

Holly A. Taylor, Betty S. Black, and Peter V. Rabins, "Deciding in the Best Interest of Clients with Dementia: The Experience of Public Guardians," *The Journal of Clinical Ethics* 19, no. 2 (Summer 2008): 120-6.

# Deciding in the Best Interest of Clients with Dementia: The Experience of Public Guardians

*Holly A. Taylor, Betty S. Black, and Peter V. Rabins*

**Holly A. Taylor, PhD, MPH**, is an Assistant Professor in the Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Berman Institute of Bioethics at Johns Hopkins University in Baltimore, Maryland, [htaylor@jhsph.edu](mailto:htaylor@jhsph.edu).

**Betty S. Black, PhD**, is an Assistant Professor of Psychiatry, Division of Geriatric Psychiatry and Neuropsychiatry, Johns Hopkins School of Medicine, Berman Institute of Bioethics.

**Peter V. Rabins, MD, MPH**, is a Professor of Psychiatry in the Division of Geriatric Psychiatry and Neuropsychiatry, Johns Hopkins School of Medicine, Berman Institute of Bioethics. ©2008 by *The Journal of Clinical Ethics*. All rights reserved.

## INTRODUCTION

Dementia, a syndrome characterized by multiple cognitive impairments, adult onset, and normal alertness, is a major public health problem affecting an estimated 4.5 million elders in the United States.<sup>1</sup> Dementia is usually progressive and results in severe disability. Most individuals with advanced dementia lack the capacity to make important decisions and must rely on a surrogate decision maker. While most elders either expect or plan for a loved one or trusted friend to serve as a surrogate decision maker if needed, some gradually or suddenly reach the point of incapacity without having such a person. In the absence of an advance directive or legally eligible surrogate decision maker, a public guardian may be appointed.

We did not find any previous studies that detail the process by which court-appointed guardians in the U.S. make medical and end-of-life (EOL) care decisions on behalf of clients with dementia. The available empirical literature on public guardians' involvement in medical and EOL care decision making on behalf of clients with dementia reports on: the infrastructure in place for the appointment of guardians;<sup>2</sup> quantitative data regarding activities in which public guardians in one state engage on behalf of their clients;<sup>3</sup> and the prevalence of public guardians as a subset of surrogate decision makers for incompetent, frail elders.<sup>4</sup>

The U.S. court system has developed two legal standards rooted in the ethical principle of respect for persons: substituted judgment and best interest.<sup>5</sup> The substituted-judgment standard relies on the notion that individuals who are knowledgeable about a patient's preferences should be able to make judgments similar to those the patient would have made in the same circumstances, if the patient were competent.<sup>6</sup> A second standard, the best-interest standard, is utilized when no one is available or is considered capable of making a decision in the manner the court would consider an appropriate substitute for the patient's own judgment.<sup>7</sup>

The Maryland Health Care Decisions Act (HCDA), passed in 1993,<sup>8</sup> created a legal framework to facilitate decisions made by physicians in cooperation with surrogate decision makers, including public guardians, regarding medical and EOL care decisions on behalf of incompetent adults. Of particular relevance to

this project, the HCDA counsels that "any person authorized to make health care decisions for another . . . shall base those decisions on the wishes of the patient, and, if the wishes of the patient are unknown or not clear, on the patient's best interest."

In the state of Maryland, local administrators for the Maryland Department of Aging (MDA) are appointed by the court to serve as the "Public Guardians" for clients age 65 and older who reside in their local jurisdictions. There are 24 such jurisdictions in Maryland: 23 counties and the City of Baltimore. Because it would be impossible for the local MDA administrator to provide for all of the clients in his or her jurisdiction, case managers are given the responsibility for addressing the daily healthcare needs of the clients.

An in-depth interview study was conducted to explore the decision-making process utilized by case managers who make medical and EOL care decisions for decisionally incapacitated elders with dementia (referred to subsequently as "clients with dementia") in three local jurisdictions in Maryland.

## METHODS

### Sample

A convenience sample of all 13 case managers working in one of the three local jurisdictions was eligible for the study; 13 case managers were asked to participate.

### Data Collection

*Interview guide:* A draft interview guide was developed based on our understanding of the Maryland public guardianship program through conversations with state officials responsible for the program. To provide background and context for the data to be collected from the case manager and to refine the interview guide to be used, we conducted key informant interviews with administrators of the statewide public guardianship program, a staff member of the Attorney General of Maryland, two judges familiar with the implementation of the HCDA, and a physician contracted by the state to be available for medical consult to all case managers. Topics in the final interview guide included:

- The public guardian appointment process,
- Involvement in routine medical decisions,
- Making EOL care decisions,
- Interactions with healthcare professionals,
- Attitudes about relevant current state law and guidelines.

