

LETTERS TO THE EDITOR

Article About Palliative Care Omitted Important Information

I am responding to an article by Anne M. Reb, MS, NP, titled "Palliative and End-of-Life Care: Policy Analysis," in the January/February 2003 issue (Vol. 30, pp. 35–50). Although the author provided readers with a comprehensive overview of the important issues in palliative care and related legislation on Capitol Hill, she excluded important information in several areas within her article.

Despite the paradigm shift that does not differentiate palliative care from end-of-life care (Davis, Walsh, LeGrand, & Lagman, 2003; Sepulveda, Marlin, Yoshida, & Ullrich, 2002), the author distinguished the two. She provided readers with the latest data from *Means to a Better End: A Report on Dying in America Today* (Last Acts, 2002), yet she excluded the revised and broadened definition of palliative care from the World Health Organization (Sepulveda et al.; World Health Organization, 2002). This definition promotes integration of palliative care earlier in the course of illness. Earlier integration of palliative interventions is widely recognized as a way to promote coordination and continuity of care and falls into the management of the disease itself (Davis et al.; Sepulveda et al.).

Reb described the lack of reimbursement structures as a barrier to palliative care. However, as experts in the field address earlier palliative interventions, reimbursement for these efforts can be captured under traditional and existing reimbursement coding (Promoting Excellence in End-of-Life Care, 2003; von Gunten, Ferris, Kirschner, & Emanuel, 2000). Reb asserted that Medicare and Medicaid reimburse advanced practice nurses (APNs) 70%–80%. However, Medicare is the federal mandate for reimbursement fee structures for APNs regardless of state-specific practice acts. The Balanced Budget Act of 1997 was amended in 1999 to provide Medicare Part B reimbursement to APNs at 85% of what physicians receive for services in the *Physician Fee Schedule* (Buppert, 1999; Federal Register, 1998). State-specific practice acts determine the extent to which APNs can receive Medicaid reimbursement, if at all (Kuebler & Berry, 2002).

Reb described that most palliative-care experts have focused research on the hospice model of home care despite the fact that the majority of deaths occur in the acute-care setting. Palliative-care colleagues from acute-care settings such as the Cleveland Clinic, a World Health Organization demonstration project, have contributed extensively to palliative-care research, as well as colleagues from Mt. Sinai Medical Center in New York, NY; the University of Michigan in Ann Arbor; Case Western Reserve University in

Cleveland, OH; the U.S. Department of Veterans Affairs (Promoting Excellence in End-of-Life Care, 2003); the University of Texas M.D. Anderson Cancer Center in Houston; and Beth Israel Medical Center in New York to name a few.

The author discussed the Community-State Partnerships to Improve End-of-Life Care in two separate areas as an exception to the rule. Yet the Robert Wood Johnson Foundation has awarded \$11.25 million to 21 broad-based, multidisciplinary coalitions working to promote policy change and quality comprehensive palliative care (Midwest Bioethics Center, n.d.). The Michigan Governor's Commission on End-of-Life Care worked in tandem with the Michigan State Partnership to address important issues, not separately as pointed out in the article. Reb identified two graduate-level nursing programs offering palliative education, but she failed to mention the initiative funded by the Michigan Department of Community Health, which produced and disseminated graduate palliative nursing self-training educational materials and piloted them at six universities. The Michigan Nurses Association currently is offering continuing education credits for this material (Kuebler & Moore, 2002).

Although Reb described a weak link to formalized standards in palliative care, nothing was mentioned about the work under way by the Center to Advance Palliative Care. National experts have been recruited and are participating in a National Consensus Project for Quality Palliative Care: Essential Elements and Best Practice. These guidelines and standards, which are under development, will help promote competent palliative practices, regardless of specialty, for all patients.

Although Reb attempted to discuss favorable legislative initiatives pertinent to influencing palliative-care practices in the United States, I would like to note that despite the 22 bills that were introduced in the 107th Congress to address end-of-life or palliative practice, the only bill that achieved successful support and became law was the Nurse Reinvestment Act. Of the 22 bills, only 7 received slightly more than 10% cosponsorship (Goldstein & Lynn, 2002). The current legislative state of affairs, as it relates to changes in palliative practices in the United States, is anything but favorable. As Goldstein and Lynn wrote, "At this time, only a few bills have come before Congress attempting to improve care at the end of life; those do not have substantial action, and they do not reflect any coherent view of needed reforms. This is a prescription for inertia in public policy" (pp. 825–826). Tremendous efforts are under way, as pointed out by Goldstein and Lynn, but much work is required to ensure legislative support and continuity of care.

