UNITING PRACTICE AND RESEARCH IN LONG--TERM CARE: FINAL REPORT OF THE AMDA FOUNDATION RESEARCH NETWORK CONFERENCE

ABSTRACT

The AMDA Foundation Research Network held its first annual meeting in Dallas, Texas, on November 3–4, 2001. At this, its first meeting, the chief goal was to develop ideas for research that will provide a systematic base of evidence for providing care in the Long Term Care (LTC) setting.

A major initiative of the AMDA Foundation is the development of a LTC practice--based research network. Timely questions currently facing the field include the effectiveness of clinical practice guidelines in improving care; how disease management programs work in LTC; and how physicians can help create evidence--based practices for LTC. The Research Network includes among its immediate goals the development of a research infrastructure that will enable it to address such questions; the recruitment of additional members; the drafting of a research agenda for the future; and the procurement of funding for its chosen projects.

Over the day and a half of the meeting, participants gathered in small brainstorming sessions to generate topics for possible research projects. From this base of ideas, the Network members worked to focus a research agenda for the future and developed five research network projects.

[Abstract = 191 words]

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EXECUTIVE SUMMARY
UNITING PRACTICE AND RESEARCH IN LONG TERM CARE: RESULTS OF THE AMDA FOUNDATION RESEARCH NETWORK CONFERENCE

INTRODUCTION

The AMDA Foundation Research Network held its first annual meeting in Dallas, Texas, on November 3–4, 2001. Over the day and a half of the meeting, participants gathered in small brainstorming sessions to generate topics for possible research projects. From this base of ideas, the Network members worked to focus a research agenda for the future.

A major initiative of the AMDA Foundation, and the reason for this conference, is the development of a long term care (LTC) practice based research network. Larry Lawhorne, MD, CMD, Chair of the AMDA Foundation, opened the first day's proceedings by enumerating some of the timely questions currently arising in the field. These issues include the effectiveness of clinical practice guidelines in improving care; how disease management programs work in LTC; and how physicians can help create evidence-based practices for LTC. The Research Network includes among its immediate goals the development of a research infrastructure that will enable it to address such questions, the recruitment of additional members, the drafting of a research agenda for the future, and the procurement of funding for its chosen projects.

Dr. Lawhorne reiterated the importance of creating a network that will respond to the AMDA membership in a meaningful way. At this, the first annual meeting of the Network, the chief goal was to develop ideas for research that will provide a systematic base of evidence for providing care in the LTC setting. To that end, the participants would divide into small workgroups for brainstorming sessions to develop research topics from which to focus a research agenda. Before the breakout groups' deliberations, keynote presentations helped to focus and provide background information for the discussions to take place later that day.

KEYNOTE PRESENTATIONS

Seminal Studies from Family Practice Research Networks

Kurt Stange, MD, Professor of Family Medicine at Case Western Reserve University in Cleveland, Ohio, gave an overview of the practice based research network (PBRN) in primary care as a model of how to develop such a network in LTC. He emphasized the value of looking at the successes of other research networks while avoiding potential pitfalls of such an undertaking.

Dr. Stange enumerated several reasons for the value and utility of PBRNs. One has to do with the greater applicability to patient populations of studies performed under the auspices of PBRNs. The patients studied in academic medical centers, where much of research has taken place, constitute a tiny minority of the patient population as a whole. Studies (Green and Dovey

2001; White et al. 1961) suggest that fewer than 1 in 1,000 adults are hospitalized in an academic medical center. Part of a PBRN's potential for evidence based practice lies in basing research on actual practice. A network is far likelier than an academically based study to enroll patients who are, on the whole, more representative of their communities. The consistency with which practitioners within a PBRN tend to practice medicine also lends itself to better designed research. This research can range from observational studies to prospective clinical trials employing a variety of methodologies that have been found to be both accurate and feasible for office practice.

Dr. Stange reviewed seminal studies from Primary Care PBRNs in the areas of otitis media, migraine, preventive care, and urinary tract infections, as well as studies that influenced policy and payment issues in managed care and fee for service. A full description of the studies was published in the July 2002 issue of *JAMDA*, which also contains a special article about the conference, Stange K, Libow, L, *J Amer Med Dir,* 2001; 5: 330-336.

Research in the Nursing Home: An Avenue for Remarkable Progress

Leslie Libow, MD, CMD, of the Jewish Homes and Hospital in New York described some key advances in research and clinical care that have been described in the literature over the past few years, emphasizing the methodology used and the areas that may prove fruitful for increased research from the LTC setting. Much outstanding and eye opening work is being generated from within the field of LTC, and this research often has great applicability not only to residents of nursing homes but also to elderly populations in the community at large, and even to younger people as well. Dr. Libow pointed out that such research is inseparable from performance improvement and quality improvement, endeavors that must be continually pursued in order to meet the requirements for audits by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and other reviewing and accrediting bodies.

