

Quality of Life Matters

End-of-Life Care News and Clinical Findings for Healthcare Professionals



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Physicians Urged to Serve As 'Advocates and Guides' for Patients in Their Final Years and Months

Expert stresses importance of estimating prognosis for all elderly patients

With the aging of the nation's population, clinicians are increasingly likely to find themselves faced with the challenge of planning for the final phases of an older patient's life. A geriatrics expert has outlined what physicians can do today, through the coming months, and perhaps years, to guide and help older patients achieve the best quality of life now and as they near the end of life.

"In many respects, you can never address the issue of advance care planning too early," says David B. Reuben,

MD, author of an article published in the *Journal of the American Medical Association*, as part of its new series entitled, "Care of the Aging Patient: From Evidence to Action."

Using the case of Mr. Z, an 83-year-old man who is the sole caregiver for his wife with Alzheimer's disease and is himself recovering from fall-related injuries, Reuben presents a prognosis-guided approach for addressing short-term, midrange, and long-term issues confronting these patients.

"The approach should begin with an assessment of life expectancy and incorporation of evidence-based care whenever possible," writes Reuben. Care plans, based on patient goals and preferences, will need to be periodically reassessed, as older patients face physical decline, advanced illness, and death.

"Determination of prognosis provides the context for clinical and personal choices that differ in their consequences and timing," write the authors of an accompanying editorial. "Although the wisdom of this approach is understood by patients who have lived through the deaths of friends and family, clinical decisions often fail to incorporate this information."

PHYSICIAN INVOLVEMENT WITH HOSPICE IS RECOMMENDED

Although the short- and mid-range goals for a relatively robust patient such as Mr. Z are to help him remain independent, at

home, and in his community as he becomes frailer, his physician will inevitably be required to help him receive his desired care at the end of life.

Reuben suggests that physicians get to know the team caring for patients they refer to a local hospice, regardless of whether they decide to follow the patients themselves or to allow the hospice physician to be the physician of record. **"I always like to follow my patients through hospice,"** says Reuben. **"For me, it's very gratifying to see them through the final chapter of their lives."**

In conclusion, Reuben writes, "Mr. Z will need a physician who will serve as his advocate and guide as he confronts the medical and social issues of the last years of his life. Anything less is unlikely to meet his current and future needs." Reuben is chief of the Division of Geriatrics, UCLA School of Medicine, Los Angeles.

*Source: "Medical Care for the Final Years of Life: 'When You're 83, It's Not Going to Be 20 Years,'" Journal of the American Medical Association; December 23/30, 2009; 302(24):2686-2694. Reuben DB; Department of Medicine, Division of Geriatrics, David Geffen School of Medicine at the University of California, Los Angeles. "Clinical Care in the Aging Century — Announcing 'Care of the Aging Patient: From Evidence to Action,'" *ibid.*; pp. 2703-2704. Landefeld CS, Winker MA, Chernof B; Division of Geriatrics, University of California, San Francisco, and San Francisco VA Medical Center. "Author in the Room" Teleconference, Journal of the American Medical Association and Institute for Healthcare Improvement; February 2010. Accessed at <http://jama.ama-assn.org/authorintheroom/authorindex.dtl>.*

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Inpatient Palliative Care Promotes Greater Use of Follow-Up Services and Earlier Hospice Referral

Involvement of a palliative care team (PCT) during hospitalization of seriously ill patients may improve the quality of care not only during their stay, but also following discharge, a team of University of California, San Francisco, researchers has found.

“Inpatient palliative care teams’ contribution to improved quality of life and patient satisfaction, as well as decreased utilization and costs, has been well established,” write the authors of a report published in a recent issue of the *Journal of Palliative Medicine*.

“This study found that patients who received an inpatient PCT consultation were associated with a greater likelihood of receiving formal follow-up services upon discharge, particularly hospice care services,” the authors report. **“PCT patients were also referred to hospice earlier in their disease trajectory, rather than in the last few weeks of life.”**

In what the authors designate the first study of its kind, the team analyzed data on two individually matched cohorts (PCT group and usual care [UC] group). Each group consisted of 361 adult, acute-care patients (mean age, 69 years; Caucasian race, 69%) admitted to one of three campuses of a large, urban, nonprofit hospital in the San Francisco area from July 2004 to December 2006.

