.e. the physical or cognitive decline of an aging relative) is crucial
- Unresolved issues will resurface
- Joint responsibility for problems
- Creation of a new system with a new organization

VI. Post-Modern Perspective – Family Mutuality

- Continued growth in old age, both psychological and relational
- Redefinition of dependency in old age as normal
- Acceptance of necessary shift in generational roles; adult-adult vs. role reversal
- Role reversal is not normative
- Despite the elder's decline, remains the parent within the family system
- Filial Crisis – normative; adults learn to balance love and duty to their parents with autonomy
- Filial Maturity – adult children learn to accept and meet parents’ dependency; emotional readiness to relinquish earlier roles
- Maturity involves being depended on and being dependable

VII. Intergenerational Relationships

A. Caregiving requires re-engagement with most powerful and influential attachment of one’s life – the parent.

B. Intergenerational relationships between parents and adult children are frequently characterized by ambivalence.

C. Adult child must deal with 2 different sets of parents – the parents we grew up with (idealized/demonized) and the living parent of today.
D. In order to realistically care for and relate to a parent, the adult child must let go of this mythical parent.

VIII. Genograms

A. No “right-way” to develop
B. Part of a comprehensive, SYSTEMIC, clinical assessment
C. View the larger picture
D. Developed out of Bowen’s Family System theory

Sample Genogram
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Legend of family relationships

Legend of emotional relationships
IX. Family Assessment

A. Precipitating Problem
   1. Each individual’s perception
   2. History of problem – why are they seeking help NOW?

B. Family Relationships
   1. Marital
   2. Parental
   3. Siblings
   4. Other significant players
   5. History of caregiving role

C. Level of Commitment
   1. Who?
   2. Why?
   3. How much?
   4. Conditional?
   5. Knowledge related to providing assistance
   6. Satisfaction with current plan

D. Dynamics of Family Meeting
   1. Assess for strengths
   2. Watch the process/pathology
   3. Educate
   4. Facilitate
   5. Integrate

X. Family Interaction Patterns

A. Compatible vs. Conflictual – always in agreement or always arguing; resurfacing of old conflicts

B. Cohesive vs. Fragmented – present as a unit or as individual members

C. Productive vs. Non-Productive – mobilize to create changes needed or powerless to act

D. Fragile vs. Stable – family stability or disruption in relationships

E. Rigid vs. Flexible – exchange and share roles and respond readily to crisis
XI. References


Module # 13: Settings of Care
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Module # 13: Settings of Care

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I. Overview

One of the most complex decisions facing people as they get older is where to live. A home is much more than four walls - it represents security, memories, family, and the possibilities of the future. When thinking about the retirement years, some people consider moving to a new home, perhaps in a different region of the country, but most desire to remain in the same home, or at least community. In general, governmental support of affordable housing and incentives to remain in one's home remain quite limited, and there are often weak linkages between services and housing. This has resulted in older people living in inadequate, and sometimes unsafe, housing, and having no option but to move from the community to assisted living or nursing home facilities because of unavailable health and social services. For middle and upper income retirees, however, there has been an increase in the development of housing options, such as continuing care retirement communities and assisted living facilities, by the business sector because of market demands.

While there are an increasing number of options available for retirement housing, the decision is complicated by confusing terms and overlapping definitions. The recent 2005 White House Conference on Aging invited public comments regarding themes and issues which should be highlighted at the Conference. Four of the top 50 resolutions voted on by the delegates were specifically related to housing. These include expanding opportunities for developing innovative housing designs for seniors’ needs, encouraging community designs to promote livable communities that enable aging in place, enhance the availability of housing for older Americans, and enhance the affordability of housing for older Americans.

II. Learning Objectives

1. Define key issues related to housing for older adults.
2. Describe housing settings and options for older people.
3. Delineate mechanisms to “age in place”.
4. Identify future trends in housing for older adults.
III. Housing Issues

a. “Aging In Place”

b. Linking Housing and Services

c. Affordability

  i. Dwindling supply of affordable housing due to decreased production and conversion of affordable properties to market rate housing

  ii. Additional 730,000 rent-assisted units will be needed by 2020 (e.g., Section 202 Supportive Housing for the Elderly)

d. Choice and autonomy

  i. Older adults often worry about giving up choice and autonomy when moving into a facility

  ii. Major challenge is enabling residents to have choice and independence in housing arrangements

e. Privacy vs. Interaction

  i. Research demonstrates that the ability to have and control privacy is vital to psychological well-being.

  ii. At the same time, possibilities for social interaction and the ability to access support when needed are also necessary.

  iii. Finding the appropriate balance in a residential setting for older adults can be difficult.

  iv. Research has found that satisfaction and well-being are higher for those older people who feel they are in control in deciding when to be with others and when to be alone. In fact, having a sense of control often compensates for other shortcomings in the housing setting.

IV. Housing Arrangements Of Older People

f. Demographics

  i. Where people 45 and older live
1. 77%, live in single-family residences
2. 8% live in mobile homes
3. 5% reside in semidetached homes
4. 9% live in multiunit buildings, such as apartment buildings

ii. Home ownership among Americans age 55 and over is 86%

iii. Who they live with
1. Most people over 45 live with at least one other person (72%), with 28% living alone
2. Those sharing a home are most likely to live with a spouse (77%)
3. 29% live with children or stepchildren, with the remainder living with other relatives or nonrelatives

iv. Tendency to not move
1. Most (60%) have lived in their homes for 11 or more years
2. 20% have lived in their home for between 1 and 5 years, and 5% have lived there less than 1 year
3. Reasons for a move within last 5 years:
   a. better neighborhood (13%)
   b. job change (10%)
   c. Larger home (8%)
   d. Retirement, wanting a smaller place, or being closer to family (7%)

g. Desire to “age in place”

i. Many are modifying their residences to enable them to “age in place”

ii. More than 8 in 10 respondents age 45 and over (including many Baby Boomers) - and more than 9 in 10 of those 65 and over - say they would like to stay where they are for as long as possible

iii. Even if they should need help caring for themselves, 82% would prefer not to move from their current homes

iv. Home modifications are common

1. 70% of those able to make changes have made at least one modification to make their homes easier to live in

2. 85% have made simple changes to their homes

3. 67% of those making changes or modifications to their homes believe doing so will allow them to live there longer than they would have otherwise been able to - most for another 10 or more years

h. Living arrangements tied to poverty

i. Those older adults with less money pay a
greater percentage of their incomes to housing than those with more money

1. This percentage rose slightly between 1987 and 1998

2. This impacts ability to afford vital goods and services such as food, heat, and medications

ii. Older women are more likely to live alone than are older men. In 1998, older women were as likely to live with a spouse as they were to live alone, about 41% each. Approximately 17% of older women lived with other relatives and 2% lived with nonrelatives.

iii. The percentage of women age 75 or older who live alone increased from 37% in 1970 to 53% in 1998.

iv. Poverty rates are higher for older women who live alone than they are for older women who live with a spouse. In 1998, about 19% of white older women who lived alone were in poverty and approximately half of older black and Hispanic women who lived alone were in poverty.

v. Living arrangements among older women also vary by race and Hispanic origin.

1. In 1998, 41% of older white and older black women lived alone, compared with 27% of older Hispanic women and 21% of older Asian and Pacific Islander women.

2. While 15% of older white women lived with other relatives, approximately one third of older black, Asian and Pacific Islander, and Hispanic women lived with other relatives.
V. Types Of Housing

These are alternative types of housing for older adults in addition to the option of remaining at home with or without supports. Housing developments can be subsidized or market rate (private pay). These categories include types of licensed housing specific to New York State; types of licensed housing categories vary from state to state.

1. Active Adult Community
   a. This is an age-restricted (often aged 55 and over) community of single-family homes, condominiums or cooperative units.
   b. It includes lifestyle amenities such as a tennis court, swimming pool, golf course, fitness center, clubhouse and / or restaurant.
   c. This housing is NOT licensed by a government agency.
2. Senior Housing with no Services
   a. Only older adults, and sometimes younger adults with disabilities, can live in this kind of housing
   b. There are no supportive services or personnel
   c. This type of housing is not licensed by a government agency; however subsidized versions, such as the federal HUD Section 202 program, may be supervised by a government housing agency.

3. Supportive Senior Housing
   a. This housing includes one or more of the following: non-licensed supportive services, meals, housekeeping, recreational activities, transportation, laundry, and a service coordinator
   b. This housing is not licensed by a government agency, although subsidized versions may be supervised by a government housing agency.

4. New York State Licensed Adult Home
   a. In this type of housing, 5 or more adults live in housing with private or shared rooms, meals, housekeeping, laundry, transportation, socialization, some personal care, and around-the-clock supervision.
   b. Housing is licensed and regulated by New York State

5. New York State Licensed Enriched Housing
   a. Residents live in apartments with services that include meals, housekeeping, homemaking, shopping, transportation, social activities, and some personal care assistance

6. Assisted Living Facility
   i. Many different kinds with wide variety of design, operational, regulatory, and payment approaches
      1. This segment of the housing industry is still evolving and wide variation is likely to continue
      2. Great variation from state to state
         a. 41 states and the District of Columbia have adopted the term “assisted living”.
ii. Basic models of assisted living

1. Housing with services

2. Personal care (similar to traditional board and care)

3. Service-intensive “nursing home replacement”

iii. Concern that assisted living not widely available to lower income people

1. Although 41 states and the District of Columbia have chosen to use Medicaid dollars to pay for assisted living services, these programs are quite small.

7. Continuing Care Retirement Community (CCRC)

a. Restricted to seniors, it includes independent living units (apartments and/ or cottages), social activities, meals, supportive assistance and personal care on one campus

b. Nursing home care also is included and may be provided on- or off-campus

c. Residents’ housing and health care are covered under a life-care contract or under a long-term housing and health care contract.

d. In New York State, a CCRC’s health and nursing care is licensed by the State Health Department and the financial arrangements are overseen by the State Health Department

8. Shared Living Residence

a. In this type of housing, generally 2 to 10 people share a residence as a “family”.

b. Tenants share the finances and upkeep of the residence.

c. Each resident has a private bedroom and bath.

d. All share a common living room, dining room and kitchen.

e. Shared living may or may not include activities, supportive services or personal care services for tenants.

f. In New York State, shared housing is licensed and regulated by the State Health Department if personal care services are provided.

9. Elder Co-Housing
a. With origins in Scandinavia, it was introduced in the US in the late 1980s

b. There are now about 5,000 people in 80 co-housing communities

c. Key elements of co-housing

   1. Shared facilities, such as gardens and the common house, are extensions of
   2. privately owned homes.
   3. Community members actively participate in neighborhood design resulting in close ties.
   4. Decision making is non-hierarchical.
   5. Part of the “culture change” movement, emphasizing the later years as a period of growth and reflection in a peer-focused and supportive environment.

10. Naturally Occurring Retirement Community (NORC)

a. Communities, including apartment buildings, not originally intended for older people, but which have evolved over a number of years to have more than half of their residents over the age of 60.

   i. NORCs enable a continued sense of independence in a familiar setting and the opportunity for a greater intensity of services and programs geared to older adults

11. Nursing homes

a. Provide skilled nursing and medical services and custodial care for older adults requiring intensive, ongoing supervision

b. State licensed

c. Just 5% of older people in nursing homes at any given time

d. Most admissions result in a stay of less than 6 months

e. Culture change movement in nursing homes geared to:

   1. “Person centered”
   2. “Communities” rather than units
VI. Aging In Place

a. Preferred option by most older people, but sometimes difficult because of changing function and needs

b. However, there are a number of measures which make staying in one's home feasible, including:

i. Home modifications

   1. Universal or transgenerational design

   2. Low tech solutions – e.g., grab bars in bathroom, non-skid rugs, higher wattage light bulbs – can usually be done by homeowner, family member or through government programs

   3. High tech home modifications are more costly

ii. A community which is "elder friendly"

iii. Various forms of financial incentives to keep one's home, such as tax credits;

iv. Formal and informal services;

v. Professional care coordination (see Module #x)

vi. Shared housing arrangements.

VII. The Future

1. Increasing emphasis on an accommodating environment to

   i. promote viable aging in place

   ii. maximize independence and autonomy for older persons.

2. Greater variety in living environments to

   i. respond to the significant differences in needs and preferences found among the older population

   ii. Respond to increasing racial and cultural diversity.
3. Increasing focus on technology to

   i. Extend the capacity of older persons to be self-managing;

   ii. Increase opportunities for older persons to communicate and interact with the wider community

   iii. Utilize opportunities for efficiency in service delivery.

4. Greater emphasis on intergenerational matters to

   i. Support interdependence and mutual support among generations

   ii. Maximize connections among age groups

   iii. Optimize general community viability.

5. Greater response to individual preferences for:

   i. Privacy

   ii. Personal autonomy

   iii. Self-determination

   iv. Choice

   v. Independence

VIII. References

2 Ibid.


Module # 14: Cultural Competency
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Module # 14: Cultural Competency

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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 14: Cultural Competency

I. Overview

A “culturally competent” approach to health care emphasizes an awareness and understanding of how professionals can most effectively interact with people from other cultures. For health care providers, this means considering a client’s cultural context including age, gender, sexual orientation, ethnicity, religion, race, language, beliefs, and values. This module will define “cultural competence” and address the historical events that have led to its heightened awareness in the field of health care. In addition, this module will focus on the importance of maintaining a culturally competent approach when working with patients, as well as discuss ways in which health care professionals may incorporate and strengthen their own cultural competencies to best meet the needs of their clients, patients, and co-workers.

II. Learning Objectives

1. Define “cultural competence” and the principles of cultural competence.
2. Provide an overview of the older population with respect to minority representation.
3. Describe why it is important to consider the historical experiences of older ethnic populations when working with them.
4. Describe the different factors which health care providers must be aware of when working with different cultural groups.
5. Delineate the main components of a cultural assessment.
6. Identify communication considerations when providing care to members of different ethnic groups.
7. Describe the effect of culture on end-of-life decision making.
8. Describe the importance of practitioner self-assessment in terms of values.

III. Definitions

A. What is culture? Culture is “the shared values, traditions, norms, customs, arts, history, folklore, and institutions of a group of people.”

1
B. What is “cultural competence”?
1. “Cultural competence is a set of cultural behaviors and attitudes integrated into the practice methods of a system agency, or its professionals, that enables them to work effectively in a cross-cultural situation.”
2. “Cultural competence in geriatrics is the ability to give health care in ways that are acceptable and useful to elders because it is congruent with their cultural background and expectations.”
3. “Culturally sensitive health care is a phrase used to describe a health care system that is accessible and respects the beliefs, attitudes, and cultural lifestyles of professional and of patients.”

C. Cultural Diversity refers to differences between people based on treasured beliefs, shared teachings, norms, customs, language and meaning that influence the individuals’ and families’ responses to illness, treatment, death and bereavement.

D. Situational Ethnicity refers to the fact that patients may reveal more of their traditional culture and beliefs depending on the social setting.

E. Intraethnic Variation points out that a person’s life never encompasses all aspects of one culture but is an approximation- a conglomeration of pieces of that ethnic culture. Practitioners must be especially responsive to subtleties within ethnic classes, for example Puerto Rican vs. Dominican.

IV. Demographics

A. In 1970, 16% of the population in the U.S. was a member of a minority group. In 1998, the proportion grew to 27%, and it is projected that it will be 50% by the year 2050.

B. The United States Census Bureau projects the following redistribution of the 65 and over population between 2000 and 2050.

<table>
<thead>
<tr>
<th>TOTAL</th>
<th>2000</th>
<th>2050</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic White</td>
<td>83.5%</td>
<td>64.2%</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>8.1%</td>
<td>12.2%</td>
</tr>
<tr>
<td>Non-Hispanic American Indian and Alaska Native</td>
<td>0.4%</td>
<td>0.6%</td>
</tr>
</tbody>
</table>
C. On the average, elders from most ethnic groups use formal health care services and long-term care services to a lesser extent than their white counterparts, with the exception of emergency room visits and acute care.

V. The Acculturation Continuum

A. The Acculturation Continuum is the degree to which an older person is acclimated to American culture.

B. Providers should be aware of the vast range in acculturation found among elders within each ethnic population. There are many different domains of culture and a person may differ in degree to which he or she is acculturated to the different domains affecting health care.

C. Indicators of acculturation include use of the English language, length of time in the United States, and the process of adaptation; however, it is important to note that how long ago the patient emigrated may have no bearing on how “traditional” or “American” the patient is.

VI. Cohort Components To Consider Within Cultures

A. It is important to consider the historical experiences of older ethnic populations.

1. Cohort analysis helps us to understand the impact of these experiences on elders of varying ethnic groups.

2. It also helps us to take appropriate social histories and to understand the influences on the older client’s trust and attitudes about health care.

B. The following domains should be considered:

- Ethnic Identity
- Gender
VII. Varying Factors Among Different Cultures

A. In order to provide the most effective health care, providers must be aware of a number of varying factors that exist across the different cultural groups. Such disparities may be a result of genetic variation, environmental factors, specific health behaviors, or factors of service delivery.

1. For instance, for men 65 years and older 73.5% of non-Hispanic Whites reported good to excellent health, whereas 59.3% of non-Hispanic Black and 65.4% of Hispanic men in this age group reported similar health. 8

2. Similarly, for Medicare beneficiaries 65 and older, 4.4% of non-Hispanic White elders reported delays in accessing care due to cost, with the percentage being 9.5% for non-Hispanic Blacks. 9

VIII. Components Of Cultural Assessment ¹

A. Patient/Family/Community

- Birthplace
- Ethnic identity, community
- Decision making
- Language and communication
• Religion
• Food preferences/prohibitions
• Economic situation
• Health beliefs re: death, grief, pain
• Gender and power issues
• Views of patient and family about location of death
• Degree of fatalism or activism in accepting or controlling care and death
• How hope is maintained
• Sources of support within the community

IX. Major Cultural Differences

A. Different cultures have different perceptions. It may be helpful to discuss these perceptions with the patient early on in the provider-client relationship.

1. Respect
   • Role of the elder, child, caregiver, provider, etc.
   • Trust/Mistrust and deference towards the healthcare provider
   • Relationships among family members

2. Death and Dying
   • What constitutes a good death?
   • What happens after death?
   • Attitudes towards life-sustaining treatment, advance directives

3. Pain
   • Reason for pain (biological vs. punishment)
   • Behaviors concerning pain
4. Independence

- Value of independence with old age
- Medical decisions made independently or within a family context
- Preferred caregiving setting and other issues in caregiving
- What older people should be told about their illnesses: some cultures prefer that medical information, particularly that of a life-threatening prognosis, be given to the family and not to the patient.
- Informed consent
- Issues in dementia
- Long-term care

5. Traditions and Rituals

- Transitions (e.g., birthdays, settings of care)
- Holidays (e.g., food, decorations, songs, prayers)
- Death (e.g., funeral preparations, shiva, burial, cremation)

6. Effect of Culture on End of Life Decision Making

- There is no single description of end-of-life preferences for any specific cultural group, but rather considerable variations.
- Three primary issues where there is ethic variation is:
  1. Communication of bad news
  2. Locus of decision making
  3. Advance planning for terminal illness
7. In a qualitative study by Bullock based on a sample of African-Americans (n = 102), nearly three quarters of participants refused to complete an advance directive. The themes identified were:

- Faith and spirituality—belief that what happens is God’s plan
- Perceptions of suffering—prolongation of life does not necessarily indicate suffering
- Death and dying—are not to be discussed in terms of planning and anticipating
- Social support network (friends and family) will provide care
- Barriers—lack of knowledge about advance care planning, feeling of being pushed by health professionals
- Mistrust of the health care system—lack of trust that health professionals will respect the patient’s and families’ wishes. 12

X. Individual Culture And The Patient-Practitioner Relationship 13

A. Aspects in which cultural differences can affect the patient-provider relationship:

- Language and cultural barriers between providers, patients, and patients’ families
- Explanatory models of illness
- Dietary habits
- Medication compliance
- Alternative (non-Western) practices (e.g. herbal medicines)/belief in existence of non-biomedical illnesses or in the efficacy of scientific treatments
- Role of religion, with ethical dilemmas of life-sustaining interventions conflicting with religious beliefs
• Cultural attitude of some communities and families concerning expectations that patients should be cared for at home

• Western emphasis on “independence” as a goal of therapy

• Unrealistic expectations

• Different expectations as to entitlement to good medical care

• Difficulty establishing trusting relationships

• Ignorance of how the American medical system works and lack of skills in navigating it

• Patient unable to verbalize his or her symptoms in detail

B. Communication Considerations

1. Be creative in finding ways to communicate with population groups that have limited English-speaking proficiency.

2. Spend time listening to needs, views, and concerns of the community.

3. Ask the older patient for his or her preference for decision making early on in care.

4. Use the language and dialect of the people you serve.

5. Use communication vehicles that have value and use by your target audience.

6. Use a cultural broker or cultural guide from the elder’s ethnic or religious background.

C. Recognize cultural differences related to:

1. Conversation style

2. Personal space

3. Eye contact

4. Touch
5. Time orientation
6. View of healthcare professionals
7. Learning styles

D. Appoint a spokesperson
1. Ask the older patient to identify a family spokesperson.
2. In emergencies, ask the family to appoint a spokesperson.
3. Respect the appointment, even if the person is not a family member or does not live nearby.

E. Role of Family
1. Who makes the decisions?
2. Who is included in discussions?
3. Is full disclosure acceptable?

F. Physical Environment
1. Create culturally, linguistically friendly interior design, pictures, posters, and artwork to make facilities more welcoming.
2. Display material and information with recognizable props that hold significance, value, and interest for your target audience.
3. Put props in the hands of people that will maximize their distribution, circulation.

G. Policies and Procedures
1. Mission statement must articulate principles and rationale for culturally competent service delivery.
2. Develop structures to assure community participation in planning, delivery, and evaluation of services.
3. Institute procedures to recruit, retain, and train a diverse and culturally competent workforce.
4. Familiarize the interdisciplinary health care team with cultural explanatory models of the elder’s conditions.

H. Population-Based Service Delivery

1. Appreciate the importance of culture while avoiding stereotypes.

2. Understand the socio-political influences that shaped your consumers’ attitudes, beliefs and values.

I. Training and Professional Development

1. Provide informal opportunities for staff to explore their attitudes, beliefs, and values.

2. Recognize that cultural sensitivity occurs on a continuum.

3. Provide specialized training for interpreters.

J. Physical Examination/Assessment

1. Cross-gender physical examinations are unacceptable in many cultures.

2. Consider preference of presence of family member.

3. Ask permission to examine various areas of the body.

4. Preferred amount of information provided to the patient and family oftentimes varies.

5. Symptom recognition, report, and meaning may vary.

K. Proactive Attitudes and Activities Toward Cultural Sensitivity (14)

1. Seek information to enhance cultural awareness.

2. Consider own attitudes and behaviors that enhance or hinder relationships.

3. Evaluate use of terms of phrases that may be interpreted as degrading or hurtful.

4. Attended workshops on cultural diversity.

5. Openly disagree with racial, cultural or religious jokes, comments or slurs.
6. Create a culturally supportive environment with colleagues and patient/families.

XI. Values Clarification

1. Culturally competent practice begins with values clarification on the part of the practitioner.
   • It is important that the healthcare provider be aware of his or her own feelings toward other cultures, ethnicities and races.
   • One cannot make assumptions based on our own cultural norms and expectations.
   • Whereas elimination of cultural bias is very difficult, recognition of individual biases and expectations.

2. Health Professional’s Self-Assessment

   • What are your own beliefs about illness and death and how do they influence your attitudes?
   • How significant is religion in your attitudes toward illness and death?
   • What kind of death would you prefer?
   • If diagnosed with a terminal illness, whom would you want to tell?
   • What efforts should be made to keep a seriously ill person alive?

3. Values and Attitudes Underpinning Culturally Competent Practice

   • Avoid stereotyping and misapplication of scientific knowledge.
   • Be knowledgeable about cultural differences and their impact on attitudes and behaviors.
   • Be sensitive, understanding, non-judgmental and respectful in dealing with people whose culture is different from your own.
   • Be flexible and skillful in responding and adapting to different cultural contexts and circumstances.

XII. References


7. Ibid.


9. Ibid.


York, NY: Springer Publishing.


<table>
<thead>
<tr>
<th>Time Period</th>
<th>African American Elders</th>
<th>Indian American Elders</th>
<th>Chinese American Elders</th>
<th>Mexican American Elders</th>
</tr>
</thead>
<tbody>
<tr>
<td>1900-1920</td>
<td>Urban Migration</td>
<td>Harlem Renaissance</td>
<td>WWII: Segregated Troops; factory work in North and West</td>
<td>Civil Rights Movement and Law</td>
</tr>
<tr>
<td>1920-1940</td>
<td>NAACP and Urban League Founded</td>
<td>Marcus Garvey’s back to Africa Movement</td>
<td>Desegregation in plants, schools and military.</td>
<td>Dr. Martin L. King, Jr. led non-violence and then was assassinated</td>
</tr>
<tr>
<td>1940-1960</td>
<td>Ku Klux Klan Active</td>
<td>Klan marched on Washington</td>
<td>Montgomery Bus Boycott</td>
<td>Affirmative Action</td>
</tr>
<tr>
<td>1960-1980</td>
<td>WWI and the &quot;Red Summer&quot;</td>
<td>Depression</td>
<td>Jackie Robinson</td>
<td>Political Activism</td>
</tr>
<tr>
<td>1980-Present</td>
<td></td>
<td></td>
<td></td>
<td>Million Man &amp; Woman Marches</td>
</tr>
</tbody>
</table>

- Civil Rights Movement and Law
- Dr. Martin L. King, Jr. led non-violence and then was assassinated
- Black Muslims
- Affirmative Action
- Rodney King trial
- Political Activism
- Million Man & Woman Marches
- Kennedy assassinated
- Declining Affirmative Action
- The Black Panthers
## COHORT EXPERIENCES - AMERICAN INDIAN ELDERS

<table>
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<tr>
<th></th>
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<tbody>
<tr>
<td>Reservations</td>
<td>Citizenship</td>
<td>World War II Service</td>
<td>Vietnam War</td>
<td>Education of Professionals</td>
</tr>
<tr>
<td>&quot;Vanishing American&quot;</td>
<td>Adoption of Indian Children by Whites</td>
<td>Relocation by BIA to Urban Areas</td>
<td>Indian Activism</td>
<td>Litigation</td>
</tr>
<tr>
<td>Forced Boarding Schools</td>
<td>Loss of Land by Allotment System</td>
<td>Termination of 100 Tribes</td>
<td>Youths Return to Traditional Practices</td>
<td>Self-Determination of Tribes</td>
</tr>
<tr>
<td>Traditional Culture &quot;Bad&quot;</td>
<td>Forced Assimilation</td>
<td>Forced Assimilation</td>
<td>Urbanization for Education &amp; Jobs</td>
<td>Urban Pan-Indianism</td>
</tr>
<tr>
<td>Law Banned Spiritual Practices</td>
<td>Boarding Schools</td>
<td></td>
<td></td>
<td>Reservation Gaming</td>
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</tbody>
</table>

## COHORT EXPERIENCES - CHINESE AMERICAN ELDERS

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<tr>
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</thead>
<tbody>
<tr>
<td>Chinese exclusion act in effect</td>
<td>1924 Immigration Act Excludes all Asians</td>
<td>Repeal of Exclusion Act</td>
<td>New immigration act favors family members</td>
<td>Continued heavy immigration, from Taiwan, Hong Kong and Vietnam</td>
</tr>
<tr>
<td>Urbanization</td>
<td>Families emerge in</td>
<td>Chinese Americans in</td>
<td>Increased educational</td>
<td>Seen as &quot;Model&quot;</td>
</tr>
<tr>
<td>Immigration of &quot;Paper Sons&quot;</td>
<td>Family Associations</td>
<td>Immigration of wives</td>
<td>Continued discrimination in union employment</td>
<td>&quot;Followers of Children&quot;</td>
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<td>-----------------------------</td>
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<td>-----------------------------------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Predominantly male</td>
<td>Pearl Buck novels</td>
<td>Fear of Chinese Communists</td>
<td>Anti-immigrant bias</td>
<td></td>
</tr>
</tbody>
</table>

**COHORT EXPERIENCES - MEXICAN AMERICAN ELDERS**

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Heritage of Loss of Land</td>
<td>Massive Immigration</td>
<td>WWII Participation</td>
<td>Chicano Movement</td>
<td>Increasing Political Power</td>
</tr>
<tr>
<td>Mexican Revolution</td>
<td>Depression</td>
<td>Immigration</td>
<td>Bilingual Education</td>
<td>Anti-Immigrant Bias</td>
</tr>
<tr>
<td>Repatriation</td>
<td>Urbanization</td>
<td>Latino Arts and Media</td>
<td>Welfare Reform Movement</td>
<td></td>
</tr>
<tr>
<td>GI Forum</td>
<td>Deportation and Amnesty</td>
<td>Anti-Bilingual Education Trend</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source:  
### Learning Resource B

#### Major Systems Of Culturally Based Health Beliefs

<table>
<thead>
<tr>
<th>Biomedical Model (Western, Allopathic)</th>
<th>Biomedical model of medicine and nursing, the primary healing system of the dominant culture/group in the United States. Based on scientific reductionism and characterized by mechanistic model of the human body; separation of mind and body, and discounting of spirit or soul.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traditions from American Indian Nations</td>
<td>Health beliefs and views of death predate European immigration and vary by tribe. Many are characterized by mind-body-spirit integration, spiritual healing, and use of herbs from native plants. Harmony with natural environment (e.g., animals, plants, sky, and earth) was important for health. Illness is sometimes seen as a result of an individual's offenses, to be treated by a ritual purification ceremony or a ceremony by a medicine person. In many tribes, life and death are viewed in a circular pattern rather than linear as in European traditions.</td>
</tr>
</tbody>
</table>
| Traditions from Africa and Early African American Heritage | Various African traditions frequently integrated with American Indian, Christian, and other European traditions. In the variety of systems, most illness could be seen as:  
- a natural illness, which is a result of a physical cause, such as infection, weather, and other environmental factors;  
- a occult illness, which is resulted from supernatural forces, such as evil sprits and their agents (e.g., conjurers); or  
- a spiritual illness is a result of willful violation of sacred beliefs or of sin, such as adultery, theft, or murder  
Common characteristics of healing include:  
- healing power of religion, Christian in some cases; and  
- use of herbs, or "root working".  
In some Caribbean Islands, African traditions evolved into strong beliefs in power of spirits and use of healers to maintain health and treat illnesses. However, those beliefs probably have a weak influence on most urban African Americans today.  
Many current African American elders, particularly those from the rural South, grew up using alternative practices of self-treatment, partly in response to lack of access to mainstream care. Experiences of segregation and memories of the Tuskegee experiment may make the current cohort of older African Americans skeptical and distrustful of mainstream medicine, especially when making |
decisions about care at the end-of-life.

