



Making A Difference: Part Two

NINR Research Results

*National Institute of Nursing Research
National Institutes of Health
U.S. Department of Health and Human Services*



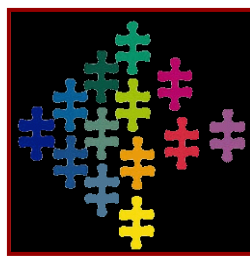
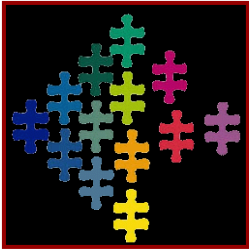


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National Institute of Nursing Research

Making A Difference

NINR Research Results

- **INTRODUCTION**

Nurses have a longstanding and well-documented societal role in providing care for the sick and injured, especially in times of war or disaster. However, the role of nurse as scientist is less recognized. In the United States, federal funding for nursing research, initially under the guise of health services research, only started in the 1950s, and it was not until 1986 that the National Center for Nursing Research, later to become the National Institute of Nursing Research (NINR), was established on the NIH campus.

NINR's mission is to support the science that advances the knowledge of nurses to:

- understand and ease the symptoms of acute and chronic illness;
- prevent or delay the onset of disease or disability, or slow its progression;
- find effective approaches to achieving and sustaining optimal health;
- and improve the clinical settings in which care is provided.

While the development of science for our discipline is indeed young, still we must begin to look at how nurses use our research findings for the benefit of patients in the practice arena. The time has come to ask: Are we making a difference?

The following stories give a few examples of projects by NINR-supported scientists that demonstrate how nursing research is working to improve the health of the nation's populace and better the care of the sick and injured in many areas of concern across the lifespan.



- **Behavioral Intervention for Children and Adolescents with Diabetes: *Coping skills training improves metabolic control***

Type 1 diabetes is a major health problem among the nation's youth, affecting nearly 130,000 children and adolescents in the US. In the landmark Diabetes Control and Complications Trial (DCCT), investigators found that adolescents over thirteen years of age,



intensive insulin therapy and better metabolic control reduced the risk of complications by 27-76%. While

this report was encouraging, the total number of teenagers in the DCCT study was only 190 and the investigative team reported that they were the most difficult to manage and keep under metabolic control. Other research on teenagers with diabetes has shown that they are difficult to engage in an intensive therapeutic regimen, that difficulties in management are often associated with social situations, and that depression is common in these teens. More education is *not* the answer.

The trouble with teenagers. As we all know, the teen years are a time of both physical and emotional development, making teenagers a particularly challenging population to work with. Adolescents with diabetes are at significant risk because of the hormonal changes that occur at this time making them more insulin resistant, and the social pressures that threaten consistent adherence to regular monitoring of diet, blood glucose, or exercise. Social situations often influence teenagers to

do unhealthy behaviors even when they know better. In the case of a teenager with diabetes, this non-adherence can have devastating effects.

Dr. Margaret Grey and her team of researchers have taken this difficult population and designed a program to increase teens' sense of competence and mastery by retraining inappropriate or non-constructive coping styles and forming more positive styles and patterns of behaviors.

A behavioral intervention for coping.

The primary goal of this research was better metabolic control through improved decision-making and coping. The intervention used in their study is called Coping Skills Training (CST). The 6-week coping skill training focuses on four primary areas:

- Social problem solving
- Communication skills
- Cognitive behavior skills
- Conflict management

Role-playing of scenarios was used to assist these teens in difficult situations with friends such as managing food choices, decision making about drugs and alcohol, and interpersonal conflicts.

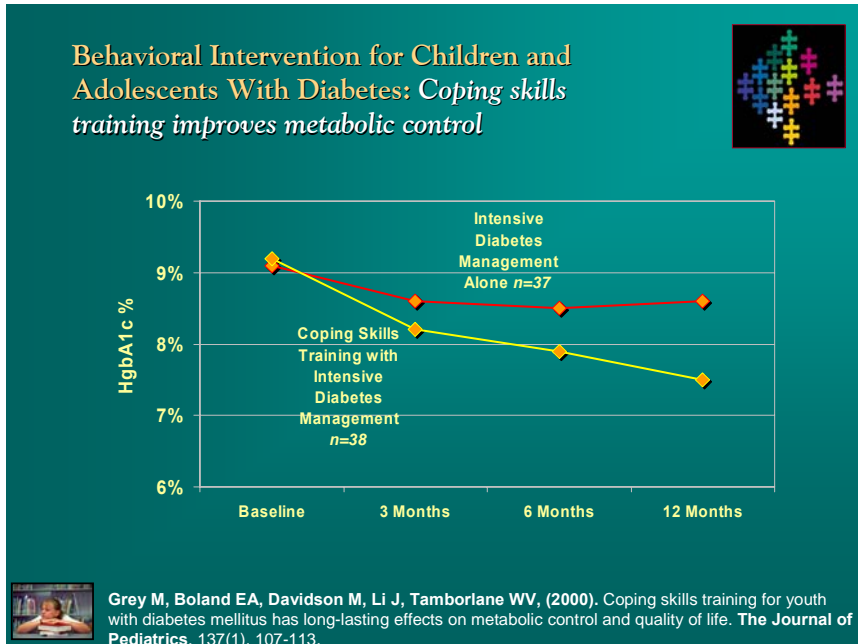
Improved control and improved life.

The results demonstrated that CST helps teenagers with diabetes maintain better metabolic control, and perceive a better quality of life while dealing with their chronic illness. This slide shows the

significant increase over time in metabolic control as measured by HgbA1c in the diabetic teens that participated in the CST program as compared to a group who did not.

behavioral care, not just disease management.

The usefulness of behavioral interventions is very promising and need to become standard practice just like the teaching of signs and symptoms of diabetic coma. One cannot help but notice as you read the content of the CST program how useful this type of training would be for *all* teenagers as they struggle through the turbulent years of puberty. The challenge will be making the CST accessible to all diabetic teens and



Beyond the basic results, this research has shown that strict control does not compromise quality of life as is so often predicted, and that the use of the CST program can easily be incorporated into routine care for these adolescents. So far over 100 practices that manage the care for teenage diabetics have requested the CST manual developed by Dr. Grey and her team and have incorporated Coping Skills Training into their routine care. Furthermore, current clinical guidelines on the care of children and adolescents with diabetes emphasize the need for comprehensive

consistent and clear enough to make it useful to all who use it. The researchers have tried to elucidate the “black box’ of their intervention through their CST to make it easier to use and transferable to other teenagers with other chronic conditions.

Future research. The next step in this program of research is to examine the usefulness of behavioral interventions with parents of younger children with diabetes in order to improve metabolic control and quality of life for young children with diabetes.

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- **Transitional Care Model:
*Improving Patient Outcomes***

NINR has funded a series of studies that have used Advanced Practice Nurses (APNs) in the complex care of vulnerable populations. Beginning in the mid-1980's with the work of Dr. Dorothy Brooten and her research team on the early discharge of very low birth weight infants, this model of using Advanced Practice Nurses (APN) to deliver complex, competent care has been shown to be effective and cost-saving with many different populations, including at-risk pregnant women, women with unplanned cesarean births, pregnant women with diabetes and hypertension, and women who have had hysterectomy surgery. This model has also been refined and tested by Naylor and her team working with elders hospitalized for complex medical and surgical conditions transitioning from hospital to home. Finally, Hoffman and her group are testing the use of APNs in the Intensive Care Unit to help manage ventilator-dependent patients as they wean from the ventilator.




a well defined population of patients, expertise of the nurses with the patient population of concern, a comprehensive approach to care that goes beyond medical management of the disease state, medical team back-up and referrals in place, and responsibility and authority for the care vested in the APN delivering the care. The slide below, based on the work by Naylor and her team, shows significantly improved outcomes in numbers of readmissions, cumulative readmission days, and Medicare costs for the group who were followed by APNs.

Even with these successes there is a need to more clearly define and delineate the "black box" that represents the group of interventions used by the APNs as they manage these patients. Naylor and her colleagues are looking more closely at this


Closely aligned to this growing body of literature on the use of APNs is the work by Daly and colleagues in the establishment of a Special Care Unit for the chronically critically ill. **Testing the model.** This growing body of literature based on research findings from multiple studies have several themes in common:

Transitional Care Model: *Improving patient outcomes and reducing healthcare costs*



Elderly Hospitalized Patients					
	Subjects	Readmitted at least once	Multiple re-admissions	Cumulative re-admission hospital days	Medicare reimbursement at 24 weeks
Control	n=186	37.1%*	14.5%*	760 days*	\$1.2 m*
Experimental	n=177	20.3%*	6.2%*	270 days*	\$0.6 m*

*significant @ p<.01

 Naylor JD, Brooten D, Campbell R, Jacobsen BS, Mezey MD, Pauly MV, Schwartz JS, (1999). Comprehensive discharge planning and how follow-up of hospitalized elders: a randomized clinical trial. JAMA. 281 (7): 613-620.

question as they examine differences in processes and outcomes of care between control and intervention group patients.

Daly and her team did not limit the nurses to APNs and they were in the critical care setting instead of focusing on the transition from the hospital to home. Nonetheless, their findings are very similar to those of Brooten and Naylor—better patient outcomes at less cost. The mechanism of the interventions is still not well described as it includes a complex, interacting set of activities, including careful and continuous surveillance of medical therapies and patient responses, support and counseling, and case management. Their study did, however, result in the establishment of a Special Care Unit for chronically critically ill patients that remained operational long after the study ended. In addition, nurses from many ICUs across the country visited the study site in order to learn how these patients were being cared for and to try and implement this model in their own hospitals as a means of reducing the cost of care for their patients.

Finally, Dr. Hoffman from the University of Pittsburgh is testing the use of APNs in the management and weaning of ventilator-dependent patients. While this study is not completed, preliminary data shows no difference in the success of weaning patients between APNs and physicians (residents and fellows) in these ICU patients. The published results of using APNs in managing vulnerable patients has helped to open positions in community hospitals for APNs to manage the care of ventilator patients without a physician on site.

Influencing clinical care. It is perhaps premature to say that this model of care is well accepted in clinical settings. However, as the population continues to age, and health care costs continue to rise, a more affordable model with better outcomes for both the patients and the health care system seems logical and timely.

Health care facilities that have at-risk patients or high-users of resources would be well served to emulate this advanced practice nurse model of care. These results show that the use of APNs to deliver specialized or transitional care can make a real difference in clinical outcomes.

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- **End of Life Care:**
Program reduces stress associated with family decision-making

During the 20th century, advances in biomedical technology and therapeutics have greatly improved our capacity to prolong life. We can place patients on mechanical ventilators, externally pace failing hearts, and replace diseased organs. However, people will die, and with aggressive medical management as the “norm” we are now facing the difficulties of dying in America.

