

Office of Promoting Excellence in End-of-Life Care: Surgeons' Palliative Care Workgroup Report from the Field

Dedicated to patients, families, and surgeons who have shared countless vigils.

SUMMARY

In recognition of a growing interest in palliative care by clinicians, patients, and families, the *Promoting Excellence in End-of-Life Care* national program of The Robert Wood Johnson Foundation (RWJF), in conjunction with the American College of Surgeons, created a national Peer Workgroup to facilitate introduction of the precepts and techniques of palliative care to surgical practice and education in the United States and Canada. The Surgeons Palliative Care Workgroup brought together surgeons with demonstrated interest and experience in palliative care to share resources, strategies, and expertise, and, in so doing to act as a catalyst for change. This report is an account of its analysis of the current state of palliative care in the surgical field, the recommendations for a competency-based approach to palliative care in the surgical setting, and opportunities for surgical palliative care research and education.

The Surgeons Palliative Care Workgroup, which met four times in addition to periodic sub-committee conference calls during a period of 14 months from September 2001 through November 2002, has now accomplished the intended purpose under its grant.

Co-chaired by two general surgeons with experience in hospice and palliative care, the initial Workgroup membership of twenty consisted of seventeen surgeons representing six subspecialties, representatives of the Executive and administrative staff of the American College of Surgeons, two recognized leaders in palliative care research and education, and a representative of the National Program Office of the Robert Wood Johnson Foundation. Subsequent additions to the group included the Executive Editor of the *Journal of the Ameri-*

can College of Surgeons and the Director of the Division of Education of the American College of Surgeons.

The Surgeons Workgroup divided into seven subcommittees: Executive, Needs Assessment, Symposia Planning, Residency Education, *Journal of the American College of Surgeons (JACS)* articles, Liaison, and Palliative Care Interest Group. As time went on, the work of the Liaison and Palliative Care Interest Group became assimilated by the other subcommittees. The major thrust of these combined efforts was education of surgeons and surgeons-in-training. The Workgroup chose the American College of Surgeons' *Statement of Principles Guiding Care at End of Life* (1998) as its compass in the execution of its charge.

The Executive Committee's primary tasks were the planning of meetings, coordination of subgroups, guidance from the Robert Wood Johnson Foundation in matters related to facilitating the Workgroup's function, creation of the final Workgroup product (*Report from the Field*), the Executive Summary (*JACS* April 2003), and maintaining contact with thought leaders in palliative care outside the field of surgery.

The Symposia subcommittee planned, prepared, and presented three well-attended and favorably reviewed symposia on palliative care held at the 2001 and 2002 Clinical Congresses and the 2002 Spring Meeting of the American College of Surgeons. A symposium also took place at the 2003 ACS Spring meeting, and a symposium for the Fall 2003 Clinical Congress is planned. The topics presented have included approaches to pain and non-pain symptom control, medical futility, issues related to withholding or withdrawal of system support, and communication and clinical care during the last days of life in a critical care setting.

The *JACS* sub-committee planned a monthly series of articles about palliative care written by surgeons from the Workgroup for publication in the *Journal of the American College of Surgeons*. The purpose of the series was to (1) introduce the readership to the background,

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philosophy, principles, and practice of palliative care as they would apply to surgical practice, and (2) identify ethical principles and subjects for future surgical palliative care research. The collaboration of the Workgroup members writing these articles provided much of the cohesion and direction of the Workgroup. The series of articles, currently running beyond the original number planned, has been available to the public at the RWJF website, and several of the articles have been among the most frequently accessed at the site. Future publication of these articles in a single volume is under consideration by the Workgroup.

The Residency Education sub-committee was charged with the task of promoting palliative care education in post-graduate surgical training programs. This was accomplished by the participation of Workgroup members in the End-of-Life Education Project for Post-graduate Training Programs, another RWJF funded initiative (David Weissman, MD, Principal Investigator). Six members of the Workgroup have attended with their own residency programs, with a total of 27 programs signed up to date. Feedback from participants has been overwhelmingly positive.

In the course of the Workgroup's educational activities, a consensus was reached that for the entire spectrum of surgical specialties, competence in two basic elements of palliative care, pain management and communication skills, is essential for all surgeons. To this end, the Workgroup put forth core competencies in surgical palliative care for the practicing surgeon. Several group members have collaborated in publishing a research agenda for surgical palliative care as well as a set of ethical principles for research in this highly vulnerable population.

At the mid-point of the grant period, the Workgroup made a proposal to the Division of Education of the American College of Surgeons to become incorporated in the College structure as a Task Force. This was proposed in October 2002 by Ajit Sachdeva, MD, FACS, Director of the Division, and approved by the Board of Regents.

During the month prior to this report, the newly created Task Force created its own section of the ACS website, providing a number of helpful references, an online discussion area focusing on the complex and often difficult palliative care issues involving surgeons, and links to off-site sources of related information.

The Surgical Palliative Care Task Force has several ongoing projects including: the continuation of the

JACS series of articles; performance of a needs assessment of the College membership; future College symposia presentations; continued involvement in the End-of-Life Education Project for Post-Graduate Training Programs including recruiting more surgical programs for this project; a national conference on surgical palliative care to be sponsored by the College in conjunction with a leading university medical center; and efforts to link its activities with other divisions of the College inclusive of all surgical sub-specialties as well as organizations active in the promotion of palliative care. A list of recommendations from this Workgroup appears (as Section IV) at the conclusion of this report.

I. BACKGROUND: SURGERY AND PALLIATIVE CARE

During the past two decades the attention of the public and the health care professions has been increasingly directed to the needs of the incurably ill and the dying, to widespread popular approval. The result of this raised collective consciousness has been the proliferation of hospice and palliative care programs, research, and education programs in the United States and many other countries of the world.

Although the first modern, comprehensive concept of palliation embracing not only physical but emotional, psychologic, social, and spiritual dimensions of an individual's experience was initially developed and applied as hospice care for the terminally ill, the same concept has been increasingly applied earlier in the course of illness and in more categories of illnesses. The World Health Organization defines palliative care as, "The active total care of patients whose disease is not responsive to curative treatment."¹

Because of the large number of patients with advanced and terminal illnesses undergoing operations or receiving care from surgeons, it was only a matter of time before surgeons became directly involved in palliative care initiatives. With this conviction or calling, members of the surgical community, including representatives of the executive staff of the American College of Surgeons with an active interest in palliative care, organized and sought grant support from the Robert Wood Johnson Foundation's *Office of Promoting Excellence in End-of-Life Care* "to facilitate introduction of the precepts and techniques of palliative care in to surgical practice and education."² The grant applicants believed that the participation of the American College of Surgeons was cru-

cial because of its historic and current position of ethical, scientific, and socioeconomic credibility in the field of surgery.

Despite the numerous contributions made by the field of surgery and surgeons to the relief of suffering in the setting of advanced and incurable illness, and the rich contributions to the literature of death and dying by surgeons, there is currently no formal systematic philosophy or comprehensive approach to palliation available to practicing or in-training surgeons in the United States. Although an occasional article in the surgical literature had addressed palliative care since the opening of the first hospice in the United States in 1974, recent reviews^{3,4} of surgical textbooks and journals find little mention of palliative and hospice care and even fewer discussions of how to provide it.

Even the definition of palliation in surgical writing is problematic because of its inconsistency. The term “palliative” is used to characterize procedures in widely divergent, even contradictory, ways: “Palliative” has been used to describe: (1) procedures in which histologically positive margins have been left behind or later detected, (2) procedures that failed or will fail to cure, and (3) procedures that are designed for the relief of symptoms regardless of their impact on disease.⁵ The last definition, the one most directly related to quality of life perceptions, is frequently undermined because the judgment of that quality of life outcome or degree of symptom control is the judgment of the surgeon, not the patient.

Despite the relatively late arrival of surgery institutions to the field of palliative care, a number of precedents for an eventual systematic philosophy of palliation can be identified in surgical experience since the hospice concept arrived in the United States in the mid-1970s. Surgeons numbered among the founders and volunteers of the first hospice programs, and more than one of the Presidential addresses to the annual Clinical Congress of the American College of Surgeons have addressed aspects of humanism⁶ in surgical practice closely associated with core principles of palliative care—empathic communication and non-abandonment.

In 1976, J. Englebert Dunphy, a well-known and revered surgeon and educator, delivered an address⁷ to the Massachusetts Medical Society in the course of his own advanced and incurable illness, about the role of the surgeon in the care of the dying patient; he focused attention on the importance of non-abandonment and

release of imminently dying patients from burdensome and futile treatments. The eloquence and wisdom of this address will ensure it an enduring place in the literary heritage of surgical palliative care. In 1972, a plastic surgeon, John Gaisford, published an article that succinctly defined palliative surgery's place in the management of incurable disease, and in it he noted that operative management was only part of the surgeon's obligation to the patient with incurable disease.⁸ He also stressed the importance of collegiality with non-surgical partners in the patient's care, especially those entrusted with spiritual care.