<table>
<thead>
<tr>
<th>Traditions from Asia</th>
<th>Classical Chinese medicine influenced traditions in Japan (Kampo), Korea (Hanbang), and Southeast Asia. It is characterized by</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• need for balance between <em>jīn</em> and <em>yáng</em> to preserve health, especially through the use of herbs and diet;</td>
</tr>
<tr>
<td></td>
<td>• unblocking the free flow of <em>qì</em> (chi) or vital energy, through meridians in the body by acupuncture, <em>tái chí</em>, moxibustion, and cupping; and</td>
</tr>
<tr>
<td></td>
<td>• interaction of basic elements of the environment (e.g. water, fire, earth, metal, and wood).</td>
</tr>
<tr>
<td></td>
<td>In parts of Asia, Taoism and Buddhism have influenced the healing traditions.</td>
</tr>
<tr>
<td></td>
<td>• Taoism emphasizes the need to adapt to the order of nature, and</td>
</tr>
<tr>
<td></td>
<td>• Buddhism emphasizes meditation for spiritual and physical health.</td>
</tr>
<tr>
<td></td>
<td>Ayurvedic medicine practiced in India:</td>
</tr>
<tr>
<td></td>
<td>• is shaped by Hinduism and traditional Indian culture.</td>
</tr>
<tr>
<td></td>
<td>• includes basic elements of the environment (e.g., air, water, and wind) which have analogues in the body.</td>
</tr>
<tr>
<td></td>
<td>• is characterized by the use of yoga, meditation, herbs, and by integration of mind-body-spirit.</td>
</tr>
<tr>
<td></td>
<td>Traditional Hmong health beliefs are characterized by:</td>
</tr>
<tr>
<td></td>
<td>• interventions of a wide variety of spirits that promote health or cause illness; and</td>
</tr>
<tr>
<td></td>
<td>• risk of loss of soul that brings illness.</td>
</tr>
<tr>
<td></td>
<td>For many Asian American elders, traditional healers’ offices serve as meeting places to socialize with other elders. The socialization function of traditional healing parallels the traditional Chinese medical view that illness should be addressed not only through medicine, but also through social and psychological aspects of life. End-of-life decisions about care may be characterized by:</td>
</tr>
<tr>
<td></td>
<td>• family vs. individual decision making—even if the elder is competent to make decisions, family members might feel that it is their filial duty to take the decision-making role;</td>
</tr>
<tr>
<td></td>
<td>• non-disclosure of terminal illness to protect the elder; and</td>
</tr>
<tr>
<td></td>
<td>• placement of the dying person or the body—wanting to &quot;go home to die&quot; and the practice of not disturbing the body reflecting reluctance of organ donation or autopsy.</td>
</tr>
</tbody>
</table>
| Traditions from Latin America | Most Latino Americans practice the biomedical model, but among some elders there may be reminiscences of other beliefs.  
- Beliefs rooted in models developed from Native American, European, and African practices form an intricate cultural blend. Examples are *Santeria*, *Espirito*sm, and *Curanderismo*, in which religion is an important component of the system.  
- CAM practices are seen as exogenous, and in opposition, to the biomedical model. There is an integration of elements from both practices forming a complex cultural product.  
Latino Americans are less likely than European Americans to:  
- make individual decisions on end-of-life issues or complete advance directives,  
- endorse the withholding or withdrawal of life prolonging treatment,  
- use hospice services,  
- support physician-assisted death, and organ donation.  
Cultural themes that can influence beliefs and practices concerning end-of-life decisions may include the emphasis on the well-being of the family over the individual; respect for hierarchy; and the emphasis on the present as opposed to past or future. |
| Other European American Systems | Folk healing systems from European countries predating biomedicine, many of which include religious healing and use of herbs, may still be practiced in some areas of the U.S.  
Variations on the belief systems of allopathic medicine, or competing health philosophies have emerged in the U.S. in the past century. Two of the major ones are:  
- Osteopathy, similar to allopathic medicine, but deals with the "whole person" and emphasizes the interrelationship of the muscles and bones to all other body systems;  
- Homeopathy emphasizes the healing power of the body, and relies on the "law of similars" to choose drug therapy. |

## Multicultural Outcomes: Guidelines
### For Cultural Competence

**Summary of the Domains of Culture**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnic Identity</td>
<td>Country of origin, ethnicity/culture with which the group identifies, current residence, reasons for migration, degree of acculturation/assimilation, and level of cultural pride.</td>
</tr>
<tr>
<td>Communication</td>
<td>Dominant language and any dialects, usual volume/tone of speech, willingness to share thoughts/feelings/ideas, meaning of touch, use of eye contact, control of expressions and emotions, spokesperson/decision maker in family.</td>
</tr>
<tr>
<td>Time and space</td>
<td>Past, present, or future orientation; preference for personal space and distance.</td>
</tr>
<tr>
<td>Social organization</td>
<td>Family structure; head of household, gender roles, status/role of elderly; roles of child, adolescents, husband/wife, mother/father, extended family; influences on the decision-making process; importance of social organization and network.</td>
</tr>
<tr>
<td>Workforce issues</td>
<td>Primary wage earner, impact of illness on work, transportation to clinic visits, health insurance, financial impact, importance of work.</td>
</tr>
<tr>
<td>Health beliefs, practices, and practitioners</td>
<td>Meaning/cause of cancer and illness/health, living with life-threatening illness, expectations and use of Western treatment and healthcare team, religious/spiritual beliefs and practices, use of traditional healers/practitioners, expectations of practitioners, loss of body part/body image, acceptance of blood transfusions/organ donations, sick role and health-seeking behaviors.</td>
</tr>
<tr>
<td>Nutrition</td>
<td>Meaning of food and mealtimes, preferences and preparation of food, taboos/rituals, religious influences on food preferences and preparation.</td>
</tr>
<tr>
<td>Biological variations</td>
<td>Skin, mucous membrane color, physical variations, drug metabolism, laboratory data, and genetic variations-specific risk factors and differences in incidence/survival/mortality of specific cancers.</td>
</tr>
<tr>
<td>Sexuality and reproductive fears</td>
<td>Beliefs about sexuality and reproductive/childbearing activities, taboos, privacy issues, interaction of cancer diagnosis/treatments with beliefs about sexuality.</td>
</tr>
<tr>
<td>Religion and spirituality</td>
<td>Dominant religion; religious beliefs, rituals, and ceremonies; use of prayer, meditation or other symbolic activities; meaning of life; source of strength.</td>
</tr>
<tr>
<td>Death and dying</td>
<td>Meaning of dying, death and the afterlife; belief in fatalism; rituals, expectations, and mourning/bereavement practices.</td>
</tr>
</tbody>
</table>
Learning Resource D

Cultural Self-Assessment


1. Where were you born?
   
   If an immigrant, how long have you lived in this country?
   How old were you when you came to this country?
   Where were your grandparents born?

2. What is your ethnic affiliation and how strong is your ethnic identity?

3. Who are your major support people: family members, friends?
   Do you live in an ethnic community?

4. How does your culture affect decision regarding their medical treatment?
   
   Who makes decisions - you, your family, or a designated family member?
   What are the gender issues in your culture and in your family structure?

5. What are your primary and secondary languages, speaking and reading ability?

6. How would you characterize your nonverbal communication style?

7. What is your religion, its importance in your daily life, and current practices?
   
   Is religion an important source of support and comfort?

8. What are your food preferences and prohibitions?

9. What is your economic situation, and is the income adequate to meet the needs of you and your family?

10. What are your health and illness beliefs and practices?

11. What are your customs and beliefs around such transitions as birth, illness and death?
    
    What are your past experiences regarding death and bereavement?
    How much do you and your family wish to know about the disease and prognosis?
    What are your beliefs about the afterlife and miracles? Beliefs about hope?
Module # 15: Aging Policies and Entitlements
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 15: Aging Policies and Entitlements

James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

This interdisciplinary curriculum is geared to allied health students and may be reproduced and used with attribution.
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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 15: Aging Policies and Entitlements

I. Overview

As our society continues to age at a rapid speed, it is crucial that healthcare professionals become familiar with entitlements available to the older population as well as keep abreast with local, state, and federal policy changes affecting the elderly. By doing this, healthcare professionals will be able to better understand their patients’ needs as they navigate the various complex healthcare systems. This module introduces the major entitlements utilized by older adults and offers valuable resources to healthcare professionals so they may expand their knowledge and provide assistance to their patients.

II. Learning Objectives

1. Provide an overview of the major entitlement programs utilized by older adults.
2. Define Social Security and its offered benefits.
5. Identify available resources offering assistance with entitlements.

III. Facts About Social Security

Social Security is a type of social insurance program whereby workers contribute while they are employed and employers pay matching contributions. Social Security benefits are available to support workers and their families in retirement; or when they lose their livelihood due to career-ending disability; or as a result of death of a family worker.

A. How Many People Receive Social Security?

- 47.7 million people receive Social Security each month
B. Who Receives Social Security?

- 30.0 million retired workers
- 4.8 million widows and widowers
- 6.2 million disabled workers
- 0.8 million adults disabled since childhood
- 3.1 million children

C. How Much Does Social Security Pay? ²

While Social Security benefits are designed to serve as a foundation of retirement income, they are often supplemented by pensions, savings, and earnings. Social Security benefits alone typically do not provide a comfortable level of living.

<table>
<thead>
<tr>
<th>Type of benefit or family</th>
<th>Before 5.8% COLA</th>
<th>After 5.8% COLA</th>
<th>Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>All retired workers</td>
<td>$1,090</td>
<td>$1,153</td>
<td>$63</td>
</tr>
<tr>
<td>All disabled workers</td>
<td>1,006</td>
<td>1,064</td>
<td>58</td>
</tr>
<tr>
<td>Aged couple</td>
<td>1,773</td>
<td>1,876</td>
<td>103</td>
</tr>
<tr>
<td>Surviving child(ren) only</td>
<td>936</td>
<td>991</td>
<td>55</td>
</tr>
<tr>
<td>Widowed mother and 2 children</td>
<td>2,268</td>
<td>2,399</td>
<td>131</td>
</tr>
<tr>
<td>Aged widow(er) alone</td>
<td>1,051</td>
<td>1,112</td>
<td>61</td>
</tr>
<tr>
<td>Disabled worker, spouse, and one or more children</td>
<td>1,695</td>
<td>1,793</td>
<td>98</td>
</tr>
</tbody>
</table>

² Family with one or more children excludes surviving parent or guardian who is ineligible to receive benefits. Note: The above estimates are based on actual benefit data through September 2008.

D. Social Security As A Primary Source Of Income ³

There is no doubt that Social Security benefits are relatively modest both in dollar amounts and in relation to retirees’ prior earnings; however, it is vital to remember that Social Security benefits are critically important to the families that receive them.


- 90% of people 65 and older get Social Security
- Nearly 2 in 3 (66%) get half or more of their income from Social Security
- About 1 in 5 (22%) get all their income from Social Security

E. Pensions

In reality, most elderly Americans age 65 and older do not receive income from pensions, either from private employment or from local, state, or federal government jobs. This is the main reason why Social Security benefits remain as the largest source of income for older adults. Percentages of employer-sponsored pensions are as follows:

- All ages 65+ 41%
- Couples 51%
- Unmarried men 39%
- Unmarried women 32%

F. Worker Contribution

- Workers pay 6.2% of their earnings for Social Security and 1.45% of their earnings for Hospital Insurance under Medicare (Part A).
- Employers pay an equal amount.
- The total is 12.4% for Social Security and 2.9% for HI.
- Social Security taxes are paid only up to a cap - that cap goes up each year with average wages.
- The Social Security tax base was $102,000 in 2008.
- Medicare taxes are based on total wages - there is no cap.
- Self-employed workers pay both the employee and employer share of the tax. They receive a deduction in their personal income taxes for the “employer” portion of the total amount.
- Upper income Social Security beneficiaries pay income taxes on part of their Social Security benefits, and some of this income tax revenue is earmarked to return to Social Security trust funds.

IV. What Is Medicare?

Medicare is a federal health insurance program that was created in 1965 for people age 65 and over regardless of income. In 1972, it expanded to include younger people with permanent disabilities. Medicare covers approximately 43 million Americans.

A. Medicare Eligibility
A person is entitled to Medicare Part A if that person or his/her spouse paid into Social Security for 10 or more years.

People younger than 65 receiving Social Security Disability Insurance (SSDI) become eligible after a two year wait with a few exceptions.

B. What Medicare Does NOT Cover

- Dental services
- Vision services
- Long-term care (home or institutional)
- Non-emergent transportation to physician

C. Size And Scope Of Medicare

- In 2006, Medicare benefits accounted for $374 billion.
- Medicare represents approximately 14% of the federal budget.

D. Four Parts To Medicare

- Part A: Facility-based Services
  - Pays for inpatient hospital, skilled nursing, home health and hospice care
  - Accounts for 41% of spending in 2006
  - Paid by dedicated tax of 2.9% of earnings paid by employees and employers

- Part B: Community-based Services
  - Physician, outpatient, home health, and preventive services including x-rays and labs, screening exams (e.g., mammograms, colorectal), and PT/OT
  - 35% of Medicare spending
  - Funded by taxpayers- general revenues and premiums
  - Most pay the standard premium ($96.40 in 2009)
  - Monthly premium is higher if single and annual income is more than $85,000 or if you are married and your yearly income is more than $170,000

- Part C: Private Managed Care Plan
  - Medicare Advantage Program
  - Beneficiaries may enroll in a private managed care plan (HMO, PPO, Private Fee-For Service Plan)
  - Plans offer combined coverage of Parts A and B, and usually Part D
Accounts for 14% of all Medicare spending

Part D: Outpatient Prescriptions

- New outpatient prescription drug benefit
- Delivered through private plans that contract with Medicare
- Provides additional assistance with premiums and cost-sharing for lower income people
- Monthly premiums averaged $25 in 2008
- Accounts for 8% of benefit spending
- Financed by general revenues, state payments, and premiums

V. What Is Medicaid?

Medicaid is a health insurance program that is means tested, without age restrictions, and funded by federal, state, and local governments.

A. 2010 NYS Medicaid Income Limits For Individuals over 65 and Families

- $767 (monthly)
- $9200 (annually)

B. What Medicaid Covers

- Community
  - Physicians/clinics
  - Dental services
  - Home health and personal care
  - Preventive care
- Facilities
  - Hospitals
  - Nursing Homes
  - Psych hospitals
- Laboratory & X-ray services, medical supplies
- Transportation to and from appointments
- Family planning/Prenatal care
- Insurance premiums including Medicare

C. NYS Medicaid Managed Care

- Managed care covers most benefits including all preventive and primary care, inpatient care, and eye care.
- Enrollment is mandatory in some NYS counties.
D. NYS EPIC Program

- Over 360,000 seniors belong and are saving, on average, over 80% of the cost of their medicines.
- Older adults qualify if yearly income is between $35,000 (single) and $50,000 (married)
- Cost Sharing
  - Older adults with moderate incomes pay a low quarterly fee and participate in the fee plan.
  - Seniors with higher incomes meet an annual deductible.
- Those receiving full Medicaid benefits are **not** eligible.
- Seniors with other prescription coverage through Medicare or most other plans may join EPIC to cover drug costs not covered by that other coverage.

VI. References

1. NASI SS Brief # 20


3. *Income of the Population 55 or Older*, 2002, SSA


Learning Resource A

Aging Policy & Entitlement Resources

202-619-0724 (Public Inquiries)

AARP Policy & Research Institute: [http://www.aarp.org/research/](http://www.aarp.org/research/)  
1-888-OUR-AARP

Veterans Health Administration: [http://www1.va.gov/health/index.asp](http://www1.va.gov/health/index.asp)

1-800-342-9871

NY State Health Insurance Assistance Program (SHIP):  
[http://www.hicap.state.ny.us/](http://www.hicap.state.ny.us/)  
1-800-701-0501

NYC Department For The Aging:  


1-800-772-1213

1-800-MEDICARE

1-877-472-8411 (New York City)

1-800-333-4114
The 2005 White House Conference on Aging (WHCoA) was held December 11 to 14, 2005 in Washington, DC, and was the fifth WHCoA in history. Like its predecessors, its purpose was to make recommendations to the President and Congress to help guide national aging policies for the next ten years and beyond. The 2005 WHCoA, which had as its theme: “The Booming Dynamics of Aging: From Awareness to Action,” focused on the aging of today and tomorrow, including 78 million baby boomers who began to turn 60 in January 2006.

The WHCoA hosted approximately 1200 delegates selected by Governors, Members of Congress, the National Congress of Americans Indians (NCAI) and the WHCoA Policy Committee. Delegates voted on 50 resolutions they considered as priorities and worked together to recommend innovative solutions reflecting actions that might be taken by federal, state and local governments, tribal organizations, business and industry, communities and individuals to prepare for the challenges and opportunities of an aging nation. The top two resolutions adopted by the delegates were the reauthorization of the Older Americans Act and the development of a coordinated and comprehensive long term care strategy. The reauthorization of the Older Americans Act occurred in 2006 and included provisions that support the development of a national long term care strategy for our nation.

The Booming Dynamics of Aging: From Awareness to Action
Executive Summary

The 2005 White House Conference on Aging (WHCoA) and its Final Report are about the future.

The future is reflected in the theme of the 2005 WHCoA, “The Booming Dynamics of Aging: From Awareness to Action.” The theme shines a spotlight on the changing face of aging in the 21st Century and the need for all Americans to take responsibility to act now to address the challenges of a new century.

As policymakers and others review the data, strategies, and suggestions generated both during the 2005 White House Conference on Aging and at hundreds of pre-WHCoA events, they must consider the reality that the future will be very different than the past. The potential scope and magnitude of the policy changes implied by the demographic shifts forecast for the future can be summed up in the words of Dr. Paul Hodge, JD, MBA, MPA, Chairperson, Global Generations Policy Institute and Director, Harvard Generations Policy Program, when he addressed the Policy Committee in 2004.
“While many experts, popular pundits and the press have made predictions about how the aging of the baby boomers will affect the United States, in actuality, no one really knows with any certainty what will happen. What is clear is that the policy implications and ramifications are unprecedented in history. America’s graying will transform politics, retirement systems, health care systems, welfare systems, labor markets, banking and stock markets. It will force a re-thinking of social mores and prejudices, from issues of age/gender discrimination in the job market to end-of-life care. Whether that transformation is positive or negative will depend on planning and preparation that must begin today.”

In the previous four decades, planning for the future meant absorbing 78 million Boomers first into the education system and then into the work force. The size of this demographic phenomenon has influenced political, social and economic systems in every decade. The Boomers will continue to influence public, social and economic policy for at least the next 30 years.

Although Boomers are still from five to 23 years away from traditional retirement age, it is not too early to begin planning for the impact they will have on every aspect of our society and culture. At a minimum, we can reasonably expect the same scope of change that was experienced as they have moved through the first four to six decades.

In areas such as Social Security, health care planning, and the workforce, we are already behind the curve. While experience is always important, it is unlikely that we will find all the answers to future problems in the past because tomorrow’s older population can be expected to differ in distinct ways from prior generations:

- They will be healthier and wealthier.
- They will be better educated and desire to make contributions beyond traditional retirement
- They will be more racially and ethnically diverse.
- The average age of the older population will increase as the number of centenarians continues to
grow, and there will be longer life expectancy.
- People are likely to stay in the workforce longer than in the last seven decades.

**THE BOOMING DYNAMICS**

The aging of the population is one of the most important demographic trends in the United States. The extent of this trend is well documented. In 1940, the majority of the population was under the age of thirty due in part to the large baby boom cohorts born following World War II. There were relatively few persons age 65 and older—approximately 16.2 million—and they represented only 9% of the total population. The aging of the baby boom cohorts (coupled with declines in fertility) gradually changed the shape of the age distribution. About 35 million Americans were age 65 and older in 2000 (12% of the total population). If projections of the population for the next forty years hold, the number of older persons will further increase to 80 million, and one-in-five Americans will be age 65 and older.
The story of the aging of the U.S. population is not simply one of increases in numbers. Over the next forty years there will be a dramatic increase in the average age of the older population. For example, 4.2 million persons were age 85 and older in 2000, and further declines in mortality could lead to a five-fold increase in the number by 2040. This could have a significant impact on health and long-term care because the use of formal and informal services is strongly correlated with age.

As the population grows larger, it will also become more diverse, reflecting the demographic changes in the U.S. population as a whole over the past decades. In 2000, non-Hispanic whites accounted for nearly 83.6 percent of the U.S. older population, followed by Blacks (8 percent), Hispanics who may be any race (5 percent) and other minorities (3.5 percent). Projections suggest that by 2040, the composition will be 66.6 percent non-Hispanic White, 14.5 percent Hispanic, 10.5 percent Black and 8.5 percent other minorities.1

A key cohort in this changing demographic story is represented by our nation’s veterans. According to the 2000 Census, there were 9.8 million veterans age 65 and older in the U.S. comprised mainly of the World War II, Korea and increasingly Vietnam era cohorts. While there is projected to be a slight drop between 2000 and 2010, the number of veterans over age 65 will again increase as the majority of the Vietnam era cohort ages. Likewise, the number of age 85 plus veterans will continue to increase steadily, reaching nearly 1.4 million by 2012. The Department of Veterans Affairs estimates that as of 2006, approximately 9 million of the nation’s 25 million veterans were Boomers. These veteran demographic changes have significant implications not only for the Department of Veterans Affairs in providing benefits, including health care, long term care and other VA services, but for state and local governments and community-based organizations since veterans may be eligible and entitled to services from more than one program.

For a more in-depth look at elements of aging demographics in the U.S., the statistical report, “A Profile of Older Americans 2005” published by the U.S. Administration on Aging is reproduced in the Appendix of this report.

Summary

Beginning January 1, 2006, on average, a new 60 year old was celebrating a birthday every seven seconds, and these celebrations will continue for another 18 years. The impact of this demographic shift will affect every level of our social, economic and political systems.

In his address to the WHCoA delegates on December 12, 2005, David Walker, Comptroller General of the United States, summed up the challenges our country faces by outlining the consequences that the projected growth of the aging population has for our nation’s health care system and its economy, especially if we take no action. Mr. Walker said that “continuing the current national direction of our country is not an option” or the result will be that “our children and grandchildren may face taxes 2.5 times today’s levels.” He suggested three ingredients needed to address these changing times: “courage, integrity and innovation,” and he challenged all delegates to draw upon these ingredients in their deliberations – to have the courage to make tough choices, the integrity to do what is right.

1 Administration on Aging, U.S. Department of Health and Human Services, U.S. Census Bureau data
and fair, and to unleash their minds in pursuit of innovative approaches that will make the coming decade one of positive and productive aging.”

Solutions to the challenges ahead will not come from looking back because there is no prologue. As one reviews this report and reflects on the discussions of the delegates and the thousands of other participants who shared their views through pre-WHCoA events, it would be wise to remember that a new lens focused on the future of an aging society, together with an understanding of the past, will be needed. This is perhaps the greatest challenge we will face in the coming decades.

WHCoA Background and Process

Decennial White House Conferences on Aging are now embedded in our national history. Past White House Conferences on Aging, first held in 1961 and again in 1971, 1981 and 1995, have been catalysts for aging policies and significant national programs such as Medicare, Medicaid and the Older Americans Act.

Each Conference has been unique and dynamic. Each has carried its own “call to action” reflecting the time in history during which it occurred.

The 2005 Conference was no exception. It was the first WHCoA of the 21st Century, and it was also the first to have a mandated focus through its authorizing statute, the Older Americans Act Amendments of 2000 (P.L.106-501), on the demographic cohort known as the “Boomers.” The Conference also continued the WHCoA tradition of using a grass-roots outreach strategy to generate public input that resulted in more than 130,000 citizens participating in forums all across the nation.

The 17-member, bi-partisan Policy Committee appointed by the President and the Congress and the 22-member Advisory Committee appointed by the President recognized the uniqueness of the 2005 WHCoA and the opportunity to address key aging issues facing our nation at a unique point in history. Both the Policy Committee and the Advisory Committee have fulfilled their distinctive roles by placing a targeted emphasis on the coming generation of seniors while paying tribute to those individuals who have contributed and continue to contribute to this country’s prominence and prosperity.

The WHCoA Process

The 2005 WHCoA process began in August 2004 and culminated with the December 2005 Conference in Washington, D.C. The WHCoA was nearly the 400th event in a series of forums that were convened across the nation to discuss aging issues and propose solutions to significant challenges.

The WHCoA process was guided by the Policy Committee’s development of a framework that provided a structure or organizational umbrella for the variety of issues that would be discussed during all pre-WHCoA events. This framework, referred to as the WHCoA Policy Tracks (which made up the Annotated Agenda), is identified below. The Delegate Workbook provided to the delegates to the December 2005 Conference was organized around these seven categories.
Annotated Agenda Categories

Planning Along the Lifespan
The Workplace of the Future
Our Community
Health and Long Term Living
Civic Engagement and Social Engagement
Technology and Innovation in an Emerging Senior/Boomer Marketplace
Cross-Cutting

A narrative description of the scope and content of each category is included in the Appendix of the report as was provided to the delegates in the Delegate Workbooks.

From the input received by the WHCoA and from the resolutions adopted by the delegates, clear themes have emerged identifying significant challenges that are before the nation with regard to our rapidly aging, diverse population. Those challenges are briefly described in the concluding section of this report.

The Voices of America: The Public Input Process

The public input process that began in August 2004 was designed to create a variety of opportunities for the widest possible participation of citizens in WHCoA activities. To solicit this wide participation, the 2005 WHCoA was based on a vigorous bottoms-up, grass roots strategy involving more than 130,000 people in towns, cities, communities, Tribal reservations and Native American villages and States across the country meeting in various forums to have conversations about aging challenges and solutions. Beginning in August 2004, forums were organized by individuals and communities, academic institutions, business and industry, national and local organizations and coalitions, non-profits, faith-based organizations, as well as Federal, State, Tribal and local agencies. These public forums took place under the titles of Mini-Conferences, Listening Sessions, Solutions Forums, and Independent Aging Agenda events.

Documenting Public Input to the WHCoA

What set this public participation process apart from previous WHCoA’s was the strong emphasis by the Policy Committee for participants to seek visionary, innovative, realistic, and fiscally responsible solutions to aging challenges. From the beginning, the Policy Committee articulated its desire to move beyond simply identifying the issues and to hear ideas about how to solve problems. The public input received by the Policy Committee came from four different types of pre-WHCoA events as described below.

It was significant that Listening Sessions and Independent Aging Agenda Events conducted around the country confirmed that this is a set of national challenges that states and communities have each been grappling with in their unique ways.
In WHCoA Solutions Forums, the Policy Committee turned to the imagination of individuals who are experiencing many of these challenges on a very personal level and asked for their recommendations.

*Mini-Conferences* developed through public-private partnerships provided the Policy Committee with focused information as well as policy recommendations on single topic areas such as long term care, caregiving, disability and aging, geriatric health care workforce, mature workforce, nutrition, financial security, retirement savings, access and development of health and financial information, and health literacy and health disparities.

Public comments received by the WHCoA from individuals and organizations provided additional insight and direction.

The issues identified during these public forums were documented and reported to the WHCoA by the leaders of those events. These reports were posted on the WHCoA website ([www.whcoa.gov](http://www.whcoa.gov)) as soon as the information became available to encourage dissemination of information. The reports from these events were synthesized through a deliberative process involving the WHCoA Policy Committee and Advisory Committee. This synthesis process resulted in the creation of a summary of the key findings and recommendations from the public input process. Those reports are included in the Appendix of this report.

The analysis of the information contained in this synthesis document formed the basis for the identification of a candidate set of resolutions that was ultimately presented to the delegates for their consideration in advance of the December 2005 Conference. Deliberations by the Policy Committee in consultation with the Advisory Committee resulted in the Policy Committee identifying and developing 73 broad-based and diverse resolutions that were then formally presented to the delegates for their consideration in advance of the December 2005 Conference and their vote on 50. These 73 resolutions were organized under the seven Tracks of the Annotated Agenda. These 73 resolutions appear in the Appendix of the report.

**The Delegates**

The 1,200 bi-partisan delegates to the 2005 WHCoA were selected by Governors of all 50 States, Puerto Rico, the District of Columbia and the Territories, Members of the 109th Congress, the National Congress of American Indians and the Policy Committee. The delegates represented aging and allied organizations, business and industry, veterans, persons with disabilities, minorities and others with an interest in the future of aging in the United States.

These delegates were the heart and hands of the WHCoA. They were vocal and passionate; experienced and informed. They were seniors and Boomers; some were children of Boomers, and others soon-to-be centenarians. They were grandparents, caregivers, advocates, policymakers, entrepreneurs, financial advisers, volunteers and interested citizens. But most important, delegates to the 2005 WHCoA were not reticent, and most came to the Conference eager and prepared to contribute.
The names of the 2005 WHCoA delegates appear in this Executive Summary and in the Appendix of this report.

The Work of the Delegates at the WHCoA

The initial work of the delegates focused on selecting the top 50 resolutions out of the list of 73 candidate resolutions they had received in advance. The selection of the top 50 resolutions was made through a monitored voting process in which each delegate was provided an opportunity to cast a ballot.

Based on the 50 resolutions that were selected by the delegates at the conference, implementation strategy sessions were scheduled for delegates to meet for discussion of individual resolutions. During these sessions conducted through a facilitated process, delegates proposed strategies to implement the resolutions. Facilitators assisted delegates in the sessions to identify strongest, strong, moderate and limited levels of support, and worked with Track Coordinators to provide a summary of the sessions which was reported by the Policy Committee on the last day of the Conference. The power point presentation presented by the Policy Committee on December 14, 2005 is included in the Appendix.

During these sessions, delegates identified implementation strategies that reflected their sense about what needed to be done to make these resolutions a reality. The Policy Committee believed it was critical for delegates to also identify those groups and organizations that have stakeholder accountability and responsibility for each of the implementation strategies as well as those where individual citizens have that same accountability and responsibility. Delegates were also provided with an opportunity to submit suggested individual implementation strategies that have been included in the proceedings and may be found in the Appendix.

The Priorities of the Delegates

The delegates recognized several critical priorities that we as a nation must address in the very near future. Through the voting process and subsequent vote count on resolutions, it was evident that the delegates felt strongly about many of the issues they were considering, but particularly about:

- The reauthorization of the Older Americans Act within six months of the WHCoA;
- The development of a comprehensive and coordinated strategy for affordable and accessible long term care including caregiving support, and
- The importance of mobility and transportation options for older Americans.

In addition and equally important, were other broad, cross-cutting themes that emerged from the work of the delegates and throughout the last two years of public input. Those themes include:

- Planning and Financing Your Longevity
Independence and Innovation In Livable Communities
Long Term Supports and Services: The Need for a Strategy
A Sense of Purpose: The Future of Work and Civic Engagement
Caregiving: Being There For Our Elders
Healthy for Life: Challenges and Solutions of Health Promotion and Disease Prevention
Improving the Health Care System

These themes all present challenges for a new century that must be addressed now if we are to take our responsibilities as policymakers, family members and private citizens seriously. The resolutions adopted and many of the implementation strategies recommended by the delegates provide significant first steps in addressing many of these challenges.

A listing of all 50 resolutions adopted by the delegates according to the votes, along with a brief overview of the issue addressed by each resolution as provided in the Delegate Workbooks and the implementation strategies developed by the delegates which received the strongest and strong support during their respective implementation sessions is included following the Executive Summary. Although the Policy Committee strongly emphasized that participants seek visionary, innovative, realistic, and fiscally responsible solutions to aging challenges, the implementation strategies developed by the delegates did not meet all these criteria to an equal degree.

A complete listing of resolutions and all implementation strategies is included in the Appendix in its entirety.

Although the delegates came from diverse viewpoints and backgrounds, a sense of purpose, bi-partisanship, and consensus permeated most of these working group sessions. The same energy, passion, and thoughtfulness present during the nationwide pre-WHCoA events carried over to the Conference. The implementation strategies reflect the discussion of the delegates who elected to attend breakout sessions on a particular topic, and the number of delegates attending each session varied widely. As such, the implementation strategies are not intended to convey the sense of all delegates who attended the WHCoA. Further, the strategies suggested by the delegates and included throughout this report are not intended to be an endorsement by the Policy Committee of any particular idea, recommendation or proposed solution.

The Conference

As stated previously, the 2005 WHCoA was unique for several reasons, but especially because of three innovative events that were held in conjunction with the Conference. These events are identified and summarized below.

Get Involved: A WHCoA Service Project

To focus attention on the importance of civic engagement and community service, this Pre-Conference event was organized by the Corporation for National and Community Service and the Washington D.C. Jewish Community Center. Volunteers from Senior Corps joined Conference delegates to help rehabilitate the Educational Organization for United Latin
Americans (EOFULA), a Washington D.C. community center for Latino senior citizens. Braving frigid weather, delegates and volunteers painted, repaired and weatherized the senior center.

**Healthy Living Celebration!**

The Healthy Living Celebration!, a Pre-Conference event, was organized to highlight the importance of healthy living as well as the commitment of the 2005 WHCoA to health and wellness while demonstrating that physical activity can be fun. These goals were accomplished through the leadership of the President’s Council on Physical Fitness and Sports, who co-sponsored the event with assistance from the National Senior Games Association (NSGA).

A renowned cookbook author shared her knowledge about healthy and nutritional cooking followed by several lively physical activity sessions. Activity leaders from the Washington, D.C. metropolitan area volunteered to lead group fitness classes (Tai Chi, Line Dancing, Resistance Training, and Aerobic Exercise).

The event concluded with the recognition of delegates who participated in the WHCoA “Profiles in Wellness Program,” who received Honorary Athlete medals donated by the NSGA, and the 2005 WHCoA President’s Challenge Program sponsored by the President’s Council on Physical Fitness and Sports who provided every participant in the President’s Challenge with a certificate and a wrist-band that could be worn in support of and in promotion for physical activity, health and wellness at the Conference and beyond.

**2005 White House Conference on Aging Exhibit Hall**

The first WHCoA Exhibit Hall to highlight technology was held at the 2005 WHCoA. Co-sponsored by ZivaGuide, a customized health care information provider, the Exhibit Hall featured over 140 exhibitors representing a wide variety of public, private and non-profit organizations, firms and government agencies presenting some of the latest initiatives and innovations in providing services to the aging community.

Large portions of the Exhibit Hall were dedicated to highlighting the potential of technology to transform aging in America. Two sponsors of the largest exhibits were CAST, (the Center for Aging Services Technologies) a program of the American Association of Homes and Services for the Aging, and the U.S. Department of Transportation (DOT). The Conference’s technology exhibit was the largest ever held by CAST, and included some of America’s leading technology companies and universities who assembled dozens of ground-breaking technologies to give policy makers a glimpse of how technology could transform the lives of older adults and those that care for them.

Another portion of the Exhibit Hall, sponsored by the DOT, was dedicated to illuminating promising trends and programs in improving mobility for America’s seniors. Secretary Norman Y. Mineta, the first Secretary of DOT to speak at a WHCoA, joined Policy Committee Chairman Dorcas R. Hardy in the opening of the Exhibit Hall. The Secretary emphasized that the DOT-sponsored programs and exhibits in the hall were but a few examples of the research and technology undertaken by the Department and its private
sector partners dedicated to achieving a safely mobile older population now and in the future.

