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Unbefriended Elders: Matching Values with Decisions

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Be the Change:
Innovative Models for an Aging Population
MGS Conference
April 30, 2010

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I. Introduction
The National Scope

Incapacitated and Alone:
Health Care Decision-Making for the Unbefriended Elderly

- Lacks decisional capacity to give informed consent to treatment at hand
- No executed advanced directive has no capacity to complete
- No legally authorized surrogate, no family or friends to assist in decision-making

Estimates: 3-4% of nursing home population

Naomi Karp & Erica Wood, American Bar Association Commission on Law and Aging (hereafter: *Incapacitated & Alone*)

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Unbefriended Elders: The Hastings Center

Isolated and unbefriended persons in LTCF; may or may not retain decision making capacity

- Have no relative, guardian, or responsible party named in medical record
- Listed relative cannot be contacted
- Relative is unresponsive or uninvolved
- Not received a visitor during the past 2 years.

Estimates: up to 30% of LTCF population

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Unbefriended Elders: Commission on End of Life Care

- "45% of next of kin listed in the chart could not be reached for participation in resuscitation status" (Fader et al. 1989)
- "One study found 47% of long term care residents lacked decision-making capacity and another 26% retained only partial capacity" (Miller & Cugliari, 1990)

MN Partnership to Improve End of Life Care
www.hospicemn.org/displaycommon.cfm?an=8

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The National Issue

- Legal framework for making treatment decisions mostly insufficient
- UE patients may be at risk for
  - Over-treatment
  - Under-treatment
  - Treatment decisions that do not reflect their values
- UE patients frequently socially isolated and suffer from multiple chronic conditions

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Over-Treatment

- Aggressive treatment as a medical imperative
- Some MDs philosophically believe they can treat, so should treat
- Perverse economic incentives to treat
- Fear of regulators
- Fear of civil liability

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Under-Treatment

- Some providers refuse treatment without informed consent
- Results:
  - Wait for emergency
  - Unnecessary delay
  - Added illness
  - Longer period of discomfort and indignity
  - Increased chance of morbidity, even if eventually treated

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II. Adult Orphans and Unbefriended Elders in MN

Survey jointly administered by Protective Services Program of VOA – Minnesota and Andrea Palumbo, Elder Justice Scholar of Center for Elder Justice and Policy at

William Mitchell College of Law

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Survey Instrument

- Adult orphans
  - Do not have a health care directive
  - No surrogate decision maker
- Unbefriended
  - Adult orphans who also **lack capacity** to execute an advance directive

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Sample Characteristics

Used MDH Health Care Facility and Provider Database:

- Mailed to 387 licensed NF in MN

Response Rate

- Overall statewide response rate: 32.3%
- Metro area response rate: 31.7%
- Greater Minnesota was slightly higher: 32.5%
- Regional response rates varied across the state from 50% to 19%

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Adult Orphans and Unbefriended: MN LTCF Residents

- Metro area adult orphans: 4.94 % (166 of 3,365)
- Metro area unbefriended: 1.84 % (62 of 3,365)
- Greater MN adult orphans: 1.64 % (91 of 5,564)
- Greater MN unbefriended: 0.74% (43 of 5,564)

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Gender Comparison

- MN LTCF
  - 66% female to 34% male
- Adult orphans MN LTCF:
  - 37% women, 63% male
- Adult orphans Metro LTCF:
  - 28% female, 72% male
- Adult orphans Greater MN LTCF:
  - 53% female, 47% male

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Ethnicity and Adult Orphans/Unbefriended

- Cultural trends account for lower % of communities of color within resident population
  - May also account for disproportionate % of African Americans and American Indians among AOs across MN and within the Metro area.
- More research is warranted, as LTCF use is related to many factors, including:
  - Overall health seeking behaviors
  - Cultural beliefs around end of life care
  - Economics
  - Geography

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Potential Unbefriended Elders in the Community

2000 US Census:

- 28% aged 65 and older lived alone
- 39% aged 85 and older lived alone

2005 Minnesota estimates:

- 31% of Minnesotans age 65+ lived alone

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Isolated Elders

- 18% of seniors who live alone have no family to support them if they need help for a few days
- 28% if needing help for a few weeks

- Seniors in poverty:
  - 1/3 don't see friends or neighbors for 2 weeks
  - 1/5 don't have phone contact

Aging Alone, The Commonwealth Fund

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III. Current Practice and Surrogacy Models Beyond Guardianship

Current Practice MN Incapacitated Without Surrogates

- Health Care Directive – Formal, POLST, Medical Record check list
- Ethics Committee
- Professional Practice
- Physician Determination "Futility" or "Harm"
- Institutional Policy –Hospital, LTCF
- Guardianship

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Professional Practice: Those Without Surrogates

- Emergency Medical Care “Implied consent”
- AMA- Ethics committee or Judicial Review
- American College of Physicians – Judicial Review
- American Geriatrics Society
  - Advises against routine court involvement
  - Recommends decisions are made by clinicians caring for the patient
- Other Professionals Practice Guidelines

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Models Beyond Guardianship

37 states identify a statutory process for making decisions absent an advance directive- Not MN

13 states have Surrogate Consent for Unbefriended in Absence of an Advance Directive – Not MN

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ABA Consensus Statement on Health Care Decisions for Unbefriended