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The Author Responds

Kuebler reviewed issues in a number of areas, including (a) language/practice, (b) reimbursement, (c) education/health systems research, (d) quality and standards, and (e) legislation. I will address the issues raised in each of these areas.

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Kuebler describes a paradigm shift that does not differentiate palliative from end-of-life (EOL) care. This discussion raises language and health system issues. The World Health Organization (WHO) recently broadened its definition of palliative care by calling for its integration in the early stages of chronic and eventually fatal illnesses (Sepulveda, Marlin, Yoshida, & Ullrich, 2002). This definition is consistent with my emphasis on the goal of integrating palliative care throughout the course of illness. Davis Walsh, LeGrand, and Lagman (2002) presented a cogent argument for using the phrase "palliative care" rather than "EOL care." These authors asserted that EOL care implies time-defined care that does not recognize the complex skills of palliative medicine. They wrote that use of this phrase may promote a discontinuous care model rather than a collaborative model with earlier referral for palliative services. Part of the problem is that current practice is influenced by definitions that are used for reimbursement (R. Donley, personal communication, March 18, 2003). By current definition, eligibility for hospice services generally is restricted to those with an estimated life expectancy of six months or less. Thus, hospice is restricted to care provided at the EOL based on language in the law. Therefore, language and definitions have important implications for practice.

If language and definitions change, the regulations and laws may need to change. It may be challenging to change thoughts and attitudes to incorporate language that better reflects the goals of palliative care because current systems and payment mechanisms promote episodic care rather than a coordinated approach that better reflects the needs of this population. Our healthcare system is based on a curative model of care (Medicare Payment Advisory Commission [MEDPAC], 1999). Because palliative care generally is perceived as supportive rather than curative, it has not historically been well integrated into reimbursement frameworks (R. Donley, personal communication, March 18, 2003). However, Introcaso and Lynn (2002) noted that "all of us must dismiss the belief that one can distinguish curative from palliative care, or that patients transition from one modality to the other" (p. 255). With advances in medical care, distinctions between palliative and life-extending treatments are blurred (Beresford, Byock, & Twohig, 2002). In addition, prognosis is not reliable as a factor in making palliative services available because it often is uncertain even at the EOL (Introcaso & Lynn). Opportunities may exist to revise language in a manner that better captures the goals of palliative care if key leaders and policy experts work together in these efforts. Changes in health systems and reimbursement policies are needed to advance this goal.

Kuebler's comments regarding reimbursement are important because this is a key area in need of reform. Introducing palliative care

earlier in the course of illness, along with concurrent treatment to prolong life, is associated with controlling costs (Beresford et al., 2002). Various studies have documented cost savings with systems that promote coordinated care (Grant, Ferrell, Rivera, & Lee, 1995; Smith, 2000). Recent demonstration projects have described the feasibility of providing concurrent palliative care along with disease-modifying treatments for patients with chronic advanced illnesses (Beresford et al.). Results show trends toward improved access, quality of care, and cost savings, including decreased hospitalizations. Despite these advances, many of these projects may not be financially sustainable because of barriers in existing reimbursement structures. Programs in fee-for-service settings, such as traditional Medicare, are especially vulnerable.

The Medicare system provides health insurance for the majority of older Americans who face chronic or life-threatening illnesses. The services that beneficiaries receive depend on the sites where care is given. In general, this system provides incentives for discrete delivery of services rather than for continuity of care over the course of an illness (Beresford et al., 2002; Lynn, Wilkinson, & Etheredge, 2001; MEDPAC, 2002). The Medicare home healthcare benefit does not promote comprehensive coordinated care. For example, bereavement counseling and most oral prescription drugs are not covered outside the hospice benefit (Moon & Boccuti, 2002). In addition, payment for home healthcare services is insufficient to meet palliative-care needs (Smits, Furletti, & Vladeck, 2002).