Some of the research described came from a single facility, some from a research network, and some from a database of information. Throughout his presentation, Dr. Libow pointed out instances in which a published article did not make clear that the study was conducted under the auspices of an LTC facility. In some of these cases, this information could be gleaned only indirectly, from the article's "Acknowledgments" section or other peripheral elements. This situation, he maintained, should change to allow proper credit to the involvement of LTC facility investigators conducing this research.

Dr. Libow provided an excellent and extremely comprehensive review of the literature issue, which appeared in the July 2002 issue of *JAMDA,* Stange K, Libow L, *J Amer Med Dir,* 2002; 5: 330-336.

RESEARCH PRIORITIES

Working in small breakout groups, participants worked to identify research priorities. These priorities were further refined during the first day of the conference as the groups developed some preliminary study models and delineated five research network projects, which are

described below and were published in *JAMDA* this summer, Lawhorne, L *J Amer Med Dir,* 2002; 5: 340-342.

Confirmatory Studies of the Use of Lipid-Lowering Medications in LTC Residents

Project leaders for this study were identified as Jurgis Karuza, Ph.D.; and John Voytas, M.D., CMD. The aim of the study is to determine the efficacy of lipid-lowering medications in nursing home patients. A two-stage process was envisioned for this topic: a descriptive survey study followed by a randomized controlled clinical trial. The survey study would be a point prevalence study of current use of statin lipid-lowering medications (LLMs) in nursing homes. This study would identify current practice patterns and determine whether practice variations are great enough to justify a controlled trial in this area. Assuming that the latter would prove to be the case, the preliminary study would be followed by a randomized controlled trial in which patients at risk would be identified and randomly assigned to receive either a statin LLM or placebo.

The survey would collect data on the percentage of patients taking LLMs in each facility, the demographics of the facility (type and size, provision of subacute care, payer mix, geography), physician characteristics, and patient profile (case mix, age, gender).

The outcomes and measures of the randomized trial would be expected to include decreased lipid levels; decreased incidence of stroke, myocardial infarction, death from all causes, and re-hospitalization; and increased cost effectiveness. Possible unanticipated secondary outcomes would be expected to include improved function (activities of daily living) and improved quality of life, including mood, functional health, and decreased incidence of fractures.

Feeding Tube Placement in Nursing Homes: When and Why Are They Placed, and Who Benefits?

Christopher Patterson, M.D., CMD, will serve as the project leader for this study, whose aim is to determine how often and under what circumstances feeding tube placement is considered in nursing home residents, what percentage of patients receiving feeding tubes have longer survival times than those who decline feeding tubes, and the most common reasons why feeding tubes are placed and why they are declined. Participating physicians would collect data on a standardized survey form. An initial data collection sheet would be completed at the time that the informed consent process is begun and again at a 6-month follow-up. Patients would be current nursing home residents for whom there is an impending decision regarding the placement of a feeding tube. The patients would be enrolled over a period of 6 months or until the participating physician has enrolled 12 patients, whichever occurs first. Information on the initial survey would include profiles of the physician (e.g., age, training, percentage of practice in nursing home), the patient (e.g., percentage of weight lost, indications for tube placement, albumin and pre-albumin, hemoglobin, and functional status), and the facility (e.g., policy regarding feeding tube placement).

Hospital–Nursing Home Interface: Transfer Documentation

Project leaders for this study were identified as Conn Foley, M.D., CMD; and Paul Katz, M.D., CMD. The study aims to determine whether a list of transfer documents requested by LTC facilities are in fact being included when patients are transferred from the hospital to the nursing home. A process will be developed that requires certain items of information to accompany patients at the time of their transfer from a hospital to an LTC facility. This would be a card study to be completed by admitting staff or physicians in nursing homes. Through the card survey, attempts would be made to identify 10 items felt to be most important by the medical directors in the study sites. The study would then attempt to determine whether these items are in fact being included in transfer documentation sent to the participating facilities. This would be determined through a review of 10 sequential admissions in each study site.