The Exhibit Hall received a great amount of positive media reports from all over the country, and its contents helped guide the policy discourse at the Conference as well as in the aging community since that time.

The Governors and National Congress of American Indians

As required by statute, within 100 days of adjournment of the 2005 WHCoA, the Governors of all 50 States, Puerto Rico, the District of Columbia and the Territories were asked to provide their input for the Final Report. In recognition of the important role of Tribal governments, the National Congress of American Indians (NCAI) was also asked to provide input as to how the resolutions will impact tribal elders across the nation. Each entity was asked to carefully review the resolutions adopted by the delegates and identify those they consider most important to their constituencies. Additionally, they were asked to share what they are currently doing, or hope to do, to implement the resolutions for the people they serve, or will serve, over the next ten years and beyond. Many of the resolutions have state or tribal impacts; therefore, the input provided by the States and the NCAI complements the efforts of the delegates and provides for a more robust Final Report. The input received from the Governors who responded and the NCAI is included in the Appendix of this report and posted on the WHCoA website.

The Appendix provides detailed information on the mechanics of the conference, identifies those who attended, and includes a listing of all resolutions and implementation strategies recorded during the sessions as well as those strategies submitted by individuals.

Concluding Remarks

Over the last two years, the members of the Policy Committee of the 2005 White House Conference on Aging and the members of the Advisory Committee have listened to professionals and volunteers in the field of aging as well as interested citizens to identify the most pressing issues facing our nation’s seniors and those who care for them.

In addition to the passionate Conference delegates, more than 130,000 individuals, representing business, associations, organizations, governments and advocates participated in several venues to contribute to the 2005 White House Conference on Aging deliberations. After reflecting on the substantial amount of input, responses and reports received, the Policy Committee has asked:

How can the 2005 White House Conference on Aging provide a foundation for positive change during the next 10 years that will result in a better world for current and future seniors? What is needed to make that happen?

From Awareness to Action – A Sense of Urgency

The 2005 WHCoA Policy Committee and the Advisory Committee believe that action must be taken now to address the many challenges that have been identified in this report by the
delegates and pre-WHCoA event participants. Throughout these past two years, it became apparent that there are critical factors that demand attention from individuals as well as private and public players at all levels, including Tribal organizations, local and community groups, and not-for-profit organizations. All must step forward now to meet these challenges. The reasons why we must act now are summarized as follows:

The U.S. is in the midst of a demographic shift that will transform our nation. The policy implications and consequences of this change are unprecedented.

The impact of longer life expectancy on all phases of life must not be underestimated. Longer participation in the workforce, individual responsibility for financing one’s longevity, and the need for long term supports and services as we age with disabilities or age into disability are all critical components of longevity.

Tomorrow’s older population will differ in distinct ways from prior generations. The characteristics of this diverse Boomer population must be viewed as opportunities rather than as problems to be solved. Yet, at the same time, one must recognize that many hardships, challenges and uncertainties that come with aging may not change for millions of Americans.

The fiscal realities of Federal, State and local government budgets transcend simple solutions. Policymakers must balance competing priorities which requires that they exercise decisive leadership, and innovation and demonstrate courage in making individual and collective choices. Public financing will continue to be essential, but cannot be the only answer.

Finally, there are limitations in our delivery of health care and social services to our older population. Whether these limitations are in the size of our caregiver or geriatric health care workforce, the investment and management of technology, the ability to address the cultural differences and needs of our growing diverse population, the availability and accessibility of transportation options for many who are disabled and aging; these and other limitations will only become greater impediments to success the longer action is delayed.

Guiding Principles for Action

The basic principles outlined in the Older Americans Act have remained relevant since the Act was first enacted in 1965, but it is imperative that they be modernized for the 21st Century. The message arising from this 2005 WHCoA is that we must now modernize our aging policies for the 21st Century to deal with the challenges we are facing and those we see on the horizon. Modernization of our nation’s aging policies and programs must be guided by some overarching philosophies.

The role of personal responsibility and accountability for planning for one’s longevity is of paramount importance. No set of new policies or changes in existing programs can be
successful unless individual citizens assume greater responsibility for planning to meet their current and future needs - to the best of their ability - from preparing for future potential long term care needs to choices about financing. Individuals must become informed about and involved in these choices and options.

In making decisions about the development and execution of modernized aging policies and programs, leaders and managers must take the following courageous steps:

- Proactively realign and modernize current aging programs and networks to be more efficient and effective in their performance, so as to free-up resources for unmet needs. These programs, by necessity, must continue in order to serve those seniors who have depended on them. Such support has greatly served to enhance the quality of their lives. That support should be continued using more modern and integrated approaches.

- Transform the “world of aging” - policies, programs, and organizations – from a series of “stove-pipes” into a 21st Century system of coordinated services and networks that will meet the future needs of the Boomers, while also improving services to current seniors. It is not useful to try to push 21st Century needs through outdated “silos” to try and achieve solutions. A true 21st Century system of aging services must be based on new concepts and designs of policies, programs, and organizations where evidence-based outcomes result.

- Proactively work to fully integrate the efforts of Federal, State, Tribal, local and community, private, and not-for-profit stakeholders. It is critical that each entity know its role and responsibility, but it is more important now than ever before for these stakeholders to collaborate.

As stated in the introduction, the 2005 White House Conference on Aging and this final report are about the future. The decade ahead will put us in the midst of one of the most dramatic demographic transformations in our history. We should embrace this future with a new commitment to planning and action at all levels of society to meet the needs of our aging population. Individuals, families, communities; the public, private and volunteer sectors have roles and responsibilities in meeting these needs.

The issue at hand is about more than the pure numbers of Americans who are aging. It is also about the changing face of America as it ages and the special responsibility we have to recognize and have our policies, practices and attitudes provide an environment of equal opportunity to age well. The role of government may change over time, but it has and will continue to have a fundamental responsibility to help those in need irrespective of age. The value of a lifetime is the essence of aging. We should not approach the challenge of aging with fear and apprehension, but rather with creative foresight, optimism, and a sense of determination.

The challenges described in this report provide each of us with extraordinary opportunities. However, we need courageous leadership from all sectors of our country; we must have the will to make changes in our social services and health care delivery systems, and we must be
innovative as we tackle the tough choices ahead. Only through this courage, will, and innovation will we be able to make the magnitude of changes that are necessary to serve the evolving needs of our aging population. This report provides a roadmap of actions for positive change.

During challenging times in our history, previous generations have been called upon to lead. Now is our time, and our mandate is clear. Let us lead by ensuring that the legacy of the 2005 White House Conference on Aging is one of relevance, vision and action. May we look back knowing that we made a difference for future generations, and may we look forward knowing we are helping our nation transition to a better and healthier future for all Americans.
Module # 16: Pharmacology
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 16: Pharmacology

James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module #16: Pharmacology

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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 16: Pharmacology

I. Overview

The proper use of medications represents one of the most crucial ways in which the practice of geriatric medicine differs from conventional medical care. Pharmacotherapy is probably the single most important medical intervention in the care of elderly patients, and its appropriate implementation requires a special understanding of the unique pharmacologic properties of drugs in this population, as well as a grasp of the clinical, epidemiologic, socio-cultural, economic, and regulatory aspects of medication use in aging.

This section includes discussion of key clinical strategies for prescribing in older adults, including the following topics: taking an accurate and thorough medication history, minimizing overmedication, maximizing compliance, and prevention of potentially life-threatening adverse side effects.

II. Learning Objectives

1. Define pharmacology
2. Identify some physiologic changes of aging that affect pharmacologic therapy
3. List some of the common adverse reactions to medications
4. Discuss causes for non-compliance
5. Identify strategies for enhancing compliance
III. What Is Pharmacology? “Pharmacology is a discipline concerned with the study of therapeutic medications, their effects on the body and, conversely, the effects of the body on the medication itself.” ¹ (Ency. of Ger. vol 2, p. 295)

IV. Demographics

- Older adults are prescribed the greatest number of medications, use the greatest number of nonprescription medications, and are more likely to be administered several medications at once for longer periods of time. Although they only comprise 12% of the US population, they receive 32% of all prescription drugs dispensed. ² (Nursing and Ger. Ency. v2, 296)

- Upwards of one half of older outpatients reportedly do not take their medications as prescribed, with underutilization being the predominant deviation. ³ (Ency. of Ger. vol 2, p. 296)

V. Physiologic Changes of Aging That Affect Pharmacologic Therapy

- Delayed gastric emptying, decreased gastric acidity, and decreased splanchnic blood flow affect absorption.

- Absorption may be delayed, postponing onset of action and peak effect of medications.

- A higher percentage of fat compared to lean body mass, a decrease in total body water, and decreased plasma albumin concentration affect drug distribution.

- Changes in body composition with aging affect the serum concentrations of water soluble drugs, and changes in fat mass affect fat soluble medications.

- Altered liver metabolism of certain drugs and decreased renal excretion of drugs affect drug clearance.

VI. Common Adverse Reactions to Medications

- Potentially dangerous side effects in many medications

- Changes in pharmacokinetics may adversely affect cognitive status

- Accidents as a result of orthostatic hypotension

- Renal or hepatic toxicity from medication and/or drug-drug interactions
VII. Iatrogenic Problems with Multi-Geriatric Syndromes and their Medication Regimens ⁴ (Nursing and Ger. Ency. v2)

- Drugs with anticholinergic side effects can cause confusion, orthostatic hypotension, dry mouth, blurred vision, and urinary retention
- Tricyclics, which are sedating, may cause confusion and unstable gait. They are known to cause anticholinergic effects in older adults. Potential adverse side effects include hypotension, tachycardia, and arrhythmia.
- Antiemetics such as the phenothiazines may cause confusion, orthostatic hypotension, blurred vision, falls, dry mouth, and urinary retention.
- Digoxin can be a controversial medication with the elderly due to toxicity that may occur even with normal serum concentrations.
- H2 blockers require dose reduction in older adults to prevent confusion.
- Long-acting benzodiazepines may have half-lives prolonged as much as four days and cause central nervous system toxicity.
- Doses of narcotics need to be started low, with careful attention to preventing constipation.

VIII. Compliance

A. Causes for Noncompliance ⁵ (Ency. of Ger. vol 2, p. 296)

- Forgetfulness
- Misunderstanding of verbal directions
- Inability to purchase the medication
- Trouble with side effects
- Difficulty in swallowing larger capsules and tablets
- For the frail and arthritic, inability to open some medication containers

- Strategies for Enhancing Compliance ⁶ (Nursing and Ger. Ency. v2)

- Social or nursing support
- Awareness of risk factors including changes in cognition, living alone without social supports, depression, and declining function
- Careful attention to patient education including written instructions
- Discouragement of pill sharing
- Medication event monitoring systems (MEMS), pill boxes, pre-poured medications, friendly calls, pill counts
IX. General Guidelines for Prescribing Appropriately and Avoiding Polypharmacy

- **Obtain a Complete Drug History:** Be sure to ask about previous treatments and responses as well as about other prescribers. Ask about allergies, OTC drugs, nutritional supplements, alternative medications, alcohol, tobacco, caffeine, and recreational drugs.

- **Avoid Prescribing Before a Diagnosis is Made:** Consider nondrug therapy. Eliminate drugs for which no diagnosis can be identified.

- **Review Medications Regularly and Before Prescribing a New Medication:** Discontinue medications that have not had the intended response or are no longer needed. Monitor the use of prn and OTC drugs.

- **Know the Actions, Adverse Effects and Toxicity Profiles of the New Medications Prescribed:** Consider how these might interact or complement existing drug therapy.

- **Start Chronic Drug Therapy at a Low Dose and Titrate Dose on Basis of Tolerability and Response:** Use drug levels when available.

- **Attempt to Maximize Dose Before Switching or Adding Another Drug:** Encourage compliance with therapy. Educate patient and/or caregiver about each medication, its regimen, the therapeutic goal, its cost and potential adverse effects or drug interactions. Provide written instructions.

- **Avoid Using One Drug to Treat the Side Effects of Another:** Attempt to use one drug to treat two or more conditions.

- **Avoid Combination Products**

- **Communicate with other prescribers:** Don’t assume the patient will – they assume the prescriber does.

- **Avoid Using Drugs from the Same Class or with Similar Actions:** (e.g., alprazolam and zolpidem)
X. References

1  Ency. of Ger. vol 2, p. 295
2  Nursing and Ger. Ency. v2, 296
3  Ency. of Ger. vol 2, 296
4  Nursing and Ger. Ency. v2
5  Ency. of Ger. vol 2, p 296
6  Nursing and Ger. Ency. v2

XI. Learning Resources

- “Drug Therapy and the Interdisciplinary Team: A Clinical Pharmacist’s Perspective” Siple J.
- “Age-Related Changes as a Risk Factor for Medication-Related Problems” Beers MH.
- “What the Literature Tells Us About: The Complexity of Medication Compliance in the Elderly” Fulmer T et al.
Module # 17: Family Decision-Making & Interdisciplinary Care Planning
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

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## Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 17: Family Decision-Making & Interdisciplinary Care Planning

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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module #17: Family Decision-Making & Interdisciplinary Care Planning

I. Overview

The interdisciplinary care plan is based on data gathered during patient assessment, identifies the patient’s care needs, and develops strategies to meet those needs. The purpose of the Care Plan is to transition the patient through the continuum of care in a seamless, safe and effective way. In order to accomplish this goal, the plan of care documents treatment goals and objectives; states criteria for terminating specific interventions, and documents the patient’s progress in meeting the goals and objectives. An interdisciplinary care plan requires that each discipline must collaborate in the assessment and reassessment of the patient, and then strive to integrate interdisciplinary documentation of needs, goals, strategies and interventions.

II. Learning Objectives

1. Describe the conceptual framework in which an interdisciplinary care plan is developed
2. Identify care plan intervention strategies
3. Explain the differences between interdisciplinary and multidisciplinary perspectives
4. Discuss the care coordination process
5. Develop a professionally sound care plan

III. Definition

A. The process of developing an agreement between client and case manager regarding client problems identified, outcomes to be achieved, and services to be pursued in support of goal achievement.”¹

B. A dynamic decision making process based on assessment.² The effectiveness and appropriateness of the care plan depends on the assessment process

IV. Conceptual Framework

A. Care plans are patient centered and individualized.
1. When developing a care plan for an older adult, the interdisciplinary team must take into consideration not only the bio-psycho-social aspects of the case, but also the patient and caregiver’s desires.

2. Especially with larger interdisciplinary teams, the size of the geriatrics team may make it increasingly difficult for patients and families to have their voices heard. The patient/client and his/her family should always be considered as integral members of the team. Patients must be asked what involvement they desire.
   a. In one study, 40% of nursing home residents reported not being involved in their health care decisions. However, 79.3% of those patients reported that the level of their participation was sufficient. 3

3. Needs that threaten life, safety and security must be a priority. Core needs, those which if not dealt with will cause other problems, must be handled first. (i.e. hip pain vs. mobility issue)

B. Perception of need
   1. By patient
   2. By family
   3. By provider

C. Problem assessment
   1. What are this patient’s/ family’s needs, expectations, strengths and history
   2. What was tried before?
   3. What worked? What did not work?
   4. What are current relationships?
   5. Who is the leader – voluntary vs. involuntary?

D. Achievable outcomes must be created
   1. Accessible
   2. Acceptable
   3. Adaptable
   4. Appropriate
   5. Affordable

E. Strength Based Care Plan 4
   1. State in positive terms
   2. Make it realistic and achievable
   3. Measurable and visible
   4. Specific and time limited
   5. Relevant and understandable
V. Intervention Strategy

A. Engagement

1. Engage the client, not the diagnosis
2. Go slow
3. Don’t make promises
4. Respect their right to disagree
5. Determine who the “other” significant players are and
6. Engage them as soon as possible

B. Implementation

1. Prioritize
2. Start slow – Go slow
3. Choose your battles wisely
4. Healthy Alliances
5. Pick a “bad” guy
6. Get it right the first time!

C. Specific strategies for assistance

1. Educating patient/family on available resources
2. Fostering clearer communication among patient and family
3. Acceptance, reassurance
4. Keep all family members in the loop via designated point person

D. Follow-up

1. Monitoring
2. Reassessment
3. Termination

VI. Interdisciplinary Care Planning

A. Team members understand the roles and contributions of each discipline on the team and include methods for communication, collaborative care planning and shared responsibility for patient outcomes.

B. Team members integrate their assessments and recommendations for intervention, which creates a comprehensive care plan. (Multidisciplinary team members function independently with limited integration and collaboration.)
VII. Care Coordination Process

A. Care Coordination Task Flow:

B. Care planning is an important part of Care Coordination. The following list describes the Sequential Tasks of Care Coordination of which care planning is an integral part.

1. *Case finding or screening* to identify people in the target population who may require services

2. *Comprehensive, multidimensional assessment* to determine any individualized unmet needs

3. *Care planning*, which requires decisions about how the needs identified in the assessment can be met

4. *Implementation of the plan*

5. *Follow Up* to determine progress of implementation
6. Monitoring both the progress of the patient and the adequacy of the services given under the plan

7. Formal reassessment at intervals to gauge continuing need

8. Care Plan re-development or Close depending on reassessment findings

VIII. A Model Care Plan

A. Model Interdisciplinary Care Plan and Its Development

The following case study provides a comprehensive assessment model. Developed by the University of South Florida GITT Program as a simulation with actors, it contains a patient script, caregiver script and physician script. The case also describes a care plan that looks at the needs of the patient, the necessary interventions as well as which discipline should address each problem. The purpose of this model is to illustrate the steps in geriatric assessment and treatment plan development.

B. Patient Script

Identifying Information:
I am an 81-year old, white widowed man, born on 6/15/1917. I have completed 7th grade education. I have lived in the area of 10 years. My sister June, who is 75 years old, brought me to the office. June has moved in with me 3 years ago to help with the management of my diabetes and also because I was starting to have problems with my memory. This is my fourth visit.

Chief Complaint or Concern:
I frequently fall and I loose my urine. June, my sister, wants me to have a prescription to control, my urine to make me sleep better at night.

Present Illness:
Within the past week, I have fallen twice while en route to the bathroom. For the past few months there, I have had urinary accidents once or twice weekly when I was unable to get to the bathroom on time. I understand and acknowledge the problem with my memory deficits and the poor control of my diabetes, but feel that there is nothing I can do. It is my sister’s role to help me with those problems.

Medical History:

Medical conditions:
- Hypertension
- Edema of the lower extremities
- Diabetes
- Degenerative joint disease, commonly known as arthritis
- Decreased visual acuity secondary to cataract in my right eye
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- Two transient ischemic attacks (TIA) in the distant past

**Medications:**
- Tylenol PM (as needed) for pain caused by arthritis
- Lente insulin U-100, 30 U in am and 10 U in pm for diabetes
- Verapamil SR 240 mg daily for high blood pressure
- Temazepam 15 mg at bedtime to help me sleep
- Furosemide 40 mg daily (as needed) for the swelling in my legs
- Benadryl 25 mg (as needed) for anxiety

**Past Psychiatric History:**
I became depressed when my spouse died and was treated with medication for a few months.

**Social Resources:**
I have three children, Jan, April and Joe. They all live in other states and have children and grandchildren. They cannot give me any support with care giving. June and I live on our social security. The home belongs to me and I have a small retirement pension left by my spouse. During the day I look at the TV, read the paper, and watch the birds and the squirrels in the backyard. My friends have stopped visiting since my sister moved in. I wish my longtime friend Mary would come by and visit me. June complains that I am very demanding, that I don’t sleep at night, and that I need constant attention. This, June says, leaves her with no free time.

**Physician Examination:**
Weight: 130 lbs., a loss of 30 lbs. over 7 months. B/P: 120/78

The patient appears disheveled and weak. The patient smells of urine and his clothes are soiled. This is a marked change from a usually neat demeanor. He needs assistance with transfers and with undressing. The patient reports being left alone for long periods of time. The patient reveals being put to bed before his sister goes out for the evening and restrained to prevent him from getting out of bed. The patient eats twice a day and frequently receives the insulin dose late at night.

- A cataract is visualized in the right eye. Visual acuity is minimal in right eye but there is no loss of visual acuity in the left eye.
- Mucous membranes appear dry, tongue is red and smooth.
- Pitting edema of ankles 1+ (minimal)
- Knee joints are large, non-tender but with crepitation
- Patient is unsteady steady while standing
- Skin shows no bruising, except for purpuric lesions on the extensor surface of the hands.
- Skin turgor is poor.
No other abnormalities are found.

Lab results: Hgb 9.9, Hct 27%, MCV 72, BS 84, albumin 2.8, cholesterol 160

**Diagnoses:** After review of systems and physical exam, the doctor/nurse practitioner lists the following diagnoses:
- Rule out neglect
- Diabetes poorly controlled
- Malnutrition
- Rule out dementia
- DJD
- Mild edema of lower extremities
- Fall risk
- Dehydration
- Urinary incontinence
- Cataract right eye
- Hypertension well controlled

**Mental status:**
The patient’s voice is a monotone. His facial expression is sad and he appears depressed. He expresses the feeling that he cannot do anything that is valuable anymore. He is tearful when talking about being left alone. He expresses fear of intruders especially when his sister is not home. He reports being afraid of placement in a nursing home. He is unhappy and hopeless about the future. He reports not sleeping until his sister comes back home at night. He states, “I had a good life and am ready to go join my deceased spouse.”

His Mini Mental State Exam score is 20/30. He is disoriented to month, date and day. He does not know the name of the office although was able to recall its name during previous visits.

When he is asked to begin at 100 and count backward by 7, he makes two mistakes. When he is asked to remember three items, he can only remember one. When asked to copy a design, he cannot do it correctly. He can read a sentence after squinting his eyes and makes two attempts.

**Functional Assessment:**
He requires some assistance with bathing and dressing because of his arthritis and unsteadiness. On the days when his arthritis is worse, he needs help with transfers from his chair to the bed, with going to the bathroom, and with walking around the house. He can walk with a cane and he is sometimes unsteady because of the arthritis in his knees.

His sister cooks lunch sometimes and prepares all the dinners. He states that he can prepare breakfast, and that he eats leftovers or frozen dinner when his sister does not prepare lunch.

He cannot prepare his insulin injection because he can’t see the small numbers on the syringe. He doesn’t like to give it to himself, and states, “that’s what my sister is there for.”

**C. Caregiver Script**

**Social Resources:**
My brother has three children, Jan, April and Joe who live out of state and cannot give any support with care giving. My brother and I live on our social security. The house belongs to my
brother. My brother has a small retirement pension left by his deceased spouse. I am not sure what my brother does during the day; I am busy with my work and with continuously answering the same questions. We have a TV that is on all the time. Some friends used to come by and visit, but they don’t anymore. Who would want to visit when they hear the same questions and the same stories all the time?

There is always something my brother wants me to do. I never do enough. I cannot even have rest during the night, and I have no free time anymore.

**Physical Health:**

There is always something wrong. You have to do this, you have to do that. Take the blood pressure, check the sugar, and give the injection. I don't know why he has to take an injection since they have pills now for diabetes. I know because my friend takes pills.

My brother is always tired and cannot see well. He needs to go to the bathroom all the time and cannot even make it to the bathroom. He does not complain of pain.

**Mental Status:**

My brother keeps repeating that he is ready to die and join his deceased spouse. He never knows what date it is and asks me every 5 minutes. He never knows what’s going on.

**Functional Assessment:**

I have to help him with bathing and dressing because he is unsteady on his feet. Sometimes I have to help with transfers from the bed to the chair and from one room to another.

I have to help with getting him to the bathroom. I don't know why I have to do that, the cane is there to use. Also, I have to do all the cooking and cleaning.

**D. Interdisciplinary Care Plan**

**Main Problem** - Impaired coping by caregiver with suspected neglect and safety issues.

**Main Goal** – Caregiver: mobilize support and decrease stress

**Patient:** improve mood and health care management

**Team:** restore a safe patient environment

<table>
<thead>
<tr>
<th>Date</th>
<th>Problems/Needs</th>
<th>Goals</th>
<th>Interventions</th>
<th>Discipline</th>
<th>Evaluation Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>6/21</td>
<td>Impaired coping by caregiver with suspected neglect as evidenced by malnutrition, dehydration, and</td>
<td>1. Caregiver will verbalize understanding of diabetes management and the relationship</td>
<td>1. Provide caregiver with education in diabetes management; assess ability to administer insulin, observe her draw up and administer; assess ability to do home blood sugar monitoring. If</td>
<td>MD/NP; RN or HHA</td>
<td>6/28</td>
</tr>
</tbody>
</table>
| Use of restraining device. | Between insulin, diet, medication, and blood sugar. 2. Caregiver will verbalize decreased stress. 3. No evidence of patient’s emotional and physical neglect. | Unable, refer to home health for daily injections. Give instructions about diet and exercise. 2. Refer caregiver to support group. 3. Refer to protective service (P.S.) to help mobilize support such as respite care, adult day care, home health services and to follow-up on suspected neglect. 4. Counseling to validate feelings and discuss concerns. | 6/28
6/21
2.SW
3. MD/NP, SW, RN
4. PSY, SW |
|---|---|---|---|
| 6/21 At risk for fall secondary to poor vision, DJD, incontinence, and self-care deficits. | 1. Potential home safety problems will be resolved. 2. Patient will use assistive devices. 3. Patient will follow an exercise regimen. 4. Occurrences of falls will be decreased. 5. Patient will show improvement in self-care ability. | 1. Home evaluation for potential safety problems. 2. Ophthalmologist consult for cataract evaluation. 3. Referral to OT/PT for evaluation and treatment of arthritis pain and limitations, gait training, exercise program, assistive devices (wheelchair, bedside commode, urinal, bathtub railings, handles, etc.). 4. Refer to HHA for bathing assistance three times per week. | 6/28
1. MD/NP: order, SW, RN
2. MD/NP
3. MD/NP : order, OT, PT
4. MD/NP : order, SW |
| 6/21 Knowledge deficit in diabetes management leading to poor blood sugar control, memory impairment, and incontinence, dehydration and malnutrition. | 1. Diabetes control will be maintained average (160-200 BS and 8.0 to 9.0 HgbA1c). 2. Dehydration symptoms will resolve. 3. Malnutrition symptoms will be reduced (goal: albumin 3.0, low normal Hgb and Hct). | 1. Visiting nurse daily for education on insulin, diet exercise. 2. Refer to dietitian for evaluation of food intake and to prepare dietary plan. 3. Obtain support for Meal-On-Wheels. 4. Refer insulin administration to home health if caregiver unable to do. 5. Monitor weight weekly. 6. Have patient and/or caregiver record fluid and food intake for period of 3 days and blood sugar for one week. | 6/28
1. MD/NP: order, HHA, 2. MD/NP: order, SW, RD
3. SW
4. MD/NP: order, RN
5. pending |
<p>| 9 |</p>
<table>
<thead>
<tr>
<th>6/21</th>
<th>Patient exhibits memory impairment secondary to pseudo-dementia; this is aggravated by poor diabetic control</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Weight will stabilize</td>
<td>7. Review one week of above monitoring and re-evaluate insulin and diuretic requirements</td>
</tr>
<tr>
<td>5. Patient will verbalize relationship between insulin, diet, exercise, and BS results</td>
<td>8. Re-evaluate HgbA1c, albumin, Hgb, Hct</td>
</tr>
<tr>
<td>6/30</td>
<td>1. Geriatric depression scale will show improvement in depressive status</td>
</tr>
<tr>
<td></td>
<td>2. Volunteer visitor twice weekly</td>
</tr>
<tr>
<td></td>
<td>3. Plan enjoyable activities twice weekly</td>
</tr>
<tr>
<td></td>
<td>4. Encourage former friends to visit</td>
</tr>
<tr>
<td></td>
<td>5. Encourage children’s telephone contacts</td>
</tr>
<tr>
<td></td>
<td>6. ST referral to teach cognitive skills</td>
</tr>
<tr>
<td></td>
<td>7. Initiate antidepressants if above does not improve depressive status or if suicidal ideations occur</td>
</tr>
<tr>
<td></td>
<td>8. Taper off Temazepam and start on melatonin or Ambien if medication still needed for sleep</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6/21</th>
<th>Probable financial issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Available financial resources will be used where feasible</td>
<td>1. Assess financial needs</td>
</tr>
<tr>
<td></td>
<td>2. Explore sources of financial aid such as food share program, pharmacy medical program, drug company patient assistance program</td>
</tr>
<tr>
<td></td>
<td>1. SW</td>
</tr>
<tr>
<td></td>
<td>2. SW</td>
</tr>
</tbody>
</table>

IX. References


Module # 18: Elder Abuse and Neglect
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 18: Elder Abuse and Neglect

James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center
Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

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</tr>
<tr>
<td>1. Ms. R.</td>
<td></td>
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</tbody>
</table>
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 18: Elder Abuse and Neglect

I. Overview

A. Elder Mistreatment is a health care problem which continually rises as the elder adult population grows.

   A. Between one and two million Americans age 65+ have experienced mistreatment at the hands of those whom they depend on. (National Research Council Panel to Review Risk and Prevalence of Elder Abuse and Neglect, 2003)

   B. Elder mistreatment can result in long term health consequences including death. The condition encompasses physical, psychological, financial, sexual abuse, caregiver and self neglect, exploitation and abandonment. (Fulmer, T. & Greenberg, S. 2008)

B. The detection of elder mistreatment is difficult, so is monitoring for trends and prevalence

   A. Social stigma, fear of retribution and shame keep people from reporting incidents.

   B. For every one case of elder mistreatment reported to authorities five more go unreported. (National Center on Elder Abuse at American Public Human Services Association, 1998)

   C. Statutory and Regulatory definitions and reporting methods are different in every state. (The National Committee for the Prevention of Elder Abuse & The National Adult Protective Services Association, 2006, p. 9)

   D. Mechanisms such as advanced interdisciplinary training and uniform state wide reporting to monitor trends would enhance Elder Abuse detection.

II. Learning Objectives

1. Define “elder mistreatment” and “elder neglect”.

2. Describe the prevalence of elder abuse in the United States.

3. Describe the multiple forms of elder mistreatment.
IV. Definitions

A. Elder Mistreatment

A. The American Medical Association’s Diagnostic and Treatment Guidelines on Elder Abuse and Neglect defines elder mistreatment as “The act of omission or commission that results in harm or threatened harm to the health or welfare of an older adult.” The act can be either intentional or unintentional. The term encompasses elder abuse and neglect. (Cobbs, E.L., Duthie, E. H., & Murphy J.B., (Eds.) 1999)

B. The majority of substantiated reports of elder mistreatment occurred in domestic settings, followed by long term care settings, hotels, motels, workplace and assisted living facilities. (The National Committee for the Prevention of Elder Abuse & The National Adult Protective Services Association, 2006, p.19)

IV. Demographics

A. 50 states and the District of Columbia have Adult Protective Services (APS) statutes establishing APS programs for identification and investigation of elder abuse and neglect. (Capezuti, Brush & Lawson, 1997, 23(7), 24-32)

A. Adult Protective Services substantiated 88,455 reports of elder mistreatment on persons aged 60+ in 24 states. (The National Committee for the Prevention of Elder Abuse and The National Adult Protective Services Association, 2006, p.16)

B. Adult Protective Services substantiated 46,794 reports of self neglect on persons aged 60+ in 20 states. (The National Committee for the Prevention of Elder Abuse and The National Adult Protective Services Association, 2006, p.16)

C. “Total reports of elder and vulnerable adult abuse for people of all ages represent a 19.7% increase from the 2000 survey. Of the 565,747 reports, 253,426 reports were for those 60 years of age and older. Women made up 65.7% of elder abuse victims and 52.7% of alleged perpetrators.” (Teaster, P.B., & Dugar, T.A., 2005)

D. 20.8 % of victims were between the ages of 60 and 69, 36.5% were between 70-79 and 42.8 % 80 years of age and older in 20 states where 75.1%
of perpetrators were under the age of 60 in 7 states. (The National Committee for the Prevention of Elder Abuse and The National Adult Protective Services Association, 2006, p.19)

E. The relationship between the alleged perpetrator and the victim were mostly adult child 32.6% then other family members 21.5 %, unknown relationship 16.3% and spouse or intimate partner 11.3% in 11 states. (The National Committee for the Prevention of Elder Abuse and The National Adult Protective Services Association, 2006, p. 20)

V. Forms of Elder Mistreatment

A. Abuse – Also known as “mistreatment” or “maltreatment and is harmful behavior directed toward an older person by a family member or professional caregiver whom the older person trusts or depends on for assistance. (Fulmer, T. & Greenberg, S. 2008)

B. Neglect-Intentional or unintentional harmful behavior on the part of an informal or formal caregiver in whom the older person has placed his or her trust. Examples include the refusal or failure to carry out a caretaking responsibility such as withholding food, medicine, or aids (glasses, dentures), and actual abandonment of the older adult.

C. Active Neglect-The caregiver refuses or fails to fulfill a caretaking obligation, including a conscious and intentional attempt to inflict physical or emotional distress on the elder; deliberate abandonment, or deliberate denial of food or health-related services.