Using data from the hospital’s administrative database and the Social Security Death Index, and controlling for multiple factors, the team determined the impact of PCT consultation on the discharge disposition of patients.

Beneficial Qualities of a Palliative Care Team in the Inpatient Setting May Include:

- Greater expertise in recognizing the severity of illness at an earlier stage
- Better ability to assess and anticipate each patient’s individual discharge needs
- More skill in discussing discharge plans with patients and/or family members
- Greater awareness of the types and availability of follow-up services in the community

— Adapted from Brody et al, *Journal of Palliative Medicine*

COMPARED WITH THOSE RECEIVING USUAL CARE, SERIOUSLY ILL PATIENTS SEEN BY THE PALLIATIVE CARE TEAM WERE:

- 3.24 times as likely to be discharged to hospice
- 1.59 times as likely to be discharged home with home health services
- 1.52 times as likely to be discharged to a skilled nursing facility

Among patients discharged with follow-up health services who died within 30 days, PCT patients were 17.03 times more likely than UC patients to be discharged to hospice.

“Discharge disposition, particularly to hospice (whether at home or in a facility) or home health care, has been shown to decrease patient rehospitalization and utilization rates,” comment the authors.

OVERALL FINDINGS INCLUDE:

- Median survival among all patients was 97 days.
- Among patients who died within 31 to 90 days of discharge, 46.2% of patients seen by a PCT were discharged to hospice, compared with only 2.8% of UC patients.
- Nearly half of patients receiving UC were discharged home without any type of follow-up health services, compared with one-fifth of PCT patients (46% vs 20.2%).
- Among patients discharged home, seven times as many PCT patients were admitted to hospice than were UC patients (17.8% vs 2.5%).
- Of those discharged to a facility, five times as many PCT patients as UC patients entered a hospice facility (9.1% vs 1.7%).

While further study is needed to better understand and confirm the impact of PCT on discharge disposition, “it is clear that PCTs promote earlier referrals to hospice,” the investigators conclude. “Better referral to appropriate services on discharge represents another benefit of inpatient PCT consultation, and adds to the rationale for improved end-of-life policy and reimbursement.”

Source: “The Effects of an Inpatient Palliative Care Team on Discharge Disposition,” *Journal of Palliative Medicine*; May 2010; 13(5):541-548. Brody AA, Ciemins E, Newman J, Harrington C; Department of Social and Behavioral Sciences; Sutter Health Institute for Research and Education; and School of Nursing, University of California, San Francisco, San Francisco; and Center for Clinical Translational Research, Billings Clinic, Billings, Montana.

Hospice as the Practical — Not Just Philosophical — Option for the Last Months of Life

Physicians offered guide to being the ‘good doctor’ who gets patients the help they need

“The referral of patients to hospice care for their last months of life has moved from a ‘choice’ to the approach that achieves the best outcomes for patients with advanced disease.” With that bold statement, two experts in hospice and palliative medicine introduce their article reviewing the benefits of hospice and offering physicians a practical guide for timely referral.

“Physicians have tended to present the hospice alternative as a philosophic option rather than a truly practical one,” write the authors in a recent issue of *Chest*. “This is understandable, because the services and benefits are still not well understood by many physicians.”

Hospice care has been shown to provide “better outcomes” for patients and families, the authors point out.

PATIENTS IN HOSPICE ARE MORE LIKELY TO:

- Receive better symptom control
- Be provided with more practical support
- Receive more emotional and spiritual support
- Say they feel more respected
- Report their overall care as “excellent,” compared with those not in hospice care

It is important that physicians understand and communicate the value of hospice services in helping patients and families achieve their goals in the last months of life. “**As difficult as it sometimes is for a patient and family to make an informed decision to choose hospice, they often choose it because of its service, not just because there are no other alternatives for care,**” state the authors. Patients and families need to hear that:

- Frequent visits from the hospice care team are standard.
- Practical, hands-on support is provided.
- Information about what to expect and how to handle each step will be given to them.
- Hospice is a Medicare benefit.
- Their own physician can continue to guide their care.