Concern has grown within the general population, and among health care professional in particular, that care of the dying patient has become costly, inhumane, and often at odds with the wishes of the patient and family. In an effort to give patients better control over end of life decisions, Congress passed the Patient Self Determination Act (PSDA) in 1991. This Act required that each patient, upon admission to the hospital complete a

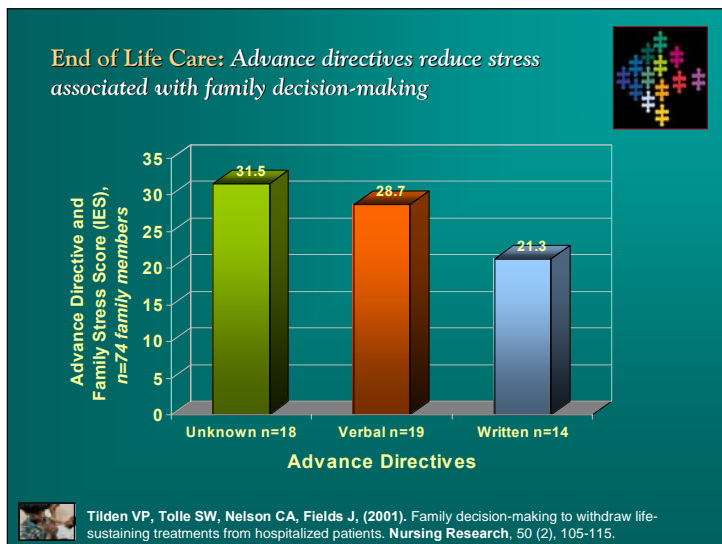
care. This law has been less effective than hoped as only about 20-30% of Americans fill them out. Nurse researchers have found that people need more education and support as they deal with planning their own care. Group meetings in communities, churches and in the home have proven to be much more useful in getting people to address the question of advance directives.

Reducing family stress. Dr. Virginia Tilden and her team of researchers have documented clearly that families who make the decision to stop life-sustaining treatments of the terminally ill without benefit of an advance directive from the patient experience a high level of stress. The extraordinarily high stress occurs at the time the decision is made to stop the life-sustaining treatments and continues for weeks and months afterwards. Family

members express a common theme, “I am still not sure that we did the right thing.” This slide shows that family stress was highest in the absence of advance directives, lower when verbal advanced directives guided the family and lowest when written advance directives guided the family.

This team of researchers has shown that, in acute care settings, advance directives do significantly relieve the high level of family stress associated with decision-making related to terminal care. However,

most terminally ill patients do not have advance directives. As family members try to deal with treatment decisions, there are behaviors, attitudes and



form called an advance directive, outlining the desired level of treat in the event of life-threatening complications. The advance directive is an effort to give the patient more control over terminal

communications by nurses and physicians that may exacerbate the stress instead of relieve it. For families who's loved ones had a written advance directive, family stress was 50% lower than for families whose loved ones did not have an advance directive. The findings from this program of research have been incorporated into the Robert Wood Johnson Foundation *Last Acts* campaign with the message that "you can lift a burden from those you love—complete an advance directive."

Changing nursing home policy. In nursing home settings, a simple alternative form of advance directives substantially improves the extent to which elderly residents' preferences for type of care at the end of life matches what they actually receive. The form called the Physician Order for Life-sustaining Treatments (POLST), translates people's wishes into a medical order that is signed by a physician or nurse practitioner. Research on the effectiveness of the POLST has been reported in many publications in research journals, but in addition, is used by Dr. Tilden and her team for policy change. Their study results have been published in the statewide *Oregon Report Card: Improving Care of the Dying* and in the statewide report, *A Decade of POLST in Oregon*. They have produced a pamphlet entitled, "Physician Orders for Life-Sustaining Treatment," that provides a format for supplying an advance directive to any physician caring for you. The POLST is

endorsed by Senator Mark Hatfield and received wide acceptance in the state of Oregon. Several other states are in various stages of adapting the POLST for use elsewhere in the country.

Advancing end-of-life care. The NINR is the lead institute at NIH in advancing the science of end of life care. It had the "request for proposals" on bioethical and clinical decision-making. The program of research by Dr. Tilden and her colleagues is impressive and has become well-accepted, particularly in the state of Oregon. In addition to their research on the usefulness of advance directives and the barriers to having these available, this team has also done additional work in pain management for dying hospitalized patients and other areas of end of life care.



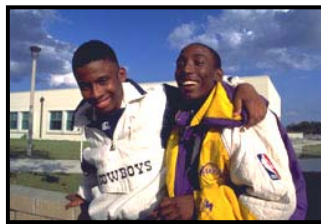
There continues to be a great deal we do not know about end of life. We need to understand how terminally ill patients die, how nurses provide effective, sensitive care, and in what way nurses and physicians can help the families cope with dying patients. There are studies currently funded by NINR that are examining in more detail how patients die in the ICU and the role of technology in the dying process. This is a field of study that will continue to evolve and which nurse scientists have much to contribute.

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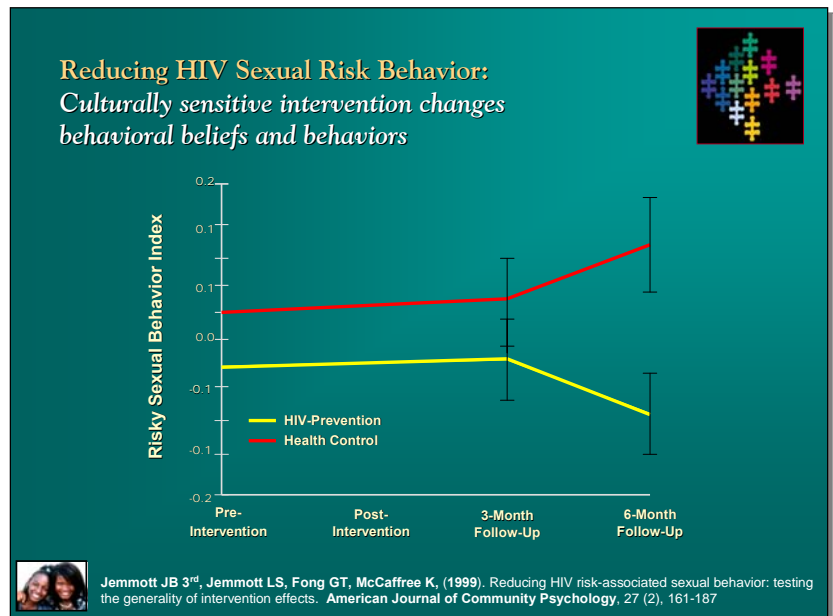
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- **Reducing HIV Sexual Risk Behavior:**
Culturally sensitive intervention changes behavioral beliefs and behaviors

HIV continues to be a growing health problem in the United States. While still concentrated in populations of homosexual males, intravenous drug abusers and low-income populations of African Americans, the disease continues to spread to all populations. Sexual behavior is the most common mode of transmission except among IV drug abusers, who transmit the virus through needle sharing. While new drugs have extended the life of people with HIV, no vaccine has yet been developed that can provide immunity to this devastating disease. The key to stopping the spread of HIV lies with prevention. Considerable evidence indicates that behavioral interventions are effective in reducing self-reported sexual-risk behavior in high-risk populations. The researcher that has had outstanding success is Dr. Loretta Jemmott. Her program of research funded by a variety of sources, including NINR, has focused on reducing HIV sexual risk behavior among African American men and women, African American adolescents, Latino adolescents, and African American and Latino families.



outcomes in reducing HIV sexual risk behaviors. These improved behaviors include increasing condom use, reduced frequency of sex, lower number of sexual partners, less times of unprotected sex, and a reduction in sexually transmitted diseases. The slide below shows results from one study where HIV risk-associated behavior was summarized into an “index score” and evaluated across six months. While little differences were noted at three months post-intervention, there was a significant decline in risky sexual behavior at six months between the intervention and control groups. This research was on a sample of 496 inner-city African American adolescents with a



An approach to prevention. Dr. Jemmott has tested several interventions with these high-risk and hard to reach populations and has produced significant positive

mean age of thirteen.

Research results. Dr. Jemmott and her team have shown that both one-on-one counseling and small group interventions are appropriate and successful in primary care settings. She has made a significant breakthrough by demonstrating that the



intervention sessions can be very short in length, in some cases only one or two sessions, and still be successful and with much better follow-up and tracking of subjects than the usual six week sessions often tried with preventive interventions. The interventions are designed to be educational, but entertaining, culturally sensitive, and gender appropriate.

In addition to the positive outcomes of this prevention research, the investigators have developed a methodology that utilizes focus groups with members of the study population prior to developing the actual intervention, thus making it amenable and culturally sensitive to different populations (e.g. African American, Latino). In addition to the very positive results of the preventive intervention, the investigators have reported successful outcomes of the interventions were irrespective of the race or gender of the facilitator. This is important since it allows for replication and application to many primary care settings by trained facilitators regardless of the race and gender of the group receiving the intervention.

Expanding the program. Due to the success of these programs, the Centers for Disease Control (CDC) has selected three of the interventions for use as model curricula in their Division of Adolescent and School Health. These intervention curricula and models of care are being disseminated both nationally and internationally.

This very productive program of research is now moving to additional hard-to-reach populations, such as monolingual Spanish speaking adolescents and, poor, drug-using women. The investigators are also testing the success of having the intervention delivered by community-based organizations and trying to determine exactly what level of training is required for positive outcomes. They are also concerned with long-lasting effects, testing new interventions to try and determine the relevant predictive factors. This investigative team took on a very hard-to-reach population and has been extremely successful in recruitment and follow-up. Recognition by the CDC has led to acclaim as a national model for other primary care settings in preventing the spread of HIV, which can make the difference between life and death.

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- **Lead Awareness North Philly Style:**
Program increases awareness and reduces risks of lead poisoning among urban youth

Lead is a powerful neurotoxin, and ingestion or inhalation of lead can result in a variety of health problems. Most notable of these health risks is the damaging effect it can have on the developing nervous system of young children. There is ample evidence that high levels of lead in the body of young children causes reductions in intelligence and short-term memory, slower reaction times, poorer hand-eye coordination, and a variety of social and behavioral problems.

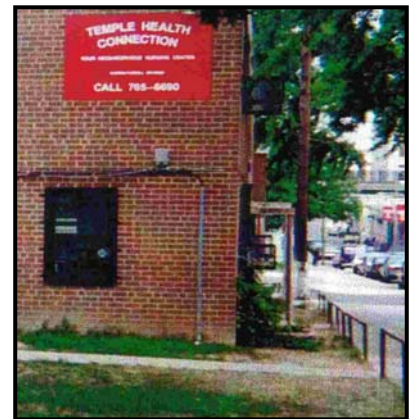
While there are a variety of sources of lead in the environment, the past use of lead in household paint is usually the major contributor to elevated blood levels in our nation's children. Not surprising, this environmental hazard is most often found in poor, urban dwellings of many inner city American neighborhoods. Since childhood lead poisoning is almost always preventable, the challenge is to locate the areas of high exposure, engage



the community to increase the awareness of the hazard, create easy interventions to lessen the prevalence of environmental lead, and encourage nutritional intake that will decrease the uptake and retention of lead (iron, calcium and vitamin C).