D. Passive Neglect-In this type of mistreatment, the caregiver unconsciously or unintentionally refuses or fails to care for the older person. Examples include abandonment, non-provision of food or health-related services because of inadequate knowledge, laziness, infirmity or disputing the value of the prescribed service, includes failing to meet the older adults social and emotional needs. Usually occurs when the caregiver is overburdened.

E. Physical Abuse-Physical mistreatment entails the infliction of physical pain or injury, physical coercion, or confinement against one’s will. Examples include pushing, shoving, shaking, slapping, kicking, punching, hitting, bruising, burning, sexual coercion or molestation, force-feeding and improper use of physical restraints or medications.

F. Physical Neglect-The caregiver neglects to provide the goods or services that are necessary for optimal functioning. Examples include not giving or delaying needed health care, such as meals and water, failure or delay in medical treatment, physical therapy, and washing, and failure to provide such assistive devices as glasses, hearing aids, or canes, inadequate housing, failure in preventing or treating bed sores.
G. Psychological/Emotional Abuse-This type of mistreatment entails psychological and mental anguish and despair. Examples include insulting, ignoring, yelling, threatening remarks, mean jokes, humiliation, treating the older adult as an infant, harassment, forced isolation and controlling behavior.

H. Psychological Neglect-The caregiver fails to provide social or emotional stimulation and opportunities for social interaction, such as leaving the older adult alone for long periods of time. Denying contact with other family members. Other examples include ignoring requests of the older person and failing to give him new or information.

I. Financial Exploitation-This is illegal or unethical exploitation and/or use of cash, credit cards, funds or other financial resources of the older person. Examples include coercing the individual to sign contracts or sign over assets or making changes in a will, forging signatures, cashing checks without consent, stealing money and or possessions.

J. Financial/Material Neglect-In this type, the caregiver fails to use the available funds or resources which are needed to provide an optimal quality of life for the older person such as not providing necessities for daily living such as food, shelter, medicine, hygiene or failing to pay bills.

K. Violation of Person Rights-The older person’s rights and capability to make decisions for him-self are ignored. Examples include denying privacy, autonomy in decision making with respect to health care and other personal issues (e.g., marriage) and forcible placement in an institution.

L. Self-Abuse or Self-Neglect-This occurs when the older person commits any of the above activities on himself or herself for example not providing oneself with food, shelter, neglecting personal hygiene and not seeking adequate medical care.

VI. Risk Factors For Elder Mistreatment And Abuse

A. Care Giver Stress

The older person is overly dependent for physical, emotional and financial support which may become burdensome to the care giver.

B. Who is susceptible

The frail and more physically vulnerable who require physical care from family caregivers.

C. Mental illness in older person, family members and caretakers

Older person or Caregiver experiencing depression/delirium/progressing dementia/anxiety/agitation/passive behavior/evasiveness/fear or confusion. (Greenberg, D., 2009)
D. Other contributing factors-caregiver and or older person partaking in (Wagner, L., Greenberg, S. & Capezuti, E., 2002)

A. Alcoholism
B. Drug abuse
C. Childhood trauma
D. Family violence
E. Financial strain/poverty
F. Increased age
G. Isolation of caregiver or older adult

VII. Elder Mistreatment Assessment

A. Interdisciplinary assessment and intervention planning is most important in keeping the elder adult safe and in good health. Physicians, nurse practitioners, nurses, social workers along with other professions are the make-up of interdisciplinary teams.

A. Find a confidential intimate environment.

B. Interview and evaluate the elder adult and the caregiver separately then together. Assess for cognitive functioning and decision making capacity to evaluate risk benefit and potential consequences of the presenting situation and of interventions.

C. Gather history by beginning with general, open-ended questions and move toward more specific questions, avoid leading the individual. For example, “General: ask about living situation, relationships, functional status/assistance? Specific: Do you feel safe at home? Are you afraid of anyone? Has anyone threatened you (verbally or physically)? Has anyone touched you without permission? Has anyone asked you to sign documents you don’t understand? Has anyone taken your things without permission? Has anyone refused to help you when you needed it? Are you alone a lot of the time? Are you prone to encountering accidents? Questions for caregivers: How long have they cared for the patient; Do they understand and are they able to verbalize the elder persons medical condition; have the caregiver describe their responsibilities in caring for the elder adult; get an understanding of how the caregiver copes with their responsibilities.” Note inconsistency in stories and their reactions to questions be mindful of body language (yours and theirs). Try not to judge or become confrontational. Allow for empathy in relation to care giving burden. Remember your work is with the entire family and many times there are no villains’ only victims in elder mistreatment. (Greenberg, D., 2009)
B. Physical Indicators of Mistreatment

A. Be aware of inadequately explained injuries for instance bruises usually bilaterally due to grabbing, black eyes, welts, lacerations, rope marks, fractures, untreated injuries, bleeding broken eyeglasses, use of physical restraints, sudden change in behavior and pressure ulcers. (Fulmer, T. & Greenberg, S., 2008)

B. Unexplainable dehydration or malnourishment, excessive weight loss and lose rings. (Greenberg, D., 2009)

C. Be aware of lack of cleanliness, grooming, personal hygiene, inappropriate clothing in relation the weather, no assistive devices and mismanaged medications. (Greenberg, D., 2009)

D. “Presence of head injury, hair loss, or hemorrhaging beneath the scalp. Signs of possible sexual abuse: discharges, bruising, bleeding or trauma around genitalia or rectum, unexplained venereal disease or genital infections.”

C. Behavior of the Patient Indicating Mistreatment (Greenberg, D., 2009)

A. Be aware of crying and silences.

B. The patient acting overly medicated or overly sedated.

C. Fearful of speaking in caregivers presence and appears anxious and eager please.

D. Be aware of expressions of anxiety, confusion, withdrawal, shame, fear, embarrassment, depression, hostility, secrecy and vague complaints.

E. The older adult makes little to no eye contact or communication.

F. Explanation is not consistent with the medical findings.

D. Assessing the Caregiver-usually primary caregiver (Greenberg, D., 2009)

A. Makes threatening remarks and or behavior.

B. Is defensive and shifts blame.

C. The presenting stories conflicting.

D. Caregiver insults and is aggressive towards the elderly person.

E. Withholds attention, security and affection.

F. Gives excuses for failing to provide care.
G. With holds food or medication.

H. Caregiver experiencing unusual fatigue and or depression.

I. There is prevalence of substance abuse.

J. There is a history of abusive behavior.

K. Explanations given by the elder adult and the caregiver conflict.

VIII. Elder Mistreatment Interventions

A. Goals (Greenberg, D., 2009)

A. To protect the elder adult and ensure safety.

B. “Develop and implement safety plan, such as safe home placement/discharge, hospital admission and/or protective court order”

C. Possible removal from harmful or potentially harmful situation, with the approval of the elder adult or without when decision ally incapacitated to choose. (Fulmer, T. & Greenberg, S., 2008)

D. Work towards having more oversight for the elder adult and increasing caregivers.

E. Assist with guardianship if indicated

F. In reducing the risk of future mistreatment work towards improving functional capacity, ease dependency and stress of the caregiver.

G. Discuss entitlement and resources.

B. Begin with Creating a Joint Plan

A. Assess whether there is a willingness to accept the intervention. If there is resistance to help assess whether the elder adult is capable of making decisions and understanding there consequences. “Competent older adults have the right to remain in dangerous situations (if no duress or undue influence.” (Greenberg, D., 2009)

C. Key Questions to Guide Interventions

A. “How safe is the patient if I send him or her back to the current setting?

B. What services or resources are available to help a stressed family?

C. Does the elderly person need to be removed to a safe environment?
D. Does this situation need an unbiased advocate to monitor the care and finances for this patient?

D. Reporting Mistreatment:
   A. Close to all states have a requirement designating health care professionals to report suspected elder mistreatment to a state authority.

E. Community Resources Available to Victims: (Greenberg, D. 2009)
   A. Case management services
   B. Protective services
   C. Support counseling services
   D. Victims’ services network, police services
   E. District Attorney’s office-Bronx District Attorney’s Office Elder Abuse Coordinator for Criminal Offenses
   F. Legal services specializing in the elderly
   G. Social Service Support-JASA Home evaluation DIFTA/NORCC case management, CHHA
   H. Respite services-Hebrew Home for the Aged Harry & Jeanette Weinberg Center for Elder Abuse Prevention
   I. Reporting Laws- Social Service Law 473-B reporting of endangered adults, confidentiality insured
   J. Adult Protective Services Voluntary/ Involuntary-Financial Management/Article81/Heavy Duty Cleaning
   K. Emergencies 911

IX. A Unique Intervention Model (Dyer, C.B. & Goins, A.M., 2000)
   A. “Geriatric interdisciplinary teams focus on the overall condition of the patient and may be limited in ability to intervene in cases of abuse or neglect.
   B. Adult Protective Services specialize in assessment and intervention in cases of possible neglect or abuse- focus here precludes comprehensive medical assessment
   C. In light of above factors, Baylor College of Medicine Geriatric Program has collaborated with Adult Protective Services (APS) Division, making an APS representative a member of the Geriatric Interdisciplinary Team.
D. Interdisciplinary care plan now includes findings from APS assessment.

E. Assessments are carried out both in outpatient geriatric clinic and in the older clients’ homes.

F. This model fully addresses 3 vital domains of older adult’s life: a) medical problems b) social milieu, and c) functional status. Medical and APS assessments complement each other to address each domain.”

*Special thanks to Ms. Jessica Gutierrez for her contribution to this Module.
X. References


Learning Resource A

Elder Abuse/Neglect Screening Assessment Tool

Patient’s Name: ____________________________ Date: _____________

Introductory comment: No matter how well people get along there are times when they disagree on major decisions, get annoyed about something the other person does, or just have arguments because they are in a bad mood or for some other reason. People also use many different ways of trying to settle their differences. I am going to read you some things that people do when they have arguments or problems, and ask you whether this has ever happened to you.

<table>
<thead>
<tr>
<th>Ask patient directly:</th>
<th>Yes</th>
<th>No</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Has anyone ever hurt you?</td>
<td>___</td>
<td>___</td>
<td>___________</td>
</tr>
<tr>
<td>2. Has anyone ever touched you when you didn’t want to be touched?</td>
<td>___</td>
<td>___</td>
<td>___________</td>
</tr>
<tr>
<td>3. Has anyone forced you to do something against your will?</td>
<td>___</td>
<td>___</td>
<td>___________</td>
</tr>
<tr>
<td>4. Has anyone ever taken anything that was yours without permission?</td>
<td>___</td>
<td>___</td>
<td>___________</td>
</tr>
<tr>
<td>5. Have you ever given anything away even though you really didn’t want to?</td>
<td>___</td>
<td>___</td>
<td>___________</td>
</tr>
<tr>
<td>6. Does anyone ever talk or yell at you in a way that makes you feel lousy or bad about yourself?</td>
<td>___</td>
<td>___</td>
<td>___________</td>
</tr>
<tr>
<td>7. Are you afraid of anyone?</td>
<td>___</td>
<td>___</td>
<td>___________</td>
</tr>
<tr>
<td>8. Has anyone ever threatened you?</td>
<td>___</td>
<td>___</td>
<td>___________</td>
</tr>
<tr>
<td>9. Has anyone ever refused to help you take care of yourself when you needed help?</td>
<td>___</td>
<td>___</td>
<td>___________</td>
</tr>
<tr>
<td>10. Has anyone used your money in a way you did not like?</td>
<td>___</td>
<td>___</td>
<td>___________</td>
</tr>
</tbody>
</table>

Y  N  Comments
11. Do you have ready access to a telephone?  ___ ___ __________________

12. Do you live with anyone, or have any close family members who abuse drugs or alcohol, or have a psychiatric or emotional illness?  ___ ___ __________________

13. Do you feel that your basic needs for food, clothing, shelter and medications are adequately available to you all the time?  ___ ___ __________________

14. Are you able to go out of your house when you want?  ___ ___ __________________

15. Are you happy with how often you see your relatives and friends?

If any answers to questions 1-11 are “yes” or 12-15 are “no”, please elaborate and consider consulting the Elder Abuse Team.

**Physical Assessment**

Describe patient’s general appearance (e.g., inadequate or inappropriate clothing, dirty or odorous): ______________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________

Check if any of the following are present:

- [ ] Bruises  - [ ] Rashes
- [ ] Fractures  - [ ] Scars
- [ ] Burns  - [ ] Welts
- [ ] Lacerations  - [ ] Punctures
- [ ] Abrasions  - [ ] Decubiti
- [ ] Other

**Stages of decubitus/pressure ulcers:**

I. Redness not resolving after 20 minutes following relief of pressure, epidermis intact.

II. Break in skin involving the epidermis. May appear as a blister with erythema
and/or induration.

III. Skin break exposing subcutaneous tissue.

IV. Skin break exposing muscle and bone.

**Dating of Bruises:**

<table>
<thead>
<tr>
<th>Date</th>
<th>Appearance</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2 days:</td>
<td>Swollen, tender</td>
</tr>
<tr>
<td>0-5 days:</td>
<td>Red-blue</td>
</tr>
<tr>
<td>5-7 days:</td>
<td>Green</td>
</tr>
<tr>
<td>7-10 days:</td>
<td>Yellow</td>
</tr>
<tr>
<td>10-14 days:</td>
<td>Brown</td>
</tr>
<tr>
<td>2-4 weeks:</td>
<td>Clear</td>
</tr>
</tbody>
</table>

**Status of Assistive Devices:**

If patient needs and does not have devices, or patient has but does not use devices, this may be evidence of neglect.

<table>
<thead>
<tr>
<th>Device</th>
<th>Needs</th>
<th>Has</th>
<th>Uses</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dentures</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cane</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walker</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing Aid</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Ask Patient Directly:

Has anyone ever prevented you from obtaining or using aides?
* Yes _____ No _____

* If yes, please explore further and consider consulting the Elder Abuse Team.

Reference:

Written by: Pamela Ansell, MSW, Mount Sinai/Victim Agency Abuse Team Project, New York City.; Judy S. Bloom, MPA, Montefiore Medical Center Elder Abuse Project; Karl Pillemer, PhD, University of New Hampshire's Family Research Laboratory; Contributors: Barbara Paris, MD and Meryl Weiss, RN, Mount Sinai/Victim Services Agency Elder Abuse Project.

This tool is adapted from a research survey titled “Family Relationship of the Elderly,” developed by the Center for Survey Research, University of Massachusetts-Boston and the center for Family Studies University of New Hampshire (Fall, 1985).

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Winter, 1988
Learning Resource B

Case Studies

Case Study # 1: Ms. R.

Ms. R is an 85-year old woman who lives in a New York City apartment with her 60-year-old daughter, Ms. S. Ms. R was born in Puerto Rico and moved to the mainland shortly after she was married. All four of her children were born in New York. Three of Ms. R’s children are married, and two of them along with their spouses, retired and moved to the Miami area a few years ago. One daughter lives in central New Jersey. Ms. R has 11 grandchildren, and five of them live within an hour’s trip of New York City. Ms. S has never married, and after her mother was widowed, Ms. S gave up her own apartment and moved in with her mother.

Recently, Ms. R developed a high fever and was diagnosed with pneumonia. Her physician admitted her to the hospital, where her daughter sits at her bedside for most of the day. When you speak to Ms. S, she tells you that Ms. R frequently seems to “lose track of time.” In fact, before admission to the hospital, Ms. R was awake much of the night at home and slept during the day. As a result, Ms. S says she herself is very tired most of the time and is experiencing difficulty at work.

After a few days of intravenous therapy and antibiotics, Ms. R recovers from pneumonia, and plans are made for her to be discharged home. Ms. S expresses concern to you that her caregiving responsibilities are becoming somewhat overwhelming, and she is feeling very stressed.

Case Study # 2: Dr. S.

Dr. S. is a 74-year-old divorced woman, mother of one son, retired neurologist, who was referred to the Geriatrics Practice by her orthopedic surgeon for general evaluation and medical care. Dr. S.’s medical diagnoses included hypothyroid disease, severe arthritis of the hip, and memory loss. Her son accompanied Dr. S. to her medical visit. She was agitated, tearful, uncooperative with a physical examination, and unable to provide a history. Her son was cooperative but appeared unrealistic about his mother’s capabilities.

Dr. S. was subsequently seen in the Gero-Psychiatry Clinic and hospitalization was recommended. During this admission, past medical history came to light indicating physical and emotional abuse by her son. Protective Services for Adults previously knew the case and Guardianship procedures were already underway.

The patient’s son was upset by her hospitalization and repeatedly requested that his mother be discharged. He denied abusing his mother and felt that other people were just trying to take her money. Dr. S. was discharged of the care of a home attendant and a guardian was instituted. The son was given limited supervised visitation privileges.

Dr. S. was started on physical therapy in her home. Physical therapists were unable to work with the patient due to her dementia and agitation. A private therapist, experienced in working with dementia patients was recommended but the guardian would not pay for the services. The guardian subsequently requested that the patient’s psychotropic medications be increased to help calm her down, as she could no longer afford to pay the two 12-hour home attendants.

Questions:

1. Should we have been able to detect a history of abuse on the day of the initial visit?

2. Do we feel that the guardian was acting in the best interest of the patient?

3. What role does the medical team have in contacting the courts or Protective Services for Adults to advise about concerns about guardians and financial difficulties?

Module # 19: Sexuality and Aging
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module #19: Sexuality and Aging

James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

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## Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

### Module # 19: Sexuality and Aging

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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 19: Sexuality and Aging

I. Overview

“Sexuality in the elderly is a ‘dark continent’ that most people, including physicians, prefer not to think about.” ~ J. LoPiccolo

There is no question that we live in an ageist society whereby prejudices and stereotypes are frequently used when describing sex and sexuality in older adulthood. Thus, it is imperative to examine how society has shaped and constructed our views of sexuality as well as educate others about the key issues surrounding sexuality within the elderly population. This module highlights several important areas regarding sexual health and aging and outlines vital topics that healthcare professionals are encouraged to educate themselves on so they may better care for their elderly patients.
II. Learning Objectives

1. Provide a general overview of key topics related to sexuality and aging.
2. Identify myths and barriers about sex and the elderly.
3. Examine sexual activity among the elderly.
4. Define common sexual problems.
5. Identify sex drugs and their associated risks.
6. Examine sex as it relates to the elder LGBT community.
7. Examine the prevalence of STD and HIV among the elderly.
8. Identify the roles of healthcare professionals.

III. Myths And Barriers About Sex And The Elderly

A. What do some people think of when they think of the elderly and sex?
   - The elderly do not want to be sexually active.
   - Sexual interest decreases with age.
   - The elderly are not capable or desirous of sex.
   - Sexual dysfunction = the end of an active sex life.
   - Elderly sex is dysfunctional.
   - Sexual performance is impossible for those with cognitive loss.
   - There is no risk of STDs and/or HIV.

B. Common Barriers That Preclude The Elderly From Having Sex
   - Physiological and biological changes
   - Illness and/or decline of health (self or partner)
   - Impotence
   - Feelings of guilt (i.e. cultural and/or generational attitudes about sex)
   - Widow’s Syndrome
   - Lack of freedom
   - Lack of privacy
   - Lack of a partner
   - Fear of what others will think or say
   - Inability to discuss issues and concerns with healthcare professionals
   - Low self-esteem

IV. Sexual Activity Among The Elderly

A. New England Journal Of Medicine Study- Sexuality Among Older Adults
• Unprecedented national population-based study conducted from 2005-2006 looking at sex and seniors
• Interviews held with 3,005 community-dwelling adults ages 57-85
• Population-based sample with minority over-sampling
• 120-minute in-home interviews + leave-behind questionnaire
• Findings of the study were very significant:
  o 73% of Americans aged 57-64 reported being sexually active
  o 53% of Americans aged 65-74 reported being sexually active
  o 26% of Americans aged 75-85 reported being sexually active
  o Women reported less sexual activity than men
  o Women lacked partners more so than men
  o People whose health was excellent or very good were almost 2x as likely to be sexually active as opposed to those in fair or poor health
  o 50% of Americans reported at least one sexual problem.
    ▪ Women: low sexual desire (43%); vaginal lubrication difficulties (39%); inability to climax (34%)
    ▪ Men: erectile dysfunction as the common problem

B. Where Do Older Adults Have Sex?

• Home
• Assisted Living Facilities
• Nursing Homes
• NORCs

C. What are the benefits of having sex during older adulthood?

• Improves overall quality of life
• Psychological benefits
• Allows for sexual expression and freedom
• Promotes intimacy between partners
• Physical, intellectual, and spiritual fulfillment
• Encourages open communication
• Dispels stereotypes about the elderly

V. Common Sexual Problems For Older Adults

A. Lack Of Interest / Decreased Desire

• Self or partner not interested in having sex
• Hormonal changes (i.e. menopause and post menopausal status) may result in low sexual desire
• Fear of pain and/or discomfort
• Cognitive decline and/or impairment
• Change in relationship status- single, divorced, widow(er), etc.
B. Female Sexual Dysfunction

- Decreased sexual function and responsiveness
- Dyspareunia- pain associated with intercourse
- Estrogen deficiency
- Difficulty with lubrication and reduced size of vagina and vulva
- Delayed or absent orgasm
- Multiple medical ailments and chronic diseases which may affect sexuality
- Psychological factors
- Increased bodily sensitivity

C. Male Sexual Dysfunction

- Delay of erection
- Decreased tension of scrotal sac
- Loss of testicular elevation
- Erectile Dysfunction (ED)- inability to achieve or maintain an erection adequate for sexual intercourse
- ED is commonly caused by (1) vascular disease and (2) neurologic disease
- Adverse medication side effects
- Endocrine problems
- Psychogenic issues- i.e. relationship conflicts, performance anxiety, childhood sexual abuse, etc.

VI. Sex Drug Market Geared Towards Older Adults

A. Mass Global Marketing of Erectile Dysfunction Drugs

- The United States is the biggest market for drugs.
- Doctors prescribe impotence drugs approximately 17 million times a year to less than 5 million men.
- In 2004, global sales of Viagra (sildenafil), Levitra (vardenafil), and Cialis (tadalafil) reached 2.5 billion dollars.

B. Viagra

- The construction of male sexuality by the medical community led to the creation of Viagra.
- Millions of men turn to Viagra as the answer to erectile dysfunction.
- Some feminist scholars believe Viagra is a step backwards in gender equality because of the “phallocentric” perspective that the penis is key to good sex.
- Some men have had negative experiences with Viagra, resulting in less penile-focused sexual activities.
- For older adults, heart palpitations associated with taking Viagra can be dangerous and possibly deadly.
- Other reported problems- heartburn and indigestion; functional problems (i.e. overly rigid and inflexible during intercourse)

C. Drugs For Women

- Many women are turning to drugs in order to improve their sex life.
- FDA has not yet approved one single sex drug geared towards women due to lack of long-term safety data.
- Increased number of postmenopausal women are turning to estrogen and progestin treatments.
- Many elderly women do not feel comfortable talking about sex with their healthcare professionals, resulting in the purchase of over-the-counter sex pills.
- Medication management and reconciliation is absent.

VII. Sex And The LGBT Community

A. GLBT Older Adults

- There are very limited programs that provide resources to the elder LGBT community about sex and sexual health.
- In most healthcare facilities, same-sex “partners” are not permitted to share a room.
- Some GLBT older adults are reluctant to reveal sexual orientation and activity to their healthcare professionals out of fear that they will face discrimination and/or receive inadequate medical care.
- Many GLBT older adults will retreat back into the closet due to homophobia by others.

B. Met Life Study Of Lesbian And Gay Baby Boomers

- Offers an unprecedented snapshot of the concerns of lesbian, gay, bisexual and transgender (LGBT) baby boomers in the United States as they are faced with caregiving responsibilities later in life.
- Study was produced by the Met Life Mature Market Institute and ASA’s Lesbian and Gay Aging Issues Network (LGAIN).
- Zogby International conducted a national poll using a random sample of LGBT Americans ages 40-61.
- This is the first national survey of LGBT baby-boomers in the entire world.
- Results of the report have powerful implications:
  - About 40% of respondents believe that being LGBT has helped prepare them for aging.
  - 27% report a great concern about discrimination as they age.
o 20% of respondents are unsure of who will be their caretaker if the need shall ever present itself.
o 75% expect to take on a caregiver role for someone else.
o 51% of respondents have not yet completed advance directives.
o Less than 50% of respondents expressed confidence that they would be treated with “dignity and respect” by healthcare professionals.

VIII. Sexually Transmitted Diseases And HIV/AIDS

A. Impact On Older Adults

- STDs are not just limited to younger people.
- Lack of screening for STDs may result in serious complications later in life.
- Cervical cancer and HPV is often untreated in women, causing thousands of deaths each year in the United States.
- Many older people do not use condoms because they do not consider themselves at high risk for sexually transmitted diseases.
- Naturally weaker immune systems later in life result in increased risk of sexually transmitted infections.

B. HIV/AIDS Among The Elderly

- 19% of all people with HIV/AIDS in the United States are age 50 and older.
- Numbers may be higher due to lack of testing among older adults.
- The current elderly population does not know as much about HIV/AIDS as the younger generations.
- Women’s vaginal tissues become thinner after menopause, increasing the risk of tears and transmission of HIV/AIDS.
- There is not enough education and/or prevention messages for elderly people regarding this topic.
- Healthcare professionals fail to discuss sex and drug use with their elderly patients.
- Elderly people may mistake symptoms of HIV/AIDS for common aches and pains associated with “normal” aging.

C. Importance Of Getting Tested

- Healthcare professionals should encourage regular screenings for STDs and HIV for their elderly patients.
- Easy-to-comprehend materials discussing screenings/testing should be readily available at senior centers as well as various healthcare settings.
- Testing should not be limited to one partner- all individuals engaged in some form of sexual activity should be tested.
- Some testing centers/facilities may provide condoms and lubricants for patients after screening is complete.
IX. Role Of Healthcare Professionals

A. Why is it important to talk about sex with your patients?

- Helps build trust/rapport with patients
- Shatters myths about sexuality and aging
- It is a very significant subject matter to older adults
- Massive demographic shift over the next several years will result in huge growth of the elderly population
- Increased longevity will promote a more holistic approach to healthcare, including greater focus on sexual health
- Several common medications have sexual side-effects
- Sexual problems may stem from underlying chronic conditions or diseases

B. What is the role of healthcare providers?

- Treat older adults with respectful and non-judgmental attitudes
- Conduct thorough sexual health assessments/histories as part of a visit
- Ask direct questions about sexual activity and attitudes
- Educate patients and their caregivers about topics in sexuality and aging
- Provide appropriate treatment options
- Recommend treatments and adaptations for sexual problems
- Listen to patients’ sexual concerns
- Incorporate patients’ sexuality into counseling
- Provide appropriate referrals to specialists as needed
X. References


Module # 20: Grief and Bereavement
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# Module # 20: Grief and Bereavement

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I. Overview

- We are dying from the moment we were born.
- Dying persons are living human beings.
- Dying is a special situation in living.
- Death is the outcome of dying, not its equivalent.
- Like all other individuals, dying persons have a broad range of needs, desires, plans, projects, joys, suffering, hopes, anxieties, and fears.
- We cannot become effective providers unless we listen actively to those who are coping with dying and identify with them their own needs.
- We need to learn from those who are dying and coping with dying in order to know ourselves better.

II. Learning Objectives

1. Discuss the use of denial in coping with terminal illness.
2. Identify the settings of end of life care.
3. Discuss dying as a physical, psychological, social, and spiritual event.
5. Discuss ways of promoting an appropriate death.
6. Assess and treat the common physical symptoms during the last hours of life.
7. Describe physiological changes after death.
8. Identify the principles of care following death.
9. Discuss communication with families and ways of providing support following patient death.
10. Define key terms related to loss, grief, death, and bereavement.
11. Identify factors influencing the grief reaction.
12. Describe psychological, physical, and social manifestations of grief.
13. Discuss the processes of grief and mourning.
III. Reactions And Coping With Dying

A. Initial Awareness of Dying From:  
- Direct or indirect statements from physicians, health professionals, or family  
- Changes in behavior of others  
- Changes in treatment  
- Changes in physical environment  
- Self-diagnosis from one’s body

B. Task-Based Model for Coping with Dying  
   - Physical tasks: satisfy bodily needs and to minimize physical distress in ways that are consistent with other values.
   - Psychological tasks: maximize psychological security, autonomy, and richness of living- get dressed use perfume, taste desired food (dignity).
   - Social tasks: sustain interpersonal relationships that are significant (concern for self and family) and to address social implications of dying. (i.e. Meals on Wheels, obtaining hospital equipment, and transportation assistance.)
   - Spiritual tasks: to identify, develop, or reaffirm sources of spiritual energy and in doing so to foster hope. (Life review)

C. Three Spiritual Tasks When Dying:  
   1. Find meaning in life.  
   2. To die appropriately consistent with one’s identity.  
   3. Find hope that extends beyond the grave.  
      - Hope to be without pain.  
      - Hope to see his grandchild born.  
      - Time to say good-byes.  
      - Hope may be based on personal aspirations or emphasize desires and welfare of the group.  
      - Hope is grounded in reality and is really about faith and trust in the meaning and goodness of life.

D. Emotional Reactions and Fears of the Dying Patient  
   1. Anxiety  
      Deal with anxiety by breaking it down into its component parts to delineate the specific fears and address each one. Such fears may include:
   2. Fear of the Unknown- especially in the acute crisis phase.  
      a. Questions that may be answered or are philosophical and cannot be
answered:

- What life experiences will I not be able to have?
- What is my fate in the hereafter?
- What will happen to my body after death?
- What will happen to my survivors?
- How will my family and friends cope?
- What will happen to my projects and life plans?
- What changes will occur in my body?
- What will be my emotional reactions?

3. **Fear of Loneliness**
   In sickness, others are often uncomfortable to see the person ill and in pain, so there is avoidance leading to loneliness and isolation from social contacts. Family members have their own fear of death and isolation in hospital environment. Loneliness is the prospect that they will be abandoned in their sickness. In the acute phase, determine who will remain with the patient. In the chronic phase, need to engage person in everyday relationships so that dying does not become their sole focus. Indicate to the patient that he need not feel loneliness, although at times he may be alone.

4. **Fear of Loss of Family and Friends**
   Dying person needs to clarify and accept ambiguous and conflicting emotions between himself and his loved ones in an effort to achieve some acceptable resolution and reaffirm the meaning and value of relationships.

5. **Fear of loss of self-control**
   Help patient maintain control such as decision-making in daily tasks and arranging the funeral. This allays the sense of guilt, frustration and helplessness due to the illness.

6. **Fear of loss of body parts and disability**
   Loss of body parts brings shame, inadequacy, guilt feelings, and fears of being unloved. Continue to show respect and not disclose aversion to them physically. Let the dying person do as much as possible in terms of feeding, bathing, grooming and exercise.

7. **Fear of Suffering and Pain**
   Increase person’s ability to tolerate pain by:
   - Knowing that pain is not a form of punishment;
   - That they will not be ignored or left alone;
   - That pain will be managed as rigorously as possible.
   - Remaining open and available to the person despite the pain and anxiety of attending to the terminally ill (also physical presence).
8. **Fear of Loss of Identity**  
Loss of friends, function, and control along with attempts to maintain respect, dignity and integrity in the dying process-this can be accomplished through four processes:

a. Contact with those who have been an important part of their life.  
b. Being treated as a living person rather than someone who is already dead (think of the person not the disease).  
c. Maintain continuity with friends, family work and help them live as fully as possible.  
d. Help recognize continuum of those who have died previously and those who will come after.

9. **Fear of Sorrow**  
Identify sources of sorrow and work through them individually rather than all at once. Avoid premature detachment and sorrow.

10. **Fear of Regression**  
Be attuned to the psychic changes of dying person turning inward and allow this withdrawal. Signs of withdrawal:

- No interest in seeing others.  
- Stop watching TV and reading.  
- Lie down facing the wall rather than the door.

11. **Fears of mutilation, decomposition, and premature burial**  
Allow choosing own body deposition and providing appropriate information about it.

12. **Depression** is a natural reaction to perception of imminent loss.

   Signs of depression include:

   - expressions of sadness  
   - social withdrawal  
   - psychomotor retardation  
   - apathy  
   - nonverbal body language like facing away from people or crying  
   - somatic complaints  
   - agitation  
   - restlessness.

13. **Anger and Hostility**  

   Evidenced by negative verbalizations, aggressive behavior, sarcasm, negativity, obstinacy, passive-aggressive, withdrawal, or jealousy. Anger may really be a cover for grief and anxiety. Anger by patient may lead to
avoidance of caregivers. Caregivers need to recognize the anger and hostility as natural and appropriate reactions. Do not react with counter-hostility. Allow the patient to express anger and hostility without being judged or made to feel guilty. Also investigate appropriate sources of anger.

14. Guilt and Shame
Guilt evident by words and behaviors that demonstrate self-punishment, withdrawal, or self-sabotage.

a. Guilt felt when:
   - People behave contrary to their ethical principles.
   - Fall short of their self-image.
   - Violate their conscious or unconscious standards.
   - Believe they are stressing loved ones and are drains on resources.
   - Experience dependence on others—loss of self-reliance, and loss of independence and productivity.
   - Believe that illness is a form of punishment for past real and imagined offenses.
   - Experience guilt for angry feelings towards others who are not terminally ill.
   - Feel guilty because he has lost control of emotions and cried.

b. Relieve Guilt by:
   - Self-help group—see that feelings are normal.
   - Irrational belief or standards may be relinquished.
   - Learn to forgive self for changes that are out of one’s control.
   - Finishing unfinished business.