- Appropriately assess decisional capacity – use communication techniques to enhance capacity
- Diligently search for existing surrogates
- Identify those at risk of becoming unbefriended and incapacitated and intervene:
  - education
  - advance directives
  - identification of values

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ABA Consensus Statement on Health Care Decisions for Unbefriended: Well Designed System

- Focus on the Patient – Substituted Judgment and Best Interest
- Independence and Freedom from Conflicts of Interest
- Continuity of Care
- Applicable to a Full Range of Decisions
- Emphasis on Least Restrictive Alternatives
- Prompt
- Cost Effective
- Accountable
- Expertise and Credibility

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IV. A New Minnesota Model

Unbefriended Elders:
Matching Values with Decisions

Project Support

The Unbefriended Elders: Matching Values with Decisions project is supported, in part, by a Community Service/Services Development (CS/SD) grant from the Minnesota Department of Human Services and by the Stevens Square Foundation

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Project Purpose

- Create systems change
- Develop protocols to identify, locate and support potential family or other informal decision-makers

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Formal Project Partners

- VOA National Health Care Facilities
- VOA MN Senior Services programs
- EverCare Health Systems
- Little Brothers Friends of the Elderly
- Anoka County
- Collaborations with U of MN 1st and 2nd year Medical Students and Wilder Research

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Clients served

Referrals must meet all the following criteria:

- Resident of Hennepin, Anoka, Ramsey or Washington County
- Age 65+
- No Emergency Contact/Responsible Party Known

And, one or more of the following criteria must be met:

- No written Health Care Directive on file
- No verbal health care instructions
- At risk of Guardianship

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Project Goals

- Avoid inappropriate/unwanted medical care
- Increase communication between physicians and patients who are at risk
- Identify and sustain support systems for AOs
- Increase capacity by providers to develop and enhance older adults' support systems
- Increase public policy attention on AOs' needs

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Project Objectives

- Complete HCDs, with copies delivered to primary physician and other pertinent individuals
- Professionals from the participating organizations will be trained to work with adult orphans and surrogate decision-making issues
- Develop and share with community partners protocol partner programs can replicate

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Activities of the Project

- Train partner organization professionals to work with AOs
- Facilitate communication between AOs and their primary care physicians/practitioners
- Work with the AOs to identify a surrogate decision maker when possible
- Facilitate and distribute completed Health Care Directives

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V. Wilder Research Evaluation

- Launched simultaneously with pilot project
- Strong focus on process evaluation

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Key evaluation questions

- Is project meeting its target goals and objectives?
- Is the project being implemented as planned?
- What types of individuals are being served by the program?
- What benefits are they receiving?
- What are the prospects for replication?

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Evaluation methodology

"Mixed-method" evaluation:

- Analysis of client data
- Analysis of training evaluations
- Key informant interviews
- Interviews with VOA staff

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Preliminary evaluation findings

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Findings from client records

From October 2008 to February 2010, the project:

- Trained over 550 professionals on Unbefriended Elders issues
- Served 54 AOs
  - ❑ 43 cases closed
  - ❑ 11 still in process as of February 2010

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Client outcomes

- Twenty-six clients completed HCDs (approx. 60% of closed cases)
- Twenty-two of these had follow-up conversations with their physicians
- Twenty-one also designated a healthcare agent/surrogate decision-maker

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Client demographics

- Majority living at or below poverty level
- Majority have only a high school education or less
- Over 80% have no prior HCD/healthcare planning experience
- Mostly female (68%)
- At least 70 % white
- Thirty-eight percent widowed or divorced
- Range in age from 65-95

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Clients' living situation

- 25 clients living in an assisted living facility or nursing home
- 23 living in own home or rental unit
- 6 "other" living situations reported (e.g., foster care)

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Findings relating to surrogate decision-makers

- From 2008-February 2010, the project contacted 55 potential surrogates
- Some surrogates lived as far away as NY & Arizona
- Approximately half agreed to serve as designated health care agents
- Common HCA relationships included:
  - ❑Children
  - ❑Grandchildren
  - ❑Nieces/nephews
  - ❑Family friends
  - ❑Clergy

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Findings from Key Informant Interviews

Interviews gather information on:

- Elements for program success
- Significant barriers to program implementation
- Perceived benefits of the program for clients and providers
- Potential for program replication

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Findings from the Key Informant Interviews

Key informants include:

- Partner organizations
- Referral sources
- Physicians
- Clients
- Surrogate decision-makers

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Key informant interviews continued

Discussion of emerging themes

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Next steps in Wilder's evaluation

- Review and analyze a random sample of client case files
- Review March – July 2010 client records and data
- Conduct final statistical analysis of all project data
- Prepare final evaluation report (August 2010)

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Resources and References

- Minnesota Commission on End of Life Care 2000-2001 www.mn-palliativecare.org
- "Life Support for Patients without a Surrogate Decision Maker: Who Decides"?, Annuals of Internal Medicine, 2007; 147:34-40
- State Initiatives in End of Life Care www.practicalbioethics.org
- American Bar Association www.abanet.org/aging
- The Hastings Center, www.thehastingscenter.org
- American Medical Association, Ethics Finder www.ama-assn.org
- Values History http://hsc.unm.edu/ethics/advdir/vhform_eng.shtml

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