The term “palliative care” actually was coined by a surgeon, Balfour Mount, well known internationally in palliative care circles for his work as a pioneer of hospice care in North America in the mid-1970s as well as his extraordinarily rich original contributions to clinical care and teaching.⁹

Other hints of what would become the spirit and methodology of palliative care research applied to surgery could be seen in the work of Sugarbaker and associates as early as 1982 in their research on quality of life assessment of patients in extremity sarcoma trials.¹⁰ A particularly important insight reported at the end of this article was that directing attention to quality of life matters, as they had done in their research, had a “humanizing” effect on the researchers themselves.

Surgeons such as Sherwin Nuland¹¹ and Marc Flitter¹² have also provided the public with keen insights into “life's last chapter” as well as some of the rewarding aspects of the surgeon-patient relationship during that time.

The dormant state of palliative care teaching and research in the field of surgery began to change in 1997, by which time the American Board of Internal Medicine had published its educational resource document on the identification and promotion of physician competency in care for the dying,¹³ and the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)¹⁴ study had demonstrated beyond any doubt the deplorable state of end-of-life care in seriously and terminally ill hospitalized patients, especially in matters of pain control and communication about patient preferences.

In May 1997, Milch and Dunn, each possessing a clinical background of general surgery and hospice care, wrote at the beginning of their collaboration that both the worlds of surgery and end-of-life care would greatly

benefit by coming together and, in so doing, would help “reclaim the lost ground” of the surgeon-patient relationship.³ During this same time, the debate about physician-assisted suicide was intensifying nationally and was taken up by the surgical community at a symposium moderated by Thomas Krizek during the fall 1997 Clinical Congress of the American College of Surgeons. A recent survey of surgeons in Australia should add a sense of urgency to educating all surgeons about definitions of palliative care that have achieved cross-cultural consensus. In this study of 992 eligible general surgeons, 247 of whom responded, more than a third of those 247 reported giving drugs with an intent of hastening death, often in the absence of an explicit request.¹⁵ Despite positions pro and con for physician-assisted suicide during the 1997 symposium, there was a strong consensus on both sides on the moral and practical value of good palliative care, yet all agreed with the late James Carrico that there was little existing direction for how surgeons should “walk the talk” versus “talk the talk.”¹⁶

Many surgeons advocating palliative care during this time believed the coming challenge of introducing the concept of palliative care to surgeons would be the dual task of acknowledging death as a natural endpoint of the normal process of dying, while at the same time shifting the basis of care from a time-based expectation to a needs-based imperative. In simpler terms, surgeons would need a comprehensive philosophy that would allow separation of the concept of palliative care from the more limited setting of end-of-life care.

In February 1998, the *Statement on Principles Guiding Care at the End of Life* (see facing cover page of this article) developed by the American College of Surgeons Committee on Ethics was approved by the Board of Regents of the American College of Surgeons. This placed the College in alignment with the majority of the other medical specialties that had adopted similar position statements.¹⁷

During 1999, following the initiative of Olga Jonasson, MD, FACS, representing the Department of Education and Surgical Services of the College, and James C Carrico, MD, FACS, representing the Program Committee of the College, a symposium on palliative care to be presented at a future Clinical Congress was planned along with the simultaneous development of a palliative care curriculum for surgeons who used the highly successful advanced trauma life support (ATLS) training

program as a possible model. Because the ATLS program, developed under the auspices of the College, represented one of its most outstanding clinical, educational, and social achievements, it was believed that possibly the College could once again play a major role in educating a wide spectrum of surgeons and associated disciplines about the equally complex and demanding skill of palliative care.

The following year, the first of a series of symposia at the annual Clinical Congress of the American College of Surgeons was held by members of the Workgroup and Dr Carrico. Kathy Foley, MD, of Memorial Sloan-Kettering Hospital was invited as a panelist because of her internationally recognized expertise in matters of pain management and her insight into systems implications of palliative care. The well-attended and well-reviewed symposium (unpublished) provided the first opportunity for some of the more junior members of the then embryonic Workgroup to address the Fellowship on this topic.

Shortly after this, the Surgical Oncology Clinics of North America published a volume entitled *Palliative Care and the Surgeon*⁹ edited by and including chapters by several members of the Workgroup. The purpose of the volume was to bring the worlds of palliative care, as it had been developed up to that point in the non-surgical disciplines, and the world of surgery closer together. The hope was that this book would be a small island of credibility about palliative care theory and practice on which surgeons could subsequently build.

An important breakthrough for initiating palliative care education in post-graduate surgical training programs was the American Board of Surgery's inclusion of palliative care as one of the areas in which the certified surgeon “...has acquired during training specialized knowledge and experience...” as of July 2001.¹⁸ The Royal College of Surgeons had previously listed palliative care among the expected competencies for those sitting for its qualifying examination.¹⁹

Another encouraging sign of surgeon interest in the concept of palliative care is the rapid increase of articles addressing quality of life measurement in surgical outcomes,²⁰ and even an article addressing the quality of quality life outcome studies in surgery.²¹ Palliative surgery was addressed at the Spring 2001 Society of Surgical Oncology and was the main focus of the February 2001 meeting of the Society of Critical Care Medicine. In a survey of surgical oncologists conducted by McCahill

and associates, a majority of respondents stated that palliative care was an important part of their practice.²²

At a conference for national leaders in palliative care, sponsored by the Kellogg Foundation in November 2000, organized and moderated by Francis Lee, MD, FACS, a member of the Workgroup, members of the Workgroup were introduced to representatives of the Robert Wood Johnson Foundation. With the considerable support of Ira Byock, MD, of Robert Wood Johnson's Office of Promoting Excellence in End-of-Life Care, the grant submission and grant approval for the formation of the Surgeons Palliative Care Workgroup was subsequently expedited.

Members of the Workgroup were selected based on their previous experience in clinical palliative care or hospice, interest in medical ethics related to palliative care, and research interests related to surgical techniques and quality of life outcomes assessment after surgical care. A number of the members of the group established contact with each other by acquaintance through individuals active in medical palliative care. Although the group did not see itself as comprehensively representative of the field of surgery or cross-culturally representative, it was hoped that with time representatives of different interest groups and cultural backgrounds would affiliate themselves with the activities of the Workgroup.

Workgroup convening process

The Surgeons Workgroup convened for its inaugural meeting, auspiciously enough, on September 10, 2001. The events of the following day, however, consecrated this task in a way no one could have predicted or imagined. At the inaugural meeting the group consisted of surgeons from six subspecialties (general surgery, cardiovascular surgery, neurosurgery, otolaryngology, trauma, and oncologic surgery) with demonstrated previous interest in palliative and hospice care, a representative of the American College of Surgeons (Jonasson), an authority on palliative care physician education (Weismann), and representatives of Robert Wood Johnson's Office of Promoting Excellence (Byock, Bumagin). Since that inaugural meeting, several other members were added to the Workgroup because of the degree of their involvement or anticipated involvement in Workgroup activities (Appendix 1).

The charter for the Workgroup (Appendix 2) was drafted as was the list of six sub-committees (Appendix 3) to direct the various initiatives. The *Statement on*

Principles Guiding Care at the End of Life, approved by the Board of Regents of the American College of Surgeons in February 1998, was used by the Workgroup as the compass for its initial discussion and its subsequent direction. As an ongoing reminder, the *Statement on Principles* was published with each of the articles in the Workgroup's palliative care series published monthly since September 2001 in the *Journal of the American College of Surgeons*.

In retrospect, some of the Workgroup's subcommittee mandates increasingly overlapped, while other initiatives such as the Surgical Palliative Care web page at the American College of Surgeons' website subsequently emerged and commanded much more attention than initially anticipated.

One of the more nagging problems facing the Workgroup was achieving consensus on terminology. Some believed that "end-of-life care" and "terminal care" were too limiting and negative, while others thought that the term "palliative care" was laden with negative connotations for many surgeons and seemed to be an unwieldy term. The term "comfort care" was written off as too vague and insipid. The term "palliative" remained in the ensuing discourse, if for no other reason than its broad familiarity outside the field of surgery, where so much work had already been done. Inspired by what we saw of palliative care philosophy, brought into focus through the lens of surgical experience, there was always the danger of "re-inventing the wheel" and duplicating ideas and material already available as a result of the work of our medical colleagues during the past 25 years.

After the initial organizational meeting, there was a less formal meeting during the 2001 Clinical Congress of the American College of Surgeons at which several new members were introduced to the Workgroup. The Workgroup also gave its first symposium as a group organized under the RWJF grant. The attendance of 223 was higher than the previous year (significant, given the lower overall Congress attendance during the month following 9/11), and the reviews were again quite favorable.