The community problem. While we know the dangers of environmental lead in contributing to lead poisoning, we do not know what it takes to get a poor, inner-city neighborhood to engage in a

lead awareness program, and we do not know if such a program will work. This was the unique challenge taken on by Dr. Rothman and her team of researchers and clinicians in North Central Philadelphia. What makes this project particularly noteworthy is that they combined a research project with the actual clinical application by making it a community-based demonstration project. The strength of this program is not only in demonstrating the improvement in blood lead levels of the children in the community, but in the engagement and participation of the entire community in the lead awareness project.




The creativity and holistic approach of this research/demonstration project cannot be fully explicated here, but the key to the success of the project clearly lies in the effort that went into engaging the adults and the children of the targeted community in the project aimed at improving their own health. The literature and printed materials used for this project "tell the story" of why it succeeded. For example, children were taught catchy jingles such as, "Wash those hands, wipe those feet, don't bring lead from off the street," and, "Iron, calcium, and Vitamin C help keep me lead-free."

Decreasing lead levels by increasing awareness. This slide shows the decrease in percent of children with high levels of lead before the project and after the project as compared to similar census tracts receiving the normal public health interventions.


A vital component of this research was not just the actual lead-awareness strategies, but the way in which the community was engaged and activated. The challenge will be to see if such a project is portable to other similar communities and if the program has “staying” power after the funding for the research/ demonstration program is gone.

This project has several important features that are worth highlighting. First, the science is not on how lead affects the nervous system. We know that. The science is on how to get a community to take responsibility for its own health with proper education, support and shared goals and activities. This may be more the science of motivation than anything else. Because the project engaged in so many different activities to lessen the lead exposure, it will be difficult to know which ones worked best and why.

Lead Awareness North Philly Style:
Program increases awareness and reduces risks of lead poisoning among urban youth



Census Tracts	Baseline			One Year into Intervention		
	Number tested	No. ≥10µg at baseline	Percent	Number tested	No. ≥10µg at baseline	Percent
Control	483	217	45%	530	222	42% (-3%)
Experimental	284	162	57%	360	166	46% (-11%)

 Rothman NL, Lourie R, Gaughan J, White N. (1999). A community-developed, community-based lead poisoning prevention program: lead awareness North Philly style. *Holistic Nursing Practice*, 14 (1): 47-58

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Rothman NL, Lourie R, Gaughan J, White N. (1999). A community-developed, community-based lead poisoning prevention program: *Lead Awareness North Philly Style*. **Holistic Nursing Practice**, 14 (1), 47-58.

Lead Awareness: North Philly Style Presents WIPE OUT LEAD Funbook. An educational pamphlet that is available from the Philadelphia Department of Public Health by calling 215-685-5263.

Rothman, N. L., Lourie, R.J., Gaughan, J. (2002). Lead awareness: North Philly Style, **American Journal of Public Health**, 92(5), 739-741.

- **Making the Patient a Partner in Care:**
Improving the employment status of post-transplant patients

Organ transplantation can be viewed as one of the real biomedical miracles of the 20th century. However, replacement of a diseased or non-functioning organ is only the first step. Following successful transplantation many of these patients suffer from a

multitude of symptoms stemming from the drug therapy or the long-term effects that

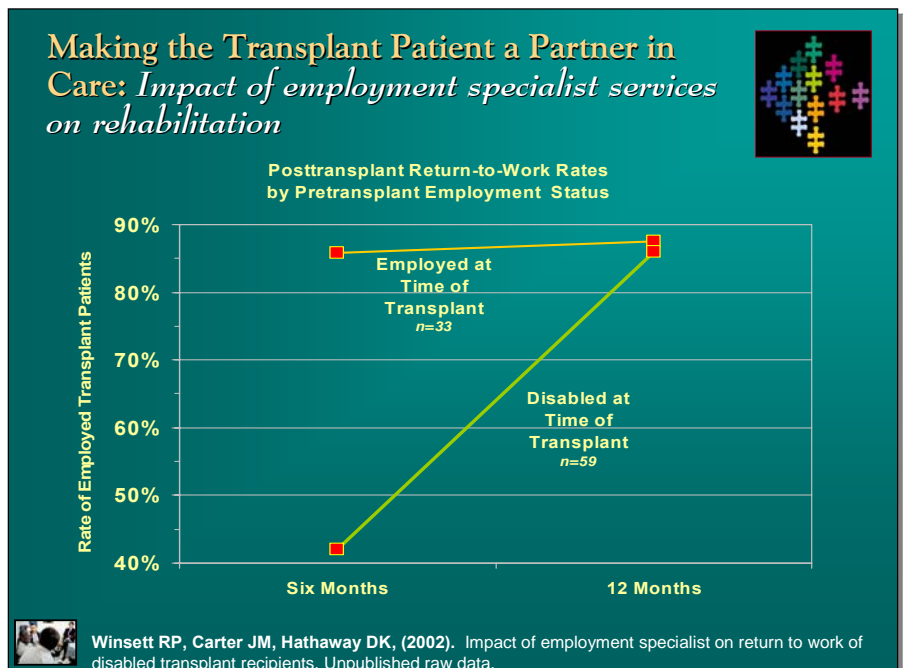


organ failure had on their overall health. Dr. Donna Hathaway and her colleagues have developed a comprehensive plan that helps transplantation patients take responsibility for their own care. This program has created some startling results. For example, their findings show three primary factors in predicting the quality of life that patients enjoy following an organ transplant: employment, social support, and the presence of adverse events that require hospitalization in the first six months following transplantation.

Patients taking charge. Armed with these data, Dr Hathaway and her team have designed a program for transplant patients that helps them take more responsibility for their own care, decreasing their reliance on the medical team, their family or other people for managing their lives. Allowing patient to “take charge” of their care has

resulted in fewer problems with symptoms, fewer adverse events requiring hospitalizations, and, perhaps most striking of all, return to employment status or in-training for employment for 73% of the patients in the program. This is an amazing statistic when you consider that nationally the majority of the transplant population are unemployed prior to surgery and remain unemployed after transplantation. When measured in terms of societal productivity, self esteem, and health care costs, this research adds further evidence that “quality of life” goes well beyond psychosocial adjustment.

Shifting the paradigm. While the original intent of this program of research was on quality of life, the results have contributed to a paradigm shift in allowing patients to become partners in their own care, showing their input has helped to improve their own care and the way they are viewed by the health care team.



The results of this research have changed the way transplant patients are cared for in the University of Tennessee Medical Center. First, all patients are now taught to perform self-physical assessments and to report their results. Out of this measure alone has come an improvement in communication and quicker and more accurate diagnosis of infections and signs and symptoms of rejection. Patients were able to identify the early signs of infection and respond appropriately, increasing the treatment of minor infections from 46% to 67%. By treating infections before they become a major problem, they were able to decrease hospitalizations for infection by 50%!

Patient records now contain more complete and comprehensive documentation of patient progress and treatment plans. Since the NINR study involved a support group, this activity has also improved the communication between patients and the health care team and has contributed to an improved feeling of support and quality of life.

Finally, all patients in the NINR intervention group were counseled on returning to work, even those who were considered disabled and not working prior to transplant. The results in getting patients to return to work have been amazing. The slide above shows the employment rate of both transplant recipients who were disabled and

unemployed prior to transplant and recipients who were actively employed prior to transplant. The average disability time for this group of unemployed patients prior to transplant was 57 months. However, following transplant and the team's intervention, both groups of post-transplant patients achieved an employment rate of over 80%.

Disseminating the model. The results from the work of Hathaway and her colleagues are very impressive. All of this adds up to lowering the cost of care and improving the quality of life for each transplant patient. The approach that Hathaway and her research group have taken to making the patient an active and participating partner in their care instead of just a "recipient" of care has now changed the way all transplant patients are cared for in the University of Tennessee Health Science Center. There is a need for this model of care to be implemented in other transplant centers throughout the country and to monitor the patient outcomes. One of the major difficulties in transporting such multidimensional programs is getting the professional staff in a new setting trained in the new treatment modality and indoctrinated into a new philosophy of patient care. Without an ability to export such positive results, the impact on patient care may not extend beyond the initial site of the research program.

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- **Neurotoxicity in Treatment of Acute Lymphoblastic Leukemia:**
Cognitive and academic abilities of children receiving cancer treatment

There have been major successes in the treatment of children diagnosed with cancer. Five-year disease-free survival rate for children with cancer is 72% for all tumors and 80% for children with acute lymphoblastic leukemia (ALL). Since the central nervous system can act as a sanctuary for lymphoblasts that cannot be

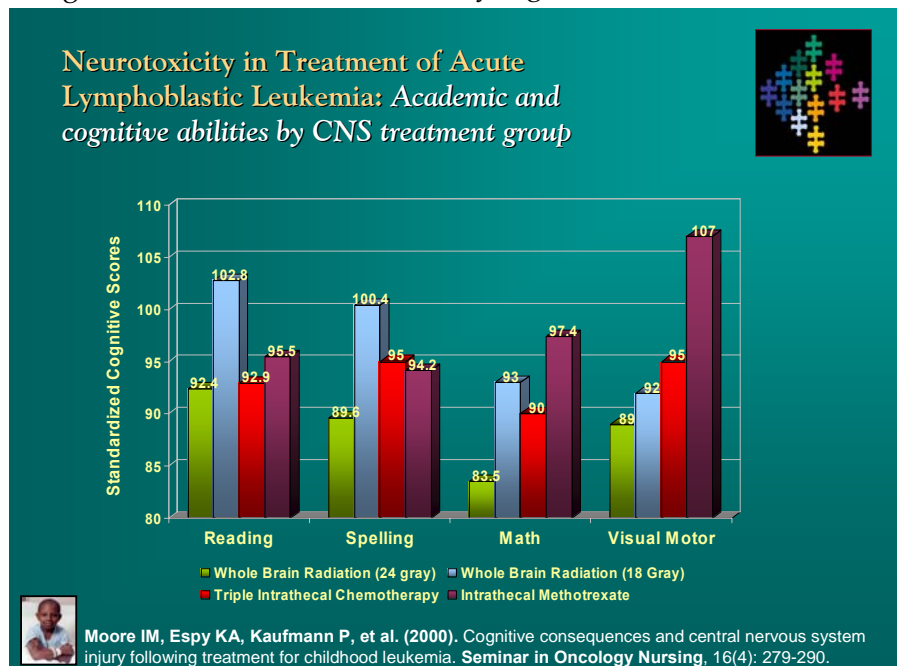


effectively eradicated by routine systemic chemotherapy, treatment now includes the routine targeting of the CNS for both radiation and chemotherapy as a means of increasing the long-term survival for children with leukemia. The long-term effects of this treatment on the developing brain, especially in children under five years of age, have resulted in cognitive and academic deficits.

