Designing an Agenda for the Nursing Profession on End-of-Life Care

1 Report of the Nursing Leadership Consortium on End-of-Life Care

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Note: The views expressed in this report do not necessarily reflect those of the author's institution or the sponsoring organizations
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Designing an Agenda for the Nursing Profession on End-of-Life Care

Introduction and Background
The quality of care provided to persons near the end-of-life is of utmost concern to nurses, individually and collectively. Nurses in all practice settings and roles are faced with quandaries about the provision of humane and dignified end-of-life care. Care of the dying occurs across the life span and is rendered across all settings including hospitals, long term care facilities, hospices, and home settings. Attention to the specialized care of the dying needs to be integrated into all clinical and education settings, and permeate the practice of all health professionals. Throughout the decades, nurses have been the mainstay of care for dying persons and their families and have played a vital role in promoting responsible, competent, compassionate, appropriate, and ethically sound care.

The convergence of significant trends in legislation, societal opinion, judicial decisions, research data and the media have highlighted concern about the quality of end-of-life care. There is an increasing acknowledgment of the inadequacies in the care of dying persons and their families. The goal of improving the quality of end-of-life care is a challenge to the very integrity of health care professionals and the health care system. Nurses have invaluable experience and insight that must be heard to inform efforts to improve end-of-life care.

The nursing community's commitment to care of the dying and critically ill has been evidenced through numerous and varied initiatives. There is a breadth of experience, knowledge, and skill among nurses and nursing organizations related to end-of-life care. Many nursing organizations have developed educational programs, position statements, policies, guidelines, research projects, and clinical resources with the goal of adequately preparing nurses to provide competent and compassionate care and improving the plight of dying patients and their families.

In January 1999 the Nursing Leadership Consortium on End-of-Life Care was funded by The Open Society Institute through its Project on Death in America (PDIA). The Nursing Leadership Consortium on End-of-Life Care (Consortium) was developed to advance the nursing profession's commitment and efforts to improve care at the end-of-life.

The Consortium brought together key national nursing organizations with education, administration, research, practice, and policy responsibility and specialty organizations with particular expertise in end-of-life care to develop a coordinated, broad-based plan within the profession to improve end-of-life care (Appendix A). Specific aims included the following:

1) to formalize a collaborative and supportive effort within the nursing profession focused on end-of-life care;
2) to examine what is presently available (e.g., educational materials, clinical guidelines, conferences, etc.) on end-of-life care within nursing;
3) to develop mechanisms of collaboration and resource sharing between nursing organizations;
4) to identify gaps and future needs within the policy, research, education, administration, and practice domains of nursing;  
5) to recommend specific strategies; and .  
6) to build agreement on a plan to improve the organization, delivery, and quality of care for those who are dying.  
The Consortium is an attempt to provide an organized and coordinated approach to nursing's end-of-life care improvement efforts and responsibly plan for new initiatives. It is believed that as the leadership within the nursing community clarifies and establishes its end-of-life care agenda, it will be able to continue its contribution to current and future interdisciplinary and consumer efforts. Through the Consortium, new strategic partnerships can be formed, initiatives designed, opportunities for project finding identified, and mechanisms for continued communications and collaboration solidified. All of this allows the nursing profession to demonstrate and advance its commitment to dying persons and their families.  
**Process And Results**  
The Consortium meeting June 12-14, 1999 brought together 34 individuals representing 23 nursing specialty organizations, the National Institutes of Health, Project on Death in America, the Robert Wood Johnson Foundation, and other institutions with a variety of perspectives on end-of-life care to engage in a systematic, facilitated process for developing new projects and increasing collaboration on existing activities related to end-of-life care.  
In preparation for the June invitational meeting, representatives of each of the participating organizations were asked to complete a survey. The survey was designed to ascertain the scope of end-of-life activities and resources in each of the organizations. This information was valuable in planning the meeting and provided helpful information to participating organizations about the existence and availability of end-of-life resources in other professional organizations.  
Completed surveys were received from most participating organizations representing over 600,000 nurses in combined memberships. Respondents identified end-of-life care as equally important to both organizational leadership and membership (7 on a scale of 0 to 10, with 10 being very important). However, only a third of the respondents identified end-of-life care as a current organizational strategic priority.  
While only a small number of organizations had a designated structure related to end-of-life care (e.g., appointed staff, end-of-life committee) the majority of organizations described internal mechanisms (e.g., practice councils, access to experts) that were utilized for end-of-life care activities.  
The survey requested that respondents identify organizational activities related to end-of-life care in the areas of education, research, policy development and communication. Within education, organizations most commonly identified the availability of seminars, conferences, and national meetings. Less common was self-study and computer-assisted programs. Within research, several organizations seek external funding for research projects, while only
a small number provided internal organizational funding for research projects or held research
conferences on end-of-life care. Within policy development, many organizations reported having
policies and position statements on end-of-life care and engaging in advocacy activities. Within
the area of communications, articles on end-of-life care in organizational publications including
newsletters and journals were frequently identified. Only one organization offers specialty
certification in the area of end-of-life care.