E. Exclusion of the Threat of Death or Its Significance from Awareness

Done by repression, suppression, denial, rationalization, depersonalization, and projection.

1. Repression: Force anxiety-producing thoughts from your mind into the unconscious—only useful for a limited time since symptoms are constant reminders.

2. Suppression: Conscious attempt to dismiss anxiety-provoking thoughts by diversionary activities. It is helpful to allow patients to distance themselves from the ever-present threat of death. Constantly bombarding patients with questions and experiences and forcing them to face their own death can be harmful.

3. Denial: Pushes into unconscious uncomfortable thoughts and ideas. Respite from the threat of death.
4. Rationalization: Attempt to understand the circumstance and find a reason for the experience.

5. Depersonalization: Consider the experience as not related to oneself.

6. Projection: Project feelings about the experience onto other individuals.

F. Denial in Terminal Illness

1. Types of Denial:
   a. Denial of specific facts about the illness.
   b. Denial of the implications and extensions of the illness (realizes the seriousness but denies that it will end her life).
   c. Denial of extinction (recognizes seriousness of the illness but does not believe that she will die of it).

If denial serves to hold the individual together then it is therapeutically useful. During the illness, denial may be intermittently employed when the patient is confronted with anxiety that is too overwhelming.

In the living-dying interval, the individual will vacillate between denial and acceptance. There are different degrees and combinations of denial and acceptance over the living-dying interval. Yet, extreme denial is detrimental or harmful because eventually they will have to face the threat all at once.

Denial can have positive or negative value—if it blocks action it is negative; if it directs action, it may reduce the stress. Denial is time-related—helpful in the initial stage of coping with the illness. Denial of known is more harmful than denial of the unknown. Denial is more helpful if it is partial or minimal.

IV. Settings At The End Of Life

A. In end-of-life care, an important role of the health professional is advocate for the patient/family in any setting.

- Deaths occur in hospitals, homes, nursing facilities, assisted living facilities, prisons, hospice residences and other health care settings.
- In a hospital setting, patients may die in intensive care or the emergency room, and infants may die in labor and delivery.
- No matter where or how death occurs, the nurse has the responsibility to follow patient/family choice and create a supportive physical, psychological, social and spiritual care environment.
Patient/family choice may include advocating for where the patient wants to die, and with who they want to die.

B. Each setting should provide a supportive physical environment. Following are suggestions for various settings:

- Putting family pictures on the wall in a nursing facility, bringing a favorite blanket to the hospital, allowing a pet to visit in an assisted living facility, allowing family members to visit and/or stay during a death vigil in a prison are part of a supportive physical environment that may be comforting to the patient.
- In the hospital setting, visiting hour restrictions and lack of space for privacy may require the nurse to be creative in providing a quiet place for family members to find privacy to be alone with loved ones.
- In a nursing facility, privacy may also be an issue in terms of space for family members to spend time alone with their loved ones.
- These situations and many others challenge the nurse to creatively find ways to provide a supportive physical environment according to patient choice.

C. It is important not to change the setting in final stages of life unless desired by the patient

- Transferring an imminently dying patient such as from a nursing home to hospital can be very disruptive and distressing.
- The setting should only be changed as a last measure and preferably only if the patient and family request the change.
- Patients and families should be given options in care, education about care and/or increased support so the patient can die where he/she chooses.

V. Dying As A Physical, Psychological, Social, And Spiritual Event

A. General Considerations:

- Patient and family together are the unit of care (family is defined by the patient which may include friends, significant others, partners, lovers).

- To meet the needs of dying patients and their families, an interdisciplinary approach to care is crucial. The nurse should seek support from other professionals in care of the dying including psychosocial professionals (e.g. social workers, counselors), spiritual care providers (e.g. pastors, chaplains, priests, rabbis, and spiritual advisors), nurses’ aides, volunteers, and physicians. Each discipline has expertise in specific areas and that combined expertise makes the highest quality care possible.

- The team will need to do an individualized assessment and identify problems, issues and opportunities specific to patient/family choice in end-of-life care.
At the time of nearing death, the interdisciplinary team serves as advocate for the patient/family and provides interventions directed at comfort, minimizing physical, psychological, social and spiritual pain and suffering, and honors and respects patient/family choices/wishes.

B. Dimensions of Care at the End of Life: 1,2

1. Physical Care
   - Relief of pain and other symptoms. Terminally ill patients do not become addicted to opioids but they will develop physical tolerance.

2. Psychological Care
   - Most helpful is just be present.
   - Anger must be recognized, acknowledged and expressed. Anger must be worn off (anger that others are enjoying life; anger at physical restrictions.) Most helpful just to listen.
   - You don’t know how they feel.
   - Don’t want them to stop having their negative feelings—that is our own distress as caregivers—dying people must be helped to identify their feelings, acknowledge their feelings as appropriate to the situation and give them permission to vent their feelings.
   - Helpers should turn off their own internal monologue of the right response and listen empathetically.
   - Touch, such as massage, holding hands or giving a hug, may be psychologically helpful.

3. Social Care

   Helped by fostering interpersonal relationships and attachments. The dying person wants to be able to give care and receive care from special people in their lives. Caregivers need to be sensitive to the identities of these special people and to the nature of the attachments, and to how the relationships could be maintained and nurtured.
   Social needs also include concerns for roles in family, work and community. Help patient cope by allowing them to discuss concerns and by being an advocate for the person. Help them identify their options.
4. Spiritual Care

Questions Patients may Ask: Where is God in all of this? What is the meaning of life and my suffering? Have I achieved the goals I wanted to achieve?

Frequently people ask these questions just to articulate their own thoughts but not to receive an answer. Just listen. Dying people need to work out their own answers to their own questions.

Care should give “Another good day of living” verses “Another terrible day of dying.” Hope centers on fulfilling expectations and a focus on what still can be done. We must listen to the individual to find out the object of their hope.

C. Guidelines for Interventions with Dying Patients

- Care requires collaboration to meet the individuals and families’ physical, emotional, social, legal, economic and spiritual needs.
- Dying involves the needs of patients, family, and caregivers.
- Isolation should be avoided. Social events and shared work are needed to sustain relationships.
- Profound involvement without the loss of objectivity by caregivers.
- Organizational structure that provides links with health care professionals in the community.
- An environment should be provided with adequate space and furnishing to put people at ease.
- Patients need professionals highly specialized in terminal care.
- Patient should be kept symptom free.
- Continuity of care should be provided.
- Patient's own values, frameworks and preferences must be respected.
- Patient’s wishes for information should be respected allowing full participation
- Patient should have a sense of security and protection with involvement of the family and friends.
- Twenty-four hours of care available.
- Help provided to the family.
- Interchange between the family and clinical team.
- Discuss all aspects of the dying process with the family.
- Patient and family should have time alone with privacy.
- Procedures arranged to provide maximal family time.
- Religious, philosophical and emotional components of care are essential and should be included in the team approach.
- Care for survivors who gave care and support to the deceased.
- Staff should be educated and supported in terminal care by the institution.
- Staff needs time to develop and sustain relationships with patients and families.
- Staff should receive support.

D. Objectives for Interventions:

1. Safe conduct for the dying
   - Alleviate emotional suffering, loneliness and anguish of patient and family.

2. Significant survival and dignified death
   - Realizing the value in what we are and what we do—find significance in the last few phases of living.
   - What was significant to the patient during earlier and healthier days to recall a sense of well-being and self-esteem—Remembrances preserve dignity.

3. Dignified death
   - When an individual is regarded as a responsible personal, capable of clear perceptions, honest relationships, purposeful behavior, with privacy and without neglect or infantilization.
4. Appropriate Death

- One that is not necessary ideal but is consistent with an ego ideal with the continuity of important relationships and with reactive grief resolved. There is an absence of suffering and exercise of options.

E. Suggestions to Promote an Appropriate Death

- Accept person as he would be like without the illness.
- Make allowances for deterioration and disability.
- Encourage the person to talk about how the illness has changed him.
- Understand the difference between the sickness, disease, and sickness until death.
- Ask about the person, his pursuits and possessions that meant the most to him.
- Preserve communication that preserves self-esteem.
- Monitor your own feelings and elicit support.
- Time your discussions about death.
- Unless the person’s consciousness has compromised his judgments, do not exclude the patient from decisions and information.
- Encourage decisions to be made with the family.
- Assess the changes that death will bring to the family.
- Help bereaved families with the practical adjustment.
- Recognize iatrogenic distortions and psychosocial complications.
- Recognize the patient's cultural, social and personal value systems along with personality characteristics and factors specific to the illness.

F. Common Physical Symptoms During the Last Hours of Life

1. Increased Weakness and Fatigue (Asthenia)
   
a. Weakness and fatigue are likely to increase as the patient gets closer to death. In the last hours of life, it is likely that the patient will not be able to move very much.

b. Joint position fatigue: joints become uncomfortable if they are not moved and require passive movement of the joints every 1 to 2 hours

   c. As death approaches, the need for turning lessens as the risk of skin breakdown becomes less important.

2. Decreased Appetite (Anorexia)
   
a. Most dying patients lose their appetite and lose weight (cachexia). Anorexia and cachexia are due in part to proinflammatory cytokines and
other humoral factors which induce catabolism. Therefore, artificial feeding to improve nutrition often does not impede weight loss.

b. Families often fear that the patient is giving in, or suffering from starvation. They should be reminded that food may be nauseating for the patient and anorexia may be protective. By forcing food, the risk of aspiration is increased and tensions. Clenched teeth on the patient’s part often-express desires and control. Help family find alternative ways to care.

c. Families should be educated that there is little evidence that prolonged anorexia is uncomfortable.

3. Decreased Fluid Intake

a. Oral rehydrating fluids – parenteral fluids, either intravenously or subcutaneously may be considered, especially to reverse delirium. However excess can lead to fluid overload with consequent peripheral or pulmonary edema, worsened breathlessness, cough, and orotracheobronchial secretions, particularly if there is significant hypoalbuminemia. There is no evidence that indicates that rehydration improves patient comfort. In contrast, dehydration may improve comfort by inducing uremia, hyperosmolality and endorphin release.

b. Families often fear that the patient is suffering from dehydration and thirst. They must be reminded that dehydration does not cause distress and that it may be protective.

c. Mucosal / Conjunctival Care: In order to alleviate discomfort, moisture should be maintained in the mucosal membranes. Oral mucosa should be moistened and cleaned every 15-30 minutes with either baking soda mouthwash or an artificial saliva preparation to minimize the sense of thirst. Lips and anterior nasal mucosa should be coated every hour with a thin layer of petroleum jelly. If eyelids are not closed, the conjunctiva should be moistened either with ophthalmic lubricating gel every 3-4 hours or with artificial tears every 15-30 minutes.

4. Decreased Blood Perfusion and Renal Failure

a. Tachycardia, hypotension, peripheral cooling, cyanosis, and mottling of the skin are normal.

b. Diminished urine output as perfusion of the kidney diminishes.

c. Parenteral fluids will not reverse this circulatory shut down.

5. Neurological Dysfunction During the Last Hours of Life

The result of multiple concurrent nonreversible factors, including hypoxemia, metabolic imbalance, acidosis, toxin accumulation due to liver
and renal failure, adverse effects of medication, sepsis, disease-related factors, reduced cerebral perfusion, etc.

a. Decreasing Level of Consciousness

1. The usual road to death: normal, sleepy, lethargic, obtunded, semicomatose, comatose, death.

2. The difficult road to death: normal, restless, confused, tremulous, hallucinations, mumbling delirium, myoclonic jerks, seizures, semicomatose, comatose, death.

3. Absence of eyelash reflexes on physical examination indicates a profound level of coma equivalent to full anesthesia.

4. The capability for complex communication by dying patients declines, particularly if the patient is receiving high doses of opioids.

5. Patient's inability to communicate is usually very distressing to family.

6. Patient's awareness is generally greater than ability to respond, therefore one should assume the patient can hear everything.

7. In order to maximize the patient's comfort, help the family strive to create familiar environment and include the patient in conversations. They should be encouraged to give the patient permission to die, and to touch the patient.

b. Terminal Delirium

1. Delirium is characterized by fluctuating disturbances in consciousness, cognition, and perception in 28% to 83% of patients near the end of life.

2. Search for possible causes:
   - may include indirect or direct effects of another disease or treatment on the Central Nervous System
   - cause is usually multifactorial.
   - causes are often irreversible.

3. Work Up:
   - Work-up may be limited by the setting.
   - Unpleasant or painful diagnostic procedures may be avoided because the focus of care is usually more on patient comfort
4. Three types of terminal delirium are:
   - Hyperactive (with restlessness, agitation, and hallucinations)
   - Hypoactive (with somnolence)
   - Mixed (with alternating features of both)

5. This usually causes great distress for the family or caregiver, as it often seems as though the patient is in more pain than he is actually in.

6. Medical management: benzodiazepines (lorazepam, midazolam) and neuroleptics (haloperidol, chlorpromazine). For seizures, high doses of benzodiazepines.

6. Changes in Respiration
   a. Breathlessness (Dyspnea). Parenteral or oral opioids relieve dyspnea but there is no evidence that nebulized opioids are of benefit. Benzodiazepines may alleviate dyspnea if there is an anxiety component. A fan blowing on the face stimulates the trigeminal nerve and often improves breathlessness.
   
   b. Altered breathing patterns: diminishing tidal volume, periods of apnea, Cheyne-Stokes respirations and accessory respiratory muscle use may all appear; last reflex breaths may signal death.
   
   c. The family usually fears suffocation, however the patient generally will not experience feelings of suffocation.
   
   d. Oxygen administration likely provides no benefit but is used widely to address caregiver concerns.

7. Loss of Ability to Swallow
   a. Loss of gag reflex and build-up of saliva and secretions may lead to gurgling, crackling, or rattling sounds sometimes referred to as “death rattle”
   b. Once patient is unable to swallow, oral intake must be ceased or will risk aspiration.
   c. Scopolamine to reduce production of saliva and other secretions
   d. Postural drainage, turning patient on one side to reduce gurgling, semi-prone position (only for a few minutes)
   e. Suctioning is not recommended

8. Loss of Sphincter Control: incontinence of urine, stool
   a. Family needs knowledge, support, as this symptom often comes as a surprise
b. Cleaning and skin care are very important

c. Absorbent pads, surfaces – can be used if incontinence is minimal

d. Urinary catheter – may minimize the need for frequent changing and cleaning, prevent skin breakdown, and reduce the demand on caregivers.

e. Rectal tube – may be useful if diarrhea is considerable and relentless

9. Loss of ability to close eyes

   a. Advanced wasting causes the loss of retro-orbital fat pad. This in turn causes the orbit to fall posteriorly within the orbital socket. Insufficient eyelid length to both extend the additional distance backward and cover the conjunctiva leads to conjunctival exposure.

   b. Increased risk of dryness, pain.

      Maintain moisture by using ophthalmic lubricants, artificial tears, or physiological saline.

G. Psychiatric Symptoms During the Last Hours of Life

   Often greatly affects the patient’s quality of life as well as serve as major source of distress for family members

1. Anxiety

   a. Symptoms: feelings of tension, apprehension, worry; signs of restlessness, an autonomic hyperactivity, hypervigilance, insomnia, distractibility, shortness of breath, tingling and numbness

   b. Treatment: Psychotherapeutic Intervention and Pharmacotherapy: benzodiazepines, neuroleptics, antihistamines, anti-depressants, opioid analgesics

2. Terminal Depression

   a. Psychological/cognitive symptoms: worthlessness, hopelessness, excessive guilt, suicidal ideation, especially when pervasive and accompanied by a sense of despair or despondency

   b. Symptoms such as fatigue, loss of energy, and other somatic symptoms are often not helpful in diagnosing cases of terminal depression, as they are generally characteristic in a dying patient.

   c. Must take prognosis and time for treatment into consideration when deciding which drug to administer

   d. Common treatments include tricyclic antidepressants or Selective Serotonin Reuptake Inhibitors. Ritalin may improve depression until the antidepressants take effect.

   e. Psychotherapy may also relieve depression.
H. Signs That Death Has Occurred

1. Absence of heartbeat and respirations
2. Pupils fixed
3. Color turns to a waxen pallor as blood settles
4. Body temperature drops
5. Muscles and sphincters relax: release of stool and urine, jaw falls open, and body fluids may continue to trickle internally

VI. Care Of The Patient And Family Immediately Following Death

A. Physiological Changes After Death

1. Algor Mortis: Body temperature decreases with resultant loss of skin elasticity. Be careful removing tape to avoid skin breakdown.

2. Liver Mortis: Bluish-purple discoloration that is the byproduct of red blood cell destruction. Occurs in dependent areas - elevate the head of the bed to prevent discoloration from the pooling of blood.

3. Rigor Mortis: Stiffening of the body due to contraction of the smooth and skeletal muscles. To prevent disfiguring close the eyelids, insert dentures, close mouth and position the body in a natural position. After a period of hours, rigor passes and body becomes malleable.

B. Principles of Care

1. Body should be clean and wrapped in clean coverings. Identify the body. Often nurses bath the body, comb the hair and put on clean covers. Remove any medical equipment or tubes. Allow family to assist in cleansing the body if they desire and to select the clothing they wish the deceased to wear.

2. Keep normal position of features and form - eyes close, body straightened, arms at side, mouth closed, dentures replaced, folded towel used to prop up chin, raise head on one pillow. Don't use bandages to hold jaw as it may discolor or indent the skin.

3. Find hairpieces.

4. Before bathing remove all jewelry. Itemize all valuables and give to family and have them sign the receipt. If request to leave on wedding ring - make note and bandage.

5. Replace soiled dressings and place waterproof plastic to prevent the escape of urine or feces. Reinforce any dressings.
6. May put on a mortuary gown or wrap in shroud—tag is attached to the outside bearing the same information as on the wrist.

7. Prepare stretcher—body covered and taken to the morgue with dignity.

8. In hospice, family and friends may stay with body and may bathe it. Muslim religious practice is to bathe the body by family.

9. When families and friends do not assume the responsibility for funeral arrangements, the institutions may have to assume this responsibility.

10. Local health departments have set up special regulations governing the treatment of bodies of persons who die of communicable diseases—Physician must notify any people handling the body.

11. Evaluate the circumstances of the death. Any signs of foul play, suicide, missing medications should be reported to the appropriate authorities and/or coroner.

12. If the patient is an organ donor, follow procedures as planned and in accordance with state, setting guidelines, policies and/or procedures.

C. Communicating the Death and Providing Support

1. Telling the family that the patient has died should be done with sensitivity.
   - Be open, honest in communication, and provide small amounts of information at the family's level of understanding.

   - Information about the death may need to be repeated due to the family feeling overwhelmed or shocked by the actual death.

   - Health professionals should have a general understanding of cultural beliefs, death rites, and rituals of the major cultures/population in their practice areas.

   - Belief systems about death may be influenced by age, race, religion, spirituality, gender, socioeconomic status, education level, traditions, rites, and rituals, beliefs about pain, suffering, death, life and after life.

   - Following the death, family members may feel numb, and confused about what to do next. Explain the process/procedures following the death.

   - If the family has planned for burial, embalming is best done within 12 hours of death.
In most settings, the funeral home will require a time of death, social security number, diagnosis, physician, and survivor contact.

Family members may need time to adjust to the immediate loss before they are able to make phone calls. Some family members, however, find healing in immediately telling the story of the death to family, friends. Offer to assist with phone calls and assist per family request. Notifications: Assist with notifying the physician, co-workers, and other involved health care agencies.

Pastoral care can assist with services and help facilitate decision-making about funeral/memorial services.

Following the death, the practitioner should initiate bereavement support by providing compassion, active listening, and presence. In addition, the practitioner should assess grief reactions and assess bereavement risk factors. Follow-up bereavement support through phone calls, cards, attending funeral/memorial service and visits are helpful for the family and nurse's closure with the deceased.

VII. Grief And Bereavement

A. Introduction

1. Grief is a process. Grief begins before the death for the patient and survivor as they anticipate and experience loss. Grief continues for the survivor with the loss of the patient.

2. The grief process is not always orderly and predictable. Usually the grief process includes a series of stages and/or tasks that the survivor moves through to help resolve grief. This is sometimes referred to as "grief work."

3. No one really "gets over" a loss, but he/she can heal and learn to live with a loss and/or live without the deceased.

B. Definitions

1. Loss

The absence of a possession or future possession. The value of the possession is determined by and unique to the individual experiencing the loss. Losses are experienced in daily life such as through divorce or children leaving home. Losses may also occur before the death for the patient and significant others as they anticipate and experience loss of health, changes in relationships and roles and loss of life. After a death, the survivor experiences loss of the loved one. Most losses will trigger mourning and grief and accompanying feelings, behaviors and reactions to the loss. Patients, family members and survivors experience loss.
2. **Grief**  
The emotional response to a loss. Grief is the individualized and personalized feelings and responses that an individual makes to real, perceived, or anticipated loss.

3. **Bereavement**  
Both the situation and the long-term process of adjusting to the death of someone to whom a person feels close.

4. **Mourning**  
The outward, social expression of a loss. How one outwardly expresses a loss may be dictated by cultural norms, customs, practices including rituals and traditions. Some cultures may be very emotional and verbal in their expression of loss, some may show little reaction to loss, others may wail or cry loudly, and some may appear stoic and businesslike. Religious and cultural beliefs may also dictate how long one mourns and how the survivor "should" act during the bereavement period. In addition, outward expression of loss may be influenced by the individual's personality and life experiences.

5. **Anticipatory Grief**  
Occurs with loss associated with diagnosis, acute and chronic illness and terminal illness experienced by patient, family and caregivers. Examples: actual or fear of potential loss of health, loss of independence, loss of body part, loss of financial stability, loss of choice, loss of mental function.

6. **Disenfranchised Grief**  
Encountered when a loss is experienced and cannot be openly acknowledged, socially sanctioned or publicly shared. Those at risk include partners of HIV/AIDS patients, ex-spouses, ex-partners, fiancées, friends, lovers, mistresses, co-workers, children experiencing the death of a stepparent, the mother of a stillborn delivery, terminated pregnancy.

C. **Factors Influencing the Grief Reaction**
   1. **Psychological Factors**
      - The unique nature and meaning of the loss sustained or relationship severed.
      - The individual qualities of the relationship lost—strength of the attachment—hard to resolve ambivalent relationships—if small degree of attachment easier to deal with loss.
      - Role the deceased played in the family can reveal primary and secondary losses.
      - Individual’s coping behaviors, personality and mental health. Usual coping mechanisms of grief.
Avoidance of painful stimuli (not talking about deceased, Hiding pictures or mementos).

Distraction with work, school etc.

Food, alcohol or drugs.

Obsession rumination—preoccupation with the cognitive details of loss.

Impulsive behavior or escape—sell house—become deeply involved with another person.

Prayer—offers hope, allows for relief of guilt and suffering.

Rationalization and intellectualization—put loss in a less painful perspective.

Contact with people—mitigates the intense feelings of loneliness and despair.

Individual's level of intelligence and maturity.

Individual's past experience with death and loss.

Individual's social, cultural, ethnic and religious backgrounds.

Individual's sex role conditioning.

Individual's age—younger widows under 40 more at risk.

Age and characteristics of the deceased.

Death parent—lose past.

Death spouse—lose present.

Death child—lose future—hardest death to handle.

Amount of unfinished business between the griever and the deceased.

Individual's perception of the deceased’s fulfillment in life.

Immediate circumstances of death—location, type, reason, degree of preparation.

Timeliness of death—psychological acceptability of death for this person at this time. Death of young is untimely.

Individual's perception of preventability.

Sudden versus expected death

Anticipatory grieving doesn’t lessen the grief but unexpected overwhelms people and severely reduces their functioning.

Length of the illness prior to death—too long can lead to poor bereavement outcomes. —Because of length of social isolation in caring for dying, physical debilitation from caring, and emotional exhaustion—remissions and relapse can lead to death wishes, which cause guilt. Better adjustment is short-term chronic illness less than six months rather than long term or sudden death.
2. Social Factors

- Individuals support system and acceptance of support—as well as timing of support—and support over time.
- Religious, cultural and philosophical backgrounds.
- Educational, economic and occupational status of bereaved.
- Funeral rituals.

3. Physiological Factors

- Use of sedatives harmful—need to vent their feelings.
- Need for nutrition, sleep and rest, exercise, and physical health.

VIII. Psychological, Physical, And Social Manifestations Of Grief

A. Psychological Manifestations:

1. Avoidance Phase

- Characterized by shock, denial, disbelief, and intellectualization and making funeral arrangements, loss recognized but emotions denied. Difference between denying the death and denying the feelings stimulated by the death.

2. Confrontation Phase

- Characterized as full pain of grief—angry sadness—feeling indifferent to others—anxiety or panic—anger at deceased, God, others, self—mixture of negative and positive feelings toward deceased may lead to feelings of guilt (normal)—guilt at still being alive—guilt from unrealistic expectations of self—failure to protect—self reproach or worthlessness may be pathological if extreme. Depression and despair are normal.

- Feelings of loss of control—fleeting ideas of suicide.
- Heightened psychological arousal—irritability, anxiety, tension.
- Preoccupation with deceased—hugging tightly before saying goodbye—involves dreaming about the deceased, thinking he has seen her, or actively searching for her.
- To gain control—there may be an obsessive review of the circumstances of death.
- Grief attacks—come on unexpectedly with physical sensations- must stop activities to gain control.
Identification with the deceased—take on their habits or hobbies.

- Sense of relief—termination of responsibilities.

3. Reestablishment phase

- Beginning decline in grief and beginning of social and emotional reentry into the everyday world. Loss is not forgotten but put in a special place. Waxes and wanes with confrontation phase—it never arrives all at once.

B. Social Manifestations of Grief

- Restlessness and inability to sit still.
- Lack of ability to initiate and maintain a pattern of activity.
- Social withdrawal behavior—pain of seeing others with their loved ones.

C. Physical Manifestations of Grief

- Anorexia or GI problems.
- Loss of weight.
- Inability to sleep.
- Crying.
- Sighing.
- Lack of strength, exhaustion.
- Feelings of emptiness or heaviness.
- Something in the throat.
- Nervous.
- Heart palpitations.
- Loss of sexual drive or hyper sexuality.
- Psychomotor retardation.
- Restlessness.
- Short of breath.

D. Rando’s 6 Processes of Mourning or Grief Work

1. Recognize the loss—acknowledge and accept the death.
2. React to the separation—experience the pain, feel, identify, accept.
3. Recollect and re-experience the deceased and the relationship. Review and remember realistically.
4. Relinquish old attachments to the deceased and the assumptive world.
5. Readjust to move adaptively in the new world without forgetting the old. Develop new relationships with the deceased and form a new identity.

6. Reinvest.

Rando\(^1\) defined **Complicated Grief** as grief that is present whenever, taking into consideration the amount of time since death, there is some compromise, distortion or failure of one or more of the six “R” processes.

**IX. Assessment Of Loss And Grief \(^{1,2,3}\)**

A. General Considerations

1. Grief assessment begins at the time the patient is admitted to a hospital, nursing facility, assisted living facility, time of diagnosis of acute or chronic illness, terminal illness.

2. Grief assessment is ongoing throughout the course of an illness for the patient, family members and significant others and for the bereavement period after the death for the survivors. Grief should be assessed frequently during the bereavement period to alert the nurse to possible signs/symptoms/reactions of complicated grief.

3. The survivor’s anticipated and actual losses, emotional responses, and coping strategies must be repeatedly assessed. The interdisciplinary team, including the hospice nurses, social workers, and chaplains are particularly important in assessing and monitoring grief.

4. Many caregiver survivors do not care for themselves when caring for the deceased. As such, an assessment should also include:
   - A general health check-up and assessment of somatic symptoms;
   - A dental visit
   - An eye check-up as appropriate
   - Nutritional evaluation
   - Sleep assessment
   - Examination of ability to maintain work and family roles
   - Determination of whether there are major changes in presentation of self
   - Assessment of changes resulting from the death and the difficulties with these changes
   - Determine survivor's cultural practices in mourning and grief reaction.

B. Conduct a Grief Assessment by: \(^1\)

Asking questions such as:
• Can you tell me about the death? What happened?
• Tell me about him about your relationship from the beginning?
• What has been happening since the time of death?
• Have you been through other bad times like this?

Identify:
• Illogical or magical thinking.
• Increased guilt and responsibility.
• What loss means to the mourner.
• All factors influencing grief.
• History of prior losses.
• Determine which tasks of grief are incomplete.

X. Intervention Strategies For Loss And Grief

1. Need acceptance and nonjudgmental listening.
2. Establish a relationship and be physically present especially during shock and disorganization and weeks and months later when the loss sinks in.
3. Reach out in concrete ways—don’t just say call me if you need me.
4. Minimize the tendency for the bereaved to be overwhelmed. Remind to eat—get rest—suggest priorities—help with funeral decisions—help focus on problems one at a time.
5. Give permission to grieve.
6. Do not allow the griever to remain isolated. Absence of support creates complicated grief. Suggest self-help groups or psychotherapy.
7. Maintain family system perspective.
8. Medical evaluation when symptoms warrant.
9. Be realistic: You can’t take away pain.
10. Overcome your own sense of helplessness—don’t pull back.
11. Expect volatile emotions—especially early.
12. Gift of presence—willingness to remain present—suspend judgment.
13. Show care and concern.
14. Don’t let your own needs determine the experience of the mourner.
15. Don’t try to explain the loss—or pretty up the situation.
Plant the seeds of hope—life will someday have meaning again—someday they will be in less pain allows them to carry on.

Don’t tell the griever not to cry.

Help realize that he deals with his grief he can look forward to overcoming the pain and carrying on with life.

Encourage verbalization and recollection of the deceased.

Help the bereaved actualize and accept the loss.

Assist griever in identifying the feelings such as anger sorrow, depression and relief, helplessness, anxiety.

Help the griever own the feelings.

Explore the griever’s defenses if resisting the grief process such as excessive dependency, anger or guilt.

Balance positive and negative—what do you miss about him—what don’t you miss.

Allow crying, talking, and reviewing—may go over situation or memory repeatedly.

Don’t be afraid to mention the dead person to the griever. Encourage the griever to realistically review the relationship.

Help identify and resolve secondary losses and unfinished business such as loss of time with children due to second job, loss of sex partner, loss of social life, and loss of dreams hopes and fantasies.

XI. Worden’s Counseling Principles

Principle One: Help the Survivor Actualize the Loss

- Help the survivor come to a more complete awareness that the loss has actually occurred by:
  - Talking about the loss—when, where, how did the death occur; what was the funeral like—reviewing the loss over and over is normal.
  - Visiting the gravesite.

Principle Two: Help the Survivor to Identify and Express Feelings

- Anger—directed toward the deceased or displaced to others is normal. Anger that is directed toward self may lead to depression and suicide. Ask the individual such questions as:
  - “Has it been so bad that you thought of hurting yourself?”
  - “What do you miss about him?”
“What don’t you miss about him?”

- Holding on to only negative feelings may be a way of trying to avoid the sadness.
- Guilt is also a common reaction. Individuals question whether they obtained adequate medical care or what else could have been done?
- Anxiety, helplessness, and fear of their own death are often manifested. As professionals you can help them articulate these fears. By asking individuals how they managed on their own before the loss, you can help put feelings of anxiety and helplessness into perspective.
- Sadness is a common reaction. Suggest that they give themselves permission to cry.

**Principle Three: Assist Living Without the Deceased**

- Facilitating their ability to live without the deceased and to make decisions independently, involves using a problem solving approach. What are the problems that the survivor faces and how can they be solved?
- Help the person deal with the loss of their sexual partner. Recognize that the need to be held and touched is normal.
- Encourage bereaved not to make major life changing decisions in the first year.

**Principle Four: Facilitate the Emotional Relocation of the Deceased**

- Reminiscing helps to establish new relationships with the deceased. Encourage them not to jump into new relationships within the first year.

**Principle Five: Provide Time to Grieve**

- Critical time points are three months after the death when the support systems have pulled back, during anniversaries of the death, birthdays of the deceased, and holidays.

**Principle Six: Interpret Normal Behavior**

- People may feel that they are going crazy. Yet, hallucinations, distractibility, and a preoccupation with the deceased are normal.

**Principle Seven: Allow for Individual Differences**

- There is a wide range of behavioral responses.

**Principle Eight: Provide Continuing Support**
• Make yourself available to the grievers over the most critical periods for the first year.

**Principle Nine: Examine Defenses and Coping Styles**

• Be alert to coping with drugs and alcohol, which can intensify the experience of grief and depression.

• Try to figure out why an individual refuses to look at pictures of the deceased or refuses to keep anything around as a reminder.

**Principle Ten: Identify Pathology and Refer**

**Useful Techniques for Counseling**

• Evocative language: “Your son died verses you lost your son”. Speaking of the deceased in the past tense: “Your husband was”.