The Workgroup sub-committees held scheduled conference calls every few months facilitated by the staff of the Office of Promoting Excellence. Minutes taken by the administrative staff of the ACS were distributed to Workgroup members electronically. Because of the collaboration of several Workgroup members writing articles for the *Journal of the American College of Surgeons's*

series on palliative care during the grant period, many opportunities were available for follow-up discussion and planning of future projects.

Representatives of the Workgroup and the Robert Wood Johnson Foundation met in July 2002 with Drs John Cameron and Keith Lillemoe of the Department of Surgery, Johns Hopkins University, to discuss future palliative care educational opportunities.

The July 2002 meeting of the Workgroup, held at The Center for Hospice and Palliative Care in Buffalo, NY, hosted by Co-Chair Robert Milch, MD, FACS, drafted a proposal and submitted the work to Ajit Sachdeva, MD, FACS, Director of the Division of Education of the American College of Surgeons for incorporation of the Workgroup into the Division of Education. During this very well-attended and collegial meeting, the group planned future symposia topics and articles to be written, and a basic plan for writing the *Report from the Field* was developed. An equally important result of this meeting was the strong consensus reached by the group regarding educational and clinical priorities of surgical palliative care.

About this time representatives of the Workgroup visited the ACS for discussions with Dr Thomas Russell, Executive Director of the College, Dr Sachdeva, and members of the Communications and Information Services staffs about future collaboration of the Workgroup with the College after the RWJF grant period. The reception by these representatives of the College was enthusiastic and helpful.

The final meeting of the Workgroup prior to the writing of this report took place in Chicago in November 2001. During this meeting the transition from Surgeons Palliative Care Workgroup under RWJF grant to a Task Force of the American College of Surgeons was made. The Workgroup was introduced to clerical and administrative staff of the College assuming responsibilities with the Task Force, and plans about the Task Force's web page at the College site were made. The Workgroup developed an outline and assignment list for the final report.

After this meeting, 13 of the RWJF Workgroup surgeon members were retained in the Task Force as the executive group. An advisory group to the Task Force including surgeons and non-surgeons was also formed. One of the Advisory Group members is the American Academy of Hospice and Palliative Medicine's representative to the ACS Commission on Cancer. Membership

to the advisory group is currently open to members of the College.

The Task Force is planning continued bi-annual meetings, symposia for future College meetings, continuation of the series on Palliative Care in *JACS*, and a national conference on surgical palliative care in addition to participation in any activities that may result from the list of recommendations concluding this report.

II. CLINICAL SKILLS—CORE COMPETENCIES

The practice of surgical palliative care is the fundamental component of good surgical clinical care. The relief of suffering and maintenance of quality of life are outcomes surgeons must strive for in *all* patients, not merely those who are clearly dying or at the end of life. Surgeons therefore must be competent at (1) providing palliative care alongside curative care, (2) understanding when a transition from one to another may be appropriate, and (3) using procedural skills appropriately for palliation as well as for cure. This portends a subtle but real shift in the skills of surgeons in patient care and the practice of evidence-based surgery.

In considering a broad range of surgery disciplines, competence in two basic elements of palliative care, pain management and communication skills, is essential for all surgeons, whether their practice encompasses the care of many dying patients or merely a few. For those surgeons who care for dying patients more frequently, additional skills in the management of end-of-life care are important. To this end, the Workgroup put forth the following core competencies in surgical palliative care for the practicing surgeon.

Patient care

1. Possess the capacity to guide the transition from curative and palliative goals of treatment to palliative goals alone based on patient information and preferences, scientific and outcomes evidence, and sound clinical judgment
2. Perform an assessment and gather essential clinical information about symptoms, pain, and suffering
3. Perform palliative procedures competently and with sound judgment to meet patient goals of care at the end of life
4. Provide management of pain and other symptoms to alleviate suffering
5. Communicate effectively and compassionately bad news and poor prognoses
6. Conduct a patient and family meeting regarding advance directives and end-of-life decisions

7. Exercise sound clinical judgment and skill in the withdrawal and withholding of life support

Medical knowledge

Surgeons should acquire knowledge in the fundamentals of palliative care applicable to the breadth of their own surgical patients. These include:

1. Acute and chronic pain management
2. Non-pain symptom management
3. Ethical and legal basis for advance directives, informed consent, withdrawal and withholding of life support, and futility
4. Grief and bereavement in surgical illness
5. Quality of life outcomes and prognostication
6. Role of spirituality at the end of life

Practice-based learning and improvement

1. Recognize quality of life and quality of death and dying outcomes as important components of the morbidity and mortality review process
2. Understand their measurement and integration into peer review process and quality improvement of practice
3. Be skilled in the use of introspection and self monitoring for practice improvement

Interpersonal and communication skills

Surgeons must be competent and compassionate communicators with patients, families, and other health care providers. They should be effective in communicating bad news and prognosis and in redefining hope in the context of cultural diversity. The interdisciplinary nature of palliative care requires that the surgeon is skilled as both a leader and a member of an interdisciplinary team and maintains collegial relationships with other health care providers.

Professionalism

Surgeons must maintain professional commitment to ethical and empathic care, which is patient focused, with equal attention to relief of suffering along with curative therapy. Respect and compassion for cultural diversity, gender, and disability is particularly important around rituals and bereavement at the end of life. Maintenance of ethical standards in the withholding and withdrawal of life support is essential.

Systems-based practice

Surgeons must be aware and informed of the multiple components of the health care system that provide pal-

liative and end-of-life care. Surgeons should be knowledgeable and willing to refer patients to hospice, palliative care consultation, pain management, pastoral care, social services, etc. and to understand resource utilization and reimbursement issues involved.

III. EDUCATION

The role of the Workgroup in educational activities related to palliative care has focused on two main targets: practicing surgeons and surgical residents. Because palliative care is an unfamiliar concept to many, if not most, practicing surgeons, the majority of the educational effort has been aimed at surgeons already in practice. These practices vary widely, whether operating or non-operating surgeons in both community and academic practice. In addition to issues faced by general surgeons, specific areas of specialty practice that have particular educational needs include hospice, surgical oncology, otolaryngology, and surgical critical care. Symposia held at the Clinical Congresses and at the Spring Meetings of the American College of Surgeons; a series of articles published in the *Journal of the American College of Surgeons* including CME questions; information presented on the website of the American College of Surgeons' Surgical Palliative Care Task Force; and questions proposed for incorporation in the Surgical Education and Self-Assessment Program, 2002–2004 (SESAP 12) are the current palliative care educational programs designed specifically for practicing surgeons.

The second main area of educational effort has focused on surgical resident education, through involvement in the End-of-Life Education Project for Post-Graduate Training Programs, a previously established Robert Wood Johnson Foundation funded initiative. Rappaport and Witzke²³ reported that only 50% of senior surgery residents reported ever discussing death and dying with their attending surgeons. The participation of the Workgroup in this project was coordinated through its Residency Education sub-committee.

In many ways these two focuses have similar aims because the knowledge deficits in residents and faculty have been similar in the experience of the National Residency Training in End-of-Life Care project. Data about knowledge deficits were obtained from surveys administered to participants in the Residency Training project. Specific deficits about pain and symptom management are the most striking features of these data.

Symposia

Members of the Workgroup have conducted six symposia at the fall and spring meetings of the American College of Surgeons. These symposia (Appendix 4) have covered diverse aspects of palliative care. Lively question and answer sessions have been one of the highlights of these well-attended symposia and have provided encouragement for the Workgroup to continue participation in the Clinical Congresses. The 2001, 2002, and Spring 2003 Clinical Congress symposia were transcribed for publication in the *JACS* Palliative Care Series.

JACS

A series of articles on palliative surgical care began with the September 2001 issue of the *Journal of the American College of Surgeons (JACS)*, formerly *Surgery, Gynecology, and Obstetrics*. Twenty-six articles (including this Field Report) have been published in *JACS* by members of the Workgroup; 12 articles have been chosen by the Education Editor as part of the online *JACS* CME program.

The purpose of the series, using *The surgeon and palliative care*¹⁸ as a model, was to introduce surgeons to the fundamentals of palliative care through the writing of surgeons familiar with hospice and palliative care. Beginning with an introduction to the field of surgical palliative care, the series has covered such diverse topics as communication, pain management, withdrawing mechanical ventilation, nutrition and hydration in advanced illness, prognosis, malignant bowel obstruction, and research in palliative care. Links to these articles are available on the Robert Wood Johnson Promoting Excellence in Palliative Care website (<http://www.PromotingExcellence.org>) as well as on the *JACS* website. These *JACS* articles have been among those receiving the most "hits" at the site.

National conference

In 2003 preliminary proposals are being made by the Division of Education of the American College of Surgeons to a leading surgery institution to host a national conference on surgical palliative care in conjunction with the Division of Education's newly designated Surgical Palliative Care Task Force. Such a conference would encourage the emergence of a consensus statement by surgeons defining surgical palliative care as well as exposing more surgeons in all subspecialties to the concepts, knowledge, and skills necessary for the fulfill-

ment of the American College of Surgeons' *Statement on Principles Guiding Care at the End of Life*.