Although reimbursement for earlier interventions in palliative care can be captured under existing billing codes, barriers limit access to services in many settings. Experts in the field have commented on barriers such as payment regulations for services provided to hospitalized patients (von Gunten, Ferris, D'Antuono, & Emanuel, 2002). For example, reimbursement for services of the interdisciplinary team is limited before a patient enters hospice (J. Ingham, personal communication, March 26, 2003). Palliative-care specialists frequently use evaluation and management (E/M) codes for billing Medicare or various other insurers (Moss, 2001; von Gunten, Ferris, Kirschner, & Emanuel, 2000). However, the current E/M codes do not reflect the complexity of the population served. Furthermore, much time is spent in case-management activities. Although billing codes address these services, these codes may not be paid or are undervalued in the Medicare Fee Schedule (von Gunten et al., 2002). Despite these mechanisms, denial of payments for palliative services for hospitalized patients has been reported (Smits et al., 2002; von Gunten et al., 2002). Medicare reform is needed to facilitate better payment for services and continuity of care (Goldstein & Lynn, 2002; MEDPAC, 2002; von Gunten et al., 2002). Creative models for organizing and reimbursing palliative

care are being addressed through various initiatives, including health systems research.

Kuebler commented on various education and research initiatives. I was pleased to read her comments about the pilot programs incorporating palliative-care education in six graduate nursing programs (Kuebler & Moore, 2002). The incorporation of palliative care in nursing education represents an important advance and reflects the ongoing efforts of nursing leaders. The nurses involved in the development of the EOL Nursing Education Consortium deserve special recognition for their work in this area.

Palliative-care research falls into several realms, such as symptom mechanisms, interventions, epidemiology, methodology, health services research, and others. Early symptom management and health services research are based on the hospice model. In fact, "Hospice programs have been the primary drivers of improved end-of-life care" (Beresford et al., 2002) and have focused attention on the need for system improvements (von Gunten et al., 2002). Kuebler highlighted a number of creative models and ongoing research currently being explored by leading hospitals and federal and private organizations. Although several innovative demonstration projects have shown beneficial results, such initiatives have not been adequately integrated into national health systems and policies overall (Sepulveda et al., 2002). Further research and large-scale demonstration projects are needed in various areas. Research has shown that quality-improvement initiatives are important for reform and have resulted in improvements in healthcare delivery for the chronically ill (Introcaso & Lynn, 2002). In addition, the development of measures of quality will provide important contributions to education, evidence-based practice, and research.

The development of measures of quality and standards in palliative care is important to document outcomes and evaluate the quality of services. Palliative care is one of the priority areas of the WHO Program on Cancer Control (Sepulveda et al., 2002). In addition, the Institute of Medicine (IOM) recently identified EOL/palliative care as a priority area for improvement in the quality of health care across the lifespan (Adams & Corrigan, 2002). The IOM committee recommended that the Agency for Healthcare Research and Quality develop measurement systems and measures of quality to assess progress in various priority areas.

Various multidisciplinary leaders are working on a National Consensus Project (NCP) for Quality Palliative Care (2003). I described this project under the "Standards" section of the article (p. 39). The goal of the NCP is to develop elements of best practices that may serve as norms for clinical palliative-care programs. Although the Center to Advance Palliative Care (CAPC) organized the initial meeting, the NCP currently re-

ceives funding and support from various sources (C. Sieger, personal communication, February 24, 2003). Five organizations have provided leadership in advancing this initiative: the National Hospice and Palliative Care Organization, the American Academy for Hospice and Palliative Medicine, CAPC, the Hospice and Palliative Nurses Association, and the Partnership for Caring (M. Meyer, personal communication, February 25, 2003). The development of standards will provide benchmarks for various programs and initiatives.

Palliative care has received increased attention in recent federal and state legislation, as well as recognition based on many innovative initiatives. Although progress is being made, palliative care is not yet recognized as a priority in U.S. healthcare policy. In a recent article discussing the 107th Congress legislative proposals, Goldstein and Lynn (2002) noted that healthcare reforms for the care of people with chronic, progressive illnesses are not a main concern of advocates and legislators. Despite the fact that various palliative-care bills were introduced in the 107th Congress, these bills did not see substantial legislative action. Furthermore, most bills lacked adequate numbers of sponsors (Goldstein & Lynn; Lynn, 2002; Reb, 2003). Although the Nurse Reinvestment Act (NRA) was not specifically focused on palliative care, its passage by the 107th Congress represents an important advance because of implications regarding access to care.