• Use of symbols: bring in photos of the deceased, videos of the deceased, articles of clothing and allow the person to speak about their feelings.

• Writing: have the survivor write a letter to the deceased expressing thoughts and feelings- keep a journal of one’s grief experience or suggest writing poetry.

• Drawing: reflects ideas and feelings.

• Role playing: help model new behaviors.

• Cognitive restructuring—our thoughts influence our feelings—help clients identify those thoughts and reality test them such as the thought “no one will ever love me again.” Instead, have the individual say often “I am loved by others.”

• Memory book of photos, or mementos can help an individual create a new relationship with the deceased.

• Direct imagery—help people imagine the deceased and encourage them to say what they need to say to him or her talking to the person rather than talking about the person.

**XII. Complicated Grief Reactions**

A. Chronic grief: characterized by normal grief reactions that do not subside and continue over very long periods of time

B. Delayed grief: characterized by normal grief reactions are suppressed or postponed. The survivor consciously or unconsciously avoids the pain of the loss

C. Exaggerated grief: the survivor may resort to self-destructive behaviors such as suicide
D. Masked grief: the survivor is not aware that behaviors that interfere with normal functioning are a result of the loss

XIII. Conclusion

A. No one can predict when the grief work will be complete.

B. Grief work is never completely finished as there will always be times when a memory, object, anniversary of the death or feelings of loss occur.

C. Grief can diminish and healing occur as characterized by: the pain of the loss is less, the survivor has adapted to life without the deceased, the survivor has physically, psychologically and socially "let go." The survivor, however, will continue to experience memories of the deceased.
XIV. References


Module # 21: Ethics
Geriatrics, Palliative Care and
Interprofessional Teamwork
Curriculum

Module # 21: Ethics

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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 21: Ethics

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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 21: Ethics

I. Overview

The delivery of ethical patient care is a goal of all health care providers, but this objective can be more challenging when the patient is older with an array of conditions and diseases. An interdisciplinary health care team may have an advantage in dealing with these issues because of the multiple perspectives brought to bear in case discussion. However, a possible disadvantage to the resolution of ethical issues in a team context is a tendency for “groupthink”, with the strongest team members dominating the discussion. Advance care planning is an ongoing process that offers the patient the opportunity to have a dialog with his or her family members and physician regarding the choices for care at the end of life. During this process, the patient's questions, fears and values are explored. As the important issues are uncovered, the information can be translated into a plan of action, called the advance directive. Ultimately, advance care planning is designed to clarify the patient's questions, fears and values, and thus improve the patient's well-being by reducing the frequency and magnitude of over treatment and under treatment as defined by the patient.

II. Learning Objectives

1. Define and describe ethical principles within a health care setting.
2. Compare personal values and professional codes of ethics.
3. Describe a seven-step process for ethical decision-making.
4. Delineate the role of the health care team in ethical decision-making.
5. Define Advance Care Planning.
6. Describe the benefits and barriers to Advanced Care Planning and Directives.
7. Describe the purpose and health care responsibilities related to the Patient Self-Determination Act.
8. Discuss informed consent, including definition, importance, related procedures, and influence of age.
9. Identify the legal consensus on treatment limitations.
10. Discuss the issue of physician-assisted suicide.
11. Discuss medical futility.
III. Definitions

The following two definitions are important for an understanding of ethics in health care:

A. **Ethics** can be defined as declarations of what is right or wrong and what ought to be. Ethics is a specialized area of philosophy with origins dating back to ancient Greece. The ethical principles enunciated by Hypocrates still serve as the underpinnings of many of today’s ethical issues. In an ethical decision making process, one asks in a systematic way, “what do dignity and respect demand in terms of response from others”? Following are some questions that may follow from this initial question:

1. Do our values, behaviors, and character traits pass the test of further examination when measured against this standard?
2. Which values, duties, and other guidelines are the most important in situations where conflicts arise?
3. When situations present uncertainty, what aspects of present moralities will most reliably guide individuals on a path of survival?

B. **Ethical dilemma** can be defined as 1) a difficult problem seemingly incapable of a satisfactory solution, or 2) a situation involving choice between equally unsatisfactory alternatives. This is not to suggest that all dilemmas in life are ethical in nature; rather, that ethical dilemmas arise when moral claims conflict with each other.

IV. Ethical Principles Within Health Care

A. **Autonomy**: the right to self-determination, independence, and freedom. Involves the provider’s willingness to respect a patient’s right to make decisions about and for him or herself, even if the provider does not agree with the patient’s decision.

B. **Justice**: the obligation to be fair to all people, regardless of race, sex, marital status, medical diagnosis, social standing, economic level, or religious belief. It is sometimes expanded to include equal access to health care for all.

C. **Beneficence**: requires that providers do good for patients under their care. Good care requires that the provider understand the patient from a holistic perspective that includes the patient’s beliefs, feelings, and wishes as well as those of the patient’s family and significant others. Involves acting in ways that demonstrate caring; listening, empathizing, supporting, and nurturing.

D. **Nonmaleficence**: requirement that providers do not harm their patients and opposite of beneficence. Also requires that providers protect those individuals from harm if they cannot protect themselves.
E. **Veracity**: “truthfulness” requires that providers not intentionally deceive or mislead patients. Based on mutual trust and respect for human dignity. As with other rights and obligations, there are limitations to this principle; an example would be a situation where telling the patient the truth would seriously harm or produce greater illness or go against the cultural mores of the patient.

V. Framework For Ethical Analysis

There are several frameworks to analyze an ethical dilemma in a health care setting. (Refer to Figure 1, a modified case analysis structure originally developed by Jonsen, Siegler, and Winslade.) This framework is useful when discussing a particular case in a health care team setting.

VI. Personal Values vs. Professional Code Of Ethics

A. Personal values are generally derived from society. Providers need to know the patient’s values about life, health, illness and death. Some important ethical issues include:

1. Individual’s right to make decisions for self
2. Euthanasia (active and passive)
3. Blood transfusions
4. AIDS/HIV
5. Withholding fluids and nutrition
6. Cultural differences
7. Spiritual and religious differences

B. Professional Values are often a reflection and expansion of personal values. They may come from ethic codes, healthcare experiences, teachers, and peers.

C. A Code of Ethics is a formal statement that sets standards of ethical behavior for a group of people. Professional societies have developed codes of ethics for their members. It reflects the groups’ moral judgments over time and serves as a standard for their professional actions. Please go to the following sites to review professional codes of ethics:

1. National Association of Social Workers
2. American Pharmacists Association
   [http://www.aphanet.org/AM/Template.cfm?Section=Pharmacy_Practice_Resources&Template=/CM/HTMLDisplay.cfm&ContentID=2903](http://www.aphanet.org/AM/Template.cfm?Section=Pharmacy_Practice_Resources&Template=/CM/HTMLDisplay.cfm&ContentID=2903)
3. American Nursing Association
   [http://www.nursingworld.org/ethics/chcode.htm](http://www.nursingworld.org/ethics/chcode.htm)
4. American Medical Association
VII. When The Provider Cannot Support The Patient's Decision

A. Typically occurs when goals are unreasonable or illegal.

B. Provider must set limits on what he or she will do without implying abandonment or destroying the relationship with the family.

C. Provider should make the conflict explicit and offer to help find an alternate solution.

VIII. Overview Of Advance Care Planning

A. Advance Care Planning is the process of planning for future medical care, particularly for the event when the patient is unable to make his or her own decisions. It also involves the patient deciding and designating whom they would like to make those decisions on their behalf in the event they cannot make them for themselves.

B. Advance care planning involves decision making and the communication of those decisions between the person and their family, friends, physicians and other health care providers that ensure that patient's choices are known, preferably long before a crisis situation or when they can no longer communicate their wishes. The process helps patients identify and clarify their personal values and goals about health, medical treatment, and how, where, and with whom they want to live the end of their lives and puts in place concrete arrangements for services.

IX. Definitions

A. The living will (or "medical directive" or "declaration" or "directive to physicians") is a written instruction spelling out any treatments you want or don't want if you are unable to speak for yourself and terminally ill or permanently unconscious. A living will says in effect, "Whoever is deciding, please follow these instructions!" On its own, a living will is very limited—it usually applies only to end-of-life decisions, and standard instructions tend to be general.

B. A health care power of attorney (or health care "proxy," or "medical power of attorney") is a document that appoints someone of your choosing to be your authorized "agent". You can give your agent as much or as little authority as you wish to make health care decisions. The decisions are not limited to just end-of-life decisions. Appointing an agent provides someone with authority to weigh all the medical facts and circumstances and interpret your wishes accordingly. A health care power of attorney is broader and more flexible than the living will.
C. A comprehensive **Health Care Advance Directive** combines the living will and the health care power of attorney into one document. In addition, you may include any other directions, including organ donation or where and how you prefer to be cared for. Because it is more comprehensive and more flexible than the other tools, it is the preferred legal tool.

**X. Why Have Advance Care Planning?**

A. States have laws supporting the appointment of a health care proxy.

B. All states but New York and Michigan have a living will statute, but these documents are still recognized as a matter of practice in those states.

C. The Patient Self-Determination Act (1990) requires all health care facilities that receive Medicare payments inform patients of their rights to complete advance directives under their state law.

   1. Insurance companies and regulatory agencies see advance directives as quality indicators.
   2. We will all die someday from a variety of disease for which there is a wide spectrum of treatments.
   3. Many of us will achieve advanced age and mental incapacity, where others will be deciding medical treatments for us.

D. Benefits and Barriers to Advanced Care Planning and Directives

A. Benefits

   1. Advance Directives allow the individuals to exercise control over their bodies and direct health care in the event that they will lack decision-making capacity at the time a medical decision needs to be made. Older adults are more likely to develop impaired decision-making capacity than are younger people.13

   2. When patients communicate these wishes ahead of time, it decreases the chance of conflict in future decision making, decreases the potential for ethical dilemmas, and takes the burden of the family and healthcare team when the patient can no longer communicate for him/herself. The sense of control and peace of mind that this process fosters in the patient and the reduction in anxiety of proxy decision-makers are important benefits.

B. Barriers

   1. Vague language.
   2. They do not guide treatment decisions by physicians - (SUPPORT Study).
3. Surrogate decision makers often unaware of patient wishes, or unwilling to support them.
4. Physicians do not bring them up, and patients feel it is the physician’s responsibility to do so.
5. Physicians have difficulty with truth-telling and breaking bad news.
6. Physicians want to maintain “hope”.
7. Problems with prognostication.
8. Anticipated disagreement between physician and patient or family over appropriateness of specific treatments.
10. Medical-legal concern
11. Physicians feeling advance directives not appropriate for healthy patients.
12. Time.

XI. Preparing A Living Will 14

- Prepared while the patient has decisional capacity.
- Describes the patient’s preferences in the event they become incapable of making decisions or communicating decisions.
- Usually describes what type of life prolonging procedures the patient would or would not want and circumstances under which they would want these procedures carried out, withheld, or withdrawn.
- Documentation of living will - Copy should be in patient’s home, physician’s record, hospital record, outpatient record and with surrogate/proxy.
- Variations exist by state so professionals must be familiar with state laws.

XII. Patient Self-Determination Act

A. The Federal Patient Self-Determination Act (PSDA): (enacted by Congress in 1991) creates obligations for health care facilities participating in the Medicaid and Medicare program to: 1) ask patients whether they have an advance directive and to record this information in the medical record; 2) to honor advance directives; 3) to educate patients about advance directives; and 4) to conduct community education. 15

B. The Patient Self-Determination Act requires providers to tell patients what their state provides in the form of an advance directive, and hospitals are required to inform patients of their right to accept or refuse medical treatment and to make advance directives. The Act is intended to protect the views and choices of patients when they become incapacitated to make decisions. 16
XIII. Informed Consent

A. Definition

Informed consent is a legal doctrine requiring the disclosure of information about a proposed treatment before obtaining consent for its performance. Informed consent involves providing factual information, including the benefits and burdens of an action, and determining a person’s understanding of that information. After being given information, a person is thought to be able to give informed consent if they can: a) evidence a choice; b) understand and appreciate the issues; c) rationally manipulate information; and d) make a stable and coherent decision.  

B. The Importance of Informed Consent

Many patients and families who are facing treatment withdrawal may have not been fully informed of the risks and benefits of the therapy at the time it was begun, nor, often are they told that treatment could be withdrawn if no longer effective. Patients and families who refuse further treatment should be told the consequences of the discontinuation of treatment.

C. Procedures of Informed Consent

1. The informed consent process is one of discussion and shared decision making.

2. It is ideally woven into regular clinical interaction.

3. The health care provider should bring news and information to the patient about his or her disease and its management in as timely and sensitive a fashion as possible.

4. Age Changes Which May Influence Informed Consent in Older Adults

   a. Sensory deficits in hearing and vision.

   b. Adult learning needs for both written and verbal information presented slowly with opportunities to repeat and clarify content.

   c. Values and beliefs about making health care choices (i.e., “let the doctor decide”).

   d. Decision-making capacity that fluctuates or is diminished.
XIV. The Steps Of Advance Care Planning 20


A. Preparing for the Discussion

1. Discussions can never be all-inclusive.

2. Discussion should be directed toward expected clinical situations whenever possible.

3. Appointment of a surrogate is an important first step for both patients with and without identifiable risk factors for specific treatment issues.

4. Discussion must address patient values - prolong life or comfort care.

5. Discussions should take place over time, whenever possible.

6. Information should be presented in a thorough and unbiased fashion.

7. The physician needs to recognize that some patients do not want to have these discussions - may or may not be based in culture - need to ask.

8. Must address medical uncertainty - concept of time-limited trials.

9. Directives must be well documented and available.

10. The possibility that the patient may change his or her mind must be anticipated, and wishes periodically reviewed, as long as the patient retains decisional capacity.
B. Introducing the Topic

1. Be straightforward and routine: whenever possible, routinely initiate the advance care planning process with every adult patient, regardless of age or current state of health.

2. Determine patient familiarity: some patients may already have advance directives. If this is the case, review the documents and amend if appropriate.

3. Explain the process: before beginning, explain the goals and the process. Literature or validated worksheets may be helpful.

4. Determine the patient’s comfort level: be aware of the patient’s comfort level during the introduction of the topic. If a patient does not seem comfortable, be supportive and provide information, but do not force the conversation.

5. Identify a proxy: ask the patient to identify a possible proxy decision-maker who might act on his or her behalf, to be involved in subsequent conversations.

C. Surrogate Issues

1. Surrogates should be chosen who are familiar with and willing to support the patient’s wishes and values.

2. Surrogates must be decisional capacity.

3. Directives should address if surrogate has discretion to override previously stated wishes.

4. Surrogates must be informed and reachable.

D. Engage in Structured Discussions

1. Proxy decision-maker(s) should be present: potential proxy decision maker should be present at the discussions and planning so that he or she can have a thorough and explicit understanding of the patient’s wishes.

2. Describe scenarios and options for care: this will provide insight as to scenarios that might arise and the types of decisions that proxies most commonly face.
3. Elicit patient’s values and goals: this can be done by asking about past experiences and describing possible scenarios.

4. Specific issues that ought to be discussed include: the patient’s choice of a spokesperson; beliefs; health conditions; life-sustaining treatments; vision of a good death; organ donation; and funeral arrangements.

5. Use a worksheet: worksheet should include a range of potential scenarios that patients should consider. It should elicit the patient’s values and goals related to health and medical care in general terms and should include the most common life-threatening interventions.

E. Treatments to be Covered in Discussion

1. Resuscitation
2. Mechanical breathing (intubation)
3. Surgery
4. Chemotherapy
2. Dialysis
3. Blood transfusion
4. Artificial nutrition and hydration
5. Diagnostic tests
9. Antibiotics
10. Pain medication

F. Document Patient Preferences

1. Formulate the directives: check for inconsistencies and misunderstandings. Have the patient sign the directives.

2. Enter directives into the medical record: directives should be formally documented into the patient’s medical record.

3. Recommend statutory documents: One or more statutory documents that comply with state statutes can be completed for added protection.

4. Distribute the directive: the records should be available wherever the patient may receive care.

G. Review and Update the Directive

1. Follow up periodically.
2. Note major life events: such as illness, marriage, birth of a child, which may affect a person’s attitude.

3. Discuss changes: ensure patient, provider, and proxy understand the new wishes.

4. Document changes: documents should be updated and shared appropriately.

H. Apply Prior Directives to Actual Circumstances

1. Determine the patient’s capacity to make decisions

   a. Decision-making capacity is a clinical determination as to whether a person possesses a set of values and goals, the ability to communicate and understand information, and the ability to reason and deliberate about their choices.

   b. Competency: a legal determination (by a judge) as to qualified to give testimony or execute legal documents (in the law with regard to health care decisions there is no definitive test for competency). 21

   c. Questions for Determining Decisional Capacity 22

      - Can the person make and express personal preferences at all?
      - Can the person give reasons for the alternative selected?
      - Are the supporting reasons rational, in the sense that he patient begins with a factually plausible premise and reasons logically from that premise to the result?
      - Does the person in fact comprehend the implications?

   d. Because a substantial number of older adults have altered decision-making capacity, it is an issue every time an older adult is asked to consent to treatment or execute a Health Care Proxy or living will. 23

   e. Cognitive impairment does not automatically constitute decisional incapacity. Widely used tests of mental status assessment (e.g., Mini-Mental Status Assessment of MMSE) are NOT good measure of an individual’s ability to make health care decisions. 24
2. Read the advance directive: never assume its content.

3. Interpret the advance directive: should be interpreted in view of the clinical facts of the case. No matter how thorough they are, advance directives cannot anticipate all possible circumstances.

4. Consult with the proxy: whenever significant interpretation is necessary.

5. Use ethics committee: for cases in which disagreements cannot be resolved.

6. Carry out the treatment plan.

(Refer to Figure 3, “Instructions and Definitions for VA Advanced Directives"

XV. Legal Consensus On Treatment Limitation

A. Patients May Refuse Unwanted Treatment: Patients with decision-making capacity may refuse unwanted medical treatment, even if this may result in their death. 25

B. Surrogate Decision-Making: Patients who lack capacity to make the decisions at hand have the same rights as those who have capacity. Authorized surrogate decision-makers may make decisions to limit treatment. 26

C. Sustaining medical treatment is considered neither homicide nor suicide. There are no limitations on the type of treatment that may be withheld or withdrawn. This may arise more frequently with older adults where the potential benefits of a treatment are unclear. 27

D. Legally (and ethically) there is no difference between never starting therapy and discontinuing therapy. 28

1. State laws can vary from the prevailing legal consensus on end-of-life care (e.g., in the degree of certainty that a surrogate should have about a patient’s wishes). 29

XVI. Issue Of Physician-Assisted Suicide 30

A. In 1997, the US Supreme Court held that there is no federal Constitutional right to assisted suicide. In doing so, it reaffirmed the distinction between withholding or withdrawing life-sustaining treatment and assisted suicide. Some professionals do have difficulty distinguishing professionally sanctioned end of life interventions from those that are not. This is partially
due to imprecisely defined or understood terms used in end of life interventions. For purposes of clarification, the use of the following definitions are recommended:

1. Assistance in dying: is an act that directly and intentionally brings about the death of a capable adult who voluntarily requests such assistance to end suffering.

2. Suicide: is the act of taking one’s own life, and the act of doing so was decriminalized in 1961.

3. Assisted Suicide: is the provision of the means to end life, such as through the prescription for a lethal amount of drug, the lethal drug itself, or other measures) to an adult who is capable of ending life, with knowledge of that person’s intentions.

4. Voluntary Active Euthanasia: is a deliberate and intentional act that causes death, often by lethal injection, at the voluntary request of an adult who is capable of causing his or her own death.

5. Non-voluntary Euthanasia: is the deliberate and intentional act that causes the death of a person who is incapable of expressing his or her own wishes about dying.

6. Involuntary Euthanasia: is the direct and intentional killing of a competent person who explicitly refuses receiving euthanasia.

B. Provision of medication with the intent to produce death is considered to be assisting suicide.

C. All states except Oregon, which has developed a state statutory right, have laws that make assisting a suicide by anyone a criminal offense. In the first and second year after the physician assisted suicide (PAS) law was passed in Oregon, 16 and 27 terminally ill patients, respectively, ingested lethal amounts of drugs. According to preliminary information, the reasons these individuals gave for requesting PAS was loss of personal autonomy and control of body functions, inability to participate in activities of daily living that made life enjoyable, and desire to control the manner of dying. The experience of unmanaged pain was not a factor.
XVII. Medical Futility

A. There are times when there are conflicts regarding belief of the beneficial nature of a treatment. These situations are referred to as "medical futility" and are common reasons for ethics consults or ethics committee presentations. These conflicts often involve failure in communication or misunderstandings over prognosis or benefits versus burden of treatment options. There are also important cultural and religious influences in these matters.

B. By asking the fundamental question, "Who are we doing this for?" many futile interventions can be avoided. The answer should be guided by the patient's values. Often, interventions (e.g. daily weights, mobilizing patients, continuing dietary supplements) may become questions to involving futility.

C. Many institutions have developed futility policies and have advocated the use of prognostic data to assist in determining when a treatment is futile. Such efforts alone rarely solve the fundamental disagreements about quality of life, meaning and decision making authority.
XVIII. References


(Module 4). Available from the American Association of Colleges of Nursing: www.aacn.nche.edu/elnec


Learning Resource A
Case Studies

Case # 1: Mr. Lewis

Mr. Lewis, age 71, has been a patient in the hospital for three weeks after suffering a very severe stroke. He has a tracheostomy (not ventilator dependent) and rarely leaves his bed. He has several infections that respond well to therapy. He communicates by whispering and writing. Many staff members observe that Mr. Lewis seems depressed. He has never been treated for clinical depression. His spouse of nearly 50 years, Mrs. Lewis, visits him faithfully during hospitalization. She feeds him his lunch and dinner by spoon. She is a much-admired visitor and brings gifts for the staff. She is a “lovely woman, truly devoted to her husband,” in the words of the staff social worker.

Mr. Lewis was offered an opportunity to complete an advance directive. He chose to fill out only a durable power of attorney for health care (health care proxy). He named his wife as his surrogate decision-maker should he lose decisional capacity. Mr. Lewis’s health care proxy was filed in his chart. In a subsequent discussion with his physician, he requested that no cardiopulmonary resuscitation be attempted were he to suffer an arrest. The Do Not Resuscitate order was also appropriately charted.

Later, however, Mr. Lewis told his primary nurse “when the time comes, I don’t want one of them feeding tubes. I would rather starve to death.” The nurse reported this statement to the physician. The physician brought up the matter the next day with both Mr. Lewis and his wife. This time Mr. Lewis said nothing. His wife stated, “Well, you know, his mind wanders sometimes. I know that he would not want to die without food or water.” Later, outside of the patient’s room, she told the nurse and doctor, “I don’t really care what he says. He doesn’t know what he wants. I could never let him die that way. We would both go straight to hell. If he does have another stroke, I will become the decision-maker. So it really doesn’t matter anyhow.”

Focus Questions:

1. What are some ethical issues introduced in this case study?
2. Who could be involved in assisting in this situation?
3. How would you plan care for Mr. Lewis based on the information outlined here?
4. What are any thoughts/feelings that you have about this care situation?

Mrs. Rodriguez, a 79 year old widow with a history of diabetes mellitus, breast cancer, poor vision and gait instability, lived in a senior housing facility in the inner city. Eight months prior to her death she was diagnosed with a recurrence of her breast cancer. This time the cancer was found to be widely metastasized. She was advised by her primary care physician that there was no hope of cure. She continued to live in the senior housing facility. Soon thereafter her health began to decline.

Three months after being diagnosed with the recurrence of breast cancer, Mrs. Rodriguez fell at home. She was taken to the emergency room by her daughter-in-law, and was subsequently hospitalized at an academic medical center with a fractured arm. Due to Mrs. Rodriguez’s decline in functional status, the medical center’s inpatient social worker recommended that Mrs. Rodriguez be aced in a nursing home. The patient and her close confidant, a local pastor, were very clearly against her being placed in a nursing home. A nurse who had become quite close to Mrs. Rodriguez during her inpatient stay also tried to advocate on Mrs. Rodriguez’ behalf against nursing home placement in heated discussions with the inpatient social worker, but was unsuccessful in her efforts. Based on the evaluation of the inpatient social worker, the social worker at Mrs. Rodriguez’ senior housing facility steadfastly refused to allow Mrs. Rodriguez to return to her home, citing liability restrictions of the housing facility.

Mrs. Rodriguez was sent to a nursing home to convalesce while efforts continued on the part of the pastor to get her adequate home attendant services so that she could be returned to the senior housing facility. The nursing home’s chief geriatrician as well as its social worker took up the cause at the pastor’s behest. Medicare personnel would only approve nine hours of home attendant services, however, and neither the staff of the nursing home nor the senior housing social worker would accept this as adequate for her care.

An interdisciplinary meeting was held at the nursing home. The senior housing social worker, the pastor, the patient’s daughter-in-law, and the nursing home’s geriatrician and social worker were in attendance. This pastor, the nursing home’s social worker, and the patient’s daughter-in-law continued to press for discharge to the senior housing facility in keeping with the patients wishes, while the housing facility’s social worker reluctantly continued to deny permission. It was noted at this meeting that Mrs. Rodriguez had become much more withdrawn and depressed at the nursing home. At the end of this meeting he nursing home social worker promised to push Medicare for round the clock home attendance care for the patient, which the senior facility social worker reluctantly agreed would be adequate for her return. Mrs. Rodriguez also signed a health care proxy form naming her daughter-in-law as proxy. Four days prior to Mrs. Rodriguez’s death she was approved for 24-hour home attendant care. She was transferred to the senior housing facility where she died in her sleep soon after.
Mrs. Rodriguez Case Analysis

A. Patient and Family Preferences

The patient desires to be returned to their apartment in senior housing. She appears to have capacity to make this decision as she is allowed to sign a health care proxy form, and the inpatient nurse’s notes indicate that she is “alert and oriented x 3.” The patient’s daughter-in-law and pastor want Mrs. Rodriguez to be allowed to return to her apartment.

The foremost ethical issue in Mrs. Rodriguez’ case is the conflict between autonomy and beneficence: the desire to respect the patient’s wishes and right to self-determination balanced with the desire for health professionals to act in what they perceive to be the patient’s best interest. Here, several of Mrs. Rodriguez’ healthcare providers emphasize finding the optimal care setting for the preservation of her life, giving the issue of beneficence more primacy than the started desire of both Mrs. Rodriguez and her confidants to have her back in her home. Ethically, patients should be considered to have the capacity to make their own decisions unless there is a compelling reason to question their decision-making ability.

In this case the patient appears to have the capacity to make her own decisions, as evidenced by the fact that she is alert and oriented and retains the legal right to assign her own proxy. Her confidants also agree with the patients choices. Nevertheless, Mrs. Rodriguez is kept out of her home until four days prior to her death. A better compromise between autonomy and beneficence might have been worked out had round-the-clock home attendant care been readily available.

B. Quality of Life Issues

Mrs. Rodriguez will be unable to return to normal life in the senior center housing facility without round-the-clock care; however, the patient still desires this opinion over life in a nursing home.

C. Contextual Factors: Teams and Transitions

See next page
Transition in Clinical Settings

Senior Housing Facility  Emergency Room

Nursing Home Rehabilitation Unit  Academic Medical Center

Admission

Parties involved with the care of Mrs. Rodriguez:
- Primary care physician
- Family: Mrs. Rodriguez’s daughter-in-law and pastor
- Inpatient social worker, Inpatient nurse
- Senior housing social worker
- Nursing home: geriatrician, social worker, nurses
- Medical personnel

Collegiality. Another facet of team dynamics that can complicate decision-making is that of colleagues waiting to respect each other’s decisions. In order for a team to function effectively it is necessary for team members to behave toward each other in a manner that is consistent with how the team members behave toward the patient – ideally, by respecting autonomy. A premium is placed on colleagues respecting each other’s autonomy and decision making capacity: just as patients with capacity must be permitted to make poor choices. Thus the desire not to affect the group dynamic of a team adversely may prevent team members from confronting each other when they encounter what appear to be poor judgment calls by their colleagues. This may be the case with the senior housing facility social worker, who appears to lack sufficient knowledge about the importance of respecting patient autonomy. Other members of the team, had they felt comfortable educating the social worker in this regard, may have been able to convince her that transfer back to the adult home was indeed appropriate. When team members do not know each other very well, which is often the case of multiple-institutional teamwork, there is a greater reluctance to disagree with a colleague.

Legal implications. Team effectiveness can be comprised by influences entirely outside their control. One example is the senior housing social worker’s refusal to permit re-entry into the housing. Her hands were in fact tied by her duty to heed regulations of the housing facility. Here it could be argued that the senior housing social worker – or those who initially determined the housing policies – are violating Mrs. Rodriguez’ right to autonomy. This argument must be weighed against the legal liability of the housing facility should Mrs. Rodriguez have an accident upon her return or cause accidental injury to others through fire, etc. An ethical dilemma arising during Mrs. Rodriguez’ transitions is whether persons living in a housing facility have less right to autonomy that persons living in a private home; i.e., a conflict between patient autonomy and housing facility liabilities.
From the point of view of clients in need of long-term care most likely for the rest of their lives but wishing to live at home as long as possible, as in Mrs. Rodriguez’ case, a single agency responsible for providing all care and assuming complete accountability is preferable to the patient being shuttled from setting to setting. A model of care such as PACE’s may have prevented unnecessary hospitalization and avoided this particular ethical dilemma from arising.

**Allocation of Resources.** Another contextual feature of this case is Medicare’s unwillingness to provide more hours of daily home attendant care makes what could have been a logical team compromise – for Mrs. Rodriguez to remain at home with extended home attendance – an impossibility. Medicare personnel, presumable for cost control reasons, block the way for this compromise by only approving nine hours of daily home care. Medicare regulations and personal play an important role in this case, yet no Medicare representatives are part of the team. Managed care administration may very often play a central role in a team’s decisions without actually being a physical part of the team. This can engender frustration from care providers, patients, and family members alike. Here again, a mega-team model is instructive, where those parties responsible for making cost-decisions are actively involved in team decisions for each patient. In the case that follows, how the PACE accomplishes this goal will be discussed.

**Team composition.** Team composition is blurry. There are several care providers, but it is not clear if there are teams at all. Certainly the provision of care is not coordinated. The patient’s primary care physician who originally diagnosed the cancer is not actively involved throughout the transitions. The health care providers at the hospital, including the hospital’s inpatient nurse and social worker, do not play an active role once the patient make a transition beyond the hospital doors. Yet the inpatient social worker’s evaluation of the patient has such primacy that it continues to directly affect the patient by forming the basis on which Mrs. Rodriguez is prevented from returning home.

The patient might better have been served had members of the hospital involved Mrs. Rodriguez’s care – or at the very least the inpatient social worker – stayed involved in the case until its resolution. It is not known, however, what other burdens these providers faced and whether continuing involvement was even a possibility given other time and staffing constraints at the hospital. The interdisciplinary meeting involving professionals from the nursing home and senior housing facility as well as the patient’s confidants is an attempt on the part of these providers to function as a single team. In fact this meeting did serve to accomplish the patient’s goal, albeit too late to be of benefit to her.

**Team management.** Even if all the various health professionals involved in this case are regarded as functioning as a single “mega-team”, lack of clear team management still obscures what should be the central role of the patient being able to make her own choices about living arrangements. Until the last days of the patient’s life when she signs a proxy form, no one on this “team” appears to take responsibility for ensuring that an assessment of the patient’s decision-making capacity is carried out in an explicit manner such that the entire team is aware of whether or not the patient is able to make her own decisions. Without a person with the needed combination of awareness of the importance of patient
autonomy and the power to return her to her apartment, several members of the team appear to operate under the assumption that the patient lacks decisional capacity.

The de facto leader in coordinating the team’s decisions could be viewed as the senior housing social worker in that she is able to block transfer of Mrs. Rodriguez, or as the pastor in that he is consistently involved throughout the various transactions. A case manager is badly needed here, whether it be the patient’s primary care provider, someone from the hospital who had the patient’s trust, such as the inpatient nurse, or any of the other professionals involved in Mrs. Rodriguez’ care, preferably one upstream in the transition process.

Role of Family and Confidants on Team. The Pastor and the daughter-in-law both have the desire to follow the patient’s wishes, but they are powerless to convince the senior housing social worker who does not place as great an emphasis on the patient’s decisional capacity. Here the role of the family on the team and what level of involvement in decision-making should be afforded the family members and patient confidants is another central team issue.
Learning Resource B

Template For Ethics Case Analysis

1. Gather the Clinical Information
   a. What is the patient’s medical problem? History? Diagnosis? Prognosis?
   c. What are the goals of the treatment and care?
   d. What are the probabilities of success?
   e. What are the plans in case of therapeutic failure?
   f. In sum, will medical and nursing care benefit the patient and harm be avoided?