Needs assessment

From the time of their initial meeting, the Workgroup had planned a needs assessment as part of its ongoing surgical palliative care education. The assessment was to determine self-perceived weaknesses in knowledge domains as well as areas of interest. Brief needs assessments were conducted during several of the symposia held by the Workgroup for planning future symposia. The majority surveyed in this self-selected population believed: (1) palliative care education was relevant to surgical practice; (2) palliative care education should be part of surgical residency training; and (3) palliative care would be a suitable subject for future College meetings. A survey of the membership of the Society of Surgical Oncology found that for a majority of its members palliative surgery was a significant part of their practice.²³

The Workgroup believes that a more comprehensive needs assessment surveying a larger population would be better conducted after the Workgroup has had more experience working with the American College of Surgeons and after the Surgical Palliative Care Task Force's website is online. Application for funding this survey is currently under way.

Website

A website for the Surgical Palliative Care Task Force (<http://www.facs.org/palliativecare/index.html>), designed by Information Services at the American College of Surgeons, in collaboration with the Division of Education and the Workgroup, has been online since the beginning of December 2002. The public access portion of the site has links to the Robert Wood Johnson Foundation site where the texts of the *JACS* series of articles on surgical palliative care can be found. The private access (Task Force members) area allows sharing of minutes and documents in progress related to Task Force activities. Future plans for the site include its interactive use for surgical palliative care discussion and survey purposes.

Surgeons Educational Self-Assessment Program (SESAP)

SESAP 11, the current edition of this widely used ACS continuing education program, contains questions about pain and symptom management, primarily in the category of anesthesia/pharmacology. There are no ques-

tions about any other areas of palliative care. The Workgroup has submitted seven palliative care questions to the editors of SESAP 12 (October 2004) at the request of Dr Ajit Sachdeva, Director, Division of Education, American College of Surgeons. These questions will be considered by the editors and included based on quality of questions and contribution to the overall question mix.

End-of-life education project for post-graduate training programs

This is another Robert Wood Johnson sponsored project originally aimed at improving end-of-life care in internal medicine residencies. Begun in 1998 and headed by David E Weissman, MD, Director of Palliative Care Services, Medical College of Wisconsin, it has been attended by more than half of all medicine residency programs in the country. The program has expanded to include family practice residencies and neurology residencies, and, in 2002, it began incorporating general surgical residencies. It fulfills a requirement by the American Board of Surgery to acquire specialized knowledge and experience in palliative care, and it also is one way to address many of the ACGME competencies.

This 1½-day program, taught by palliative care experts in several disciplines, brings together faculty (ideally including the Surgery Program Director) and chief residents from programs around the country to “teach the teachers.” Principles of adult learning are emphasized, and participants leave with an action plan to incorporate their learning into their own residency programs. Program faculty (including one member of the ACS Workgroup) serve as mentors as the participants go back to their own programs and encounter obstacles to implementation of their action plans.

Specific topics addressed during the conference include pain management, dyspnea, delirium, nausea, delivering bad news, conducting a family conference, DNR orders and goal-setting discussions, hospice care, and nutrition. A pre- and post-course test are given to residents and faculty. Data from these tests given to surgical attendees are pending publication. The test domains include: (1) pain and non-pain symptom management, (2) communication skills, (3) ethics, and (4) terminal care.

Six members of the Workgroup have attended with their own residency programs, with a total of 30 total programs taking part as of this report date (Appendix 5).

Feedback from participants has been overwhelmingly positive.

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IV. RESEARCH FOR SURGICAL PALLIATIVE CARE

As with any new and developing area, opportunities for surgical research abound in palliative care. Potentially fertile areas of investigation cover a broad spectrum of clinical topics, such as symptom relief, quality of life, emotional well-being, and patient–physician communication.

Medical advances and better living standards during the 1900s have changed the demographics of disease. Rather than dying early and quickly from infections, injuries, or diseases, most people now die slowly and at an advanced age, resulting in growing numbers of patients who require prolonged care for their chronic, progressive, and eventually fatal disease. Advances in surgical interventions have contributed greatly to this change. The management of coronary artery disease is a good example. Patients who once died acutely of myocardial infarction in midlife today often recover with the help of interventional cardiology, intense medical therapy, and cardiac procedures. The majority of patients with coronary artery disease used to present with heart attacks or angina in their 50s and 60s, but now they suffer from congestive heart failure. Almost every second person over the age of 85 has this disease.¹ In the “younger” population of 65–74 years of age, advanced cancer has surpassed heart disease as the most frequently cited cause of death.² Congestive heart failure, advanced cancer, chronic renal failure, stroke, and dementia all share one common characteristic—there is no *cure* for the underlying disease process. Most current treatment modalities aim for *disease control and symptom palliation* rather than *cure* in the strict sense.

The field of surgery has a long tradition of palliation; well before surgeons had a modern understanding of apoptosis or transplantation, they drained abscesses and removed tumors to alleviate pain and suffering. This century, however, has seen the emergence in Western medicine of the belief that the only acceptable therapeutic goal is the absolute cure of the patient.³ This concept is so strong that many surgeons believe that the business of palliation is best relegated to non-surgeons, and they wonder how palliative care concepts and research fit into their surgical practice. As discussed, however, the presumed delineation between *cure* and *palliation* is becom-

ing increasingly blurred as more and more patients with chronic incurable diseases present for surgical interventions. This reality requires surgeons to expand their understanding of expected clinical outcomes beyond that of surgical morbidity or mortality and recurrence of disease to include outcomes that are meaningful to the patient. For most patients with advancing atherosclerotic disease, malignancy, and dementia, relief from debilitating symptoms and quality of life may be just as or more important as the number of years lived. With such an understanding, death may be seen as a natural and expected outcome of an advanced disease process such as cancer and systemic atherosclerotic disease, rather than something to be delayed at all cost.

Surgeons must aim to set appropriate goals of care as well to offer other clinical services for the total care of the patient and his or her family. To this end, a disciplined scientific investigation is necessary to determine the optimal course of intervention for most clinical surgical situations, especially for patients whose goals of care include quality of life in addition to quantity of life.

Potential areas of clinical surgical research in palliative care

Surgeons must manage a particularly broad spectrum of death and dying. Death may occur unexpectedly in an otherwise healthy patient, as in the case of the severely injured trauma patient, an aortic aneurysm rupture, or a perioperative catastrophe. It may occur after a prolonged period of care where the outcome is unknown, as in severe burn or ICU patients. Surgeons also care for patients with chronic diseases where death is an expected outcome of their disease. Death and dying is common in surgical practice. Thirty percent of trauma deaths occur after the patient has reached hospital, and a further 10–20% die in the following weeks. Hepatic transplant surgeons accept 1-year survival rates of 75%.⁴ This reality highlights the many opportunities for palliative care research in clinical surgical practice.

Surgical decision-making

“It is judgment that matters in this profession. Otherwise the surgeon is no more than a man (or woman) with a knife, and a license to mutilate.”⁵

The decision to offer any surgical procedure to a patient must balance the potential benefits of the expected outcome of the intervention with the inevitable risks of

pain and complications. This is particularly important for the patient who is suffering from a terminal illness. For the surgeon, trained to intervene, a decision to operate is often the easiest one to make. The true skill of the surgeon as physician, however, lies in the careful selection and preparation of those patients who will benefit from a surgical procedure, as well as a continued commitment to the care of patients for whom surgery is not selected. The question that must be answered is not "Can this operation be done?" rather "Should this operation be done for this patient at this time?" This section explores the surgical decision-making process with a focus on potential research areas.

Prognostication and the natural history of disease.

In order to recommend the best treatment course, whether surgical or not, the surgeon should have a thorough understanding of the natural history of disease with and without treatment as well as an accurate assessment of prognosis. Both of these areas require further study. Surgical textbooks contain little data on the terminal phases of most surgical diseases.⁶ The development of prospective databases that document the course of terminally ill patients with and without treatment would be an invaluable tool to improve the assessment of the risk/benefit ratio of a proposed course of treatment.