The project was approved by the institutional review board (IRB) of the Johns Hopkins Medical Institutions.

*Recruitment:* All case managers affiliated with the MDA from three local jurisdictions who had clients with dementia in their caseload were invited to participate. A letter from the secretary of the MDA was sent to the local administrators notifying them of the project. Contact information for eligible case managers was obtained from the MDA. A second letter was sent from the primary investigator (PI) of the project to each case manager. The letter provided a phone number for additional information and a postcard that case managers could return to indicate their willingness to be interviewed. All case managers who indicated an interest in participation were interviewed. One eligible case manager who did not call or return a postcard was not contacted.

A total of 17 interviews were conducted, five with key informants who were familiar with the public guardianship program and 12 with case managers and case manager supervisors. Interviews were conducted from October 2002 to September 2003. The average interview lasted approximately 60 minutes (range, 45 to 90 minutes).

### Analysis

All interviews were conducted in person, audiotaped, transcribed verbatim, and verified against the audiotape.<sup>9</sup> Our analytic goal was to obtain informational redundancy on key themes. Transcript data were

coded and segmented with the aid of N6 qualitative data software.<sup>10</sup> Major themes were further analyzed and sub-themes identified.<sup>11</sup> A table that included major themes and sub-themes related to the content of this manuscript was prepared. A consensus was reached regarding minor adjustments to the categorization of some data. Interpretations of the data were verified by re-immersion in the data.<sup>12</sup>

## FINDINGS

### Demographics

The majority of the case managers interviewed ( $n = 12$ ) were female (83 percent) and African-American (75 percent). All but one case manager had a degree in social work. Case managers reported responsibility for an average of 35 (range, 25 to 50) clients with dementia. The case managers interviewed had spent nine years on average in their current position (range, one to 16 years). The findings reported here focus on what case managers considered when making medical and EOL care decisions on behalf of clients with dementia and will be organized around two issues: (1) how case managers determine what is in the best interest of their client, and (2) barriers to maximizing the client's best interest.

### Best Interest, in Context

As discussed below, all case managers had strikingly similar views about what the meaning of the phrase "best interests" in the context of medical and EOL care decision making.

### Medical Decision Making

Once appointed, case managers are involved in making all routine medical decisions for their clients. They report that they act in the best interest of their clients by assuring that their quality of life is maximized and that they consider the clients' prognosis, medical history, baseline functional level, and current condition. Case managers also report weighing both the immediate and long-term risks and benefits of a given procedure or intervention and agree with the recommendation when the immediate and long-term benefits outweigh the immediate and long-term risks. This list of considerations reflects the language from Maryland's HCDA.<sup>13</sup> In fact, most case managers report that making medical decisions is routine and relatively straightforward; that is, they find it relatively easy to determine the balance of risks and benefits. "Almost from the outset, is this really working towards that person's overall well-being or not and if it is, then it should be done and if it isn't, it shouldn't be done" (case manager 2).

The process by which case managers recounted making medical decisions was similar across respondents. Case managers reported that they gathered information from the attending physician and/or from other physicians involved in the case, reviewed material (for example, text books, internet databases) on the given condition or intervention, and discussed the decision with their supervisor and/or colleagues. They spent more time reviewing information and consulting with others when they were faced with a new condition or a unique set of circumstances. Decisions became difficult, however, when risks and benefits were closely balanced. One case manager noted that in such situations it was especially helpful to have been able to glean information about the client's preferences from the client and the client's family members and friends during the process of appointing a guardian. Other case managers noted that they took particularly hard questions to court and had a judge weigh in on the decision and were comforted by this option.

### End-of-Life Care Decision Making

In the context of EOL care decision making, case managers agreed that acting in the best interest of their client meant making decisions that minimized pain and suffering. One case manager quoted a judge who articulated the goal of EOL care decision making as "passing from this life to the next with the greatest degree of comfort" (case manager 5). Case managers attempted to anticipate the outcome of particular diagnostic procedures that may have resulted only in additional pain and suffering. That is, they considered making medical EOL care decisions to be points on a spectrum, with the difference between the two contexts

being the point at which a case manager believes that any further interventions would be, using the language of the HCDA, medically ineffective. One case manager noted that EOL care decisions begin "essentially when it becomes clear that an individual's systems, his crucial systems to live, have or [are] in the process of shutting down. . . . In essence, in spite of all of the means for what you can avail to the individual, life as they know it or as we know it has pretty much passed them by" (case manager 2).