Reasons for Hospitalization and Outcomes for Patients with "Do Not Hospitalize" Orders Who Are Hospitalized

Larry Lawhorne, M.D., CMD, will serve as the study's project leader. Its aim is to identify reasons why some patients are hospitalized against "do not hospitalize" (DNH) orders. This would be a card study aimed at identifying the reasons why some patients are hospitalized against DNH orders. The proposed card would include the date and time of hospitalization and would also be pilot tested in a few facilities to determine its validity. The card would also be designed to gather qualitative information in those cases where a DNH order is reversed.

Impact on Quality of Care of the "Configuration" of the Relationship Between the Physician and the Nursing Home Clinical Management Staff and of the Extent of Physician Involvement in Resident Care

David Zimmermann, Ph.D., is the project leader for this study, which will examine two aspects of the physician's role within models of care: (1) the extent of physician involvement and (2) the "configuration" of the relationship between the physician and the nursing home clinical staff. One aspect of how this relationship is configured, for example, would be whether the facility uses physician extenders, such as physician assistants or geriatric nurse practitioners (advanced-practice registered nurses). The study would look at the elements surrounding the use of physician extenders and the relationship between them and the clinical management staff. A preliminary or pilot study would be conducted to define the configuration of this relationship in operational terms. The study would draw on previous work in this area that attempted to define the organization of nursing home care delivery models and to identify the characteristics of that organization that are important to care delivery.

OTHER CONFERENCE SESSIONS

Attendees had an opportunity to hear from representatives of AHRQ about their research priorities and the opportunities for an LTC research network, as well as from the pharmaceutical industry. On the second day of the conference, presentations were made on research fundamentals, including the role and responsibilities of investigators, IRB issues and protection of human subjects, and recruitment issues in LTC.

CONFERENCE FOLLOW-UP

Since the conference, a study on the medical director's role in falls management has been completed and is being prepared for publication. Three other studies (transfer documentation, DNH, and tube feeding) are in the process of being launched within the network. The DNH study has received IRB approval and will be launched as an "on-line" study, a new method that the network is assessing for feasibility.

Other activities since the conference include the development of a listserv where research ideas and protocols are actively discussed. In addition, 45 members of the Research Network attended a working session at the AMDA Annual Symposia in San Diego, California, in March 2002.

The Network has grown to include over 220 members, and demographic information about the network has been published on the Foundation Web site and in AMDA publications. A special article on the AMDA Foundation Research Network Conference was published in the September/October 2002 issue of JAMDA *J Amer Med Dir,* 2001; 5: 340-342 . Articles about the research network conference have also appeared in *Caring for the Ages,* Feb 2002, Volume 3, which has a circulation of 20,000 LTC professionals.

The Network will hold its next meeting in Dallas, Texas, on November 1–3, 2002. A clinical trials pre-conference workshop will be held on October 31, 2002.

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AMDA FOUNDATION RESEARCH NETWORK CONFERENCE FINAL REPORT

First Annual Meeting:
"Uniting Practice and Research in Long-Term Care"

November 3–4, 2001
Dallas, Texas

The AMDA Foundation Research Network held its first annual meeting in Dallas, Texas, on November 3–4, 2001. Over the day and a half of the meeting, participants gathered in small brainstorming sessions to generate topics for possible research projects. From this base of ideas, the Network members worked to focus a research agenda for the future.

WELCOME: Brief History of the Foundation's Interest in and Development of the LTC Research Network
Larry Lawhorne, MD, CMD, Chair, AMDA Foundation

Dr. Lawhorne started the first day's proceedings by welcoming the attendees and reviewing some of the highlights of the agenda. He acknowledged the support of the Agency for Healthcare Research and Quality (AHRQ), which provided funding for the meeting and welcomed representatives from the pharmaceutical industry .

The AMDA Research Foundation is a Maryland nonprofit corporation whose mission is to advance quality in long term care through education and research. The Foundation is a supporting organization of AMDA, which currently comprises 8000 physicians across the United States. The Foundation is committed to the following objectives:

- Identifying and nurturing future leaders
- Recognizing past and present leaders
- Providing information and tools to help physicians deliver effective and efficient care across the continuum of LTC

A major initiative of the AMDA Foundation is the development of a long term care practice based research network, which was the reason for this conference. Dr. Lawhorne summarized the purpose of the meeting by enumerating some of the timely questions currently arising in the field. These issues include the effectiveness of clinical practice guidelines in improving care;

how disease management programs work in LTC; and how physicians can help create evidence-based practices for LTC. The Research Network includes among its immediate goals the development of a research infrastructure that will enable it to address such questions; the recruitment of additional members; the drafting of a research agenda for the future; and the procurement of funding for its chosen projects.