The NRA authorized programs to address the nursing shortage by promoting nursing recruitment and retention (Donley et al., 2002). The law also calls for funding for geriatric training programs for nurses, with priority given to practice arrangements in medically underserved communities. Partial funding was allocated for the NRA in February 2003. The American Nurses Association (2002) and various other organizations demonstrated great leadership in addressing the shortage and advancing this legislation. The law should help to improve access to care in various settings, including palliative care. Nonetheless, policy and health system reforms are needed on many levels to promote an integrated approach to palliative care.

The increased emphasis on legislative, research, and educational initiatives, as well as positive findings from recent demonstration programs, likely will lead to future reform. However, the current situation is not consistent with an integrated approach to palliative care in many settings. Healthcare leaders and key legislators have worked diligently to advance the palliative-care agenda in a climate where other political priorities dominate, such as the economy and homeland security. The key will be to continue to strive for agenda status in a more coordinated manner, to maintain this agenda, and to convince legislators, health professionals, and advocates to work

together to prioritize improvements (Goldstein & Lynn, 2002; Jones, 1984).

I appreciate the comments from the various healthcare and policy leaders and reviewers who contributed to "Palliative and End-of-Life Care: A Policy Analysis," as well as the comments and updates on the published article. The article presented an overview of policy issues using a framework of access, cost, and quality. Selected issues were addressed, with an emphasis on nursing contributions and applications to practice. As a final note, Goldstein and Lynn (2002) emphasized the importance of increasing the voices that speak for policy reforms to improve care for those with serious, chronic illnesses. Healthcare professionals, various organizations, and advocacy groups should convene to promote a strong agenda and prioritize major issues in this area (Goldstein and Lynn).

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Hospice Role Validated in Article

Never have I read such a concise article that describes all of the frustrations we in hospice face ("Palliative and End-of-Life Care: Policy Analysis," January/February 2003 issue, Vol. 30, pp. 35-50). I felt so validated after reading it because my role is that of hospice liaison at Dana-Farber Cancer Institute in Boston, MA.

My previous work was in hospice as a long-term care manager trying to advocate for patients in skilled nursing facilities who were dying without proper pain management or support. I could go on forever. However, I feel as though I am preaching to the choir. Kudos to you, and thank you.

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Outcomes of Two Antiemetic Therapies Are the Same

I read with interest "Antiemetic Therapy in Patients Receiving Cancer Chemotherapy" by Cassandra Marek, RN, BSN, OCN[®], in the March/April 2003 issue (Vol. 30, pp. 259–269). However, two specific statements made in the article must be challenged. Marek wrote, "Some researchers suggested that the frequency of N&V [nausea and vomiting] is not significantly reduced by serotonin receptor antagonists" (p. 262). The reference provided in the text to support this statement deals with the topic of anticipatory emesis. In fact, it is important to very clearly state that the serotonin receptor antagonists have been a *truly major advancement in the prevention of chemotherapy-induced emesis*. Clinicians, both physicians and nurses, who were involved in the care of patients receiving cisplatin-based chemotherapy prior to the introduction of this class of pharmaceutical agents—and the patients who were forced to tolerate both the nausea and vomiting induced by this antineoplastic drug and the side effects associated with the antiemetic therapy (e.g., high-dose metoclopramide)—fully appreciate this statement.

Second, Marek wrote that "Researchers suggest that granisetron may be the most effective for the prevention of acute N&V caused by moderately or highly emetogenic chemotherapy" (p. 265). To support this statement, she cited an article describing a study that did not compare the different serotonin receptor antagonists but only examined the benefits associated with adding alprazolam to granisetron. In fact, granisetron is an excellent drug, but essentially all of the available data from randomized trials clearly reveal that at comparable dose levels, the commercially available serotonin receptor antagonists (when administered with corticosteroids) are equivalent in efficacy. It is certainly appropriate for oncologists to select a specific serotonin receptor antagonist to employ in their practice based on their personal experiences, individual choices, and costs, but this decision cannot be based on the demonstrated clinical superiority of one agent over another. The results of the two randomized studies noted by Marek, which directly compared granisetron to ondansetron, emphasized this important point.