2. Identify Patient and Family Preferences
   a. What has the patient expressed about preferences for treatment?
   b. Has the patient been informed of benefits and risks, understood, and given consent?
   c. Is the patient mentally capable and legally competent? What is evidence of incapacity?
   d. Has the patient expressed prior preferences (e.g. advance directives)?
   e. How does the patient want to include family or friends in the decision-making process?
   f. If the patient is incapacitated, who is the appropriate surrogate? Is the surrogate using appropriate standards?
   g. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?
   h. Are there family issues that might influence treatment decisions?
   i. In sum, is the patient’s right to choose being respected to the extent possible in ethics and law?

3. Evaluate Quality-of-Life Issues
   a. What are the prospects, with or without treatment, for the patient to return to a normal life?
   b. What biases might prejudice provider evaluations of the patient’s quality of life (i.e., is the patient’s or family’s definition of quality of life or the provider’s definition used?)
   c. What physical, mental, and social deficits is the patient likely to experience if treatment succeeds?
   d. Is the patient’s present or future condition such that, if it continues, he or she might judge life undesirable?
   e. Is there any plan and rationale to forgo treatment?
   f. What are the plans for comfort and palliative care?

4. Consider Contextual Factors
   a. Are there provider (physician, nurse, etc.) issues that might influence
treatment decisions?
b. Are there financial and economic factors?
c. Are there religious or cultural factors?
d. Is there any justification for breaching confidentiality?
e. Are there resource allocation problems?
f. What are the legal implications of treatment decisions?
g. Is clinical research or teaching involved?
h. Is there any provider or institutional conflict of interest?

5. Resolve the Ethical Issues and Create the Plan

6. Implement the Plan

7. Evaluate the Plan

Learning Resource C

Your Life/Your Choices: Choosing A Spokesperson

Who should speak for me?

**Instructions**  This exercise will help you choose the best spokesperson for you. On the top of each column, write in the names of one or more people you're considering to be your spokesperson. Place a check mark (✓) in the column for that person if the following statements are true. The first two statements must be true for your spokesperson to have legal authority to represent you. You should weigh how important the other attributes are to you in deciding your first choice.

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td><strong>Meets the legal criteria in my state for durable power of attorney for health care</strong> (see the instructions in the back pocket).</td>
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<td><strong>Would be willing to speak on my behalf.</strong></td>
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<td>Would be able to act on my wishes and separate her/his own feelings from mine.</td>
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<tr>
<td>Lives close by or could travel to be at my side if needed.</td>
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<tr>
<td>Knows me well and understands what’s important to me.</td>
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<tr>
<td>Could handle the responsibility.</td>
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<tr>
<td>Will talk with me now about sensitive issues and will listen to my wishes.</td>
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<td>Will be available in the future if needed.</td>
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<tr>
<td>Would be able to handle conflicting opinions between family members, friends, and/or medical personnel.</td>
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**What makes your life worth living?**

**Instructions**  This exercise will help you think about how you would feel about your life if each factor **by itself** described you.

**Life like this would be:**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Difficult, but acceptable</th>
<th>Worth living, but barely</th>
<th>Not worth living</th>
<th>Can’t answer now</th>
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</thead>
<tbody>
<tr>
<td>a. I can no longer walk but get around in a wheelchair.</td>
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<td>b. I can no longer get outside - I spend all day at home.</td>
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<td>c. I can no longer contribute to my family’s well being.</td>
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<td>d. I am in severe pain most of the time.</td>
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<tr>
<td>e. I have severe discomfort most of the time (such as nausea, diarrhea, or shortness of breath.)</td>
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<tr>
<td>f. I rely on a feeding tube to keep me alive.</td>
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<tr>
<td>g. I rely on a kidney dialysis machine to keep me alive.</td>
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<tr>
<td>h. I rely on a breathing machine to keep me alive.</td>
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<tr>
<td>i. I need someone to help take care of me all of the time.</td>
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<td>j. I can no longer control my bladder.</td>
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<tr>
<td>k. I can no longer control my bowels.</td>
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<tr>
<td>l. I live in a nursing home.</td>
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<td>m. I can no longer think clearly - I am confused all of the time.</td>
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<td>n. I can no longer recognize family/friends.</td>
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<tr>
<td>o. I can no longer talk and be understood by others.</td>
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<tr>
<td>p. My situation causes severe emotional burden for my family (such as feeling worried or stressed all the time).</td>
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<td>q. I am a severe financial burden on my family.</td>
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<td>r. I cannot seem to “shake the blues”.</td>
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<tr>
<td>s. Other (write in):</td>
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</table>
Instructions. To help others make sense out of your answers, think about the following questions and be sure to explain your answers to your loved ones and health care providers. If you checked “worth living, but just barely” for more than one factor, would a combination of these factors make your life “not worth living?” If so, which factors? If you checked “not worth living,” does this mean that you would rather die than be kept alive?

If you checked “can’t answer now,” what information or people do you need to help you decide?

Your Beliefs and Values

Instructions. Circle yes, not sure or no to indicate whether you agree with each statement. If you do not agree with the “always” statements, this could mean that you agree with these statements some of the time, but not always. You can use the space at the bottom of the page to explain and clarify your beliefs.

Personal and spiritual beliefs.
Many people have special personal or spiritual beliefs that they want respected in decision making about life-sustaining treatments? What are yours?

I believe that it is always wrong to withhold (not start) treatments that could keep me alive. Yes Not sure No

I believe that it is always wrong to withdraw (stop) treatments that could keep me alive after they’ve been started. Yes Not sure No

I believe it is wrong to withhold (not provide) nutrition and fluids given through tubes, even if I am terminally ill or in a permanent coma. Yes Not sure No

I do not wish to receive a blood transfusion or any blood products, such as plasma or red blood cells. Yes Not sure No

I would like to have my pastor, priest, rabbi, or other spiritual advisor consulted regarding any difficult health care decision that must be made on my behalf. Yes Not sure No

(Write in name) __________________________________________

I believe in other forms of treatment, such as healing through prayer, acupuncture, or herbal remedies. I want the following treatments included in my care: Yes Not sure No
I believe that controlling pain is very important, even if the pain medications might hasten my death.  

Yes  Not sure  No

I believe that my loved ones should take their own interests into consideration, as well as mine, when making health care decisions on my behalf.

Yes  Not sure  No

I believe that it is acceptable to consider financial burden of treatment on my loved ones when making health care decisions on my behalf.

Yes  Not sure  No

I believe that my loved ones should follow my directions as closely as possible.

Yes  Not sure  No

Additional beliefs and/or explanations for my beliefs:
____________________________________________________________________
____________________________________________________________________

Hope for recovery

People have different feelings about hope that influence what health care they want. What are your feelings about hope?

Imagine that you are very sick and have been told that you will very likely die soon.

I would want all possible treatment, even though my doctors don’t think they will help me, because I would hope for a miracle cure that would prolong my life.

Yes  Not sure  No

Imagine that you have been in a coma for three weeks. The doctors think that the chance that you will ever return to your previous state of health is very small.

I would want to be kept alive indefinitely because I would still hope for a new medical development that would help me to recover.

Yes  Not sure  No

Weighing pros and cons of treatment for different chances of recovery

People evaluate the pros and cons of medical treatments in very personal ways. This explains why some people choose a treatment and others reject it. A big question is, how
much would you be willing to endure if the chance of regaining your current health was high? What if the chance was low? Answer the questions below to carefully evaluate your own willingness to take such risks.

Imagine that you are seriously ill. The doctors are recommending treatment for your illness, but the treatments have very severe side effects, such as severe pain, nausea, vomiting, or weakness that could last for 2-3 months.

I would be willing to endure severe side effects if the chance that I would regain my current health was:

- high (over 80%)  
  Yes  Not sure  No
- moderate (50%)  
  Yes  Not sure  No
- low (20%)  
  Yes  Not sure  No
- very low (less than 2%)  
  Yes  Not sure  No


How would you like to spend your last days?

Many people have strong opinions about what would be important to them at the very end of their lives. For some, they want to express things they would like to have happen. Others want to be sure that certain things they dislike or fear will be avoided. What are some of the things that you would hope for that could make your last weeks, days, or hours the most peaceful?

Instructions. For each row, check (✓) one answer to express how important these issues would be to you if you were dying.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Not Important</th>
<th>Moderately Important</th>
<th>Very Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Avoiding pain and suffering, even if it means that I might not live as long.</td>
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<tr>
<td>b. Being alert, even if it means I might be in pain.</td>
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<tr>
<td>c. Being around may family and close friends.</td>
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<tr>
<td>d. Being able to feel someone touching</td>
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</tbody>
</table>
c. Having religious or spiritual advisors at my side when I die.

f. Being able to tell my life story and leave good memories for others.

g. Reconciling differences and saying “good-bye” to my family and friends.

h. Being at home when I die.

j. Being kept alive long enough for my family to get to my bedside to see me before I die, even if I’m unconscious.

k. What are your biggest hopes about the end of your life?
________________________________________________________________________
________________________________________________________________________
l. What are your biggest fears about the end of your life?
________________________________________________________________________
________________________________________________________________________

Other related matters

The topics that have been covered up to this point have related to decisions about your health care in the event you could not speak for yourself. Your decisions about the next topics would go into effect after your death. We include them here because they are related issues that you may want to communicate to others.

Organ donation and autopsy

Sometimes after death, organs and tissues can be used to help other people who need them. Family members must give consent to transplant your organs. You can help them make this decision by letting them know how you feel about this. After an autopsy, the body can be shown and buried.

Instructions. Circle one word to express how you feel.

I want to donate any viable organs/tissues.

Yes  Not sure  No

If yes, have you filled out an organ donor card?

Yes  Not sure  No

Have you told your family?

I consent to the use of all or part of my body for medical research.

Yes  Not sure  No

If yes, do you have a preference for a research institution?

Yes  Not sure  No

Have you told your family?

I permit an autopsy.

Yes  Not sure  No
Burial arrangements.
People often leave instructions about what they want done with their bodies after they die. Some want to be buried in a particular place, perhaps in a cemetery with other family. Other people would prefer to be cremated and have their ashes put or scattered in a special place. You can indicate your preferences by answering the questions below.

I would prefer to be: (circle one)  
- Buried  
- Cremated  
- No preference  

I would like my remains to be placed: _______________________________________

Other preferences: _______________________________________________________
_____________________________________________________________________

Funeral or memorial services
People have different ideas about funerals and memorial services. These services are often very comforting to family and friends as they celebrate and honor the life of their loved one. Services also can make a statement about one’s religious faith. Write in below any thoughts about a funeral or memorial service such as where it should be held, songs or readings to be included, where donations should be sent, information for an obituary notice, or other wishes.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
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Learning Resource D

Instructions And Definitions For VA Advance Directives

The new advance directive form 10-0137 expands veterans’ opportunity to express their wishes about end-of-life care and is structured to prompt veterans to give careful consideration to the care they would like to receive in different clinical circumstances. The form also encourages veterans to provide guidance for decision makers to help ensure that the treatment preferences they set out in their advance directive are appropriately interpreted.

The National Center for Ethics in Health Care anticipates that the new form will prompt veterans to ask more questions of their practitioners and that it will generate productive discussions and a better understanding of patients’ wishes regarding care at the end of life. Practitioners looking for a guide to help veterans complete the new advance directive may wish to refer to “Your Life, Your Choices” (http://vaww.ethics.va.gov/pubs/ylyc.pdf). This PDF booklet offers a step-by-step discussion guide to end-of-life planning that veterans can use on their own or together with a health care practitioner. An interactive version of “Your Life, Your Choices” will be available through the MyHealtheVet portal in the future.

   This combined Durable Power of Attorney for Health Care and Living Will permits you to specify certain treatment you may or may not want. With this form, you can:
   a. Appoint someone to make health care decisions for you if, in the future you become unable to make those decisions for yourself and/or
   b. Indicate what medical treatments(s) you do or do not want if in the future you are unable to make your wishes known.

2. Instructions:
   a. Read each section carefully.
   b. Talk to the person(s) you plan to appoint to make sure that they understand your wishes, and are willing to take the responsibility.
   c. Place the initials of your name in the blank before those choices you want to make under part 1 and 2 of VA Form 10-0137.
   d. Add any special instructions in the blank spaces provided. If you need more space for additional comments, you may use a separate sheet of paper; but you must indicate on the form that there are additional pages to your advance directive.
e. Sign the form and have it witnessed.
f. Keep the original for yourself.
g. Give a copy of this entire form to all of the following people: your doctor or your nurse, the person you appoint to make your health care decisions for you, your family, and anyone else who might be involved in your care.
h. Remember that you may change or cancel this document at any time.

3. Definitions (Words you need to know.)
a. **Advance Directive:** A written document that tells what you want or do not want, if you become unable to make your wishes about health care treatments known.
b. **Artificial Nutrition and Hydration:** When synthetic food (or nutrients) and water are fed to you through a tube inserted through your nose into your stomach or into the intestine directly or into a vein.
c. **Comfort Care:** Care that helps to keep you comfortable but does not cure your disease. Bathing, turning, pain medication, keeping your lips and mouth moist and pain medications are examples of comfort care.
d. **Cardiopulmonary Resuscitation (CPR):** Treatment to try and restart a person’s breathing or heartbeat. CPS may be done by breathing into your mouth, pushing on your chest, by putting a tube through your mouth or nose into your throat, administering medication, giving electric shock to your chest, or by other means.
e. **Durable Power of Attorney for Health Care:** A document that appoints a specific individual to make health care decisions for you if you become unable to make those decisions for yourself.
f. **Life-sustaining Treatment:** Any medical treatment that is used to delay the moment of death. A breathing machine (ventilator), CPR, and artificial nutrition and hydration are examples of life-sustaining treatments.
g. **Living Will:** Instructions you have made in advance that tell what medical treatment you do or do not want if you become unable to make your wishes known.
h. **Permanent Vegetative State:** When a person is unconscious with no hope of regaining consciousness even with medical treatment. The body may move and eyes may be open, but as far as anyone can tell, the person can’t think or communicate.
i. **Surrogate Decision-maker:** This is an individual, organization or other body authorized to make health care decisions for you if you are unable to do so yourself.
YOUR RIGHTS REGARDING ADVANCE DIRECTIVES

Advance Directives. Advance directives are legal forms that state your preferences about future health care. If you become too ill to make decisions about your care, an advance directive can help your doctors and family members understand what you want. It is up to you to decide if you want an advance directive. Your decision must not affect your access to health care or other VHA services. There are two types of advance directives. In the Department of Veterans Affairs (VA), the two types are in one form. You may complete neither, one, or both of the following: Durable Power of Attorney for Health Care. In this type of advance directive, you name a person as your Health Care Agent who is to make health care decisions for you if you are notable to do so. Your Health Care Agent is the first person your health care team contacts for decisions about your care. Living Will. In this type of advance directive, you state your preferences about treatments you want, or don't want, in different situations when you cannot make treatment decisions yourself. A living will helps your Health Care Agent or others know what treatments you would choose. Your Rights: 1. You have the right to accept or refuse any medical treatment. 2. You have the right to complete a durable power of attorney for health care. 3. You have the right to complete a living will. Your Responsibilities: 1. If you have an advance directive, it's important to give the Veterans Health Administration (VHA) a copy for your health record. 2. If you'd like more information about advance directives, or help filling out the forms, please call to schedule an appointment.

VA FORM

10-0137A

DEC 2006

WHAT YOU SHOULD KNOW ABOUT ADVANCE DIRECTIVES

As a VA patient you have a say in the health care you receive. When you are ill, your doctor should explain what treatments there are for your illness so that you can decide which one is best for you. But if you were too ill to understand your treatment choices or to tell your doctor what treatment you want:

- Who would you want to make decisions for you?
- What type of health care would you want?
- What health care wouldn’t you want?
Questions like these may be hard to think about, but they’re important. That’s why VA wants you to know about a legal form you can complete. It’s called an advance directive.

**What is an advance directive?**
An advance directive is a legal form that helps your doctors and family members understand your wishes about health care. It can help them decide about treatments if you are too ill to decide for yourself. For example, if you are unconscious or too weak to talk. There are two types of advance directives: durable power of attorney for health care and living will.

**What is a durable power of attorney for health care?**
This form lets you name the person you trust to make health care decisions for you if you can’t make them yourself—your “health care agent.” He or she will have the legal right to make health care decisions for you. You can choose any adult to be your agent. It’s best to choose someone you trust, who knows you well and who knows your values. You should make sure the person is willing to serve as your agent. If you don’t choose an agent, your doctor will choose someone to make decisions for you in the following order: legal guardian (if you have one), spouse, adult child, parent, sibling, grandparent, grandchild, or a close friend. Your health care team, or a court, will make decisions for you in accordance with VA policy if none of the above is available.

**What is a living will?**
A living will is a legal form that states what kinds of treatments you would or wouldn’t want if you become ill and can’t decide for yourself. It can help your health care agent and your doctor make decisions the way you want them to. Writing down what kind of treatment you would or wouldn’t want can help make it easier for those who are asked to make decisions for you. Talk with your family, your health care agent, and your doctor about your wishes so they won’t have to wonder what you want and if they’re doing the right thing. If you don’t have a living will, decisions will be made for you based on what is known about you in general and about your values. That’s why it’s important to discuss your wishes with your loved ones, your doctors, and your health care team.

**Must my health care agent always follow my living will?**
Most of the time, yes. Your health care agent should try to respect your wishes. But it can be hard to imagine future health and say just what treatment you would want at that time, so sometimes your agent may have to interpret your wishes. In a VA advance directive, you can say if you want your agent to do just what your living will says, or if they may make the decision they think is best for you at that time, even if it isn’t what you said you would want.
Should I have an advance directive?
Yes, it’s a good idea to have one. An advance directive helps protect your right to make your own choices. It helps make sure people respect your values and wishes if you can’t speak for yourself. *Your advance directive is used only when you aren’t able to make decisions yourself.*

How do I complete an advance directive?
Fill out VA Form 10-0137, “VA Advance Directive: Durable Power of Attorney and Living Will.” Or use any valid state advance directive form. Talk to a health care professional at your local VA health care facility. This might be a social worker or your primary care doctor. Or talk to your spiritual advisor or attorney. Your VA health care team can make your advance directive part of your medical record.

Do I need to fill out a durable power of attorney *and* a living will?
No. Even though the VA form contains both, it’s up to you whether you complete the durable power of attorney for health care, the living will, or both.

Can I change my advance directive?
Yes, you may change or cancel your advance directive at any time. In fact, you should review your advance directive periodically, especially if there is a change in your health, to make sure it’s up to date. If you change it, be sure to tell your health care team and have them put it in your health record. Share your new directive with your family members and other loved ones.

Other resources for advance directives:
*Your Life, Your Choices* has exercises to help you think about important questions. It’s available on MyHealtheVet at [http://www.myhealth.va.gov](http://www.myhealth.va.gov).

VA Form 10-0137B
DEC 2006
Learning Resource E

VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY
FOR HEALTH CARE AND LIVING WILL

This advance directive form is an official document where you can write down your preferences about your medical care. If some day you become unable to make health care decisions for yourself, this advance directive can help guide the people who will make decisions for you. You can use this form to name specific people to make health care decisions for you and/or to describe your preferences about how you want to be treated. When you complete this form, it is important that you also talk to your doctor, your family, or others who may be involved in decisions about your care, to make sure they understand what you meant when you filled out this form. A health care professional can help you with this form and can answer any questions you might have. If more space is needed for any part of this form, you may attach additional pages. Be sure to initial and date every page that you attach.

PART I: PERSONAL INFORMATION

SOCIAL SECURITY NUMBER

NAME (Last, First, Middle)

STREET ADDRESS

CITY, STATE AND ZIP CODE

HOME PHONE WITH AREA CODE

WORK PHONE WITH AREA CODE

MOBILE PHONE WITH AREA CODE

Privacy Act Information and Paperwork Reduction Act Notice

The information requested on this form is solicited under the authority of 38.C.F.R. §17.32. It is being collected to document your preferences about your medical care in the event you are no longer able to express these preferences. The information you provide may be disclosed outside the VA as permitted by law; possible disclosures include those described in the "routine uses" identified in the VA system of records 24VA19, Patient Medical Record-VA, published in the Federal Register in accordance with the Privacy Act of 1974. This is also available in the Compilation of Privacy Act Issuances via online GPO access at
http://www.gpoaccess.gov/privacyact/index.html. Completion of this form is voluntary; however, without this information VA health care providers may have less information about your preferences. Failure to furnish the information will have no adverse effect on any other benefits which you may be entitled to receive. The Paperwork Reduction Act of 1995 requires us to notify you that this information collection is in accordance with the clearance requirements of section 3507 of this Act. The public reporting burden for this collection of information is estimated to average 30 minutes, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. No person will be penalized for failing to furnish this information if it does not display a currently valid OMB control number.

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VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (Last, First, Middle)

SOCIAL SECURITY NUMBER

PART II: DURABLE POWER OF ATTORNEY FOR HEALTH CARE

This section of the advance directive form is called a Durable Power of Attorney for Health Care. This section of the form allows you to appoint a specific person to make health care decisions for you in case you become unable to make decisions for yourself. This person will be called your Health Care Agent. Your Health Care Agent should be someone you trust, who knows you well, and is familiar with your values and beliefs. If you become too ill to make decisions for yourself, your Health Care Agent will have the authority to make all health care decisions for you, including decisions to admit you to and discharge you from any hospital or other health care institution. Your Health Care Agent can also decide to start or stop any type of clinical treatment, and can access your personal health information, including information from your medical records. NOTE: Information about whether you have been tested for HIV or treated for AIDS, sickle cell anemia, substance abuse or alcoholism cannot be shared with your Health Care Agent unless you give special written consent. Ask your VA health care provider for the form you must sign (VAFORM 10-5345) if you wish to give permission for VA to share this information with your Health Care Agent.
A - HEALTH CARE AGENT

Initial the box next to your choice. Choose only one.

Initials

I do not wish to designate a Health Care Agent at this time. (Skip this section and go to Part III, page 3.)

Initials

I appoint the person named below to make decisions about my health care if there ever comes time when I cannot make those decisions.

Name (Last, First, Middle)

Relationship

Street Address

City, State and Zip Code

Work Phone with Area Code

Mobile Phone with Area Code

Home Phone with Area Code

B - ALTERNATE HEALTH CARE AGENT

Complete this section if you want to appoint a second person to make health care decisions for you in case the first person you appointed is unavailable.

Initials

If the person named above cannot or will not make decisions for me, I appoint the person named below to act as my Health Care Agent.

Name (Last, First, Middle)

Relationship

Street Address

City, State and Zip Code
VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY
FOR HEALTH CARE AND LIVING WILL

NAME (Last, First, Middle)

SOCIAL SECURITY NUMBER

PART III: LIVING WILL

This section of the advance directive form is called a Living Will. This section of the form allows you to write down how you want to be treated in case you become unable to make decisions for yourself. Its purpose is to inform the people who will be making decisions about your care.

A - SPECIFIC PREFERENCES ABOUT LIFE-SUSTAINING TREATMENTS

This section gives you a place to indicate your preferences about life-sustaining treatments in particular situations. Some examples of life-sustaining treatments are CPR (cardiopulmonary resuscitation), breathing machine (mechanical ventilation), kidney dialysis, feeding tubes (artificial nutrition and hydration), and medicines to fight infection (antibiotics). Think about each situation described on the left and ask yourself, ”In that situation, would I want to have life-sustaining treatments?” Place your initials in the box that best describes your treatment preference. You may complete some, all, or none of this section. Choose only one box for each statement.

Yes. I would want to have life-sustaining treatments.

It would depend on the circumstances.

No. I would not want to have life-sustaining treatments.

If I am unconscious, in a coma, or in a persistent vegetative state and there is little or no chance of recovery
If I have permanent severe brain damage (for example, severe dementia) that makes me unable to recognize my family or friends

If I have a permanent condition that makes me completely dependent on others for my daily needs (for example, eating, bathing, toileting)

If I am confined to bed and need a breathing machine for the rest of my life

If I have pain or other severe symptoms that cannot be relieved

If I have a condition that will cause me to die very soon, even with life-sustaining treatments
VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY
FOR HEALTH CARE AND LIVING WILL

NAME (Last, First, Middle)

SOCIAL SECURITY NUMBER

PART III: LIVING WILL (Cont’d)

B - ADDITIONAL PREFERENCES

You may use this space to write any other preferences about your health care that are important to you and that are not described elsewhere in this document. This may include general preferences about how you would like to be cared for, or specific requests. For example, you might have clear opinions about whether you would want a particular treatment (for example, a feeding tube or blood transfusions). You might want to comment on treatment of pain, or whether you would want life-sustaining treatments on a trial basis. Or you might want to write about your preferences regarding treatment of mental illness.

C - HOW STRICTLY YOU WANT YOUR PREFERENCES FOLLOWED

Initial the box next to the statement that reflects how strictly you want your preferences to be followed. Choose only one.

Initials

I want my preferences, expressed above in this Living Will, to serve as a general guide. I understand that in some situations the person making decisions for me may decide something different from the preferences I express above, if they think it is in my best interest.

Initials

I want my preferences, expressed above in this Living Will, to be followed strictly, even if the person who is making decisions for me thinks this is not in my best interest.
VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (Last, First, Middle)

SOCIAL SECURITY NUMBER

PART IV: SIGNATURES

A - YOUR SIGNATURE

By my signature below, I certify that this form accurately describes my preferences.

SIGNATURE

DATE

B - WITNESSES' SIGNATURES

Two people must witness your signature. VA employees of the Chaplain Service, Psychology Service, Social Work Service, or non-clinical employees (e.g., Medical Administration Service, Voluntary Service or Environmental Management Service) may serve as witnesses. Other individuals employed by your VA facility may not sign as witnesses to the advance directive unless they are your family members.

Witness #1

I personally witnessed the signing of this advance directive. I am not appointed as Health Care Agent in this advance directive. I am not financially responsible for the care of the person making this advance directive. To the best of my knowledge, I am not named in the person's will.

Date

SIGNATURE

Name (Printed or Typed)

Street Address

City, State and Zip Code

Witness #2
I personally witnessed the signing of this advance directive. I am not appointed as Health Care Agent in this advance directive. I am not financially responsible for the care of the person making this advance directive. To the best of my knowledge, I am not named in the person's will.

SIGNATURE

Date

Name (Printed or Typed)

Street Address

City, State and Zip Code

**VA FORMDEC 2006 (RS)**

**10-0137**

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VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (Last, First, Middle)

SOCIAL SECURITY NUMBER

PART V: SIGNATURE AND SEAL OF NOTARY PUBLIC (Optional)

This VA Advance Directive form does not have to be notarized to be valid in VA facilities. However, you may need to have this document notarized for it to be recognized outside the VA health care setting. Space for a Notary’s signature and seal is included below.

On this day of, in the year of, personally appeared before me known by me to be the person who completed this document and acknowledged it as their free act and deed. IN WITNESS WHEREOF, I have set my hand and affixed my official seal in the County of, State of, on the date written above. Notary Public Commission Expires.

[SEAL]

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Module # 22: Interdisciplinary Care
Planning: Leading to Healthy
Transitions
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 22: Interdisciplinary Care Planning: Leading to Healthy Transitions

James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

This interdisciplinary curriculum is geared to allied health students and may be reproduced and used with attribution.
### Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

**Module # 22: Interdisciplinary Care Planning: Leading to Healthy Transitions**

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Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum

Module #22: Interdisciplinary Care Planning: Leading to Healthy Transitions

I. Overview

The interdisciplinary care plan is based on data gathered during patient assessment, identifies the patient’s care needs, and develops strategies to meet those needs. The purpose of the Care Plan is to transition the patient through the continuum of care in a seamless, safe and effective way. In order to accomplish this goal, the plan of care documents treatment goals and objectives; states criteria for terminating specific interventions, and documents the patient’s progress in meeting the goals and objectives. An interdisciplinary care plan requires that each discipline must collaborate in the assessment and reassessment of the patient, and then strive to integrate interdisciplinary documentation of needs, goals, strategies and interventions.

II. Learning Objectives

1. Describe the conceptual framework in which an interdisciplinary care plan is developed.
2. Identify care plan intervention strategies.
3. Explain the differences between interdisciplinary and multidisciplinary perspectives.
4. Discuss the care coordination process.
5. Develop a professionally sound care plan.

III. Definition

A. The process of developing an agreement between client and case manager regarding client problems identified, outcomes to be achieved, and services to be pursued in support of goal achievement. ¹

B. A dynamic decision making process based on assessment. ² The effectiveness and appropriateness of the care plan depends on the assessment process.

IV. Conceptual Framework

A. Care plans are patient centered and individualized.
1. When developing a care plan for an older adult, the interdisciplinary team must take into consideration not only the bio-psycho-social aspects of the case, but also the patient and caregiver’s desires.

2. Especially with larger interdisciplinary teams, the size of the geriatrics team may make it increasingly difficult for patients and families to have their voices heard. The patient/client and his/her family should always be considered as integral members of the team. Patients must be asked what involvement they desire.
   a. In one study, 40% of nursing home residents reported not being involved in their health care decisions. However, 79.3% of those patients reported that the level of their participation was sufficient. ³

3. Needs that threaten life, safety and security must be a priority. Core needs, those which if not dealt with will cause other problems, must be handled first. (i.e. hip pain vs. mobility issue)

B. Perception of need
   1. By patient
   2. By family
   3. By provider

C. Problem assessment
   1. What are this patient’s/ family’s needs, expectations, strengths and history
   2. What was tried before?
   3. What worked? What did not work?
   4. What are current relationships?
   5. Who is the leader – voluntary vs. involuntary?

D. Achievable outcomes must be created
   1. Accessible
   2. Acceptable
   3. Adaptable
   4. Appropriate
   5. Affordable

E. Strength Based Care Plan ⁴
   1. State in positive terms
   2. Make it realistic and achievable
   3. Measurable and visible
4. Specific and time limited
5. Relevant and understandable

V. Intervention Strategy

A. Engagement

1. Engage the client, not the diagnosis
2. Go slow
3. Don’t make promises
4. Respect their right to disagree
5. Determine who the “other” significant players are and
6. Engage them as soon as possible

B. Implementation

1. Prioritize
2. Start slow – Go slow
3. Choose your battles wisely
4. Healthy Alliances
5. Pick a “bad” guy
6. Get it right the first time!

C. Specific strategies for assistance

1. Educating patient/ family on available resources
2. Fostering clearer communication among patient and family
3. Acceptance, reassurance
4. Keep all family members in the loop via designated point person

D. Follow-up

1. Monitoring
2. Reassessment
3. Termination

VI. Interdisciplinary Care Planning

A. Team members understand the roles and contributions of each discipline on the team and includes methods for communication, collaborative care planning and shared responsibility for patient outcomes. 

B. Team members integrate their assessments and recommendations for intervention, which creates a comprehensive care plan. (Multidisciplinary team members function independently with limited integration and collaboration.)

C. See Learning Resource:
“Interdisciplinary Practice and the Geriatric Care Manager,” by F. Ellen Netting, PhD.

VII. Care Coordination Process

A. Care Coordination Task Flow:

B. Care planning is an important part of Care Coordination. The following list describes the Sequential Tasks of Care Coordination of which care planning is an integral part.

1. *Case finding or screening* to identify people in the target population who may require services

2. *Comprehensive, multidimensional assessment* to determine any individualized unmet needs

3. *Care planning*, which requires decisions about how the needs identified in the assessment can be met

4. *Implementation of the plan*
5. **Follow Up** to determine progress of implementation

6. **Monitoring** both the progress of the patient and the adequacy of the services given under the plan

7. **Formal reassessment** at intervals to gauge continuing need

8. **Care Plan re-development or Close** depending on reassessment findings

C. See Learning Resource:

“Care Planning: The core of case management” by Barbara Schneider

VIII. A Model Care Plan

A. Model Interdisciplinary Care Plan and Its Development

The following case study provides a comprehensive assessment model. Developed by the University of South Florida GITT Program as a simulation with actors, it contains a patient script, caregiver script and physician script. The case also describes a care plan that looks at the needs of the patient, the necessary interventions as well as which discipline should address each problem. The purpose of this model is to illustrate the steps in geriatric assessment and treatment plan development.

B. Patient Script

**Identifying Information:**

I am an 81-year old, white widowed man, born on 6/15/1917. I have completed 7th grade education. I have lived in the area of 10 years. My sister June, who is 75 years old, brought me to the office. June has moved in with me 3 years ago to help with the management of my diabetes and also because I was starting to have problems with my memory. This is my fourth visit.

**Chief Complaint or Concern:**

I frequently fall and I lose my urine. June, my sister, wants me to have a prescription to control, my urine to make me sleep better at night.

**Present Illness:**

Within the past week, I have fallen twice while en route to the bathroom. For the past few months there, I have had urinary accidents once or twice weekly when I was unable to get to the bathroom on time. I understand and acknowledge the problem with my memory deficits and the poor control of my diabetes, but feel that there is nothing I can do. It is my sister’s role to help me with those problems.
Medical History:

Medical conditions:
- Hypertension
- Edema of the lower extremities
- Diabetes
- Degenerative joint disease, commonly known as arthritis
- Decreased visual acuity secondary to cataract in my right eye
- Two transient ischemic attacks (TIA) in the distant past

Medications:
- Tylenol prn (as needed) for pain caused by arthritis
- Lente insulin U-100, 30 U in am and 10 U in pm for diabetes
- Verapamil SR 240 mg daily for high blood pressure
- Temazepam 15 mg at bedtime to help me sleep
- Furosemide 40 mg daily prn (as needed) for the swelling in my legs
- Benadryl 25 mg prn (as needed) for anxiety

Past Psychiatric History:
I became depressed when my spouse died and was treated with medication for a few months.