That is, the reference point for decisions changes when the case manager concludes that no additional medical intervention will improve the client's quality of life, but that intervention can be made to minimize pain and suffering. This concept was articulated by another case manager who referred to a case she had had prior to the passage of the HCDA. She and all of the medical professionals involved in the case believed that the client, who had terminal cancer that had metastasized to her chest, should have a do-not-resuscitate (DNR) order. The judge denied the DNR. The case manager knew that if CPR were performed, "every bone in her chest [was] going to go through to her heart and it is going to be excruciatingly painful for her" (case manager 11). The case manager added that since the HCDA has been in place such a scenario has not been repeated.

Most case managers discussed DNR orders when they were asked to describe their experiences with EOL care decision making. Requests for DNR orders were usually initiated by the attending physician, but it was then up to the case manager to decide whether a DNR order was in the client's best interest. Case managers reported that they generally agreed with any considered request for a DNR, and they reported that they followed the procedures outlined in the HCDA once a physician requested a DNR. Two physicians must state that cardiopulmonary resuscitation (CPR) or other lifesaving procedures would be "medically ineffective" and that the client was in an "end-stage condition," was in a "persistent vegetative state," or had a "terminal condition."<sup>14</sup> The case manager must provide the court with a memo describing the facts of the case and the justification for the DNR. Case managers from all three jurisdictions reported that DNR requests were routinely approved by the courts.

### **Barriers to Making Decisions in the Client's Best Interest**

In the context of medical and EOL care decision making, case managers identified physicians as barriers to acting in a way that they believed to be in the best interest of their clients. Case managers generally referred to any recommended action that they believed was not in the best interest of their client as "overtreatment" or "undertreatment." In general, the case managers in this study sample were more likely to report examples of physicians' recommendations that they believed would result in overtreatment for their client, rather than in undertreatment.

### **Overtreatment**

A number of case managers reported encounters with physicians who appeared to make recommendations for diagnostic procedures based on a belief that every patient of a certain age should have a particular procedure (for example, every patient ought to have a colonoscopy at age 50), but case managers reported that they generally did not consent to a diagnostic procedure unless there was intent to change the client's current plan of care based on the results of the procedure. This was especially true if the diagnostic procedure was an invasive one. One case manager noted, "For example, if the overall plan for Joe is not to perform surgery if a colonoscopy would determine a tumor, then one would be hard pressed to justify the colonoscopy with medical practice as well as legal practice" (case manager 2).

Almost every case manager reported having the experience of challenging a physician's recommendation for the placement of a feeding tube. When a feeding tube was recommended, case managers first reviewed the medical history to determine if less invasive alternatives had already been pursued. Many of the case managers reported that they believed physicians in nursing homes often recommended the placement of feeding tubes out of convenience, and recounted specific cases in which less-invasive options, such as observed feeding, encouraged feeding, food consistency change, or appetite enhancement medications, were not pursued prior to the feeding tube request.

---

## Undertreatment

With the exception of one instance in which a case manager found herself advocating for a colostomy against the recommendation of a physician who was satisfied with prescribing several daily enemas for her client (case manager 12), case managers rarely described physicians who avoided aggressive medical treatment when caring for elders with dementia. Case managers did report occasionally encountering "ageist" attitudes from physicians, in the context of EOL care decision making, and stated that they were unlikely to consent to DNR orders in response to physicians' requests that were driven by what they believed to be an "ageist" attitude that all elders with dementia should have a DNR. Case managers also voiced their dissatisfaction with institutions that believed all residents should have a DNR.

One case manager reported a case in which a client's stated preferences created an obstacle to acting in what she believed to be in the client's best interest. This client, despite her dementia, clearly articulated her discomfort with a physician's recommendation, believed by the case manager to be in the client's best interest, to have a diagnostic exam for cervical cancer (case manager 7). The case manager found the client's statement so powerful that she refused the procedure on behalf of the client. Another case manager noted that if she believed that her client's request to refuse a procedure was "solid," she would take the request to the court.