PHYSICIAN BARRIERS TO TIMELY HOSPICE REFERRAL

The optimal time for consolidating the full medical, psychosocial, and spiritual support offered by hospice services is 80 to 90 days, note the authors. Yet, the average length of stay in hospice is two months, with nearly 30% of patients receiving hos-

pice care for less than one week. The authors discuss several possible physician barriers to appropriate timing in hospice referral, countering them with statements from the evidence.

- **Discomfort with introducing the topic of hospice:** “Referring a patient to hospice services may require courageous conversations between the physician and the patient, and a mutual comfort with the fact that doing so often provides the highest-quality end-of-life care.” The authors offer physicians a step-wise approach to “the hospice talk.” [See sidebar.]
- **Viewing the hospice choice as a professional failure:** “Patients and families who are referred for hospice care identify the referring doctor as a ‘good’ doctor for getting them the help they need.” These patients see the progression of their illness as nature taking its course, rather than the “fault” of their physician, studies have shown.
- **Belief that patients may “give up hope” and die more quickly:** “On the contrary, the evidence is that patients who receive hospice care have a better sense of hopefulness and

Continued on Page 4

The Hospice Talk: Steps for Physicians

- Confirm the patient/family understanding of the underlying diagnosis and prognosis. “Tell me what you understand about your illness.” “What are you expecting?”
- Elicit goals. “What are you hoping for in the time you have left?”
- Summarize the patient’s goals, and introduce hospice. “For all my patients at this stage, I recommend hospice.”
- Explain why hospice care would be appropriate. “Hospice helps me take care of people like you and your family when the goals of the medical care are the things you just said you wanted. They take care of you at home; they are my eyes and ears.”
- Offer to contact the local hospice to arrange a meeting. “Let me ask the hospice program to call you. Someone can come out to your home to explain their services.”
- Confirm that you intend to remain involved. “You and I can discuss what they tell you. In my opinion, this is the best care I can give you at this time in your life.”

— Adapted from Moore and von Gunten, *Chest*

RESEARCH MONITOR

Hospice Collaboration Relieves the Burdens of Family ‘Advocacy’ in Nursing Homes

Families often feel the need to advocate for a seriously ill relative in a nursing home, in order to obtain basic information and improve their loved one’s care. A recent study has found that the provision of hospice services can alleviate this family burden at the end of life.

“End-of-life advocacy takes on increased urgency when those close to the dying resident have concerns about basic care and do not understand the dying course,” write the authors of a report published in the *Journal of Palliative Medicine*. “[Our] findings support research that nursing home care improves when hospice-nursing home collaboration is strong.”

A multidisciplinary team of researchers analyzed interview responses of 54 close relatives/friends of residents who spent at least 24 hours of the last month of life in a nursing home. Participants had been part of a previous quantitative national survey on end-of-life care.

The team found it noteworthy that the theme of advocacy, defined as “the perceived need to promote improved care for the dying resident,” emerged so strongly and was mentioned so frequently by participants, since none of the interview questions had specifically targeted this topic.

Families felt that without their watchfulness and persistent advocacy, their loved one would not receive even basic care, and worrisome changes in the patient’s condition were unlikely to be addressed.

BENEFITS OF HOSPICE CARE AS PERCEIVED BY FAMILIES

- Improved symptom relief, and increased emotional support for both patient and family
- Added surveillance of the patient’s condition, in partnership with the family

- Improved communication about the end-of-life process
- Provision of better treatments during end of life

BARRIERS TO HOSPICE CARE

Participants perceived the following as barriers to the effective use of hospice:

- Late or missing referrals
- Lack of information or misinformation about the hospice benefit
- Inadequate collaboration between the nursing home and hospice service

“Overall positive hospice responses suggest the benefit of timely hospice referral,” state the authors. **“Families and nursing home staff need a clear understanding of the hospice benefit, including a better appreciation of timely referral.”**

The authors conclude, “Better collaboration between family members, nursing home and hospice staff can help achieve decent and compassionate care and im-

Nursing Homes Can Improve Care of Dying Residents by:

- Enhancing communication between staff and patients/families
- Improving the preparation of families for the end of life
- Developing a better staff understanding of hospice
- Encouraging and providing support for timely hospice referrals

— Adapted from Shield et al, *Journal of Palliative Medicine*

proved end-of-life care experiences of nursing home residents and their families.”