The researchers found no difference in the outcomes of patients treated with the two serotonin receptor antagonists.

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Note. Dr. Markman is the recipient of a research grant from GlaxoSmithKline, based in Research Triangle Park, NC, which manufactures ondansetron (Zofran[®]).

The Author Responds

Thank you for your careful and critical reading of my review of antiemetic therapy for patients who are receiving cancer chemotherapy. As we both agree, management of this common side effect of chemotherapy is extremely important to improve patients' quality of life and enable them to tolerate potentially life-saving treatment.

Your point that the use of serotonin receptor antagonists for chemotherapy-induced nausea and vomiting (CINV) is well taken and is supported in the article. The fact that the use of these agents almost doubled within the first four years after their introduction in the United States, from about 50% of patients receiving chemotherapy to more than 90%, illustrates just how valuable patients and clinicians find them. Even so, researchers (Anastasia, 2000; Eckert, 2001) have not yet demonstrated that the use of serotonin receptor antagonists significantly reduces the *frequency* of CINV; their major impact has been the reduction of the *severity* of CINV to levels that are tolerable for patients. Even though patients may report sensations of nausea and episodes of vomiting while on chemotherapy and despite the use of antiemetic medications, these symptoms are less severe and, therefore, have a significantly reduced negative impact.

Your second point regarding the comparison of granisetron and other serotonin receptor antagonists requires a careful examination of the studies cited in the article (Anastasia, 2000; Bauduer, 1999; Gralla et al., 1998; Perez et al., 1998). Few researchers have conducted side-by-side comparisons of granisetron (Kytrel[®], Roche Pharmaceuticals, Nutley, NJ) and ondansetron (Zofran[®], GlaxoSmithKline, Research Triangle Park, NC). When such studies were conducted, they found little difference between the two drugs in efficacy. However, other factors may make granisetron slightly more valuable in the clinical treatment of CINV.

First, as mentioned in the article, researchers have found ondansetron to be effective for use with *moderately* emetogenic chemotherapy agents; granisetron, on the other hand, is recommended for use with *moderately to highly* emetogenic agents. Although side-effect profiles for both drugs are similar, ondansetron has been associated with changes in cardiac rhythms, but granisetron has not. These two medications have compa-

rable mechanisms of actions, but they are not precisely equivalent.

Second, consider dosing schedules: Although this issue may be of less interest to clinicians than the overall efficacy of a medication, convenience is a very important consideration for patients. Ondansetron requires that a dose be given 30 minutes before the start of chemotherapy, then at four hours and eight hours after administration of chemotherapy. These are followed by further doses three times each day for another 24–48 hours. Granisetron, similarly, requires a dose 30–60 minutes prior to chemotherapy; thereafter, however, dosing is required only once 12 hours after the chemotherapy is completed. Although these may not seem like significant differences, patients who are experiencing other side effects of chemotherapy (e.g., fatigue, diarrhea) or who have symptoms of the cancer disease process (e.g., dysphagia, pain) appreciate the opportunity to take fewer medications. Simplified medication administration regimens improve compliance and help patients take an active part in their treatment.

I appreciate the opportunity to emphasize perhaps the most important consideration for antiemetic therapy: patients. Patients' chemotherapy treatment plans, ability to tolerate the therapy, and capacity to participate in treatment all must be considered when determining the most appropriate type of antiemetic therapy.

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Evidence Needed of the Value of Oncology Nurse Practitioners

A scant amount of literature is available on the role of oncology nurse practitioners.

Evidence of multidisciplinary collaboration, patient satisfaction, quality of care, and the valuable, holistic role that advanced practice nurses play in this specialty area of health care should be documented. Evidence of cost-effectiveness combined with high-quality care can be of great benefit as nurse practitioners battle to obtain full reimbursement for services.

An abundant amount of information has been published confirming that the quality of care provided by nurse practitioners is equal to that of physicians. In January 2002, the *Journal of the American Medical Association* published results of a randomized trial that showed that patient outcomes were comparable for patients managed by nurse practitioners and those managed by primary care physicians (Mundinger et al., 2000). This sentiment was confirmed more recently by Horrocks, Anderson, and Salisbury (2002) in the article "Systematic Review of Whether Nurse Practitioners Working in Primary Care Can Provide Equivalent Care to Doctors." Many additional studies have confirmed that patient satisfaction with nurse practitioners is equal to or better than satisfaction with physicians (Bryant & Graham, 2002; Cooper, Lindsay, Kinn, & Swann, 2002; Pinkerton & Bush, 2000).