Studies of the ability of physicians to predict prognosis have shown mixed results. A prospective study found that clinicians estimated prognosis quite accurately when asked whether or not a patient with terminal cancer was expected to live 6 months.⁷ In other studies, however, treating physicians tended to overestimate the survival of patients, and in particular failed to predict those who died early, within 2 months.^{8,9}

One approach to this problem has been the development of clinical prognostic indices. A number of indices have been created to predict prognosis and help guide the discussion about appropriateness of continuing care in ICU and trauma patients,^{10,11} including the Acute Physiology and Chronic Health Evaluation (APACHE),¹² Injury Severity Score (ISS),¹³ and the Therapeutic Intervention Scoring System (TISS).¹⁴ More recent indices include the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) prognostic model for seriously ill hospitalized adults,¹⁵ and for terminally ill cancer patients, the Palliative Prognostic Index (PPI),¹⁶ Palliative Prognostic Score (PaP),¹⁷ and the Good/Bad/Uncertain Index (GBU).¹⁸ An example of an early surgical prognos-

tic index is the Child-Turcotte classification of portal hypertension.¹⁹ It uses 5 clinical and laboratory values to categorize patients prior to undergoing surgery for portal hypertension by a portosystemic shunt. Widely used, it proved to reliably estimate early preoperative mortality.²⁰

There is still much work to be done to improve the value of prognostic indices. No model has been developed for the risk of surgical morbidity and mortality in patients with advanced disease such as cancer. The SUPPORT study found that objective clinical criteria alone were not effective in identifying patients with a survival prognosis of 6 months or less.²¹ Prognostication in terminally ill cancer patients was improved if objective clinical criteria such as weight loss and patient function were combined with clinician estimates.²² The patient's quality of life appears to be another important prognostic factor. Extent of disease and quality of life *together* predicted survival better than each parameter alone in patients with breast cancer.²³ Symptom distress alone predicted survival in lung cancer patients.²⁴ Patients with a low quality of life score were more likely to die within 6 months than those with higher scores, but low scores were not strong predictors of survival in individual patients.²⁵ Once again, carefully constructed prospective databases would be helpful to improve clinicians' understanding of prognosis.

Selection of ideal treatment modality. Currently there are few outcomes data in the surgical literature on which to base sound palliative surgical choices.²⁶ Improvement in quality of life and symptom relief should be the best measure of any palliative therapy.²⁷⁻²⁹ Few palliative surgical procedures have been subjected to rigorous scientific assessment. Reports of outcomes after palliative surgery currently reveal conflicting results about the quality of life and survival, and furthermore, very little prospective data is available.^{26,30-32} In addition, research that compares surgical versus non-surgical palliative treatments is needed.

The management of biliary obstruction for unresectable cancer patients is an example of where such research has been done. The results of 4 randomized trials comparing endoscopic stent insertion versus surgical bypass allow for some broad conclusions to be made.³³ Both techniques are effective in initial drainage of the biliary tree and improvement of symptoms. Endoscopic stenting has a lower early morbidity and mortality rate compared to surgical bypass, and thus is more suitable for

sick and debilitated patients. Late complications of cholangitis and recurrent jaundice, however, are high with endoscopic stenting, so repeat procedures may be required every 3–6 months. Patients expected to live longer than 6 months may therefore be more suitable for surgical bypass, although this prognostication is difficult.³⁴

An example of the current state of most palliative surgical research is the surgical management of malignant bowel obstruction. Feuer and colleagues published a Cochrane literature review of the subject in 2000.³² The authors were unable to draw any conclusions and identified the following problems with the available literature. All studies were retrospective, and there was little uniformity or clarity on which patients were entered into the studies. When symptom control was used as an outcome measure, it was unclear how symptoms were measured and whether the symptom scores used were validated. Even when postoperative morbidity and mortality were used as the outcome measures, the definitions of these outcomes were unclear and varied among papers.

Rigorous clinical research that clearly defines the research question and that uses validated outcome measures is necessary for the appropriate selection of treatment for palliative surgical problems.

Validated outcome measures for surgical care. Whether the focus of clinical investigation is symptom relief or patient-physician communication, careful outcome measurement is vital to a successful research agenda. Traditional surgical research has generally focused on narrowly defined endpoints such as morbidity and mortality rates. Research in palliative care in surgery asks us to consider a much broader spectrum of patient-oriented outcomes, such as symptom relief, quality of life, and spiritual, psychological, and emotional well-being. This echoes a growing trend in clinical surgical research, which is beginning to focus on these outcomes for all surgical patients.³⁵ This change is not unique to surgical research. Medical oncology research underwent a fundamental change in 1996 when the FDA approved the use of gemcitabine for advanced pancreatic cancer because the authors demonstrated that the main benefit of the drug was the relief of symptoms.^{27,36} The methodology required to design and analyze trials using quality of life endpoints is an active area of investigation in clinical epidemiology departments and represents an enormous opportunity for surgical researchers interested in palliative care.³⁷

In surgical oncology, for example, there are a number of validated quality of life and symptom outcome measures that are available for interventional research in cancer patients (Table 1). Three were created for palliative populations,³⁸⁻⁴⁰ and several others have undergone at least some validation when applied to this population.⁴¹⁻⁴⁶ Before using these measures for a surgical study, however, they must be validated for the population to be studied.

In the surgical intensive care unit (ICU), the initial focus of research has been on the use of highly invasive, technologically advanced procedures designed to support, save, and prolong life. Outcome measures evaluating ICU care from this perspective assess the number and quality of “successes,” or survivors. These outcomes do not, however, allow us to measure the care we give at the end of life to non-survivors. When the focus of care includes the provision of palliative care, a successful outcome must be redefined. The process of care and satisfaction with care, rather than mortality and long-term quality of life, may become the primary outcomes of interest. Measurable outcomes may include end-points reflecting the patient’s and family’s emotional, psychological and spiritual experience, as well as the management of the patient’s physical symptoms.

DNR orders are one aspect of the process of palliative care, and are an easy outcome to measure. It seems reasonable to use the presence of a DNR order as a surrogate for a discussion about goals of therapy. Between 9–13% of ICU patients will have a DNR order written at some point during their stay.⁴⁷ Unfortunately, the majority of studies about DNR orders are retrospective and do not suggest that the presence or timing of DNR orders in ICU patients provides relevant information about the quality of care.^{10,11,47-50} Predictive models identify age, race, chronic health conditions, acuity, coma, race, and primary disease process as important factors that determine the likelihood of a DNR order during admission to the ICU. In-depth study of different ICUs shows a distinct difference in observed and expected DNR orders. This difference did not seem to correlate with qualitative assessment of DNR practices, highlighting the difficulty in using the presence of DNR orders as a relevant outcome measure of quality end-of-life care.⁵⁰ Involvement of palliative care teams in the care of ICU patients is another measurable outcome that has been used and has some face validity in improving the quality of palliative care for these patients. Other outcomes that

Table 1. Validated Outcome Measures of Quality of Life and Symptom Control for Cancer Patients Potentially Applicable to the Palliative Population

Measure	Characteristics
Quality of Life Index ¹⁰⁰	Physician rated scale with 5 subscales: activity, daily living, health, support, outlook. Tentative utility weights available ¹⁰¹
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (QLQ-C30) ⁴¹	33-item tool with 9 subscale domains including physical, social, disease symptoms, global quality of life
Functional Living Index—Cancer (FLIC) ¹⁰²	22-item scale, “global construct of functional quality of life,” total score only
Functional Assessment of Cancer Therapy (FACT) ⁴⁵	28 items generic core, multiple specific subscales, including symptoms
Linear Analogue Self-Assessment Scale (LASA)	Symptom, mood, physical, social domains: advanced breast cancer ¹⁰³ ; colostomy patients ¹⁰⁴
Quality-Adjusted Time Without Symptoms and Toxicity (Q-TWiST) ¹⁰⁵	Utility based, discounts survival time, operable breast cancer
Gastrointestinal Quality of Life Index (GQLI) ¹⁰⁶	36-item index specific to gastrointestinal disorders
McGill Quality of Life Questionnaire (MQOL) ³⁸	16 items, 4 domains: physical, psychological, existential well-being, support. Created for a palliative care population
Missoula-Vitas Quality of Life Index—Advanced Illness ³⁹	25 items, created for a terminally ill population
Medical Outcomes Survey—Short Form (MOS-SF-36) ¹⁰⁷	36-item questionnaire, validated in many different populations
Spitzer Uniscale ^{100,108}	Single item: overall quality of life
Edmonton Symptom Assessment Scale (ESAS) ⁴⁰	10 items, numeric, for repeated use. Created for a palliative care population
Memorial Symptom Assessment Scale ^{43,44}	32-item scale that contains physical, psychological, and global distress sub-scales
Rotterdam Symptom Checklist ⁴⁶	34-item symptom scale

address the unique characteristics of palliative care research are needed to help health care providers improve the quality of palliative care in the ICU.

Assessment of new procedures. Ongoing developments in the fields of minimally invasive surgery and interventional radiology allow surgeons to select from an increasingly wider spectrum of procedures, with differing levels of invasiveness, anesthetic requirements, technical complexity, and attendant risk. Less invasive procedures may be associated with lower morbidity, which is extremely important in surgical palliation. There should be active research into the development and assessment of new interventional modalities for palliative patients.