Respondent organizations were asked to identify content areas that received a great deal of attention.
The areas of highest attention included pain assessment and management, ethical issues,
psychosocial support, bereavement, and symptom management. The least amount of attention was
directed at the issues of assisted suicide and euthanasia. Clinical practice guidelines,
computer-assisted instruction, and legislative/policy papers were the resources that organizations
were most in need of.

Working together over a 2-day period, using a facilitated design process known as Interactive
Management (IM), a group of highly qualified nursing experts was able to produce an informed and
thoughtful agenda for nursing professionals concerning end-of-life care. IM integrates the following
synergistic components of group problem solving:

1. a group of knowledgeable participants who represent the variety of perspectives that
   need to be brought to bear in dealing with the situation;
2. a trained facilitator who is able to guide the group through the problem solving and
   planning process;
3. a special set of computer-assisted consensus methodologies that have been carefully
   selected to help groups generate, structure, and make choices among ideas;
4. the use of behaviorally-sensitive technologies, including computer assistance, to increase
   efficiency and productivity of group work; and
5. the use of a specifically designed physical environment that includes visual display space
   for ideas and structures, with provision to enhance the comfort and interaction of the
   participants.

The IM approach assigns to participants all responsibility for contributing ideas, and a trained
facilitator manages the group -sessions. Methodologies for generating, clarifying, structuring,
interpreting, and amending ideas are selected to match the phase of group interaction and the
requirements of the situation. This system of problem solving is described extensively in published
articles and books (see Appendix B for a description of IM and references).

The agenda that resulted from the consortium is much more than a simple collection of good ideas
from qualified individuals. It is the result of intense group work that moved through a series of
systematic steps in producing a consensus that reflects thoughtful input from all participants and
group agreement on what is important. The group started by identifying the needs related to
end-of-life care, selecting needs of higher relative importance, generating options for responding to
these needs, choosing options that should receive the most attention, prioritizing options in order to
help make choices about where to place resources, and gaining preliminary commitments from
participants to pursue the prioritized agenda.
Anticipated Needs For End-Of-Life Care In The 21st Century

From a list of 170 items generated by the group, each participant was asked to select the five items she or he believed to be the most important, relative to the other items. Each person was also asked to rank these five items from 1 (highest) to 5 (lowest). In compiling the results, rankings were reverse scored and a "weighted score" was assigned to each item based on the sum of ranks associated with the votes it received. Results from the multi-level voting process are listed in Figure 1, starting with the item that received the most votes.

Figure 1 summarizes the conclusions of Phase 2. Priorities for the profession are listed in order of ranking.

Figure 1: Summary of Category Rankings

<table>
<thead>
<tr>
<th>Rank</th>
<th>Category</th>
<th>Example(s)</th>
</tr>
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<tr>
<td>1</td>
<td>Education</td>
<td>• To integrate end-of-life care into all curricula of nursing at the undergraduate and graduate level.</td>
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<tr>
<td></td>
<td></td>
<td>• To develop interdisciplinary education on palliative care in order to gain expertise in collaborative practice.</td>
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<tr>
<td>2</td>
<td>Professionalism</td>
<td>• To create an environment for collaboration or partnerships between and among health care systems, education, associations, government agencies and nurses to advance nursing roles to meet the needs of End-of-Life Care.</td>
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<td></td>
<td></td>
<td>• Promote formal collaboration with medical organizations to improve End-of-Life Care.</td>
</tr>
<tr>
<td>3</td>
<td>Clinical/Patient Care</td>
<td>• To promote practice guidelines so that patients will receive optimal care in a hospital, hospice, or home.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To use supportive care strategies that prevent pain and suffering and promote comfort and well-being.</td>
</tr>
<tr>
<td>4</td>
<td>Research</td>
<td>• To provide nurses with research-based information on End-of-Life Care.</td>
</tr>
<tr>
<td>5</td>
<td>Patient and Family Advocacy</td>
<td>• To communicate, educate and empower the consumer (patient) to address End-of-Life Care and participate in decisions.</td>
</tr>
<tr>
<td>6</td>
<td>Decision-making</td>
<td>• To develop a dynamic process of End-of-Life Care decision making including advance care planning.</td>
</tr>
<tr>
<td>7</td>
<td>Culture</td>
<td>• To create a national environment where End-of-Life Care is freely discussed.</td>
</tr>
<tr>
<td>8</td>
<td>Systems of Care</td>
<td>• To structure the healthcare system in a manner that allows all dying patients and their families access to pain management and hospice care.</td>
</tr>
<tr>
<td>9</td>
<td>Resource Allocation Policy</td>
<td>• To enact legislation that provides comprehensive financing for palliative care that is not limited to skilled nursing episodes or to hospice care.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To provide quality health services for all patients, despite the ability to pay for those services.</td>
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With the categories of anticipated needs as a foundation, Phase 2 of the workshop focused on identifying a set of activities, projects, proposals, and recommendations that can respond to the anticipated needs, especially the ones considered by the group to be of higher priority. The following tasks were established for Phase 2 of the design session:

1. Identify and clarify options
2. Select options that will form the agenda
3. Prioritize the selected options

With the Options Profile and Priority Structure as a basis, Phase 3 of the workshop focused on discussing how the agenda developed by the group might be carried forward. In this final phase of the workshop, participants discussed each of the selected options in order of their perceived priority to determine which organization may be willing to make commitments to help move the selected options forward.

**Recommendations**

All participants of the Consortium expressed resounding support for palliative care as an important priority for the profession. Based on recommendations from participants, suggestions were generated that every nursing organization can adopt immediately to raise consciousness, disseminate knowledge, promote open dialogue, and ultimately improve care at the end-of-life (Figure 2). Since the June meeting, many organizations have already begun to adopt and implement the strategies. For example, several participating organizations have reported about the meeting in their professional journals and organizational newsletters (see Appendix C). In November 1999 the outcome report from the meeting will be released at the joint meeting of the National Federation of Specialty Nursing Organizations (NFSNO) and the Nursing Organization Liaison Forum (NOLF), whose members include 81 specialty nursing organizations. At this meeting, member’s organizations will be asked to endorse Last Acts "Precepts of Palliative Care"16 and agree to make palliative care a strategic priority for their organization. The immediate action steps listed in Figure 2 can be accomplished without additional funding or significant organizational resources.

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**Figure 2: Immediate Actions That Can Be Taken By Nursing Organizations**

1. Disseminate the Consortium recommendations to Board of Directors, leadership members and other constituencies through newsletters, electronic communications, journals, etc.
2. Endorse the Last Acts’ Precepts of Palliative Care.
3. Include End-of-Life Care in each organization’s strategic planning process.
4. Include articles related to End-of-Life Care in each organization’s journal.
5. Include End-of-Life Care content in all national, regional and local meetings.
6. Highlight national and regional activities, research and educational opportunities related to End-of-Life Care in organizational communication mechanisms such as website, newsletters, electronic communications, etc.
7. Identify member expertise in End-of-Life Care.
8. Adopt or endorse existing position statements on End-of-Life Care.
10. Catalog organizational resources related to End-of-Life Care.
11. Establish organizational mechanisms to monitor End-of-Life Care activities.
12. Collaborate with other organizations to advance the agenda for End-of-Life Care.
13. Disseminate End-of-Life Care information to local and national media.
14. Disseminate existing knowledge of pain and symptom assessment and management to members.
15. Include End-of-Life Care in the organization’s research agenda.
Additionally, the Consortium developed a priority map of the profession's agenda for end-of-life care (Figure 3). Fifteen goals were selected from 170 options generated by participants as priorities for the nursing profession. Each box contains goals judged by group process to be of equal priority. The boxes are arranged in descending order of priority.

Establishing an ongoing network to build consensus among nursing organizations and developing nationally recognized nursing standards and practice guidelines that can be applied across all settings were viewed as the top priorities by the Consortium. Endorsing end-of-life care as a strategic priority by nursing organizations, devising mechanisms for collaborative efforts among nursing organizations to inform and influence public policy on end-of-life care, and including end-of-life care content in nursing curricula, licensure, and certification examinations were also a priority for the profession.