As a result of numerous reports, including those of Dr. Ida Moore and her colleagues, on the neurotoxic effects of whole brain radiation on cognitive and academic outcomes, this type of CNS treatment has been eliminated from most protocols for the treatment of ALL. Today whole brain radiation is used only for children who have high-risk disease characteristics or have documented CNS leukemia. Whole brain radiation was replaced by triple intrathecal chemotherapy plus systemic chemotherapy. Concerned about the neurotoxic effects of this new therapy,

Dr. Moore and her team followed children with ALL in a longitudinal study and demonstrated that with triple intrathecal therapy, cognitive and academic abilities decline significantly with the greatest declines in math, visual motor integration, and verbal fluency. The magnitude of the cognitive declines appears to be associated with the intensity of the therapy.

Effects on school and social performance. With support from clinical reports along with Dr. Moore and her team's findings, current treatment protocols for children with acute lymphoblastic leukemia have replaced triple intrathecal chemotherapy with intrathecal methotrexate alone, except for children with very high-risk disease. This



slide shows the decline in cognitive and academic abilities in children with ALL treated with whole brain radiation (two

doses, 24 and 18 Gray), triple intrathecal chemotherapy, and intrathecal methotrexate alone.

In addition to documenting the cognitive and academic effects of the treatments for ALL, these researchers have recognized the many behavioral and social adjustment problems reported by parents of these children. Dr. Moore's research has also shown that academic problems are associated with problems of attention and depression. As they note, however, it is difficult to separate academic problems from the behavioral consequences of doing poorly in school that often lead to social problems, anxiety and depression.

Developing an academic intervention.

Because of the presentations, publications and media attention that have resulted from Dr. Moore's work, she and her team have received requests for information from pediatric oncologists, psychologists, and parents of children who have CNS treatment-related academic problems.

This program of research has now moved from an examination of the symptoms and long-term outcomes of "standard" medical therapy for acute lymphoblastic leukemia to a math-skills intervention aimed at lessening the negative effects of therapy. Dr. Moore and her team have been joined by Dr. Marilyn Hockenberry of Baylor for this project. Whether such a cognitive intervention will be effective is

yet to be determined, but the pilot work indicates that it has potential. The parents and teachers of these ALL children would welcome any intervention that had the potential to improve cognitive and academic abilities of these children. Hopefully, cognitive improvements would lessen the behavioral problems some of these children exhibit. We already know in a variety of situations that poor classroom performance is a powerful predictor of behavioral difficulties in children.

The consistent observation of cognitive and academic problems following whole brain radiation and triple intrathecal chemotherapy suggests that these treatments injure non-malignant cells in the CNS. Knowing what the injury pathway is and how it is manifested would be very important in understanding the cell damage and in developing therapies that are specific to decrease the injury to the cells. Dr. Moore has done some initial work in examining cerebral spinal fluid for biological markers indicating cell damage; however, additional research is clearly needed in the basic science arena and would be a valuable adjunct to this entire program of research.



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- **Urinary Incontinence:**
Strategies to improve control

In today's aging but mobile society, many families are dealing with the care of elderly relatives. The primary reason given by families who can no longer care for their elders at home is incontinence. Thus, the need for nursing home placements is often dictated by this one symptom instead of more pressing health care needs. Nurse researchers have taken a leadership role in defining the types of urinary incontinence and in testing the use of non-invasive behavioral techniques to treat and prevent urinary incontinence. Researchers like Wells, Dougherty, McDowell, Sampsel, Engberg, Jirovec and their respective teams have been successful in reducing urinary incontinence without surgery or medication. The research is now moving toward interventions to *prevent* incontinence instead of waiting to treat it. The majority of the research in this area has been with women, but men have been

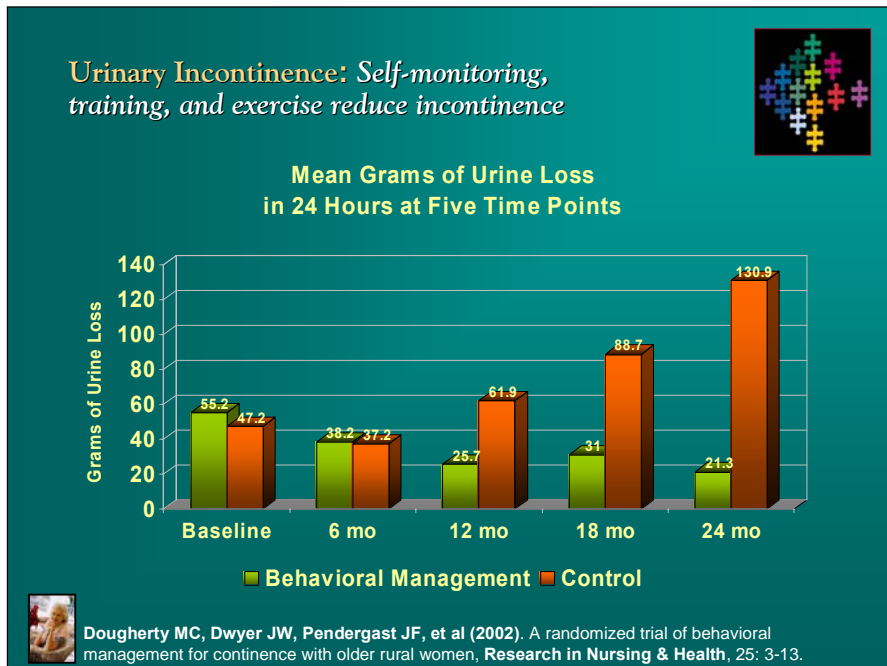


included in some of the studies and have also had positive results

Current research has focused on three primary treatment regimens: pelvic muscle training sometimes enhanced with biofeedback; scheduled voidings for cognitively impaired individuals, and bladder training for ambulatory patients and elderly rural women.

Reducing urine loss. Dougherty and her team in North Carolina have recently reported on the success of a behavioral management program for older rural women with incontinence that reduced urine loss. Self-monitoring and bladder training accounted for most of the improvement, while pelvic muscle training with biofeedback showed little effect.

Perhaps most importantly, at two years the behavioral management group's incontinence severity decreased by 61%, while the control group's severity increased by 184%. This slide shows the mean urine loss in grams (as measured by weighing incontinence pads) for the two groups over the two years of follow-up. Based on these results, their incontinence program of behavioral management for self-monitoring and bladder training has been accepted throughout North



Carolina in various state sponsored projects.

Sampsel and her team conducted a three-year project focusing on maintaining continence. They taught nurses in 21 ambulatory women's health settings across the United States about bladder training, pelvic muscle training, and preventive pre-contraction of the pelvic floor for treating incontinence in their patients. These nurses were able to teach this behavioral intervention to over 900 incontinent women of all ages.

Engberg and her team had similar success with pelvic muscle training, but went a step further in using it with patients who had indwelling urinary catheters removed.

Finally, Jirovec and her colleagues tested individualized scheduled toileting in memory-impaired elders, achieving a decrease in incontinence episodes in this difficult population.

Influencing practice in long-term and community-based care. In addition to the three year workshop for ambulatory nurses mentioned earlier, several nursing homes have adopted continence programs based on the results of these studies, and an article published in *Home Healthcare Nurse* was subsequently adapted as a continuing education program for nurses and posted on the publication website.

The strength of this area of NINR-funded research is the consistent positive results with behavioral interventions, the wonderful testimonials from the patients, and the move from treatment to prevention. Studies are now examining the long-term effects of pelvic muscle exercises in preventing incontinence and, in the case of cognitively impaired individuals, there is some hope that starting scheduled voidings as routine before impairment worsens may improve continence and delay institutionalization.

While pelvic exercises can improve, and in many cases eliminate, incontinence, long-term compliance with the exercises by elders continues to be a problem. With the cognitively impaired elder, a program of planned voidings still requires a caretaker and consistency of the voiding times. There is certainly adequate documentation of the success of these programs of research, but like many areas of health care, the lay public still needs ways to be informed of these interventions and the dramatic improvement they can have on an individual's quality of life. While websites have proven useful in spreading the word in some areas of nursing research, the current population of elders is not yet as tuned into the Internet as younger folks and additional ways to reach them need to be explored.

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- **Proper Gastric Tube Placement:**
pH used as placement indication

Few investigators can claim to have “rewritten the book” on nursing practice the way that Dr. Norma Metheny and her research team have done. Their research on assessing the proper placement of feeding tubes has completely changed what is now considered *standard* practice and has clearly demonstrated that the old method of assessing feeding tube placement is often both ineffective and inaccurate.

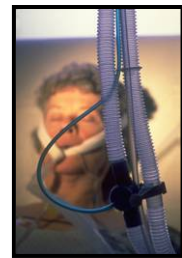


While there is increasing evidence that tube feedings are vastly superior to intravenous feedings in providing effective nourishment to patients, they are not without risks.

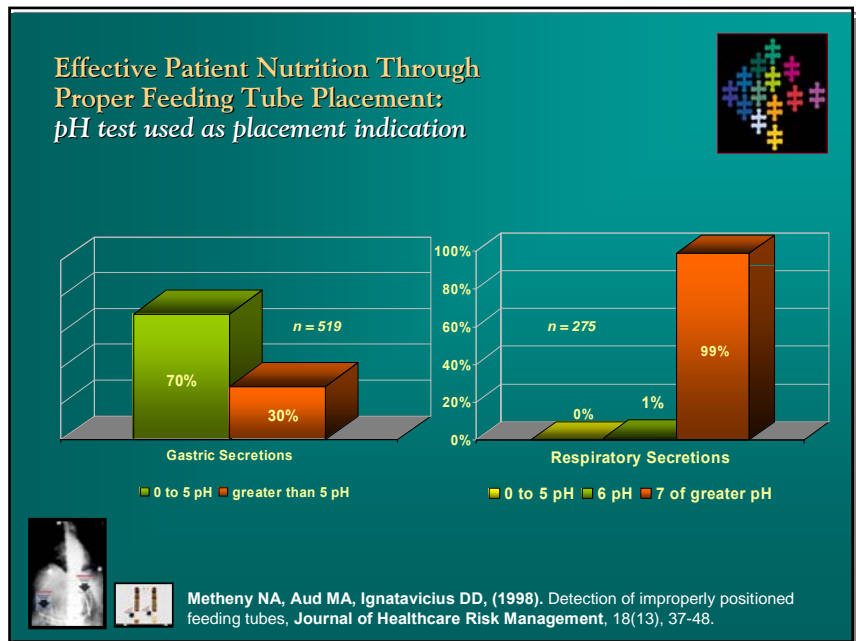
The two major complications are incorrect placement of the tube, usually into the lungs, and aspiration of tube feeding formula into the lungs.