Patient decision-making

Understanding patient preference. An important potential area of research is an improved understanding of patient preference. Since the goals of patient care should be the relief of suffering and improvement in quality of life, the patient's own perceptions and wishes are perhaps the most crucial determinants in procedure selection, yet the care provided to patients is often not consistent with their preferences. Instead, it is associated

with factors other than patient preferences or prognoses.⁵¹ Studied prospectively by SUPPORT investigators, physicians know patient preferences about life-sustaining treatment less than 40% of the time.⁴⁹

Patient preferences have been shown to be far more complex and dynamic than previously appreciated.⁵² Patient treatment choices are influenced by what the patient and family understand about the disease and prognosis. Weeks et al⁷ showed that the decision about whether or not cancer patients should have aggressive therapy related to their perception of their own survival. Cancer patients tended to overestimate their survival; those who thought that there was at least a 10% chance that they would die within 6 months were more likely to favor less aggressive therapies. If patient preferences about the trade-offs between the risks and benefits associated with alternative treatment strategies are based on inaccurate perceptions of prognosis, treatment choices may not reflect each patient's true values.⁷ The patient's decision can also be influenced by how the clinical issues are framed by the surgeon.

Decision aids. Tools such as decision aids have been developed to improve patient knowledge, reduce deci-

sional conflict, and stimulate patients to be more active in decision-making.⁵³ Thus far these tools have not led to a decrease in anxiety and have not improved patient satisfaction with care.⁵⁴

Informed consent. In order to have fully informed consent, the patient and family must have a realistic understanding of the goals of treatment and of their prognosis with and without treatment. At the time of a proposed palliative intervention, this is often not the case, and unrealistic expectations of cure are often present.⁵⁵ In critical care settings, surgeons are often brought in as consultants in dire emergencies where the psychosocial conditions of stress and pain create a sub-optimal environment for objective discussion. The above variables create an environment where optimal informed consent may not be possible.

Family and surrogate decision-making. In critically ill patients, discussions about patient preferences are often held with surrogate decision-makers, perhaps because they are postponed until the patient is unable to participate. Problems with surrogate decision-makers include their availability, knowledge of patient desires, and an overestimation of patient's wishes for resuscitation.⁵⁶⁻⁵⁸ Use of the family conference in a structured way is one method to improve communication and satisfaction with palliative care.⁵⁹

It would be valuable to understand more clearly the major variables that lead to surgical decisions that later become associated with patient/surrogate dissatisfaction or unnecessary utilization of health care resources. Clinical research in palliative surgery may focus on investigating tools that can enhance the ability of the surgeons to accurately determine patient/surrogate preferences and minimize the influence of compounding factors in decision-making, such as emotional guilt, denial, cultural bias, and misunderstanding of prognostication. In end-of-life clinical settings, the need for such research is even greater, as there appears to be significant shortcomings with DNR orders, physician knowledge of patient preferences to forgo resuscitation, delay in withdrawal of support, and inadequate pain management.⁴⁹

End-of-life decision-making

Advance directives. Decision-making at the end of life is more difficult if patients are unable to articulate their goals. An advance directive provides patients with the opportunity to express their own values and preferences. Unfortunately, vague nomenclature and changing

circumstances may make advance directives difficult to apply and limit their usefulness in practice.⁶⁰ More work is needed in this area to assist surgeons in dealing with these difficult situations.

Withdrawal of support. The decision to withdraw life-sustaining technology, medication, nutrition, or hydration is the subject of ongoing investigation.⁶¹⁻⁶⁵

Symptom management

There are a variety of surgical procedures available to manage pain and other symptoms which range the spectrum of invasiveness, from percutaneous interventions under radiological guidance to open surgery.⁶⁶ Other options for management are often available, such as chemotherapy, radiation, and other modalities. It is only by applying rigorous clinical research techniques to assess and compare these modalities that we are able to recommend the treatment that will provide the best quality of life for our patients.

Pain. The previous two decades have seen an explosion of clinical interest in pain management. Pain is a ubiquitous physical complaint, now a "fifth" vital sign mandated by the JCAHO to be monitored on all patients. Surgeons encounter pain as a formidable clinical dilemma in a number of settings. There is a need to explore the precise role of surgical intervention—whether by traditional "open" or minimally invasive surgical approach—in many pain syndromes. There is potential for an increased role for procedures such as thoracoscopic splachnicectomy for malignant visceral pain, and neurectomies for refractory postoperative inguinal neuropathic pain.

A landmark example is a study by Lillemoe and associates, from Johns Hopkins, who, in 1993, reported the results of a prospective, randomized, double-blind study of intraoperative chemical splachnicectomy.⁶⁷ They evaluated the effects of celiac plexus injection with 50% alcohol versus placebo injection in patients with unresectable pancreatic cancer. Mean pain scores were significantly lower in the alcohol group at repeated follow-up, with no increased morbidity. In patients without preoperative pain, alcohol delayed or prevented the onset of pain. Alcohol injection significantly reduced existing pain for patients with significant preoperative pain. Most unexpectedly, patients with preexisting pain who received alcohol showed a significant improvement in survival. Unfortunately, this exciting work has yet to be repeated in the surgical literature, and splachnicectomy

currently is not part of the routine management of patients with advanced pancreatic cancer at most institutions. A retrospective study from the Mayo Clinic in 1997 reported that only 15% of 292 patients with pancreatic cancer received neurolytic celiac plexus block, suggesting a significant under-utilization of a well-described palliative procedure.⁶⁸

Studies of pain in the ICU have shown that a significant number of patients have poor symptom control at the end of life. In a group of cancer patients with a 32% ICU mortality and 55% in-hospital mortality, 56% reported moderate to severe pain. Discomfort, unsatisfied thirst, difficulty sleeping, and anxiety occurred even more frequently.⁶⁹ This study, which assessed concurrent symptoms prospectively, confirmed previous retrospective studies.^{70,71} Patient-reported pain scores differed significantly from those reported by physicians and nurses, confirming the importance of this outcome measure as a valid indicator of the quality of palliative care in the ICU.⁷²

Non-pain symptoms. There are a variety of other symptoms that cause significant distress in palliative patients. Asthenia, chronic nausea, anorexia, and delirium were all reported as being more distressful than pain in a palliative cancer patient population.⁷³ Surgical interventions may play a significant role in the management of many symptoms, such as for the relief of obstruction, bleeding, and local tumor effects.⁶⁶ Exciting developments in the understanding of cachexia have resulted in an explosion in research into its management.⁷⁴⁻⁷⁶ Precise indications for surgical interventions must be delineated. For patients with significant co-morbidities whose long-term survival is tenuous, the palliative surgeon's ability to offer significant symptom relief through intensive medical or procedural intervention may add an alternative to the traditional dichotomy of "surgery-or-no-surgery" options.

Communication

Breaking bad news. Communication may be particularly challenged in the setting of "breaking bad news." The patients and/or surrogates may not fully comprehend the finality of the news of advanced cancer, for example, and physicians are often loath to take away the last vestige of hope, thus together they are susceptible to pursue a course of therapy with unrealistic goals. Although much has been written about breaking bad news in clinical medicine, empirical data are lacking in terms

of beneficial methods of communicating negative clinical results.⁷⁷

Cross-cultural issues. There is considerable variation between how people of different religions and ethnic backgrounds approach a terminal illness. For example, a devout Muslim may believe that death is a part of Allah's plan and to struggle against it is wrong. In Mediterranean cultures, families often ask that the diagnosis of a terminal illness be kept from the patient in the belief that this knowledge will hasten death. These attitudes may lead to conflict with the health care team. Because knowledge and understanding of a patient's personal cultural, spiritual, and religious background is an important part of providing good patient care, such differences are an important area of clinical research.

Communication with family and caregivers. Communication relevant for study includes communication between family and physician as well as the management of intra-familial conflict.

Inter- and intra-disciplinary team communication. Because the needs of palliative patients are many, they are often cared for by a multidisciplinary team involving physicians, nurses, social workers, physiotherapists, occupational therapists, chaplains, and others. This interaction provides fertile ground for research, in particular in the areas of communication and delegation of responsibility, especially applicable as the multidisciplinary approach is applied to other areas of clinical medicine.

Processes of care

Cost effectiveness. Increasing costs of health care have led to an explosion in research that explores the accountability of health care dollars. Increasingly, economic analyses will help make resource allocation decisions. The majority of health care resources are expended in the last few months of life, yet little is known about the effectiveness or cost of various end-of-life therapies.^{62,78,79} Cost-effectiveness analysis will continue to be the most popular form of economic analysis because it combines the results (effectiveness of treatment) with the costs of achieving the results. Cost-effectiveness studies of palliative therapy must struggle with the problem of calculating a cost-effectiveness ratio when there is no good measurement for valuing the quality of death.⁸⁰ This is an area where surgical palliative research is only beginning.