Only one case manager reported refusing consent for a physician's recommendation that she believed would result in the undertreatment of her client with dementia, and therefore was contrary to his best interest. In this case, the guardian reported that her client with dementia disagreed with a physician's recommendation that he have a DNR order in his chart. The client had suffered a stroke and was unable to speak, but the case manager reported that the client responded affirmatively to her direct question as to whether he would like the doctors to "do everything in their realm possibly to keep you alive" (case manager 10). In contrast to decisions described by other guardians that relied on the best-interest standard, this guardian acted in a way that she believed to be responsive to a direct request from her client (neither substituted judgment nor best interest). It is relevant to note that this case manager was relatively new to the job and stated she was overwhelmed by the thought of making life and death decisions. A number of case managers reported that they began their careers with a similar attitude, but became more comfortable with making decisions to withhold treatment. Specifically, a number of case managers reported that one of the signs of their maturity as case managers was their willingness to challenge physicians' recommendations.

## SUMMARY

We conducted an in-depth interview study of public guardians in three local jurisdictions in the state of Maryland to explore the decision-making process utilized by court-appointed public guardians making medical and EOL care decisions on behalf of their clients with dementia. Overall, public guardians appeared to make their decisions in the context of relevant ethical principles and relevant case law and state statute, and the basis upon which they made informed decisions was dependent on their training and experience. The stated goal of public guardians is to make decisions that they believe are in the best interest of their clients. In the case of a healthcare decision, their goal is to maximize quality of life; and in the case of an EOL care decision, their goal is to minimize pain and suffering.

In general, public guardians gathered information in order to identify previous preferences of their now-incapacitated clients, so that they could develop a preference profile to assist both an initial decision on whether an individual ought to have a court-appointed public guardian, and with healthcare and EOL decisions once an appointment was made. When guardians were unable to develop a preference profile for a particular client, they relied on past decisions in similar situations.

Healthcare and EOL decisions were most often triggered by a recommendation by the client's healthcare provider. Once a decision-point was identified, the public guardian considered the risks and benefits of the proposed intervention in light of the client's current condition. At times the guardians reviewed informational resources such as textbooks and the internet. In addition, most guardians sought advice from a medical

consultant who is available to all public guardians in Maryland. Some guardians sought the advice of this medical consultant only when faced with more complex decisions.

Guardians challenged physicians' recommendations when they believed the physicians were recommending an intervention that was not in the best interest of the client — that is, they advocated against either overtreatment or undertreatment. Ultimately, guardians took particularly difficult issues to the court and obtained a judge's opinion.

## DISCUSSION

We believe these results serve as a starting point for local and statewide discussions regarding how decisions are being made for older adults who lack decisional capacity and whether there are ways in which the approach to decision making ought to be clarified. These data may be particularly helpful to guardians and physicians who are new to the context of medical and EOL care decisions on behalf of clients with dementia. Whether this model of decision making can be generalized to decisions made by private guardians and/or on behalf of younger incapacitated adults ought to be tested.

For public guardians, the difficulty of making consequential health and EOL care decisions seems to decline with experience. For a particular family member, making healthcare and EOL decisions on behalf of a spouse, parent, or sibling with dementia may be a unique experience. Public guardians learn from their experience and become more confident in their knowledge and abilities as they mature in their professional role. Ways to take advantage of the experience of veteran public guardians to facilitate decisions made by family members ought to be considered.

One limitation of this study was our inability to observe and document decisions being made in real time. We relied on descriptions and stories told by the public guardians. In addition, we did not review the medical charts of any of the clients with dementia discussed by the public guardians to explore whether their reporting of a case was accurate. Future studies can test the applicability of the approach to medical or EOL decision making described in this report to real-time decision making about individual patients. Additional research could also be conducted to verify these results among public guardians appointed in other Maryland jurisdictions, as well as explore this phenomenon in states with similar and different policy approaches to decision making on behalf of incapacitated clients. Future research in this area is essential as the U.S. aging population grows and the number of patients with dementia who will rely on strangers to make decisions increases.

## ACKNOWLEDGMENT

Funding for this project was provided by the Niarchos Foundation.

## NOTES

1. R. Brookmeyer, S. Gray, C. Kawas, "Projections of Alzheimer's Disease in the United States and the Public Health Impact of Delaying Disease Onset," *American Journal of Public Health* 88, no. 9 (1998): 1337-42.