Social Resources:
I have three children, Jan, April and Joe. They all live in other states and have children and grandchildren. They cannot give me any support with care giving. June and I live on our social security. The home belongs to me and I have a small retirement pension left by my spouse. During the day I look at the TV, read the paper, and watch the birds and the squirrels in the backyard. My friends have stopped visiting since my sister moved in. I wish my longtime friend Mary would come by and visit me. June complains that I am very demanding, that I don’t sleep at night, and that I need constant attention. This, June says, leaves her with no free time.

Physician Examination:

Weight: 130 lbs., a loss of 30 lbs. over 7 months. B/P: 120/78

The patient appears disheveled and weak. The patient smells of urine and his clothes are soiled. This is a marked change from a usually neat demeanor. He needs assistance with transfers and with undressing. The patient reports being left alone for long periods of time. The patient reveals being put to bed before his sister goes out for the evening and restrained to prevent him from getting out of bed. The patient eats twice a day and frequently receives the insulin dose late at night.

- A cataract is visualized in the right eye. Visual acuity is minimal in right eye but there is no loss of visual acuity in the left eye.
- Mucous membranes appear dry, tongue is red and smooth.
- Pitting edema of ankles 1+ (minimal)
Knee joints are large, non-tender but with crepitation
Patient is unsteady steady while standing
Skin shows no bruising, except for purpuric lesions on the extensor surface of the hands.
Skin turgor is poor.
No other abnormalities are found.

Lab results: Hgb 9.9, Hct 27%, MCV 72, BS 84, albumin 2.8, cholesterol 160

Diagnoses: After review of systems and physical exam, the doctor/nurse practitioner list the following diagnoses:
- Rule out neglect
- Fall risk
- Diabetes poorly controlled
- Dehydration
- Malnutrition
- Urinary incontinence
- Rule out dementia
- Cataract right eye
- DJD
- Hypertension well controlled
- Mild edema of lower extremities

Mental status:
The patient’s voice is a monotone. His facial expression is sad and he appears depressed. He expresses the feeling that he cannot do anything that is valuable anymore. He is tearful when talking about being left alone. He expresses fear of intruders especially when his sister is not home. He reports being afraid of placement in a nursing home. He is unhappy and hopeless about the future. He reports not sleeping until his sister comes back home at night. He states, “I had a good life and am ready to go join my deceased spouse.”

His Mini Mental State Exam score is 20/30. He is disoriented to month, date and day. He does not know the name of the office although was able to recall it’s name during previous visits.

When he is asked to begin at 100 and count backward by 7, he makes two mistakes. When he is asked to remember three items, he can only remember one. When asked to copy a design, he cannot do it correctly. He can read a sentence after squinting his eyes and makes two attempts.

Functional Assessment:
He requires some assistance with bathing and dressing because of his arthritis and unsteadiness. On the days when his arthritis is worse, he needs help with transfers from his chair to the bed, with going to the bathroom, and with walking around the house. He can walk with a cane and he is sometimes unsteady because of the arthritis in his knees.

His sister cooks lunch sometimes and prepares all the dinners. He states that he can prepare breakfast, and that he eats leftovers or frozen dinner when his sister does not prepare lunch.

He cannot prepare his insulin injection because he can’t see the small numbers on the syringe. He doesn’t like to give it to himself, and states, “that’s what my sister is there for.”
C. Caregiver Script

Social Resources:
My brother has three children, Jan, April and Joe who live out of state and cannot give any support with care giving. My brother and I live on our social security. The house belongs to my brother. My brother has a small retirement pension left by his deceased spouse. I am not sure what my brother does during the day; I am busy with my work and with continuously answering the same questions. We have a TV that is on all the time. Some friends used to come by and visit, but they don’t anymore. Who would want to visit when they hear the same questions and the same stories all the time?

There is always something my brother wants me to do. I never do enough. I cannot even have rest during the night, and I have no free time anymore.

Physical Health:
There is always something wrong. You have to do this, you have to do that. Take the blood pressure, check the sugar, give the injection. I don’t know why he has to take an injection since they have pills now for diabetes. I know because my friend takes pills.

My brother is always tired and cannot see well. He needs to go to the bathroom all the time and cannot even make it to the bathroom. He does not complain of pain.

Mental Status:
My brother keeps repeating that he is ready to die and join his deceased spouse. He never knows what date it is and asks me every 5 minutes. He never knows what’s going on.

Functional Assessment:
I have to help him with bathing and dressing because he is unsteady on his feet. Sometimes I have to help with transfers from the bed to the chair and from one room to another.

I have to help with getting him to the bathroom. I don’t know why I have to do that, the cane is there to use. Also, I have to do all the cooking and cleaning.

D. Interdisciplinary Care Plan

Main Problem: Impaired coping by caregiver with suspected neglect and safety issues.

Main Goal: Caregiver: mobilize support and decrease stress

Patient: Improve mood and health care management

Team: Restore a safe patient environment
<table>
<thead>
<tr>
<th>Date</th>
<th>Problems/Needs</th>
<th>Goals</th>
<th>Interventions</th>
<th>Discipline</th>
<th>Evaluation Date</th>
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</thead>
<tbody>
<tr>
<td>6/21</td>
<td>Impaired coping by caregiver with suspected neglect as evidenced by malnutrition, dehydration, and use of restraining device.</td>
<td>1. Caregiver will verbalize understanding of diabetes management and the relationship between insulin, diet, medication, and blood sugar. 2. Caregiver will verbalize decreased stress. 3. No evidence of patient's emotional and physical neglect.</td>
<td>1. Provide caregiver with education in diabetes management; assess ability to administer insulin, observe her draw up and administer; assess ability to do home blood sugar monitoring. If unable, refer to home health for daily injections. Give instructions about diet and exercise. 2. Refer caregiver to support group. 3. Refer to protective service (P.S.) to help mobilize support such as respite care, adult day care, home health services and to follow-up on suspected neglect. 4. Counseling to validate feelings and discuss concerns.</td>
<td>1. MD/NP: order RN or HHA</td>
<td>6/28</td>
</tr>
<tr>
<td>6/21</td>
<td>Knowledge deficit in diabetes management leading to poor blood sugar control, memory impairment, and</td>
<td>1. Diabetes control will be maintained average (160-200 BS and 8.0 to 9.0 HgbAc1) 2. Dehydration</td>
<td>1. Visiting nurse daily for education on insulin, diet exercise 2. Refer to dietitian for evaluation of food intake and to prepare dietary plan 3. Obtain support for Meal-On-Wheels</td>
<td>1. MD/NP: order, HHA, 2. MD/NP: order, SW</td>
<td>6/28 6/28 6/28</td>
</tr>
<tr>
<td>Date</td>
<td>Note</td>
<td>Actions/Assessments</td>
<td>Responsible Party/Date</td>
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</tbody>
</table>
| 6/21   | Patient exhibits memory impairment secondary to pseudo-dementia; this is aggravated by poor diabetic control | 1. Geriatric depression scale will show improvement in depressive status  
2. Social interactions will be increased  
3. Patient will verbalize less fearful ideas  
4. Suicidal ideations will not materialize  
5. Instances of insomnia will decrease | 1. NP, PSY, SW  
2. SW  
3. SW  
4. SW  
5. SW  
6. MD/NP, PSY  
7. MD/NP, PSY  
8. MD/PSY | pending 6/28 7/1 7/1 7/1 7/21 7/21 pending 6/21 |
| 6/21   | Probable financial issues                                            | 1. Available financial resources will be used where feasible  
2. Explore sources of financial aid such as food share program, pharmacy medical program, drug company patient assistance program | 1. SW  
2. SW | 7/26 8/2 |
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X. Learning Resources

Dellefield ME. Interdisciplinary Care Planning and the Written Care Plan in Nursing Homes: A Critical Review; The Gerontologist 2006; 46:128-133.


Module # 23: Hoarding
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 23: Hoarding

James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

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# Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

## Module # 23: Hoarding

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Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum

Module #23: Hoarding

I. Overview

Hoarding refers to the excessive collection of items as well as the inability to discard them. Hoarding frequently creates such cramped living conditions that homes are usually filled to capacity, with only few narrow pathways available through stacks of clutter. Some individuals also collect animals and may keep dozens to hundreds of pets in unsanitary conditions. People who hoard generally do not see it as problematic, making treatment extremely challenging for healthcare professionals. Hoarding creates hazards and puts people and animals at risk. Therefore, it is imperative that healthcare professionals have a sound understanding of this condition and how it impacts individuals and their families.

II. Learning Objectives

1. Describe the concept of hoarding.
2. Identify the pathology of hoarding.
3. Differentiate between hoarding and collecting.

III. Definition of Hoarding

Hoarding is the name given to behavior that is characterized by:

A. The acquisition of and failure to discard a large number of possessions that appear to be useless or of limited value;

B. Accumulation of belongings to such a degree so as to impact functioning and/or preclude the activity for which a space was designed;

C. Placing people and/or animals at risk when the quantity of items create potential hazards.
IV. Hoarding Pathology

Hoarding, also called compulsive hoarding and compulsive hoarding syndrome, can be a symptom of obsessive-compulsive disorder. Currently, the DSM-IV lists hoarding as a symptom of obsessive-compulsive personality disorder (OCPD). Many people who hoard, however, do not have other OCPD-related symptoms, making it difficult to diagnose. Hoarding severity does not correlate with the severity of OCPD symptoms. In fact, of the specific diagnostic criteria for DSM-IV OCPD, hoarding has been found to have the lowest specificity and predictive value. In addition, compulsive hoarders have no more OCPD traits than comparison subjects. Furthermore, only a small percentage of them actually meet criteria for obsessive-compulsive personality disorder. As a result, many people have argued that hoarding should be removed completely from the diagnostic criteria for OCPD. Researchers are working diligently to better understand the phenomena of hoarding as a distinct mental health problem. Intensive treatment for hoarding enables people who hoard to better understand their compulsions and live a safer and increasingly enjoyable life.

V. Hoarding Versus Cluttering

It is important to make a clear distinction between hoarding and cluttering. Below are the primary differences between hoarding and cluttering:

- Collectors acquire and discard items;
- Hoarders acquire and rarely discard;
- Collecting is normal and common in children and adults;
- Hoarding is abnormal human behavior and takes years for items to accumulate to such a degree to be constituted as hoarding;
- Collecting is usually public, with items on display for showing and usage;
- Hoarding is generally private and not known to anyone outside immediate family members or close friends for fear that others would find out about this behavior
VI. Hoarding and the Elderly

Over the years, hoarding among the elderly has become a significant problem in the United States. It is important to recognize that hoarding does not begin suddenly. It takes years for someone to be classified as a hoarder. Many experts believe that the prevalence of hoarding among the elderly is higher because it compensates for the accumulation of human losses that have occurred in years prior. Another theory is that the elderly have more time to accumulate due to their age. Since most older adults have multiple chronic conditions, those who hoard have a lower rate of medication compliance, decreased mobility, and a lower chance of receiving home health assistance because most home care agencies will not provide any services until the conditions at the home are deemed safe. As more cases of extreme hoarding are being revealed, there is much more time and attention being given to help hoarders and their families.

VII. When to Seek Help

Healthcare professionals must pay close attention to any changes in behavior of individuals who exhibit symptoms of hoarding. Because hoarding may range from mild and severe, providers should communicate with their patients/clients about how this behavior impacts daily life. Recognizing risk factors for hoarding will help tremendously in the identification and treatment of hoarding. Such risk factors may include:

- Age
- Family history
- Stressful life events
- Social isolation

There is a lot of help available for hoarders and their family members. Healthcare professionals should be aware of local resources and provide ongoing assistance as needed.

“My husband Don is a hoarder. He goes to garage sales and tells people he will take whatever is left over. ‘Maybe I can do something with it’, he says. There are piles on the floor in every room in our house, broken washing machines in our front yard…I am so embarrassed…it has been six years since I have had anyone visit our home…it’s so lonely.

Don won’t consider seeking professional help. I suppose I could divorce him, but we have been married for 50 years. I don’t know what else to do.”

~ Wife of a hoarder
VIII. References


Module # 24: Spirituality
Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 24: Spirituality

James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center

Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development

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I. Overview

The history of Western medicine has been one of gradual but virtually complete disengagement from religious or spiritual explanations of and cures for disease, and an almost total embrace of biological explanations for disease and technologically-sophisticated treatments. Yet, even as health care and spirituality have come to be seen as largely separate domains in many Western countries, life-threatening disease and illness continue to provoke questions that biomedicine and the modern health care delivery have failed to address. To what extent are these ‘spiritual’ concerns the province of the chaplain and pastoral care providers, or the duty and responsibility of all health care providers, as part of their ordinary interactions with patients and families?

The relevance of spiritual concerns across the life span, but particularly as the end of life draw near, has been receiving more attention from health care providers and institutions. Linked to a renewed interest in the impact of spiritual beliefs on the lives and well-being of patients is the interest in the spirituality of the health care professionals themselves. Their faith and spirituality is being studied and programs are being developed that focus on the care and nurture of their spiritual well-being. These efforts occur in a larger context of an ongoing effort to promote relationship-centered care that depends on caregivers cultivating self-awareness and self-knowledge as prerequisites to developing therapeutic relationships with patients.

II. Learning Objectives

1. Define religiosity and spirituality.
2. Discuss the correlation between faith and health.
3. Delineate barriers to spiritual care at the end-of-life.
4. Identify components of a spiritual assessment of health professionals and others.
5. Identify signs of spiritual distress.
6. Describe an interdisciplinary approach to spiritual care at the end-of-life.

III. Religion and Spirituality

A. Definitions:
1. **Religion**: refers to beliefs, practices and traditions associated with religious groups (e.g. Catholic, Protestant, Jewish, Buddhist).¹

2. **Spirituality**: refers to the personal search for meaning and purpose in life (relationship to self, others, nature, world, God).¹

3. **Spiritual Care**: Spiritual care is defined as “meeting people where they are and assisting them with connecting or reconnecting with things, practices, ideas, and principles that are at the core of their being—the breath of their life, making a connection between yourself and that person.”²

### B. Need for spiritual care

1. The essence of spirituality is connectedness to something that imbues life with a sense of meaning and purpose. Spiritual well-being is therefore a buffer against depression, hopelessness, and desire for death in patients with advanced cancer.²

2. Recent claims indicate that spirituality is not only an adaptive trait but the gene has been located for the production of neurotransmitters that regulate profound feelings of spirituality. According to Buddhist thinking, the spirituality gene helps establish a general trust in the universe, a sense of openness and generosity.³

### C. Importance to patients and physicians:

1. Evidence indicates that some dying patients and those with life-threatening illness would like health practitioners to be attuned to their spiritual needs.⁴,⁵,⁶

2. Based on the National Opinion Research Center, 81% of physicians believe that spirituality can directly affect clinical outcomes. This is supported by a meta-analysis conducted in 1998 by Larson and colleagues who found a positive correlation between spirituality and health. Ninety one percent of physicians agreed that doctors should attempt to understand the spiritual and religious perspectives of their patients.²

### D. Spirituality as Part of the Health Assessment¹

1. Provides meaning in illness
2. Means of coping
3. Rituals, social support
4. Dynamic Interaction with all dimensions of quality of life
   a. Physical
      --Strength/fatigue
      --Sleep and rest
b. Psychological
   --Anxiety
   --Depression
   --Enjoyment/leisure
   --Pain Distress
   --Happiness
   --Fear
   --Cognition/attention

c. Social
   --Financial burden
   --Caregiver burden
   --Roles and relationships
   --Affections/sexual function
   --Appearance

d. Spiritual
   --Hope
   --Suffering
   --Search for meaning
   --Religiosity
   --Transcendence

IV. Barriers to Spiritual Care

A. Spirituality confused with religiosity
B. Lack of training
C. Poor understanding about what the spiritual dimension comprises
D. No prior self-assessment
E. Discomfort with the dimension

V. Correlation Between Faith and Health

A. Recent studies have linked religious beliefs and practices to better mental and physical health, including less depression, better coping with illnesses, less functional disability, and lower risk of death after cardiac surgery.

B. 82% of adults believe in the healing power of prayer.

C. 56-79% believe spiritual faith did or can help one recover from illness,
injury or disease.

D. 63% believe doctors should talk with their patients about spirituality.

E. 75% of elderly inpatients rate religious beliefs as a very important means of effectively coping with their illness.

F. Spirituality and/or religious commitment are associated with medical benefits including relief from physical, mental and addictive disorders, enhanced quality of life, and survival.

G. Hills, Paice, Cameron, and Shott\(^7\) conducted a pilot study which indicated that of 31 patients the majority were somewhat spiritual, and 77% were somewhat religious. Negative statement about God was correlated with greater distress, confusion, depression, and negativity associated with physical and emotional well-being and quality of life.

VI. Health Professionals’ Spiritual Self-Assessment\(^4\)

A. Personal beliefs
B. Sources of meaning/hope
C. Values
D. Religious affiliation
E. Belief in the divine; transcendence
F. Relationships: to others, God, nature

VII. Spiritual Assessment of Others

A. General Points
   - Religious affiliation alone as not sufficient
   - No right way, no right time
   - Reassessment with changing conditions/circumstances
   - Trusting relationship
   - Basic knowledge of major religions, and cultural practices of populations served
   - Always perform an individualized assessment
   - Never stereotype or generalize

B. How to Ask:
   - Use open-ended questions
   - Assess positive and negative aspects
   - Be non-judgmental
   - Do not impose your own beliefs
C. When to Ask:
   - History (any discipline)
   - After assessing religious affiliation
   - Talking cues from patient’s personal items
   - Verbal cues
     - Questions: “why…”, “I wish…”
     - Clues about spiritual nature
   - Non-verbal cues
     - Affect
     - Moaning/crying

D. What to Ask: Screening for unaddressed spiritual and existential concerns is often useful for patients and providers comfortable with more in depth discussions. Some helpful questions may include:
   - “What do you still want to accomplish during your life?”
   - “What thoughts have you had about why you got this illness at this time?”
   - “What might be left undone if you were to die today?”
   - “What’s your understanding about what happens to you after you die?”
   - “Given that your time is limited, what legacy do you want to leave your family?”
   - “What do you want your children and grandchildren to remember about you?”

VIII. Spiritual Distress

A. Questions posed to Chaplains at the End of Life
   - Meaning/story of life: Why did I get sick; Was this all there is?
   - Death and Dying: What happens when I die? Is there life after death?
   - Illness and pain: Will death be painful?
   - Relationship and separation: How will the family manage after my death?
   - Religious Issues: Has God abandoned me? Themes of forgiveness and peace

B. Reasons for Spiritual Distress
   - Disruption in usual religious activity
   - Personal and family disasters
C. Characteristics of Spiritual Distress

- Feeling separated or alienated from the deity
- Dissatisfaction with personal past or present
- Depression
- Crying
- Self-destructive behavior or threats
- Fear
- Feelings of abandonment
- Feelings of hopelessness

D. Spiritual Cues indicating unanswered spiritual or existential needs

- I am wondering if God is here for me now.
- I feel as though God is punishing me.
- I am angry at God.
- Why is this happening to me?
- I feel abandoned.
- God has not been fair to me.
- I failed God.
- I am worried that my children is not going to remember me.

E. Spiritual pain may manifest as the following:

- Physical (intractable pain)
- Psychological (anxiety, depression, hopelessness)
- Religious (crisis of faith)
- Social (denigration of human relationships)

F. Spiritual crisis at the end of life may take the form of:

- Losing one’s will to live
- Heightened desire for death
- Loss of dignity
- Loss of control
- Fear of being a burden to others

IX. Interdisciplinary Approach/Resources

A. All team members are responsible for holistic care.

B. Referral to chaplain, massage therapist, art therapist, music therapist.
C. Use of individual’s personal clergy, faith community, identified supports.

X. Offering Spiritual Care 

A. Acknowledge spiritual pain

B. Therapeutic use of self
   - Listening
   - Presence
   - Non-abandonment

C. Create a spiritually healing environment through use of music, art, massage, aromatherapy, guided imagery, or therapeutic touch.

D. Offer in-depth work as an approach that moves individuals toward a deeper level of the psyche, helping create a sense of meaning and reconnection to the ordinary things of life. Discuss areas of concern such as relationships, control, identity and meaning.

E. Encourage patients and family to speak of aspects of their life they were most proud of or that were most meaningful; the personal history they would like remembered, or things that need to be said.

F. Provide referral to clergy or spiritual advisor

XI. Documentation of Spiritual Well-being

A. Where to record information:
   - Interdisciplinary progress notes
   - Spiritual assessment form if available
   - Other

B. What to document:
   - Respect privacy/confidentiality
   - Evidence of Spiritual Distress
   - Referrals
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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 1: Introduction to Aging

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# Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

## Module # 1: Introduction to Aging

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Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 1: Introduction to Aging

I. Overview

The United States, like many countries in the world, is undergoing a longevity revolution. There are several factors leading to current increasing numbers of older Americans, including the aging of the Baby Boomers, a decline in mortality rates, higher post-war fertility rates, improved medical technology, and increased life expectancy.

Not only is the population aging, but most older adults can expect to develop one or more chronic illnesses with which they may live for many years, often with physical and psychological symptom distress and progressive functional dependence and frailty. The growing number and proportion of older adults will therefore place increasing demands on the public health system and on medical and social services.

Chronic diseases exact a particularly heavy health and economic burden on older adults due to associated long-term illness, diminished quality of life, and greatly increased health care costs. Although the risk of disease and disability clearly increases with advancing age, poor health is not an inevitable consequence of aging. Geriatricians use the term “healthy agers” to describe the large population of highly functional community-dwelling older adults. Even in the face of serious and chronic illness, these individuals remain physically and mentally active and socially engaged with family and friends.

II. Learning Objectives

1. Discuss the demographic imperative for increased care of the elderly.
2. Identify the implications of an aging society on health care resources.
3. Define “geriatrics”.
4. Define “ageism”.
5. Describe the three major dimensions of aging.
6. Identify two theories of aging.
7. Discuss prevalent myths and stereotypes about aging.
III. The Demographic Imperative For Increased Geriatric Care

A. The U.S. population is aging. The older age group (65+) is growing rapidly and there is an increased need for practitioners with geriatric training.

1. As of 2003, 35.9 million people reached 65 years of age. This was an increase of 9.5% from 1993.¹

2. A child born in 2002 could expect to live 77.3 years, 30 years longer than a child born in 1900. This is due primarily to reduced death rates for children and young adults, and, to some extent, reduced death rates for older persons since 1980.

3. There is a difference between life span and life expectancy. Life span refers to the maximum survival time for a species. In the case of human beings, this is about 120 years. Life expectancy is the average number of years of life from a particular age, say birth or age 65. This changes over time (as noted in 2) because of changes in medical care, sanitation, and other factors.²

4. The fastest growing population segment is the oldest-old. In 1900, there were about 122,000 people 85 years old and older, less than 1% of the total population. By 1990, the oldest-old numbered 3.0 million persons. By the year 2050, those 85 and older will represent almost 5% of the population.

5. By 2030, the number of older Americans will have more than doubled to 71.5 million, or one in every five Americans. By 2050, that number will grow to 80 million Americans over 65, with 18 million over 85 years of age.

6. There were 50,639 people aged 100 or more in 2003, which is a 36% increase from 1990.

7. Members of minority groups are projected to represent 26.4% of the older population in 2030, up from 16.4% in 2000.
IV. Implications Of An Aging Society On Healthcare Resources

a. Most older persons have at least one chronic condition. The most frequent conditions occurring among the elderly in 2002 were:
   a. Hypertension – 49%
   b. Arthritis – 36%
   c. Heart disease – 31%
   d. Cancer – 20%
   e. Sinus problems – 15%
   f. Diabetes – 15%

b. The increasing size of the oldest-old age cohort (85 years and older) has major implications because individuals in this age group tend to have more activity limitations, experience more chronic conditions, and require more services than the younger old.

c. Health care utilization is higher among older adults than among younger persons. In 1995 when the 65 and over population included 33.5 million persons, or 12.8% of the total population, older people accounted for over a third of the total personal health care dollars. Health care usage generally increases with advancing age. In 1996, the average annual expenditure on health care, which includes both out-of-pocket expenses as well as expenses covered by insurance, was $5,864 for those aged 65-69, $9,414 for those aged 75-79, and over $16,000 for those 85 and older. 3

d. Another major implication is the cost of caregiving for older adults. While most family members desire to care for relatives, the economic impact of informal caregiving is enormous. About 44 million adults provide unpaid assistance and support to older people and those with disabilities in the community. In 2000, the national economic impact of informal caregiving had a value of $257 billion, far outweighing the costs of nursing home care ($92 billion) and home health care ($32 billion). 4
V. What is Geriatrics?

A. Geriatrics is the **branch of medicine** that deals with the diagnosis and treatment of diseases and problems specific to the aged. Geriatricians are physicians who focus on the care of older people. Geriatricians are specially trained and focus on improving the function of older people in a proactive manner, not just treating illnesses and diseases as they occur. They are also trained to work with other primary care practitioners to enhance the health care status and quality of life of older people.  

B. Geriatrics is an **interdisciplinary field**, placing value on all health professionals. Due to the multiple conditions and illnesses that older people may have, an interdisciplinary team approach is necessary. (See Module 2, Interdisciplinary Teamwork.)

C. A cornerstone of geriatrics is **assessment**. Geriatric assessment is multidimensional and has been found to be effective in multiple studies. (See Module 3, Psychosocial and Strength Based Assessment and Module 4, Functional Assessment and Geriatric Syndromes.)

D. **Gerontology** is a closely related field and refers to the scientific study of the biological, psychological, and sociological phenomena associated with old age and aging. Scientists and educators in the field of aging are referred to as “gerontologists”.

VI. Fallacies And Stereotypes About Old Age

A. **Ageism** is defined as the denial of basic human rights of older persons. It is a widespread prejudice that negatively impacts on older people. Examples of “ageism” are negative media, images, unequal treatment in the workforce, abuse, and lack of access to appropriate medical care.  

B. There are many **myths and fallacies** about older people.

1. Biological Fallacies
   a. Older people are not attractive.
   b. Older people require less sleep.
   c. There is not much an older person can do with a chronic health condition.
   d. Urinary incontinence is to be expected when we are older.
   e. Drug misuse and abuse are not problems in the older population.
   f. Many older people are in nursing homes.

2. Psychological Fallacies
   a. Older people are more rigid and resistant to change.
   b. Older personality changes with age.
c. Aging brings a decline in intellectual abilities and learning.
d. Memory loss is inevitable in later life.
e. Older people have no interest in, and are incapable of sex.
f. It is normal for an older person to be depressed.

3. Social Fallacies
   a. Most older people are lonely and want to live with their children.
   b. Older people are often abandoned by their families.
   c. Medicare pays for most long-term nursing home and in-home care costs.
   d. Poverty no longer exists among the elderly.
   e. People become more religious as they age.

VII. Dimensions And Theories Of Aging

A. **Physiological aging** refers to changes with the passage of time in the structure and processes of tissues, major organs and systems of the body that can ultimately affect our health, behavior, functional capacity, and survival.

B. **Social aging** includes the transitions into and out of roles, expectations about behavior, societal allocation of resources and opportunities, negotiations about the meaning and implications of chronological age, and the experience of individuals traveling the life course and negotiating life stages.

1. **Psychological aging processes** include changes in personality, mental functioning and sense of self during our middle and older years. Some changes are part of normal aging and others are the result of physiological changes in the way the brain works. However, personality does not undergo major changes with age and memory and cognitive decline is not inevitable.

2. There are many **theories of aging**.

   a. **Social theories** include:

      i. **Disengagement** theory which posits that the mutual disengagement of older people from society and society from the elderly is mutually beneficial. Retirement, for instance, is a normative, expected phase of disengagement enabling older people to move into a period of leisure and enabling younger people to move into the labor force.

      ii. **Activity theory**, on the other hand, posits that it is important for older people to stay engaged in society through the assumption of new roles and pursuits in the later years.
b. **Physiological theories** include:

i. **Error theories** of aging such as the free radical theory which posits that cell damage accumulates over time and destroys cells.

ii. **Programmed theories** of aging include telomerase theory. Telomerase is an enzyme that repairs and replaces part of the telomere lost during cell replication. Telomeres usually shorten with each replication and, with aging, they reach a shortened point at which no replication occurs.
VIII. References


2. The UCSF Academic Geriatric Resource Center Online Curriculum, www.ucsfagrc.org (retrieved 7/24/06)

3. Ibid.


Learning Resource A

The Facts on Aging Quiz

1. The majority of old people (65+) are senile (have defective memory, are disoriented, or demented).
   ___ True   ___ False

2. The five senses (sight, hearing, taste, touch, and smell) all tend to weaken in old age.
   ___ True   ___ False

3. The majority of old people have incomes below the poverty line (as defined by the federal government).
   ___ True   ___ False

4. The majority of old people have no interest in, or capacity for sexual relations.
   ___ True   ___ False

5. Lung vital capacity tends to decline in old age.
   ___ True   ___ False

6. The majority of old people feel miserable most of the time.
   ___ True   ___ False

7. Physical strength tends to decline in old age.
   ___ True   ___ False

8. The majority of old people works or would like to have some kind of work to do (including housework and volunteer work).
   ___ True   ___ False
9. At least one-tenth of the aged are living in long-stay institutions (such as nursing homes, mental hospitals, homes for the aged, etc.).
   ___ True  ___ False

10. Old people tend to become more religious as they age.
    ___ True  ___ False

11. Aged drivers have fewer accidents per driver than those under 65.
    ___ True  ___ False

12. Older workers usually cannot work as effectively as younger workers.
    ___ True  ___ False

13. Over three-fourths of the aged are healthy enough to carry out their normal activities without help.
    ___ True  ___ False

14. The majority of old people are unable to adapt to change.
    ___ True  ___ False

15. The majority of old people say they are seldom irritated or angry.
    ___ True  ___ False

16. Old people usually take longer to learn something new.
    ___ True  ___ False

17. Depression is more frequent among the elderly than among younger people.
    ___ True  ___ False

18. The health and economic status of old people will be about the same or worse in the year 2010 (compared to young people).
    ___ True  ___ False
19. Older people tend to react slower than young people.

___ True      ___ False

20. In general, old people tend to be pretty much alike.

___ True      ___ False

21. The majority of old people say that they are seldom bored.

___ True      ___ False

22. Over 20% of the population is now age 65 or over.

___ True      ___ False

23. The majority of old people are socially isolated.

___ True      ___ False

24. Old workers have fewer accidents than younger workers do.

___ True      ___ False

25. The majority of medical practitioners tend to give low priority to the aged.

___ True      ___ False

# Learning Resource B

## The 'Facts on Aging' Quiz: Answer Key

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Myth #1: *To be old is to be sick.*

**Facts:**

- Only 5% of the elderly population lives in nursing homes.
- Elderly may have chronic diseases but they still function quite well.
- Only 23% of elderly claim to have a disability.

Myth #2: *You can’t teach an old dog new tricks.*

**Facts:**

- The less people are challenged, the less they perform.
- Elders therefore need to stay mentally active and stimulated. The 3 key factors predicting strong mental functioning in old age are
  1. Regular physical activity
  2. A strong social support system
  3. A belief in one’s ability to handle what life has offer (underscores why myth is harmful)
- Conditions of successful learning are different for older people than for the young.
- Learning institutions are not flexible particularly concerning the elderly.

Myth #3: *The horse is out of the barn.*

**Facts:**

- Bad habits do not always produce irreparable damage.
- It is never too late to start good lifestyle habits of diet and exercise.

Myth #4: *The secret to successful aging is to choose your parents wisely.*

**Facts:**
• Heredity is a factor, but environment and behavior choices strongly influence how well an elderly person functions.

Myth #5: *The lights may be on, but the voltage is low.*

**Facts:**

• Sexuality does decrease with age but there are tremendous individual differences among the elderly.

• The definition of sexuality and intimacy needs to be redefined and broadened.

Myth #6: *The elderly don’t pull their own weight.*

**Facts:**

• The belief that the elderly are unproductive is false. Robert Kahn at the University of Michigan found in his studies (as cited in T. Franklin Williams, “A New Scope on Retirement”) of productive activity (defined as “any that might be remunerated under certain circumstances”) that “on average, ‘retired’ people are making more contributions in terms of dollar value than they are receiving in support from society, at least up to age 75”.

• The measures for productivity are wrong; paid employment should not be the only measure. Senior citizens are volunteering in droves. An Elderlearning Survey, designed as part of the research for a book, *Elderlearning*, by Lois Lamdin with Mary Fugate, found that 72 percent of the respondents reported volunteer activities, with 43.1 percent of them volunteering either full-time or at least one to three days per week.

• There is job discrimination against the elderly.