Suffering among health care professionals. Factors that personally influence health care professionals may

significantly impact their ability to provide quality care, and therefore, their professional experiences are a valid subject for palliative care research. A survey of surgeons found that they struggled with their role as givers of bad news.⁸¹ The impact on health professionals of dealing with death and dying is an area of potential research which is only now beginning to be addressed.^{82,83}

Surgical education about palliative care

Medical students, residency, practicing clinicians. Historically, surgical housestaff have received little formal training about palliative care. While an experienced attending surgeon may serve as an educator in this area, only 50% of senior surgical residents reported ever discussing this topic with their attending surgeons.⁸⁴ Less than half of a group of surgical residents surveyed were competent in cancer pain management; of note, there was no improvement as the residents moved to more senior levels.^{85,86} The education of surgical residents and practicing clinicians is described elsewhere in this report and is an active area of activity.

Comparison of educational modalities. Because this is a new area in surgical education, an active area of research is how best to teach palliative care to surgeons at various stages of their development, whether as medical students, surgical residents, or practicing clinicians. Choices include role-play, lectures, seminars, or small group discussions, and case-based versus other approaches.

Methodologic issues for clinical surgical palliative research

The study of the care of patients who are dying from their disease offers a unique set of challenges. The disease course is frequently characterized by constantly changing symptoms and a relatively short period of final illness. Difficulty in predicting time to death makes decision-making and patient assessment more difficult. Although the best assessment of the patient's own quality of life comes from the patient, this can be difficult if not impossible to obtain as the patient approaches the terminal phase of his or her illness.

There are a number of significant barriers to palliative care research.⁸⁷ Some clinicians argue that research on patients facing the end of life may not be morally justifiable⁸⁸ although others disagree.⁸⁹ Evaluation for clinical trial eligibility can be unduly invasive, and participation in trials often requires more tests than what is usually performed in clinical practice, placing a signifi-

cant burden on an already ill patient. Further barriers to palliative care research for surgeons include financial constraints for care, patterns of referral to surgeons (or other palliative care specialists), and cultural factors influencing palliative care.⁹⁰ Funding deficiencies are only now beginning to be addressed. For example, only 0.9% of the total 1999 NCI budget went to palliative and hospice care research.⁹¹

Assessment of outcomes. The methodology required for the proper scientific evaluation of studies using quality of life and other subjective outcome measures is still an evolving discipline.^{87,92} While this can make it more challenging for clinicians to perform such trials, it also provides a tremendous opportunity for development in clinical research methodology.

Trial design. Because of the nature of the palliative patient population, it may not always be possible to design randomized clinical trials to assess the effect of interventions. Other trial designs such as parallel or crossover case control or case cohort studies, methodologically planned and carried out, may be more appropriate and just as valuable in answering clinical dilemmas for palliative patients.⁹³

Ethics. Ethical challenges, while paramount in all research, may be especially complex for clinical research for patients in the terminal phase of their illness.⁹⁴⁻⁹⁶ It may be more difficult to assess risks and benefits. Terminally ill patients often have unstable mental states, and obtaining proxy consents for trials from a designated decision-maker may be problematic. In fact, Warren et al discovered that proxy decision-makers are likely to allow a relative to participate in a trial which they thought the patient him- or herself would not agree to or that they themselves would be unwilling to enter.⁹⁷ Surgical issues mandate special consideration.^{90,98}

Conclusions

Surgical clinical research into the care of palliative patients is especially relevant in a rapidly aging society as in North America, and it offers a unique set of challenges and opportunities. Surgical dimensions worthy of clinical investigation include symptom relief and quality of life, communication and surgical decision-making, quality of process of care, and effectiveness of surgical education. Recognizing the current deficiencies in palliative surgical care, surgeons may aim for improvement by questioning the appropriate goals of treatment. True innovations in surgical care will require rigorous clinical

investigation using pertinent outcome measures. A research agenda has already been developed for end-of-life care in the Intensive Care Unit.⁹⁹ The present discussion attempts to begin to address a clinical research agenda for the future of palliative surgery.

It is a privilege when surgeons are requested to become intimately involved in patients' lives at the time that they are most vulnerable. It is important in such settings to determine the appropriate clinical endpoints and to use them rigorously to assess the role of surgical intervention. By participating in properly designed clinical studies, surgeons will increase their understanding of the variables that influence the end-of-life experience and improve the quality of the care delivered to all of our surgical patients.

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V. THE FUTURE OF SURGICAL PALLIATIVE CARE

Although in its narrowest definition palliative care pertains to addressing the total needs of the terminally ill patient, there is no reason that as a philosophy of care it should not extend well beyond the boundaries of care for the terminally ill surgical patient, and, ultimately, transform most aspects of surgical practice. Clearly the immediate concerns of this report, as outlined above, relate to the dissemination of information about basic palliative care, both knowledge and skills, to practicing surgeons, and to those receiving post-graduate training in surgery with a focus on care of the terminally ill surgical patient.

Surgical research in palliative care implies a form of palliative care practice by virtue of its being delivered by surgeons using surgical techniques or skills that may have unique features. Is there a unique contribution that the surgical community can bring to palliative care, not only in its narrowest sense (ie, care of the terminally ill) but also with regard to the broader concept of palliation, which is relief of suffering?

To illustrate this concept, it may be helpful to ask certain questions: (1) Are the procedures performed within a particular surgical discipline palliative in any way? (2) Is a given surgical patient suffering prior to an operation, and does the operation relieve suffering as its primary endpoint? (3) Is the surgical therapy reversing a disorder, or primarily relieving symptoms, distress, or disability associated with the disorder; or does it accomplish both outcomes? and (4) Is the surgeon making use of existing palliative care delivery systems (ie, hospice, pastoral care, social work, etc) for the support of the patient and family as well as the surgeon?

These questions help to illustrate the potential difficulty of defining the true goals of any surgical therapy. Two specific examples might further illustrate the issue.

A large cancer procedure may be curative, but the cure may come at a cost of producing long-term disability, disfigurement, or some other form of maiming a patient, resulting in long-term suffering. On the other hand, a loop colostomy to relieve a malignant bowel obstruction in a patient who is terminally ill with an advanced malignancy will only relieve intense physical distress from the bowel obstruction without altering the course of the underlying disease.

If a given operation is used primarily as treatment for symptoms of a chronic disease (eg, arthritic pain relieved by total joint replacement or severe life-limiting claudication relieved by peripheral vascular surgery), or the surgical therapy is not “definitive,” issues of palliation rather than cure become the predominant focus.

There is no reason why the cardinal features of palliative care (relief of suffering in the form of physical, emotional, social, or spiritual distress, and respect for individual patient autonomy) should not extend to patients before their last year of life. Because of the very intimate nature of the relationship between surgeon and patient, where patient experiences of care can heavily color the outcomes, awareness and use of palliative care principles by the surgeon are all the more important.

Ultimately, palliative care concepts and approaches to care should permeate all aspects of the care of surgical patients from the design of new procedures and development of new technologies and their use, to the process of care within the operating room, during the postoperative period (particularly in the intensive care unit), and, most especially, in the process of informed consent. Although hospital accrediting organizations' efforts to make pain a fifth vital sign are highly laudable, pain management alone is not enough.

Palliative care concepts should so permeate surgical thinking that mortality/morbidity conferences (indeed, the way surgical outcomes are assessed entirely) would be transformed. Such a transformation would include recognition of different categories of surgical therapeutic outcomes: curative, curative with residual symptoms or functional deficit, palliative to relieve symptoms, or palliative for other reasons (eg, increase functional status or prolong life). Outcomes questions would then address each of these categories in terms of whether the primary goal of the procedure was actually met.

In discussions of mortality and morbidity, the same approach would pertain so that not only death might be assessed as an outcome, but also the kind (quality) of

death would be an important part of the discussion. (Were patient symptoms and physical distress, especially pain, controlled prior to death? If the patient had an advance directive, was it honored?)

Once such principles have been integrated within the practice, education, and culture of the surgical disciplines, surgeons will be fully prepared to fulfill the time-honored aphorism that lies at the heart of our profession:

To cure sometimes.

To relieve often.

To comfort always.

VI. RECOMMENDATIONS

The Surgeons Palliative Care Workgroup makes the following recommendations to the following groups: surgical organizations, surgical educators, surgical researchers.

Surgical organizations

1. Needs assessment of the practicing surgeon through the ACS Fellowship regarding knowledge and attitudes of surgical palliative care.
2. Needs assessment of surgeons to identify barriers to effective palliative and end-of-life care.
3. American College of Surgeons–sponsored national conference on surgical palliative care.
4. An ACS consensus statement defining surgical palliative care and “palliative” in surgical procedures and practice to establish uniformity in research and outcomes language.
5. Incorporation of a palliative care “Speaker’s Bureau” as one of the services provided by the Education Committee of the ACS.
6. Creation of palliative care visiting professorships, sponsored by the ACS, matching qualified individuals with surgical training programs.
7. Representation of Task Force members to the ACS Commission on Cancer and Committee on Trauma (COT).
8. Liaison with other disciplines: nursing organizations, hospice.
9. Liaison with international surgical organizations; eg, Royal College of Surgeons.
10. Liaison with palliative care societies.