Source: “Vigilant at the End of Life: Family Advocacy in the Nursing Home,” Journal of Palliative Medicine; May 22, 2010; 13(5):573-579. Shield RR, Wette T, Teno J, et al; Center for Gerontology and Healthcare Research, Department of Community Health, Brown University, Providence, Rhode Island; and Department of Sociology and Criminal Justice Studies, Southern Illinois University, Edwardsville, Illinois.

Hospice As the Practical — Not Just Philosophical — Option for the Last Months of Life (from Page 3)

live longer than those who are not referred.” This improvement is most likely due to the comprehensive and personal benefits of the multidisciplinary approach of hospice, the authors point out.

- **Prognostic uncertainty:** “There is no penalty for referring a patient to hospice care ‘too soon.’” Some patients will live longer than expected. If at each evaluation point, they have in the physician’s best judgment a prognosis of less than six months if the disease runs its normal course, they remain eligible for hospice. Some patients will improve; they can be discharged from hospice for a time and re-enroll when their disease worsens.

“The most frequent complaint hospice programs hear from patients and families is they did not hear about hospice care sooner,” the authors conclude.

Source: “Pulmonary/Critical Care Physicians and Hospice Patients: Billing Specialty Care for Patients Enrolled in a Hospice Program,” Chest; June 2010; 137(6):1427-1431. Moore S and von Gunten CF; Institute for Palliative Medicine at San Diego Hospice, San Diego, California.

Cancer Patients Who Discuss End-of-Life Wishes with Physicians More Likely to Have Preferences Honored

Patients with advanced cancer whose physicians talk to them about their preferences for end-of-life care are 2.26 times as likely as their counterparts to receive care consistent with those preferences. In addition, when patients are aware they are terminally ill — and have discussed their wishes with their physicians — their likelihood of having those wishes honored nearly doubles.

That is according to investigators reporting on their analysis of a subgroup of patients from the Coping with Cancer Study, a multi-institutional cohort study funded by two of the federal National Institutes of Health. Their report appears in the *Journal of Clinical Oncology*.

The preferences of 325 cancer patients with disease refractory to first-line chemotherapy (mean age, 58.8 years; white race, 65%) were assessed in a baseline interview conducted a median of 125 days before death. Within two weeks of the patient's death, a questionnaire concerning patient distress and quality of life was administered to a caregiver (paid health care provider or family member) who had cared for the patient during the last week of life.

OVERALL FINDINGS INCLUDE:

- 68% of patients studied received end-of-life care consistent with their baseline preferences.
- Only 39% of patients knew they were terminally ill.
- Of those who knew they were terminally ill, 74% received care aligned with their wishes.
- 83% of patients who knew they were terminally ill preferred symptom-directed care.
- 13% of those who wished for symptom-

At a Glance

- Patients are more likely to choose symptom-directed care when they understand they are terminally ill.
- The majority of patients who receive life-extending measures in the last week of life have previously expressed a desire to receive symptom-directed care only.

— Adapted from Mack et al, *Journal of Clinical Oncology*

directed care received invasive measures in the last week of life, despite their stated preferences.

“Strikingly, forty-two patients (13%) received life-prolonging care despite a previously stated goal of minimizing suffering,” the authors report. “These patients constituted the majority of patients who received life-prolonging measures.”

The authors continue, “The presence of this group raises concerns that a desire to forgo invasive measures is not always recognized or honored...This pattern of care was associated with greater distress and lower quality of life in the last week of life, a finding that strongly suggests that the primary goal of these patients' care — minimizing suffering — was not met.”

OUTCOMES RELATED TO PHYSICIAN DISCUSSION OF END-OF-LIFE PREFERENCES

- End-of-life discussion with a physician was associated with receipt of desired care (adjusted odds ratio [OR] = 2.26; 95% confidence interval [CI], 1.64-3.11).
- Among those patients aware of their terminal illness, physician discussion was again associated with care consistent

with preferences (OR = 3.94; 95% CI, 1.82-8.51).

- Only 39% of patients had discussed their end-of-life care preferences with their physician.
- Even among those who knew they were terminally ill, just over half (56%) reported having talked to a physician about their wishes.