The priority map provides initial guidance for individuals and organizations developing initiatives for end-of-life care. Each of the goals reflected in the priority map will require further refinement in order to determine specific strategies, opportunities for interdisciplinary collaboration, existing efforts, and resources needed to accomplish each goal. As a final activity of the Consortium meeting, participants were asked to consider which goal in the priority map their organization may have interest in pursuing. It was clear by the volume of responses that nursing specialty organizations are poised to provide leadership and collaborate with others to move the agenda forward. The potential impact by major professional and specialty organizations in advancing end-of-life care will be significant and far-reaching. Members of the nursing organizations represented at the Consortium care for dying patients across the life span and include such vulnerable populations as the frail elderly, children, and individuals with chronic, life-limiting conditions such as renal and cardiac disease or neurologic disorders. It is anticipated that a variety of new initiatives will develop as a result of the Consortium meeting.

Conclusions

The agenda resulting from this workshop represents a strong statement from the nursing profession. While this was not the first time that an agenda for end-of-life care has been produced, it is perhaps the most thorough attempt to examine the issue from the perspective of nursing professionals. It contributes toward helping those concerned with nursing issues speak with a unified and amplified voice, and those who view the results will appreciate the extraordinary effort that was required to produce the findings. Nevertheless, it should be viewed as a flexible working document. It is open to revision, reconsideration, and refinement. The format of the documents allow additional voices to be added, rethinking of the current results, and influences from changes in societal conditions. For the immediate future, however, the agenda produced by these 34 experts can be used as a reliable guide for funders, researchers, practicing health-care professionals, and others concerned with end-of-life care.
- Establish an ongoing network to build consensus among nursing organizations that EOL issues are high priority and need to be addressed.

- Develop nationally recognized nursing standards and practice guidelines with application between settings of care.

- Encourage professional nursing organizations, including specialty organizations to establish EOL care as a strategic priority.

- Ensure EOL content in undergraduate/graduate education by including such content in NCLEX and all certification exams and changing accreditation standards.

- Create a mechanism/strategy for collaboration among nursing organizations to inform and influence public policy in EOL care.

- Develop strategies to implement and support nursing research on EOL care.

- Contribute to efforts to remove regulatory and financial barriers to access for comprehensive palliative services including hospice.

- Establish effective pain management as a standard reimbursable practice through traditional and complimentary modalities.

- Establish an appropriate umbrella organization as a nursing resource center/clearinghouse for existing EOL resources.

- Establish a research agenda for EOL issues for nurses and specialty groups.

- Disseminate national nursing standards and guidelines for EOL care to include educational programs, professional organizations, and certification and regulatory bodies.

- Develop appropriate outcomes criteria for EOL/ palliative care.

- Create interdisciplinary models for teaching professionals effective communication, decision making, and conflict resolution techniques in EOL care.

- Create a national campaign for patient education and rights; target schools, places of worship, and the work place.

- Establish system to disseminate EOL information to the public.
References

Appendix A: Participant List
Academy of Medical/Surgical Nurses
Randy Whitney
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Suzanne Brown
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Johnson
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Marcia Hert
American Society of Pain Management Nurses Micke
Brown

Association of Nurses in AIDS Care
Inge Corlis

Association of Pediatric Oncology Nurses
Kathy Forte

Association of PeriOperative Nurses
Jackie Berlandi
Association of Rehabilitation Nurses
Marilyn Ter Maat
Hospice and Palliative Nurses Association
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Appendix B: Overview of Interactive Management

During the past 25 years a new system has emerged that is specifically designed to assist groups in dealing with complex issues. Termed "Interactive Management" (IM), it promotes the integration of contributions from individuals with diverse views, backgrounds, and perspectives through a process that is structured, inclusive, and collaborative. A group of participants who are knowledgeable of the situation are engaged in (a) collectively developing a deep understanding of the current state of affairs, (b) establishing a clear basis for thinking about the future, and (c) producing a framework for effective action. The IM system promotes communication, consensus, and commitment from participants involved in the design effort.

The IM System seeks to appropriately balance the behavioral demands of group work with technical assistance that makes it possible to deal with the complexity of issues. The system is designed to prevent groups from (a) prematurely focusing on solutions before they have adequately defined the situation, and (b) under-conceptualizing alternatives for resolution of the conflict situation. Special methods are employed to encourage the participants' creativity, and facilitated group processes are used to effectively manage the group's communication. These include:

- **Nominal Group Technique (NGT)** allows individual ideas to be pooled effectively and is used in situations in which uncertainty and disagreements exist about the nature of possible ideas.

- **Idea writing** is a group method for developing ideas in a small group and allowing the group to explore the meaning of these ideas through open discussion.

- **Interpretive Structural Modeling (ISM)** is a computer-assisted methodology that helps a group identify the relationships among ideas and impose structure on the complexity of the issue: The ISM software utilizes mathematical algorithms that minimize the number of queries necessary for exploring relationships among a set of ideas (see Warfield, 1976). ISM can be used to develop several types of structures, including influence structures (e.g., "supports," or "aggravates"), priority structures (e.g., "is more important than," or "should be learned before") and categorizations of ideas (e.g., "belongs in the same category with").