Annually, close to one million patients receive nutritional support through feeding tubes. For many years the standard method used by nurses to check feeding tube placement was to push a small amount of air into the tube and listen over the area of the stomach with a stethoscope for a “swoosh” sound, supposedly indicating proper placement of the tube tip. Over the past decade, Metheny and her colleagues have repeatedly demonstrated the inaccuracy and danger of this method.

To more accurately and effectively determine tube placement, they have studied the use of measuring the pH of secretions aspirated from the tube. This method is particularly helpful in distinguishing gastric placement with new tube insertions. The acceptance of pH testing as the better method of determining feeding tube placement has resulted in the rewriting of hospital protocols across the country and the inclusion of this procedure into nursing and joint-practice textbooks.



This slide shows that 70% of gastric secretions are in the pH range of 0 to 5 while 99% of respiratory secretions are at a pH of 7 or more. Metheny suggests that, to err on the side of safety, a pH of 0 to 4 should be used to indicate non-respiratory placement of the feeding tube.



There are times when pH testing is not definitive, for example with continuous tube feedings or with small intestine placements. These investigators have gone on to further refine feeding tube placement by checking for the gastric enzyme pepsin and the presence of bilirubin. Bedside enzyme and bilirubin methods have now been patented. Plans are underway to make these tests available from a commercial source.

Influencing Practice Standards: While the research on proper feeding tube placement is now being used in clinical practice, Metheny and her team have gone on to address a second complication from feeding tubes, that of aspiration of

stomach contents into the lungs. Even with correct tube placement, there is always the danger of aspiration of the formula from stomach regurgitation. Metheny and her research team have used an animal model to demonstrate the ineffectiveness of using dye or glucose testing as a means of assessing aspiration events. They have, however, identified a highly sensitive and specific method of detecting minute quantities of gastric pepsin in suctioned tracheal secretions, which indicate aspiration. They are in the process of further “rewriting the book” for detecting this complication in critically ill patients.



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- **Effects of Antepartum Bed Rest: *Muscle recovery delayed with bed rest***

Each year approximately 700,000 women are treated with bed rest during their pregnancy and are labeled as “high-risk.” The situations that usually initiate this prescribed bed rest are conditions that threaten full-term pregnancy such as preterm labor, multiple fetuses, placenta previa, preeclampsia, incompetent cervix and pregnancy-related hypertension. The general belief is that bed rest prevents preterm labor by improving uterine perfusion, relieving the physical forces that may act on the cervix, and perhaps providing a period of rest and relief from physical and psychological stress. The fact is, there is little scientific evidence that prolonged periods of bed rest is effective in managing these threats to a full-term delivery. Furthermore, the physiological side effects of activity restriction in non-pregnant individuals are well known. Dr. Judith Maloni and her research team have called into question the validity of using bed rest as a routine treatment for preterm labor, and they have set out to document the deleterious effects of bed rest in pregnant women.

Based on surveys from physicians, between 89-92% use bed rest as a treatment for pregnant women determined to be at high risk and it is estimated that approximately 18% of pregnant women who carry a pregnancy to 20 weeks are prescribed bed rest. Many obstetricians admit that 18% of pregnancies is a high number to need bed rest. Since the use of bed rest for high-risk pregnancies is so well established, it is not realistically or ethically possible to have a group of high-risk pregnant women in an experimental and control group design. Dr. Maloni and her colleagues did, however, assess changes in the gastrocnemius muscle metabolism, as a measure of muscle atrophy, across antepartum bed rest and 6 weeks postpartum in pregnant women treated with bed rest. Her results demonstrate that muscle atrophy and deconditioning occur along with difficulty in mobility that extends well into the post partum period and often for months after delivery.

This slide demonstrates the increase in muscle recovery time (using the gastrocnemius muscle to measure muscle reoxygenation after exercise) in women on bed rest during pregnancy. The greatest decline is shown in those women who had been on bed rest at home prior to admission. Deconditioning was also evident in cardiovascular responses, shortness of breath, muscle soreness and pain. Recovery does occur with remobilization and shows that the greater the time a woman is on bed rest, the greater the atrophy and the longer the recovery time.

Weight loss for the mothers was not necessarily expected early in the bed rest period, but an earlier study by Maloni did document weight loss in mothers on bed rest and this was proposed as due to fluid shifts and diuresis. However, Maloni again found maternal weight loss or lack of weight gain occurred during hospitalization for bed rest treatment and concomitantly infant birth weights were also below average.

Negative emotions and emotional liability, including symptoms of depression, anxiety, and hostility have been demonstrated in these women on bed rest both at home and in the hospital.



Because these women have these symptoms before they begin their bed rest treatment, it is entirely possible that the fears and concerns of the high risk pregnancy itself cause these psychological symptoms rather than the bed rest, but it does seem that bed rest exacerbates these problems. There are a variety of other problems that occur with prolonged bed rest that include effects on family functioning, financial concerns, feelings of isolation and loneliness.

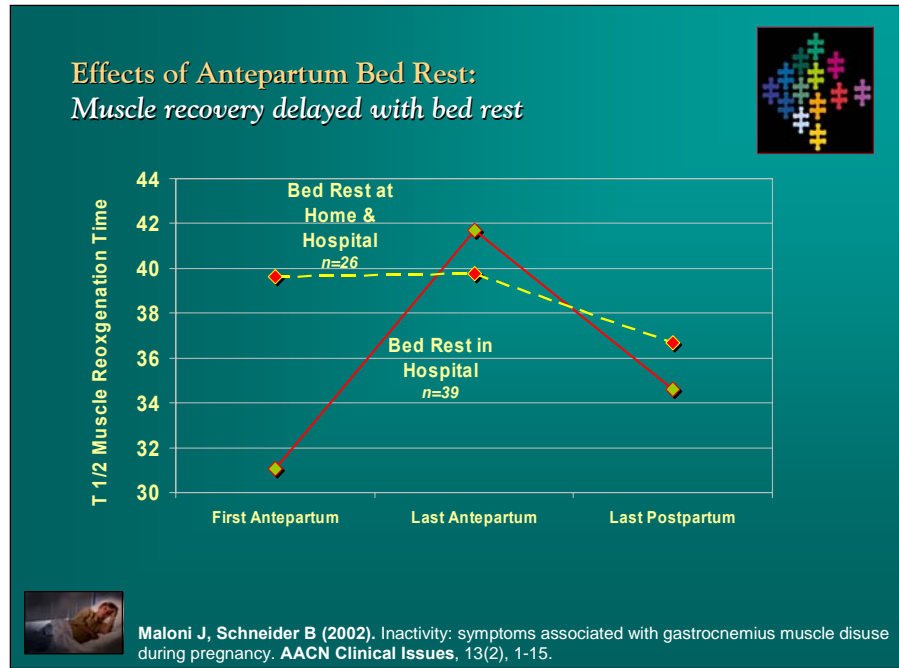
Dr. Maloni brings a passion to this research that has resulted in a variety of resources for the lay public and for health care

providers who care for pregnant women on bed rest. She has authored videotape titled, **Antepartum Bed Rest: The Price** as well as a health care provider education book, a web site for pregnant women and for health care providers, and she is participating on a list serve for women who were or are on bed rest during their pregnancy.

One of the unstated goals for this program of research is to question the widespread use of bed rest for treating a plethora of conditions of pregnancy that are thought to lead to preterm delivery. This is difficult since bed rest is a time-honored treatment that is used extensively. Despite the lack of evidence to support the use of bed rest for premature delivery, many physicians believe it works and continue to prescribe it for their patients. The possibility of contributing to an early delivery by not accepting bed rest are entirely too daunting for most pregnant women to reject the treatment.

What Maloni has done, however, is very laudable. She is systematically studying the adverse side effects of prolonged bed rest in pregnant women and she is also examining the long-term recovery process from bed rest.

The side effects are not insignificant and should be understood by both professionals and parents as they enter this treatment. Dealing with bed rest can adversely affect



both the mother and the entire family as they deal with all of the family dynamics and social and economic changes. It appears that very few people are concerned with the women once she has delivered and goes home. Maloni has clearly documented the major adjustments, both physically and psychologically that will need to be made in the post partum period. She is not only reporting this in research journals, but she is making a concerted effort to get this information to the lay public and to health care workers who care for these pregnant women.

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• Cultural Diversity in Community-Based Self-Management Programs

Not only are chronic diseases the principal cause of disability in the United States, they account for a large percentage of all health care expenditures. Treatment plans depend on self-management, and patients with chronic diseases must often follow strict medication schedules, diets, and exercise programs. In addition, they must learn to recognize adverse symptoms, cope with discomfort and disability, modify their behaviors to accommodate their disease state and treatment regimens, and deal with changes to their life roles.

Dr. Kate Lorig and her fellow researchers at Stanford University have conducted a variety of studies aimed at improving health status, delaying deterioration, and reducing health care utilization resulting from chronic conditions. Much of their work has been devoted to arthritis and resulted in the development of a six-week Arthritis Self-Management Program. This community-based, peer-led program reduced pain and increased activity levels in arthritis sufferers, while decreasing physician visits by 40%. The National Arthritis Foundation of the United States, the Arthritis Society in Canada, the Arthritis Foundation of Australia, and Arthritis Care in Great Britain have adopted this program, and it has also been presented in Hong Kong, Poland and St. Lucia.

Despite this international success, the Arthritis Self-Management Program has not reached the Spanish-speaking community in the United States, where arthritis is the leading cause of disability. To address this disparity, the investigators set out to design and test a Community-Based

Spanish Language Arthritis Education Program. Their first step was to translate into Spanish a variety of self-administered health assessment instruments, both to aid in evaluating their own intervention study and for use with other clinical trials involving Spanish-speaking subjects. Accurate translation requires a lot of time, effort, and energy to test for variations of word meanings according to culture-specific interpretations.

When completed, the research team published copies of the translated instruments. By sharing their findings so generously, this research team encouraged additional research in this field.

In addition to tool development, the investigators evaluated methods of data collection in the Spanish-speaking community. Many investigators believed the only way to collect accurate data from Spanish-speaking subjects was through face-to-face interviews, a costly and difficult practice. By comparing face-to-face interviews with telephone interviews and mailed questionnaires, the researchers concluded that the mailed questionnaire, with telephone follow-up to fill in missing information, is both acceptable and less expensive than the face-to-face method.

Armed with the appropriate translated instruments and support for their data collection methods, Dr. Lorig and her colleagues tested a 6-week community-based arthritis self-management program led by lay providers for Spanish-speaking subjects.



At a one-year follow-up, treatment subjects showed improvements in exercise, general health, and self-efficacy, along with decreases in disability, pain, and depression.