OUTCOMES RELATED TO LIFE-EXTENDING THERAPY

- The receipt of life-extending therapy was associated with poorer quality of life and increased distress in the last week of life, regardless of patient preference.
- Overall, patients who received life-extending therapy did not live longer than patients who were not given such therapy (159 vs 203 days, respectively).
- Among those patients who had chosen life-extending therapy, length of life did not vary according to whether they received it or not (171 vs 203 days, respectively).

“Our finding that patients who desired symptom-directed care were more likely to receive life-prolonging care when end-of-life discussions did not take place strongly suggests that more patients would benefit from end-of-life discussions,” conclude the authors. “Physician-initiated discussions to elicit and document their wishes have significant potential to reduce their suffering at the end of life.”

Source: “End-of-Life Discussions, Goal Attainment, and Distress at the End of Life: Predictors and Outcomes of Receipt of Care Consistent with Preferences,” *Journal of Clinical Oncology*; March 1, 2010; 28(7):1203-1208. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG; Departments of Pediatric Oncology and Medical Oncology, Center for Psycho-Oncology and Palliative Care Research, Dana-Farber Cancer Institute; and Department of Medicine, Children's Hospital, Boston, Massachusetts.

Despite National Guidelines and Benefits to Patient Well-Being, Spiritual Care Is Often Absent

Support of the spiritual needs of terminally ill cancer patients by their medical team is associated with greater use of hospice services and better quality of life near death, yet medical systems (e.g., physicians, nurses, and chaplains) are not providing this needed care, according to findings published in the *Journal of Clinical Oncology*.

Researchers analyzed interview responses of 343 patients with advanced cancer a median of four months prior to death, then assessed their medical charts and conducted postmortem interviews with their formal and informal caregivers. Overall findings include:

- 60% of patients reported their spiritual needs were supported only minimally or not at all.
- 54% received no pastoral care visits.
- In the final week of life, 17% received some form of aggressive care.

Spiritual care has been incorporated into guidelines developed by such national organizations as the Joint Commission, which accredits U.S. health care organizations and

programs, and the National Consensus Project, a coalition of leading palliative care organizations. “However,” state the authors, “despite national guidelines, spiritual care often remains absent for patients at the end of life.”

BENEFITS OF SPIRITUAL SUPPORT

- Patients whose spiritual needs were largely or completely supported by the medical team were more likely to receive hospice care (adjusted odds ratio [AOR] = 3.53; 95% confidence interval [CI], 1.53-8.12) compared with those whose needs were unsupported.
- Religious coping patients whose spiritual needs were largely or completely supported by the medical team were more likely to enter hospice (AOR = 4.93; 95% CI, 1.64-14.80) and less likely than others to receive aggressive care (AOR = 0.18; 95% CI, 0.04-0.79).
- Greater support from the medical team was also associated with better patient quality of life near death (mean score, 20 out of a possible 30), as was greater

pastoral support (mean score, 20.4 out of 30).

“Caregivers such as doctors and nurses are generally the individuals providing counsel regarding medical decision making,” the authors point out. **“Their acknowledgment of the religious and/or spiritual components of illness may be of particular importance in helping patients face the spiritual issues most directly impacting their care decisions.”**

Members of the medical team can provide spiritual support by performing spiritual assessments, recognizing spiritual needs, and making pastoral care referrals, the authors suggest.

Source: “Provision of Spiritual Care to Patients with Advanced Cancer: Associations with Medical Care and Quality of Life Near Death,” Journal of Clinical Oncology; January 20, 2010; 28(3):445-452. Balboni TA, Paulk ME, Balboni MJ, et al; Departments of Psycho-Oncology and Palliative Care, Radiation Oncology, and Medical Oncology and Center for Psycho-Oncology and Palliative Care Research, Dana-Farber Cancer Institute; and Department of Internal Medicine, Beth Israel Deaconess Medical Center, Harvard Medical School Center for Palliative Care.

American Academy of Pediatrics Adds New Focus on Hospice and Palliative Care

The American Academy of Pediatrics (AAP) has recently established an online site with information and resources on pediatric palliative care and hospice services, under the auspices of its new Provisional Section on Hospice and Palliative Medicine.