- **Field and Profile Representations** A Field Representation organizes information in a way that allows a large amount of information to be worked with effectively. Different types of Fields are useful for different types of applications. The Field Representation typically portrays a significant amount of information organized in a form that (a) is very suitable for use in decision-making and (b) is very suitable to maintain an ongoing, visible record of intermediate decision-making en route to a final portrayal of the total set of choices that has been made. A Field Representation shows a set of categories and the members of each of those sets. The members of a given category are all contained within that category.
The ongoing and terminal portrayal of choices constitutes a Profile Representation. In constructing a Profile, a group will examine the first dimension of the Field (as determined by sequence structuring) and make some choices of elements from that category. Each choice that is made is represented graphically by drawing a line from the bullet in front of a selected element down to a "Tie Line." The Tie Line is a continuous line that is drawn at the base of the graphic. After all choices are made, all selected elements will be connected to the Tie Line. All elements that have not been selected will remain unconnected.

References
Appendix C: Example of Publication

The Academy of Nursing Joins the Nursing Leadership Consortium on End-of-Life Care

The Nursing Leadership Consortium on End-of-Life Care met June 12-14, 1999, at George Mason University. Attending this meeting were Dr. Joyce Fitzpatrick (AAM), Dr. Carolyn Lewis (American Nurses Credentialing Center [ANCC]), and Dr. Laurie Badzek (ANA). The consortium leaders were representative of approximately 600,000 nurses. The consortium was supported by a grant from the Project on Death in America

The context of the consortium was based on 4 premises:
1. An increasing number of Americans are dying of chronic illness--there is little reality that they will receive quality end-of-life care.
2. Previous attempts by other groups have not always included the nursing perspective.
3. Nurses have a lot of previous experience that can be utilized.
4. As a profession, nurses need to stand together with a unified and amplified voice.

The objectives of the consortium were as follows:
1. To anticipate the figure needs for end-of-life care within the policy, research, education, administration, and practice domains of nursing in the 21st century.
2. To identify those needs perceived to be of higher priority and organize these into groupings that reflect the elements they have in common.
3. To propose options for projects, tasks, programs, and other activities that will contribute toward fulfillment of the anticipated needs.
4. To develop a consensus about which options should be adopted by the nursing profession for implementation during the next 35 years.
5. To discuss how we might move forward with the implementation of selected options.

The formal report of the consortium meeting will be completed and circulated in the next few months. The result of the consortium was development of a "Priority Map for the Nursing Profession's Agenda for End-of-Life Care." Priorities were established in categories: professionalism, research, decision making, patient and family advocacy, clinical/patient care, education, resource allocation/policy, and health systems. Most of the priorities determined by the group would have involvement by one or more of the ANA participating members. The No. 1 priority determined by the group was divided into 2 distinct parts. The first part of priority one was to establish a network through the Nursing Organization Liaison Forum (NOLF) and the National Federation of Specialty Nursing Organizations (NFSNO) to build consensus among nursing organizations that end-of-life issues are a priority and need to be addressed by the nursing community. The second part of the first priority was to develop national nursing standards and guidelines that will provide for continuous care for transition from hospital to hospice to home.

Other key priorities identified include educational initiatives including the development of curricula and continuing education programs, initiatives to include end-of-life content in certification and accreditation standards, and participation in public policy initiatives including lobbying efforts particularly in the areas of nursing research and reimbursement to nurse practitioners for pain management services.

As a result of the consortium ANA, ANCC, and AAN can expect to participate in future activities of the consortium. The presentation of the priorities and initial attempt to gain consensus will be an activity that will likely be forthcoming at the fall NOLF/NFSNO meeting. Activities that tile ANA will likely be asked to participate in include the clearinghouse activities, participation in a long-range plan, lobbying efforts, development of national standards, and financial support for grants and educational programs, campaigns, and consortium activities.

ANCC is presently reviewing its certification examinations to determine the number of EOL questions that are on the examinations. With the completion of this project, the Test Development Committee or each specialty will be asked to develop questions to address this most important issue.

The Academy will be taking a leadership role in advancing research, interfacing wide the Institute of Medicine, and other institutions working in this area. Particularly, the Academy will be establishing an Expert Panel on Palliative and End-of-Life Care, publishing a report of the meeting in Nursing Outlook, and considering endorsement of the Last Acts definition.

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