Dr. Lorig and her fellow investigators are continuing additional studies with lay-leaders in community sites that focus on improving self-efficacy and self-management with many chronic diseases. The following slide shows the results for subjects with a range of chronic conditions including heart disease, lung disease, stroke, or arthritis, following a 7-week, peer-led self-management program. At 2-years post intervention, the subjects in the intervention group self-reported significant improvements in their health, energy, and self-efficacy to manage their disease, along with less health distress and lower use of visits to the emergency room or to physicians. This low-cost, short-term intervention achieved long-lasting effectiveness across multiple disease conditions.


About 200 organizations in the US are now offering this model of self-

management of chronic disease. In addition, the National Health Service of England has adopted it as a national program and is presently putting it in place in all the primary health care trusts in the country. Parts of the program are being demonstrated in Canada, Australia and New Zealand,

Changes in health services utilization, health status, and self-efficacy over two years

		<i>n</i>	Baseline	Two Year	Change	Significance
MD & ER	(# visits in past six months)	<i>n</i> =533	5.65 (5.33)	5.09 (5.17)	-0.564 (6.22)	0.036*
Self-Related Health	(Low is better)	<i>n</i> =533	3.28 (0.870)	3.22 (0.956)	-0.060 (0.761)	0.068
Energy / Fatigue	(High is better)	<i>n</i> =533	2.20 (1.08)	2.28 (1.09)	0.077 (0.912)	0.054
Health Distress	(Low is better)	<i>n</i> =533	2.04 (1.15)	1.75 (1.15)	-0.290 (1.02)	0.0001*
Self-Efficacy to Manage Chronic Disease	(High is better)	<i>n</i> = 299	6.03 (2.10)	6.25 (2.21)	0.270 (1.78)	0.009*

* significant at the p < .05

 **Lorig, Ritter, Stewart, Sobel, et al (2001).** Chronic disease self-management program. *Medical Care*, 39(11), 1217-1223.

and the program has been presented in Holland, Switzerland, Norway, Sweden, Hong Kong, and Shanghai. This self-management model is making a difference in the lives of chronically ill adults throughout the world.

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Bodenheimer T., Lorig K., Holman H., et al (2002). Patient self-management of chronic disease in primary care. *JAMA*, 288 (20) .

● Detecting Myocardial Ischemia through Continuous ECG Monitoring

The 1960's saw the development of coronary care units (CCU) throughout the United States with advanced training of nurses for the purpose of monitoring cardiac arrhythmias and aggressively treating ventricular arrhythmias. The specialty of critical care nursing emerged from these CCUs and later the intensive care units that soon followed. Many lives were saved by this new aggressive monitoring and treatment of cardiac arrhythmias, but in the late 1980's the Cardiac Arrhythmia Suppression Trial (CAST) demonstrated that antiarrhythmic therapy can be pro-arrhythmic and can cause arrhythmic death. As a result, treatment of arrhythmias in critical care units became less aggressive and the need for critical care nurses to monitor and treat ventricular ectopic beats and other non-sustained and asymptomatic arrhythmias was no longer appropriate.

At the same time that the treatment of arrhythmias became less aggressive, treatment of acute myocardial ischemia became more aggressive, including immediate thrombolytic or angioplasty therapy for acute myocardial infarction and intravenous antithrombotic and antiplatelet agents for unstable angina. The need in the critical care units became the detection of ischemia rather than arrhythmias. However, both the technology for monitoring and the training of the nurses in the interpretation were both lacking in the early 1990's.

Dr Barbara Drew from the University of California, San Francisco began her program of research by examining the accuracy of lead placements for continuous cardiac arrhythmia monitoring. She found only 37% of the critical care nurses surveyed demonstrated proper technique for obtaining their single lead choice and even less (13%) demonstrated proper technique for obtaining their dual leads choice. These inaccuracies can result in misdiagnosis of arrhythmias and inappropriate treatments. Based on her work with accuracy in arrhythmia detection, she was able to demonstrate that the MCL₁ lead could not be

substituted for the "true" V₁ lead in diagnosing cardiac arrhythmias with a wide QRS complex. This work led manufacturers of cardiac monitoring systems to provide "true" V₁ capability in all of their monitor products. In addition to promoting proper and accurate lead placements for ECG monitoring, she was one of the first clinicians to recognize the need for continuous ST segment monitoring in hospitalized patients to detect early signs of myocardial ischemia.

Because ischemia is a localized phenomenon and detectable only in a restricted number of ECG leads directly facing the ischemic zone, multiple leads are necessary to adequately monitor the multiple areas of myocardial muscle that can potentially develop ischemia. Unfortunately, continuous monitoring of all 12 ECG leads is impractical in acute care settings because the multiple electrodes and wires interfere with diagnostic and resuscitative measures, curtail a patient's



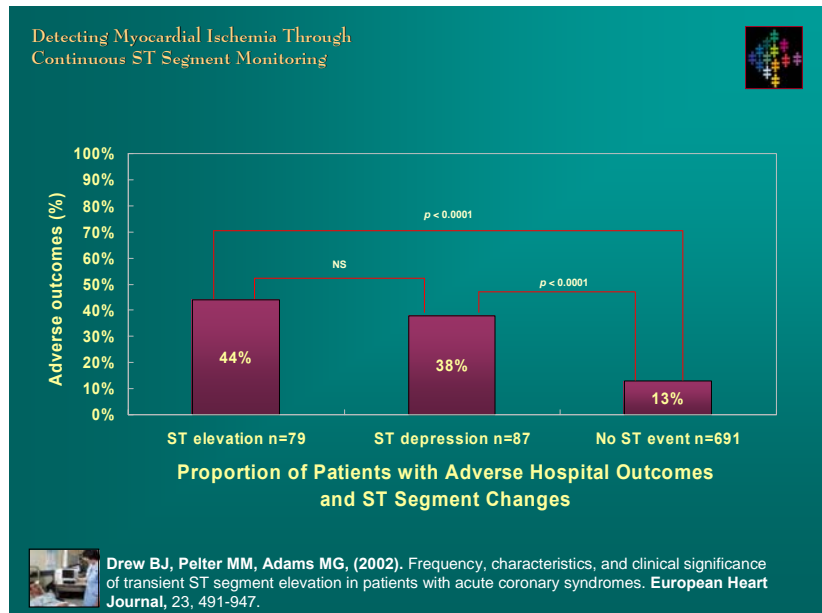
mobility, and create an unacceptable noisy signal. While much of Dr. Drew's work has provided strong support for the use of 12 lead ECG monitoring to accurately detect ischemic cardiac

events, she and her team of researchers have developed a "reduced lead set" technology method. This method uses a smaller number of strategically placed electrodes instead of a full 12 lead ECG for continuous cardiac monitoring. Using data from continuous monitoring of hospitalized patients, she has been able to clearly establish the importance of continuous multi-lead ST segment monitoring for detecting the serious complication of coronary artery reocclusion following thrombolytic therapy or percutaneous coronary interventions (angioplasty and stenting). Her studies have shown that transient ischemia following treatment for acute coronary syndromes is: 1) usually

missed with routine “arrhythmia” monitoring leads, 2) associated with poor hospital outcomes, and 3) most often (80%) clinically silent (asymptomatic).

This slide shows the results of ST monitoring of 868 patients and the proportion of patients that had adverse hospital outcomes. Twenty percent (n=177) had a total of 574 events of either ST segment elevation or ST segment depression while 80% (n=691) had no documented ST changes. (Note: 11 patients excluded from analyses as they had both ST elevation and ST depression, making n=166). The percent of patients with adverse hospital outcomes is significantly higher in the group with ST segment changes. There was no significant difference in the proportion of adverse hospital outcomes between ST segment elevation (44%) and ST segment depression (38%). Adverse hospital outcomes were defined as cardiogenic shock, acute pulmonary edema, acute myocardial infarction after hospitalization, or death. Of particular importance is the finding that the vast majority of these ST changes were “silent,” that is, without any pain or other clinical symptoms, and were not evident in the initial ECG of the patient on admission. These findings support the usefulness of ischemic monitoring in predicting adverse events as opposed to clinical symptoms or the initial 12 lead ECG.

Based on results from her studies, “reduced lead set technology” has been incorporated into the leading monitor manufacturer’s latest generation of bedside cardiac monitors (EASI 12-lead by Hewlett-Packard/Agilent/ Philips Co.) Moreover,



other monitor manufacturers are working with Dr. Drew and her team to develop “reduced lead set technology” for use in their cardiac monitors that are used for the pre-hospital phase emergency cardiac care. Such a system would be able to provide continuous ischemia monitoring in the field and automatically transmit via cell phone ST segment alarm ECGs to the target hospital emergency department. Such systems could reduce the time delay in implementing reperfusion therapy and improve patient outcomes.

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• Neurobehavioral Effects of Chronic Sleep Deprivation

Water, food, sleep—all are essential to the health and well-being of humans. A fairly large body of literature exists on what happens to the body with either food or water deprivation. Very little has been done in the area of sleep deprivation in either healthy or sick individuals. Everyone at one time or another has felt the effects of sleep disruption or sleep deprivation. This is an expected side effect of raising young children, traveling across time zones, and partying on the weekends or holidays. Such situations of sleep disruption and deprivation are usually time-limited with some potential for sleep catch-up within the same 24-hour period. Of greater concern are the situations of chronic sleep deprivation that occur across an extended time with some shift workers, with certain occupations that require



extended hours of work (e.g. physicians in training, police officers, truck drivers, etc.), and with patients who have medical disorders or who are undergoing medical procedures that chronically interrupt and shorten sleep.

Dr. David Dinges from the University of Pennsylvania and his team of researchers have set out to establish the neurobehavioral and neurobiological effects of chronic partial sleep deprivation in healthy adults. Through a series of well controlled laboratory experiments they have assessed neurobehavioral functioning, hormone (melatonin) profiles, core body temperature, and sleep/waking polysomnography for various times of chronic

sleep restriction. In addition to the sleep restriction protocol, subjects were given time in bed (TIB) at different times of the day. The goal was to assess not only increasing levels of sleep deprivation, but also the effects of sleep recovery when taken during the day instead of nocturnally.

Results from this series of studies demonstrate a significant decline overtime in neurobehavioral functioning (behavioral alertness and memory) with the greatest deprivation group showing the greatest performance declines. In addition, greater declines for all sleep deprivation conditions were noted when the sleep recovery was allowed during the day. This highlights the possible need for longer sleep periods to obtain the required amount of sleep when sleep is displaced to daytime hours.