2. W.G. Bell, W. Schmidt, and K. Miller, "Public Guardianship and the Elderly: Findings from a National Study," *Gerontologist* 21, no. 2 (1981): 194-202; K. Weiler, L.B. Helms, and K.C. Buckwalter, "A Comparative Study: Guardianship Petitions for Adults and Elder Adults," *Journal of Gerontological Nursing* 19, no. 9 (1993): 15-25; M.A. Iris, "Guardianship and the Elderly: A Multi-perspective View of the Decision Making Process," *Gerontologist* 28, suppl. (1988): 39-45; T. Drought, *Medical Decision Making for Publicly Conserved Individuals: Policy Recommendations* (Santa Clara University: Markkula Center for Applied Ethics, 2005); T. Miller, C. Coleman, and A.M. Cugliari, "Treatment Decisions for Patients Without Surrogates: Rethinking Policies for a Vulnerable Population," *Journal of the American Geriatrics Society* 45, no.

3 (1997): 369-74; M.J. Quinn, "Achieving Justice, Autonomy, and Safety," in *Guardianships of Adults* (New York, NY: Springer Publishing Company, Inc., 2005): 1-16, 71-104, 133-60.

3. Quinn, see note 2 above.

4. R. Peters, W.C. Schmidt, and K.S. Miller, "Guardianship of the Elderly in Tallahassee, Florida," *Gerontologist* 25, no. 5 (1985): 532-8; K. Bulcroft, M.R. Kielkopf, and K. Tripp, "Elderly Wards and Their Legal Guardians: Analysis of County Probate Records in Ohio and Washington," *Gerontologist* 31, no. 2 (1991): 156-64; B.L. Thomas, "Research Considerations: Guardianship and the Vulnerable Elderly," *Journal of Gerontological Nursing* 20, no. 5 (1994): 10-6; J.L. O'Sullivan and D.E. Hoffman, "The Guardianship Puzzle: Whatever Happened to Due Process?" *Maryland Journal of Contemporary Legal Issues* 7 (1996): 11-80; L.H. Coker and A.F. Johns, "Guardianship for Elders: Process and Issues," *Journal of Gerontological Nursing* 20, no. 12 (1994): 25-32.

5. A.E. Buchanan and D.W. Brock, *Deciding for Others: The Ethics of Surrogate Decision-Making* (New York: Cambridge University Press, 1990); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "Chapter 4: Patients Who Lack Decision-making Capacity," in *Deciding To Forego Life-sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions* (Washington, D.C.: U.S. Government Printing Office, 1983).

6. Ibid.

7. Ibid.

8. Annotated Code of Maryland, "Health-General, Title 5; Death. Subtitle 6," Health Care Decisions Act (HCDA), 2001; § 5-601.

9. R.S. Weiss, *Learning from Strangers: The Art and Method of Qualitative Interview Studies* (New York: Free Press, 1994); H.J. Rubin and I.S. Rubin, *Qualitative Interviewing: The Art of Hearing Data* (Thousand Oaks, Calif.: Sage Publications, 1995).

10. QSR International Pty Ltd, N6: Software for Qualitative Analysis (2002).

11. M. Sandelowski, "Whatever Happened to Qualitative Description?" *Research in Nursing and Health* 23, no. 4 (2000): 334-40; M. Sandelowski, "Combining Qualitative and Quantitative Sampling, Data Collection, and Analysis Techniques in Mixed-method Studies," *Research in Nursing and Health* 23, no. 3 (2000): 246-55; M. Sandelowski, "Qualitative Analysis: What It Is and How to Begin," *Research in Nursing and Health* 18, no. 4 (1995): 371-5.

12. J.W. Creswell, *Qualitative Inquiry and Research Design: Choosing among Five Traditions* (Thousand Oaks, Calif.: Sage Publications, Inc, 1998).

13. "(1) The effect of the treatment on the physical, emotional and cognitive functions of the individual; (2) The degree of physical pain or discomfort caused to the individual by the treatment, or the withholding or withdrawal of the treatment; (3) The degree to which the individual's medical condition, the treatment, or the withholding or withdrawal of treatment result in a severe and continuing impairment of the dignity of the individual by subjecting the individual to a condition of extreme humiliation and dependency; (4) The effect of the treatment on the life expectancy of the individual; (5) The prognosis of the individual for recovery, with and without the treatment; (6) The risks, side effects, and benefits of the treatment or the withholding or withdrawal of the treatment; and (7) The religious beliefs and basic values of the individual receiving treatment, to the extent these may assist the decision maker in determining best interest." (Annotated Code of Maryland 2001d)

14. See note 8 above, § 5-601:(i)(o)(q).