Dr. Lawhorne reiterated the importance of creating a network that will respond to the AMDA membership in a meaningful way. At this, the first annual meeting of the Network, the chief goal was to develop ideas for research that will provide a systematic base of evidence for providing care in the LTC setting. To that end, Dr. Lawhorne informed the attendees, the participants will break into small workgroups for a brainstorming session to develop research topics from which to focus a research agenda.

KEYNOTE PRESENTATIONS;

KEYNOTE: Seminal Studies from Family Practice Research Networks
Kurt Stange, MD, Professor of Family Medicine, Case Western Reserve University, Cleveland, Ohio

Dr. Stange gave an overview of the practice-based research network (PBRN) in primary care as a model of how to develop such a network in LTC. He emphasized the value of looking at the successes of other research networks while avoiding potential pitfalls of such an undertaking.

Dr. Stange enumerated several reasons for the value and utility of PBRNs. One has to do with the greater applicability to patient populations of studies performed under the auspices of PBRNs. The patients studied in academic medical centers, where much of research has taken place, constitute a tiny minority of the patient population as a whole. Studies (Green and Dovey 2001; White et al. 1961) suggest that fewer than 1 in 1,000 adults are hospitalized in an academic medical center. Part of a PBRN's potential for evidence-based practice lies in basing research on actual practice. A network is far likelier than an academically based study to enroll patients who are, on the whole, more representative of their communities. The consistency with which practitioners within a PBRN tend to practice medicine also lends itself to better-designed research. This research can range from observational studies to prospective clinical trials employing a variety of methodologies that have been found to be both accurate and feasible for office practice.

Dr. Stange reviewed seminal studies from Primary Care PBRN's in the areas of otitis media, migraine, preventive care, urinary tract infections as well as studies that influenced policy and payment issues in managed care and fee for service. A full description of the studies will be published in the July issue of JAMDA which will contain the conference proceedings.

KEYNOTE: Research in the Nursing Home: An Avenue for Remarkable Progress
Leslie Libow, MD, CMD, Jewish Homes and Hospital, New York, New York

Dr. Libow described some key advances in esearch and clinical care described in the literature over the past 2 years, emphasizing the methodology used and the areas that may prove fruitful for increased research from the LTC setting. Much outstanding and eye-opening work is being generated from within the field of LTC, and this research often has great applicability not only to residents of nursing homes but also to elderly populations in the community at large, and even to younger people as well. Dr. Libow pointed out that such research is inseparable from performance improvement and quality improvement, endeavors that must be continually pursued in order to meet the requirements for audits by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and other reviewing and accrediting bodies.

Some of the research described came from a single facility, some from a research network, and some from a database of information. Throughout his presentation, Dr. Libow pointed out instances where a published article did not make clear that the study was conducted under the auspices of a long term care facility. In some of these cases, this information could be gleaned only indirectly, from the article's "Acknowledgments" section or other peripheral elements. This situation, he maintained, should change to allow proper credit to the involvement of long term care facility investigators conducing this research.

Dr. Libow provided an excellent and extremely comprehensive review of the literature issue that will also be published in the July issue of JAMDA.

RESEARCH PRIORITIES:

Following the keynotes, the attendees broke into five different groups where they participated in a group process to identify and prioritize research priorities. These priorities were further refined during the first day of the conference and the groups developed some preliminary study models.

The five research network projects follow:

Confirmatory Studies of the Use of Lipid-Lowering Medications in Long-Term Care Residents
Project Leaders: Jurgis Karuza, Ph.D., John Voytas, M.D., CMD

Aim: Determine the efficacy of lipid-lowering medications in nursing home patients.

Methodology: A two-stage process was envisioned for this topic: a descriptive, survey study followed by a randomized, controlled clinical trial. The survey study would be a point prevalence study of current use of statin lipid-lowering medications (LLMs) in nursing homes. This study would identify current practice patterns and determine whether practice variations are great enough to justify a controlled trial in this area. Assuming that the latter would prove to be the case, the preliminary study would be followed by a randomized, controlled trial in which patients at risk would be identified and randomly assigned to receive either a statin LLM or placebo.

The survey would collect data on the percentage of patients taking LLMs in each facility; the demographics of the facility (type and size, provision of subacute care, payer mix, geography); physician characteristics; and patient profile (case mix, age, gender).

The outcomes and measures of the randomized trial would be expected to include decreased lipid levels; decreased incidence of stroke, myocardial infarction, death from all

causes, and rehospitalization; and increased cost effectiveness. Possible unanticipated secondary outcomes would be expected to include improved function (activities of daily living) and improved quality of life, including mood, functional health, and decreased incidence of fractures.