Similar declines overtime were demonstrated in subjective measures of fatigue and alertness. However, following an initial steep increase in reported levels of fatigue during the first few days of sleep restriction, these values tend to plateau. Subjects apparently perceive themselves to be adapting to the sleep deprivation and do not report increasing fatigue or declining alertness despite the continuing decline in objective measures of behavioral alertness and memory tasks. As the slide below shows, subjects did however,

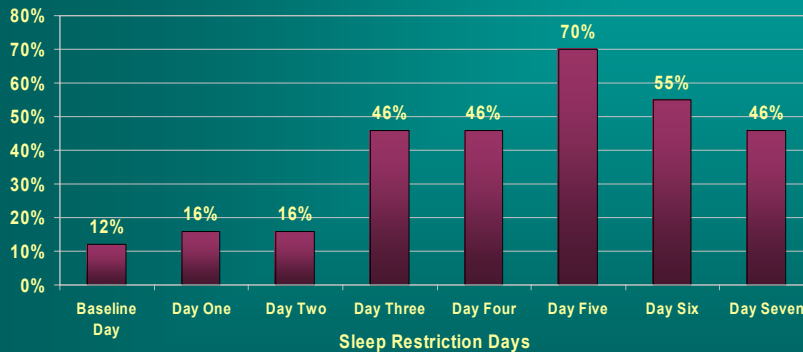
report an increasing number of complaints that included a significant “illness, infection, pain, discomfort, worry, or problem.” These complaints were captured through journal entries and generally consisted of three types: complaints of sleepiness, somatic complaints, and complaints of cognitive or emotional problems. The slide shows the proportion of subjects who recorded complaints in their logbook at baseline day (B2) through the seven days of sleep restriction (P1-P7).

The strength of this program of research is in the controlled conditions of both sleep deprivation and timing of sleep recovery (day vs. night), the number of consecutive days of the

partial sleep deprivation (10 days), the use of both subjective and objective measures to evaluate neurobehavioral responses, and the focus on young, healthy adults subjects. The findings from this research have important

The Accreditation Council on Graduate Medical Education (ACGME) responding to growing concerns that exhausted medical residents were endangering themselves and their patients, set new rules for medical residency

Proportion of subjects who listed complaints during a seven day sleep restriction



Dinges DF, Pack F, Williams K, et al. (1997) Cumulative sleepiness, mood disturbance, and psychomotor vigilance performance decrements during a week of sleep restriction. *Sleep*; 20(4), 267-277.

implications for many people in our workforce, who because of job demands, do shift work, work long hours without sleep, or continue to work in a chronic sleep deprived condition. This team of researchers has acted as experts in informing a variety of regulatory agencies on the risks of chronic sleep loss (Dept. of Transportation, NASA, US Justice Dept., National Transportation Safety Board, and the Association of American Medical Colleges).

programs that will take effect July 2003. These new rules limit the work week to 80 hours with at least 10 hours time between shifts, on-duty time to be no more than 24 hours straight, and the new standards can be exceeded by 8 hours only for approved educational reasons.

These new rules for medical residency programs are a good beginning and mandated off-duty work time is being addressed in the commercial trucking, aviation, rail and maritime industries. There is a great deal more to be done and to be learned about sleep deprivation in patient populations and the effects on both physical and emotional repair and recovery. This research is already making a difference in healthy populations and needs to be expanded into patient populations who suffer sleep loss because of both environmental and treatment factors. Interventions to protect the sleep time of patients are definitely of concern for nurses and have the potential to impact patient care practices.

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• Nurse Staffing, Organization of Care and Patient Outcomes

As managed care organizations grew in response to the governments demand for cost containment, hospital stays decreased, outpatient care increased and hospital staffing of professional nurses decreased. This downsizing of nursing resulted in a widespread view that nursing was not a viable or popular career choice. The result was a huge decrease in enrollment in nursing programs across the country, subsequently followed by a shortage of available nurses for hospitals. These changes in health care, fewer resources for in-patient care and fewer available nurses, have created consumer concern for the quality of care that is delivered, and ways to measure and assure quality patient outcomes.

Dr. Linda Aiken and her team in the Center for Health Outcomes and Policy Research at the University of Pennsylvania have built a program of research that has addressed nurse staffing, the organization of care in hospitals and the impact of these two variables on both patients and nurses. Three major studies have been funded by NINR that have provided the data to support the effects that nurse staffing and organizational climate have on positive patient outcomes.

In the early 1990's, there was concern about the most appropriate and efficient way to care for persons with AIDS. The use of dedicated AIDS units was controversial and had not been examined in terms of patient outcomes. Dr. Aiken and her team, using 20 hospitals, examined 40 hospital units, 10 of which were dedicated AIDS units to compare differences in mortality and satisfaction with care between dedicated AIDS units and scattered-bed units and between magnet hospitals and hospitals that were not designated as magnet hospitals.






Results demonstrated that while dedicated AIDS unit had superior outcomes (mortality and patient satisfaction), their advantage seemed to come from the better levels of nurse staffing and higher quality of nurse-working-environments. Of particular note is the analyses that shows that an additional nurse per patient day cuts the odds on dying within 30 days by more than one-half, and the availability of a physician who is part of an AIDSspecialty service lower the odds on dying within 30 days by almost two-thirds! Thus, the lower mortality


in dedicated AIDS units, holding constant severity of illness, appears to be attributable primarily to specialty physician AIDS services and higher nurse to patient ratios.

This study provided the prototype for the next study which examined the entire "Magnet Hospital" designation that has now evolved to magnet designation by the American Nurses Credentialing Center (ANCC). The original designation was conceived by the American Academy of Nursing (AAN) which conducted a study to identify the hospitals that attracted and retained nurses and which organizational features were shared by these successful hospitals, referred to as "magnet" hospitals since they "attracted nurses and kept them."

The purpose of this study was to determine whether hospitals selected for recognition by the American Nurses Credentialing Center (ANCC) application process are as successful in creating environments in which excellent nursing care is

Nurse Staffing, Organization of Care, and Patient Outcomes:
Nurse assessments of job satisfaction, burnout, and quality of care in five countries, 1008-1090.

	U.S. 	Canada 	England 	Scotland 	Germany 
Percent dissatisfied with present job	41.0%	32.9%	36.1%	37.7%	17.4%
Percent with scores in high burnout range according to norms	43.2	36.0	36.2	29.1	15.2
Percent describing the quality of care on their unit as excellent	35.7	35.6	29.3	35.2	11.7
Percent confident that their patients are able to manage their own care when discharged	33.8	30.0	59.7	56.1	80.9
Percent who say the quality of care in their hospital has deteriorated in the past year	44.8	44.6	27.6	21.5	17.2

 Aiken LH, Clarke SP, Sloane DM, Sochalsk JA, Busse R, Clarke H, Giovannetti P, Hunt J, Rafferty AM, Shamian J. (2001). Nurses' reports on hospital care in five countries. *Health Affairs*, 20 (1), 43-53.

provided as the original AAN magnet hospitals were. Specifically, this study was to determine if the newly designated magnet hospitals had high rates of nurse satisfaction and high quality care (as assessed by nurse) and thus offered evidence that the good outcomes shown to exist in the original magnet hospitals could be expected to exist in the ANCC Magnet Nursing Services Recognition Program.

The research team found that the ANCC designated magnet hospitals had lower burnout rates and higher levels of job satisfaction and

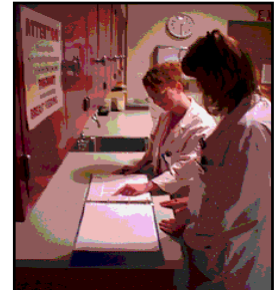
gave quality of care provided at their hospitals higher ratings than did nurse at the originally designated magnet hospitals. This study is rich in its findings reflecting nursing staff perceptions and organizational factors that contribute to a positive practice environment for nurses, and would seem to be essential reading for all nurse administrators who are struggling with nurse recruitment and retention in today's health care environment. The ANCC credentialing program for magnet hospitals is the only major approach to organizing nursing care in hospitals that now has a research base for linking the nurse practice environment to quality of care. There is still work to be done in this arena in determining how nurse staffing and skill interact with other organizational features to affect patient outcomes. In addition, the application for magnet status by hospitals has been slow and deserves higher recognition by consumers for it to be a higher priority for the practice environments to reach this status.

Dr. Aiken and her team of researchers have now broadened their approach to a cross-national study that will ultimately include data from over 45,000 nurses practicing in some 750 hospitals in the United States, Canada, England, Scotland, Germany, and New Zealand. The goal of this expansive research is to look at the work environment of nurses in different health care systems to determine the relationship between the practice environment as perceived by nurses and the quality of patient care and patient care outcomes. Inadequate nurse staffing and problems of uneven quality of care in hospitals are often blamed on the growth of managed care with the subsequent competition between hospital networks, reductions in nurse staffing and other cost cutting measures. However, news reports on the nursing shortage and concerns for discontented nurses extend to all of the countries studied.

Publications from this large international study have demonstrated that low morale in the form of low satisfaction with work and high levels of burnout in the hospital nurse

work-force are not unique to the United States. Again, the themes and patterns that are evident in this cross-national work are adding to our understanding of how the work environment can affect patient safety, family complaints, and interpersonal conflicts that lead to worker (nurse) dissatisfaction and poor productivity (quality patient care). This slide shows some of nurse survey responses from the five countries. Of particular note in this international comparison are the findings from Germany where the nurse staff are more satisfied with their jobs, but a much lower percentage rate the quality of care provided as 'excellent' on their unit. This study will provide additional insights to how nurse perceptions of hospital organization, work design and patient care are linked and reflected in nurse satisfaction and quality of patient care.

The overarching theme of this team of researchers is to unravel the many factors within an organizational climate that contribute to a high quality and productive work force of nurses at the bedside. Their work along with others has consistently shown that hospital working conditions and the adequacy of nurse staffing are important predictors of variation in hospital patient outcomes. A recent paper by Aiken's team demonstrates that hospitals in which nurses have lower patient workloads have substantially lower risk-adjusted mortality. A study by researchers from Harvard and Vanderbilt reiterated this finding by reporting that hospitals staffed with more registered nurses had fewer deaths from complications than hospitals with fewer nurses. This study has an enormous sample of patients from 799 hospitals and contributes to the theme of Dr. Aiken: more nurses are needed for quality patient care and to get more nurses, the work conditions and clinical care services need to be supportive of a positive practice environment for the nurses.



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- **Reducing Preterm and Low Birth Weight Births**

Low birth weight (LBW) and preterm births remain the major factors in infant mortality and morbidity in the United States, and consistently these rates of LBW and preterm births have been highest in black women and adolescents. Programs aimed at reducing the incidence of LBW and/or preterm births have focused on risk assessment, education, and more frequent prenatal contacts. Some of these studies have shown promising results in middle-class and rural women. However, the results have not been replicated in subsequent randomized trials. In spite of these rather daunting odds, Dr. Mary Lou Moore and her colleagues focused on low-income women and in a randomized trial testing the use of a single personal visit and regular (usually 3) telephone calls to the women from 22 to 32 weeks gestation to the time of delivery.