A collaborative role seems to be the best model of practice for oncology nurse practitioners. Kelvin and Moore-Higgs (1999) reported results of the first descriptive study of nonphysician practitioners in radiation oncology. Their report, titled "Description of the Role of Nonphysician Practitioners in Radiation Oncology," concluded that physician assistants, clinical nurse specialists, and nurse practitioners work collaboratively with physicians and do not compete with them. Druss, Marcus, Olfson, Tanielian, and Pincus (2003) reported in the *New England Journal of Medicine* a trend from 1987–1997 of an increase in collaboration between physician and nonphysician providers. Kinney, Hawkins, and Hudman (1997) reported physicians to be more facilitative of the oncology nurse practitioner role than administrators. Oncology certified nurses should endeavor to conduct more research that describes not only the role that nurse practitioners play in oncology but also its advantages to patients, physicians, and healthcare costs.

In the January/February 2003 issue of the *Oncology Nursing Forum*, the article "The Advanced Practice Nurse in Research: From Hospital Discharge to Home" (Vol. 30, pp. 27–28) (Monturo, 2003) is an excellent example of the type of studies that need to be conducted. The author is to be commended for highlighting the role that nurse practitioners play in oncology research. Monturo confirmed previous research indicating that specialized advanced practice nurses have a positive impact on patient outcomes as evidenced by effects such as decreased healthcare costs and delayed readmissions. More

published data of this sort and more randomized studies specific to oncology practice, as have been done with nurse practitioners in the primary care setting, would help to persuade employers, physicians, and healthcare policy regulatory agencies of the value of nurse practitioners in this rapidly growing and complex specialty area.

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Wanted: Documents Related to History of Cancer Nursing

I am a nurse researcher studying the history of nursing patients with cancer from 1880–1950. I am in the process of visiting archival collections throughout the United States, but, unfortunately, few records have been saved that are related to this type of nursing care. However, after casual discussion of my research with friends and colleagues, I have been given access to some privately owned documents related to cancer care during this period. This led me to wonder whether other such records exist that I could review.

I am writing to alert your readers to my historical research. A reader could own or be aware of some original material related to nursing and cancer during this early period. Possibly a distant great-aunt or a great-grandmother was a nurse and kept her nursing school notebooks that contain a reference to cancer nursing. Perhaps one of your readers owns a journal kept by a relative who experienced cancer around the turn of the century. Any information from your readers regarding such primary sources would be appreciated greatly. Please reply to Brigid Lusk, 1240 Normal Road, DeKalb, IL 60115. Call 815-753-0663 or e-mail blusk@niu.edu.

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Call for Short Nursing Stories

I am inviting nurses to participate in a book about the contribution of nurses to a special patient or situation. The book will be a trade publication for the general public. I am interested in all kinds of short stories about people from all ages and diagnoses, including death and dying experiences. This is an opportunity to let colleagues and the general public know what miracles nurses perform every day as we care for patients and influence healthcare decisions.

The short stories can be happy, sad, funny, or serious. I am looking for stories from childbirth through the end of life. Also, stories about special groups, such as prisoners, emergency situations, war, and schools, are sought, as well as instances of influencing public policy. Examples of wellness and health promotion also would be welcomed. Nurses are everywhere doing big and small things for people. We need to share these stories with the public.

The stories can be written by nurses or patients. They can be written in the first or third person. You can use real names or be anonymous. All authors will be credited in the book and will have editorial review of the final copy. Our publisher is Slack, Inc. We are seeking to publish early in 2005, so we need your stories by September 1, 2003. Send stories of approximately 1,000 words to Pat Winstead-Fry, RN, PhD, 2708 Herrick Brook Road, Pawlet, VT 05761. Fax them to 603-917-8401, e-mail to healer@together.net and ordinarymiraclesinnursing@comcast.net, or send a disc with the story in Microsoft® Word. Thank you.

*Pat Winstead-Fry, RN, PhD
Deborah R. Labovitz, PhD, OTR/L, FAOTA*