Surgical educators

1. Further needs assessment of both the surgeon in practice and surgeon in training is required to develop targeted educational efforts and systems-based changes in surgical palliative care.
2. Develop “Advance Palliative Life Support Course,” modi-

fication of AMA’s EPEC (Education for Physicians on End-of-Life Care) program for surgeons in practice.

3. Recruit more than 50% surgery residency programs to the End-of-Life Education Project for Postgraduate Training Programs.
4. Develop and legitimize surgical palliative care as an academic discipline and subspecialty within the specialties of surgery and palliative care.
5. Include surgical palliative care as a concept and practice in surgical textbooks and palliative care literature.
6. Add palliative care questions on surgery board examinations, SESAP, and ABSITE exams.

Surgical researchers

1. Continue to encourage submission of surgical palliative care articles and reports for publication in surgical and palliative care literature.
2. Establish funding sources and opportunities for surgical palliative care research.
3. Establish research fellowship/scholars program for surgeons in training and junior faculty in surgical palliative care.
4. Write a consensus statement on research agenda in surgical palliative care, identifying critical areas for research development such as quality of life outcomes, decision making, pain and symptom management, communication, etc.

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Project Coordinator, Office of Evidence-Based Surgery

Appendix 2. Charter for the Surgical Palliative Care Workgroup

PROJECT DEFINITION

The purpose of the workgroup is to facilitate introduction of the precepts and techniques of palliative care to surgical practice and education in the United States and Canada. The workgroup will do this by bringing together surgeons with demonstrated interest in palliative care to share resources, strategies, and expertise, and in so doing act as a catalyst for change.

SUCCESS CRITERIA

- An accurate description of the current state of palliative care in surgery, barriers to its growth, and opportunities for change.
- Dissemination of workgroup results; demonstrated interest and engagement of surgical specialists and educators.
- Increases in presentations and publication of information related to palliative care principles and techniques in surgical practice; arrangements for their promulgation on an ongoing basis.
- Development of content domains and quality benchmarks applicable to surgical palliative care.
- Development of a research agenda regarding systems, models, and elements of surgical palliative care.
- Development of educational materials appropriate for students, residents, and practitioners.
- Establishment of a Standing Committee for Surgical Palliative Care in the American College of Surgeons.

CONSTITUENTS AND BENEFITS

- Surgical patients and families—Improving the continuum of care and quality of life during and after surgical care.
- Surgeons and associated surgical disciplines—Availability of tools to improve end-of-life care for surgical patients and their families adapted as necessary for the specialty. Better understanding of the role of surgery in the continuum of

care, and an understanding of patient and family need for life closure and bereavement when applicable.

- Surgeons in training—Incorporation of the principles of surgical palliative care in the formative years of training increases the likelihood of its appropriate application in subsequent practice.
- American College of Surgeons—Fulfillment of the commitment made by the College in its *Statement of Principles of Care at End of Life* (Board of Regents, Feb. 1998).
- Workgroup members—Seen as leaders in the field, sharing their expertise in publications, presentations, and practices.
- RWJF—Seen as improving care in this highly publicized arena. Benefit by reaching overarching goal of improving end-of-life care for patients and families. Publication citations of workgroup results. Ease in funding second phase of workgroup process and funding of dissemination phase of workgroup process.

ORGANIZATIONAL PRIORITIES

- Select workgroup chairs
- Select workgroup members
- Conduct initial organizational meeting
- Provide project management and oversight to the workgroup
- Advance the workgroup process by convening a series of 12 conference calls among workgroup members over a 12-month period
- Conduct a final consensus conference
- Plan for dissemination of workgroup results and presentation of a “White Paper” on surgical palliative care
- Incorporation of the Workgroup into the structure of the American College of Surgeons

SCOPE

The Surgical Palliative Care Workgroup meets a number of the Promoting Excellence in End-of-Life Care National Program Office priorities by gathering data and tools that:

Demonstrate surgeons gain competence in functioning as part of an interdisciplinary team with goals and objectives consistent with the American College of Surgeons’ *Statement on Principles Guiding Care at the End of Life*.

SYSTEM IMPLICATIONS

The Surgical Palliative Care Workgroup will need to interact with a number of different audiences to ensure adequate communication and dissemination of the

project results. These, among others yet to be identified, are as follows:

The Robert Wood Johnson Foundation
 The American College of Surgeons
 The American Board of Surgery
 Association of Surgical Educators
 The Royal College of Surgeons, Canada

AUTHORITY AND RESPONSIBILITY

The Promoting Excellence in End-of-Life Care National Program Office (NPO) has contracted with the American College of Surgeons to endorse the Surgical Palliative Care Workgroup. As such, the NPO maintains overall responsibility for the conduct and success of this project, but delegates the day to day responsibility for workgroup activities to the workgroup and the representatives of the American College of Surgeons.

The Surgical Palliative Care Workgroup must provide written report of workgroup progress on a quarterly basis, and must respond to NPO questions or concerns regarding the workgroup and its activities as needed.

Team leaders

Geoffrey P. Dunn, MD, FACS
 Robert A. Milch, MD, FACS

Appendix 3. Surgeons Palliative Care Workgroup Sub-Groups

Needs Assessment

Alexandra Easson
 Joan Huffman
 Robert Krouse
 Larry McCahill
 Anne Mosenthal
 Gretchen Purcell

Symposia Planning

ACS representative
 Dan Hinshaw
 K. Francis Lee
 Anne Mosenthal

Residency Education

Peter Angelos
 Karen Brasel
 Geoff Dunn
 Robert Milch
 David Weissman

JACS

Tim Buckman
 Geoff Dunn
 Dan Hinshaw
 Wendy Husser

Liaison Committee

ACS representative
 Joe Civetta
 Alexandra Easson
 Tom Krizek
 Palliative Care Interest Group
 Dan Hinshaw
 Dennis Johnson
 Robert Milch
 Reed Thompson

Executive Committee

ACS representative
 Sue Bumagin
 Ira Byock
 Geoff Dunn

Appendix 4. Palliative Care Symposia Presented at the American College of Surgeons Clinical Congresses, October 2000–April 2003

October 2000	Palliative Care by the Surgeon: Patient Selection and Management
October 2001	Palliative Care: How I Do It
April 2002	Palliative Care in Surgery
October 2002	Medical Futility and Withdrawal of Care: When Do We Stop, and How Do We Do It?
April 2003	Clinical Palliative Care in the Trenches

Appendix 5. End-of-Life Education Project for Post-Graduate Training Programs, Medical College of Wisconsin

UMDNJ-University Hospital
 185 S Orange Ave
 Newark, NJ 07103

University of Arizona
 3601 S 6th Ave
 SAVAHCS 2-112
 Tucson, AZ

Medical College of Wisconsin
 9200 W Wisconsin Ave
 Milwaukee, WI 53226

University of Connecticut
263 Farmington Ave
MC-3955
Farmington, CT 06030

Northwestern University
201 E Huron St
Galter 10-105
Chicago, IL

University of Toronto
Mt Sinai Hospital
600 University Ave, Ste 440
Toronto, Canada

Baystate Medical Center
759 Chestnut St
Springfield, MA 01199

SUNY Buffalo
3 Gates Circle
Buffalo, NY 14207

Vanderbilt University Medical Center
1161 21st Ave S
D5203 MCN
Nashville, TN 37232-2577

University of Tennessee
1924 Alco Hwy, Box U-11
Knoxville, TN 37920

Finch University of Health Science/The Chicago Medical Center
2750 W 15th St
Chicago, IL 60608

Stony Brook University Hospital & Medical Center
Health Science Center T19-060
Stony Brook, NY 11794

Johns Hopkins Hospital
600 N Wolfe St
Halsted 614
Baltimore, MD 21287-5614

UT Southwestern Medical Center
5323 Harry Hines Blvd
Dallas, TX 75390-9031

Wake Forest University
Medical Center Blvd
Winston-Salem, NC 27157

University of Oklahoma College of Medicine
4502 E 41st St
Tulsa, OK 74135

Georgetown University Hospital
3800 Reservoir Rd NW
Washington, DC 20007

New York Presbyterian Hospital, Columbus
MHB 7GN 403
177 Fort Washington Ave
New York, NY 10032

Wright State University
1 Wyoming St, Suite 7000 CHE
Dayton, OH 45409

The Western Pennsylvania Hospital
4800 Friendship Ave
Pittsburgh, PA 15224

Wayne State University
4201 St Antoine RM 3V-26
Detroit, MI 48201

University of Texas Medical Branch
301 University Blvd
Galveston, TX 77555-0527

University of South Carolina
2 Richland Medical Park #300
Columbia, SC 29203

Mayo Clinic
200 First St SW
Rochester, MN 55905

Thomas Jefferson University Hospital
1100 Walnut St
Philadelphia, PA 19107

SUNY Downstate
450 Clarkson Ave, Box 40
Brooklyn, NY 11203

University of Oklahoma
PO Box 26901, WP2470
Oklahoma City, OK 73190