Designed to support both health professionals and families, the site includes care resources and access to connections with others involved in the care of seriously ill children and adolescents.

The AAP has also given its Affirmation of Value to “The Standards of Practice for Pediatric Palliative Care and Hospice,” developed last year by the National Hospice and Palliative Care Organization (NHPCO) to help member providers who are interested in starting or expanding their pediatric services to develop safe, effective, and high-quality programs.

In this country, 400,000 children are living with chronic, life-threatening conditions, and 53,000 children die each year.

“While these numbers pale in comparison to the number of dying adults, the impact on families and on society is immeasurable,” states the NHPCO. The 11-page booklet, “NHPCO Facts and Figures on Pediatric Palliative and Hospice Care in America,” is available at www.nhpc.org.

The AAP hospice and palliative care subspecialty certification exam is scheduled for November 16, 2010. For further information, visit www.aap.org/sections/palliative.

CLINICIAN RESOURCES

BOOKS FOR CLINICIANS

Demystifying Opioid Conversion Calculations: A Guide for Effective Dosing

This practical guidebook by Mary Lynn McPherson, PharmD, offers both new and experienced clinicians a five-step process for safely and effectively transitioning patients from one opioid to another, which can often require changing the route of administration and/or dosage formulation. Chapter titles include:

- Converting Among Routes and Formulations of the Same Opioid
- Converting Among Routes and Formulations of Different Opioids
- Titrating Opioid Regimens: Around the Clock and to the Rescue!
- Transdermal and Parenteral Fentanyl Dosage Calculations and Conversions
- Methadone: A Complex and Challenging Analgesic, But It's Worth It!
- Patient-Controlled Analgesia and Neuraxial Opioid Therapy
- Calculating Doses from Oral Solutions and Suspensions

McPherson is professor and vice chair in the Department of Pharmacy Practice and Science at the University of Maryland School of Pharmacy, Baltimore.

Published by American Society of Health-System Pharmacists, 2009; ISBN-13: 9781585281985 (Paperback); 200 pp.

Palliative Care: Transforming the Care of Serious Illness

Edited by Diane E. Meier, MD, Stephen L. Isaacs, JD, and Robert G. Hughes, PhD, this reference book offers a comprehensive overview of the newly recognized field of palliative medicine. Included are reprints of 25 of the most important articles in the field, each with a short introduction by the editors.

Articles range from classic pieces by the discipline's pioneers to more recent influential articles, showing the gains that have been made in the field over the past 20 years. Opening the book is Meier's original review of the development, status, and future of palliative care.

"Palliative care...recognizes that serious illness and the suffering that accompanies it is a universal human condition, affecting every one of us," writes Meier. "It strives to redress the fragmentation and discontinuities of the health care system, recognizing that the patient and the family still need care when they leave the hospital or the doctor's office."

Topics include: the importance of caring for the seriously ill patient, the nature of suffering, efforts to cope with death and provide care for the dying, pain management, legal and ethical issues, cross-cultural issues, and the philosophical perspective on terminal care.

Meier is director of the Center to Advance Palliative Care; and director of the Lilian and Benjamin Hertzberg Palliative Care Institute, professor of geriatrics and internal medicine, and Catherine Gaisman Professor of Medical Ethics, Mount Sinai School of Medicine, New York City.

Published by Jossey-Bass, 2010; ISBN-13: 9780470527177 (Paperback); 464 pp.

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

End of Life/Palliative Education Resource Center (EPERC)

www.epec.net

The EPEC Project (Education in Palliative and End-of-Life Care)

www.nhpco.org

National Hospice & Palliative Care Organization

www.caringinfo.org

Caring Connections: National Consumer Engagement Initiative to Improve End-of Life Care

www.promotingexcellence.org

Promoting Excellence in End-of-Life Care

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

Hospice and Palliative Nurses Association

www.medicaring.org

Palliative Care Policy Center

www.abcd-caring.org

Americans for Better Care of the Dying

www.mcw.edu/palliativecare.htm

Medical College of Wisconsin Palliative Care Center

www.painpolicy.wisc.edu

University of Wisconsin Pain and Policy Studies Group

www.capc.org

Center to Advance Palliative Care

www.stoppain.org

Pain Medicine & Palliative Care, Beth Israel Medical Center

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