For the total sample there was no difference in rates of LBW or preterm delivery between intervention and control groups. However, among black women, there was a significant decrease in LBW rates between intervention (11.3%) and control (15.3%) groups. This difference came almost entirely from a subgroup of black women 19 years

of age or older. In this subgroup there was a significant difference in both LBW rates between intervention and control groups (11.4% vs 17.3%) and in preterm births (9.4% vs 12.8%). This subgroup of black women 19 years of age and older who benefited most from the intervention may have fewer opportunities for education and social support than the pregnant teenagers and thus the low-cost telephone intervention was more effective.

This slide shows the significant findings from the study comparing the black and white women subjects and the subgroup of

Birth Weight and Gestational Age by Race and Age of Mother

	Black Women			Black Women >=19years			White or Other Women		
	n	LBW	Pre-term	n	LBW	Pre-term	n	LBW	Pre-term
Control	556	15.3%	12.8%	364	17.3%	8.7%	159	10%	5.0%*
Intervention	557	11.3%*	9.4%	395	11.4%*	15.4%*	161	9.9%	11.2%

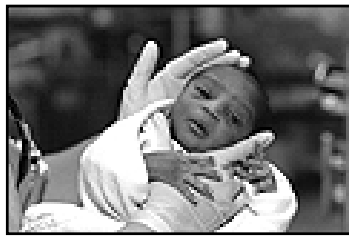
* Significant at the p< .05

Moore ML, Meis PJ, Ernest JM, Wells HB, Zaccaro DJ, Terrell T, (1998). A randomized trial of nurse intervention to reduce preterm and low birth weight births. *Obstetrics and Gynecology*, 91(5), 656-661.

older black women where the differences are more pronounced between the intervention and the control groups. The high rate of preterm delivery in the intervention group of white women was of

concern and appeared to be related to the high level of smoking in this group of women. In this group of white women, 87.2% in the intervention group smoked and 70.8% in the control group smoked.

The success of this low-cost telephone intervention with African-American women who typically have rates of preterm and LBW infants double that of Caucasian women in the US, stimulated Moore and her



colleagues to implement a four-pronged community based nurse-intervention

program using telephone contacts to supplement routine prenatal care. This project used the findings from the original research study to adapt a telephone intervention in four distinct community-based programs. The four community settings offered new challenges and opportunities for the implementation of the research into practice. Two of the

programs focused on pregnant women, one with a higher income third-party payor group. The third program focused on telephone mentoring by trained African-American women volunteers (not nurses) who make telephone contacts with pregnant African-American women who register for the program. The fourth program was an application of the model of telephone nurse-care to the parents of children between birth and five years of age.

Nurse initiated telephone care appears to be cost effective and applicable in a variety of settings for different populations needing community-based follow-up care. Moore and her team of researchers will be building on both their original research and their experiences with the community based models to further delineate the effectiveness of a telephone intervention with pregnant military personnel and with follow-up of very LBW infants after discharge.

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• Caregiving at Home for Technologically Dependent Adults

With the changes in health care over the past decade many more adults are going home while still dependent on life-sustaining technologically complex treatments. This move within the health care industry to fewer hospital days has created new challenges to family members as they try to manage not only the physical and emotional care of a family member, but also care procedures of complex technology, trouble shooting equipment, maintaining inventory supplies, prevention of complications, and assessing signs and symptoms of improving or deteriorating conditions. Examples of the more common home care technologies that families can face include parenteral nutrition, epidural infusions, mechanical ventilation, apnea and cardiac monitors, chemotherapy, dialysis, and fetal monitoring. While a significant amount of research has been conducted on family caregiving for the cognitively impaired and the frail elderly and even for the terminally ill individual at home, these models provide little direction for the caregiving of technologically dependent adults who are mentally competent and participate in their own life-sustaining home care.

Carol Smith and her research team have addressed this very important question of caregiving effectiveness with technologically dependent adults at home. Dr. Smith's goal is to develop a model of caregiving effectiveness that identifies factors that influence outcomes in order to guide population-based community nursing practice and support family caregiving for these patients. The outcomes of interest are not only patient focused, but also include quality of life indicators for the caregiver.



In testing their caregiving effectiveness model the team has done research with patients dependent on ventilators at home and with families managing home parenteral nutrition. As a result of these studies Dr. Smith has presented data to the National Academy of Science on Safety of Home Technical Care and this report became the basis for FDA rules/regulations for improvement in home mechanical equipment safety and human factors features, as well as education for laymen's use in the home. The results of this work have also been reported to the Health Care Financing Administration on

protecting the most vulnerable from Medicaid/HMO-managed care shortfalls.

Each technology that ends up in home care requires different technology expertise, different complications to assess and different ways to manage the care. In addition, each family situation is different in terms of resources and relationships. There are, however, major themes that appear to consistently predict more positive outcomes. The factors that Dr. Smith and her team have identified that are important



to positive outcomes include the relationship between caregiver and patient, caregiver preparedness to manage home care, efficient management of resources, and caregiver characteristics such as levels of distress or depression. The outcomes of the model are patient and caregiver quality of life, the physical condition of the patient and the side effects of the technology. The caregiver effectiveness model, while complex is an excellent example of how a theoretical application of an empirically based model can focus interventions to improve outcomes.

Three examples of population-focused interventions for technologically dependent adults provide support to the usefulness of this model of caregiver effectiveness. The first is the development of an infection prevention intervention for caregivers to use with patients on total parenteral nutrition that focused primarily on teaching aseptic technique and good hand washing procedures. Results demonstrated a lowering of catheter-related infections and reduced hospitalizations. This slide shows the number of catheter-related infections in the experimental and control groups at both 6 months and 18 months. Equally impressive are the lower cumulative incidence of hospitalizations for sepsis in the experimental group as compared to the control. This intervention is now in a self-guided format kit and is used by the Oley Foundation, a national patient/family advocacy group. The Caring for Your Vascular Catheter Video was awarded the Aurora Instructional Award and in independent evaluation was shown to decrease nurse provided teaching time and the length of hospital

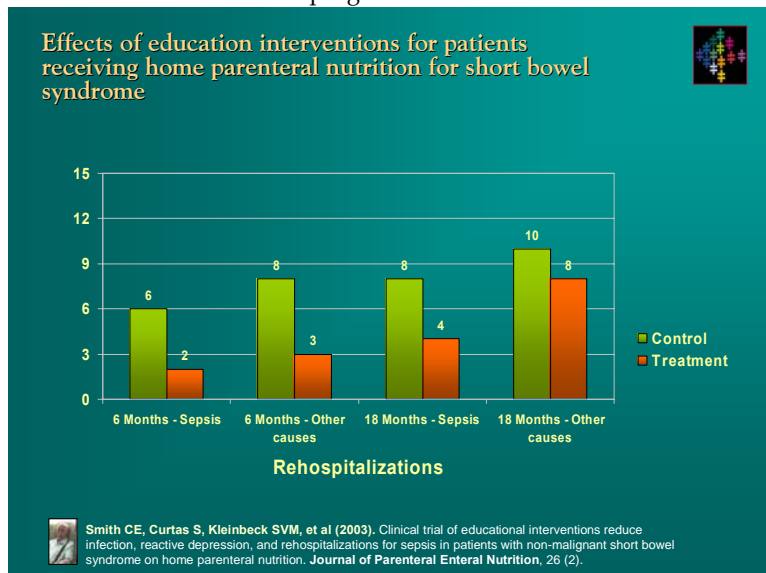
stay. A self-guided kit with handwashing audiotapes has also been adopted for use by the Kansas State Health Department for use in schools, public services and restaurants and has been translated into numerous languages and used by medical missions in six countries to teach hand washing techniques. It is amazing with the general recognition of the effectiveness of good hand washing, that it took a home-based intervention for parenteral nutrition patients to establish an effective and easy-to-use intervention for use in the public service domain.

A second, and creative intervention tested by this group of investigators was a method for combating reactive depression in the caregivers. The intervention consists of a video tape illustrating the common negative emotions and methods to manage these emotions and the use of a self-monitoring depression diary that appears to be therapeutic in combating depression in the caregivers. The materials for the depression prevention have been published in Mosby's Home Teaching Guides (1999) and in journals for other chronically ill patients and their families.

Dr. Smith and her team are now involved in testing the usefulness of using in-home telehealth and internet-based systems for education of caregivers and patients, and for providing peer and professional support for home care. Both telehealth and internet access hold great promise for families in rural and hard to reach populations thorough-out the country. Families have positively evaluated the internet problem-solving algorithms and support systems (e-mail contact to others) for managing everyday technology home care problems provided for them on-line in these studies.

Adding another type of technology (computers) for use by these families is a barrier to overcome, but it opens avenues for interventions never available to families before. If such technology is effective, it will be more cost effective than home visits and certainly more frequent in terms of contacts and oversight. Telehealth and "Virtual Nursing Care" via the internet would not only result in reduced costs for both patients and insurers, but could also help address some of the nursing shortage problems.

This program of research focused on



home care of technologically dependent adults is opening new horizons on nursing interventions for family education products and patient and family support systems that are applicable to a wide variety of populations well beyond the technologically dependent home care patients and families.

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SUMMARY

These NINR-funded projects outline the range of findings being implemented by nurses into practice in a variety of patient care settings.

Transferring clinical research into clinical practice. Only a small percentage of NINR-funded research can be called basic or bench research. Most of our investigators have a clinical background, and their findings relate directly to the clinical setting in which the research was conducted. However, problems arise with the adoption of new interventions, procedures, and techniques by nurses and other health care providers that may differ from their usual practice.

First of all, there is a natural reluctance to change the way things are already done. Second, the results of published research often do not get from the academic journals to the practicing health care provider. Finally, in cases where current nursing or medical practice is questioned, there may be resistance to change, and to doubt the validity or generalizability of the results.

Changing practice. Two things stand out as we examine the usefulness and the application of our research into practice. First, nurse scientists need to find effective ways to reach patients directly and educate

them about important research findings. Patients and families are often very receptive to new ideas and alternative methods. Some investigators have developed web sites targeted to specific populations, and they maintain an active communication with the patients and families who access their site. This takes time and money, but it provides a window that we need to take advantage of in our efforts to improve the health of the public.

Second, nurse scientists tend to publish exclusively within the arena of refereed, professional journals, since those publications favor them in tenure and promotion decisions in their academic institutions. However, there is a clear need to disseminate our significant findings outside the usual scientific journals and to publish more of our work in the lay media. How can we accomplish this? Perhaps nursing schools, colleges, and professional organizations need to hire writers able to translate the findings of nursing research into meaningful articles for the general public. Making our research more accessible to the public will better serve our patients and their families. In addition, increased media coverage would serve to further the status and credibility of nursing research, as we strive to show that our professional knowledge can and does make a difference in the health of people.

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