Feeding Tube Placement in Nursing Homes: When and Why Are They Placed, and Who Benefits?
Project Leader: Christopher Patterson, M.D., CMD

Aim: Determine how often and under what circumstances feeding tube placement is considered in nursing home residents; what percentage of patients receiving feeding tubes have longer survival times than those who decline feeding tubes, and the most common reasons why feeding tubes are placed and why they are declined.

Methodology: Participating physicians would collect data on a standardized survey form. An initial data collection sheet would be completed at the time that the informed consent process is begun and again at a 6-month follow-up. Patients would be current nursing home residents for whom there is an impending decision regarding the placement of a feeding tube. The patients would be enrolled over a period of 6 months or until the participating physician has enrolled 12 patients, whichever occurs first. Information on the initial survey would include profiles of the physician (e.g., age, training, percentage of practice in nursing home), the patient (e.g., percentage of weight lost, indications for tube placement, albumin and pre-albumin, hemoglobin, and functional status), and the facility (e.g., policy regarding feeding tube placement).

Hospital–Nursing Home Interface: Transfer Documentation
Project Leaders, Conn Foley, M.D., CMD, Paul Katz, M.D., CMD

Aim: Determine whether a list of transfer documents requested by long term care facilities are in fact being included when patients are transferred from the hospital to the nursing home.

Methodology: Develop a process that requires certain items of information to accompany patients at the time of their transfer from a hospital to a long-term care facility. This would be a card study to be completed by admitting staff or physicians in nursing homes. Through the card survey, attempts would be made to identify 10 items felt to be most important by the medical directors in the study sites. The study would then attempt to determine whether these items are in fact being included in transfer documentation sent to the participating facilities. This would be determined through a review of 10 sequential admissions in each study site.

Reasons for Hospitalization and the Outcomes for Patients with "Do Not Hospitalize"(DNH) Orders Who Are Hospitalized
Project Leader: Larry Lawhorne, M.D., CMD

Aim: Identify reasons why some patients are hospitalized against "do not hospitalize orders".

Methodology: This would be a card study aimed at identifying the reasons why some patients are hospitalized against "do not hospitalize," or DNH, orders. The proposed card would include the date and time of hospitalization and would also be pilot tested in a few facilities to determine its validity. The card would also be designed to gather qualitative information in those cases where a DNH order is reversed.

Impact on Quality of Care of the "Configuration" of the Relationship Between the Physician and the Nursing Home Clinical Management Staff and of the Extent of Physician Involvement in Resident Care
Project Leader: David Zimerman, Ph.D.,

Aim: Examine two aspects of the physician's role within models of care: (1) the extent of physician involvement and (2) the "configuration" of the relationship between the physician and the nursing home clinical staff: One aspect of how this relationship is configured, for example, would be whether the facility uses physician extenders, such as physician assistants or geriatric nurse practitioners (advanced-practice registered nurses).

Methodology: The study would look at the elements surrounding the use of physician extenders and the relationship between them and the clinical management staff. A preliminary or pilot study would be conducted to define the configuration of this relationship in operational terms. The study would draw on previous work in this area that attempted to define the organization of nursing home care delivery models and to identify the characteristics of that organization that are important to care delivery.

OTHER CONFERENCE SESSIONS:

Attendees had an opportunity to hear from representatives of AHRQ about their research priorities and the opportunities for a long term care research network, as well as from the pharmaceutical industry. On the second day of the conference, presentations were made on research fundamentals including the role and responsibilities of investigators, IRB issues and protection of human subjects, and recruitment issues in long term care.

CONFERENCE FOLLOW UP:

There has been a tremendous progress since the conference.

- A study on the medical director's role in falls management has been completed and is being prepared for publication.
- Three other studies (transfer documentation, do not hospitalize and tube feeding) are in the process of being launched within the network. The do not hospitalize study has received IRB approval and will be launched as on "on-line" study, a new method that the network is assessing for feasibility.
- A List-serv has been developed and research ideas and protocols are actively discussed.
- Forty-five members of the Research Network attended a working session at the AMDA Annual Symposia in San Diego in March 2002.
- The Network has grown to include over 200 members and demographic information about the network has been published on the Foundation Website and in AMDA publications.
- A special article on the AMDA Foundation Research Network Conference was published in the September/October 2002 issue of JAMDA. Articles about the research network conference have also appeared in Caring for the Ages, which has a circulation of 20,000 long term care professionals.
- The Network will hold its next meeting in Dallas on November 1-3, 2002. A clinical trials pre-conference workshop will be held on October 31-1st.