



Translating knowledge and skills into effective chaplaincy practice and care for the human spirit.

HealthCare Chaplaincy Network

### **Current** Issue

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This OPEN ACCESS issue of *PlainViews* introduces our new design with articles that bring you information about the recent landmark conference "Caring for the Human Spirit: Driving the Research Agenda for Spiritual Care in Health Care" sponsored by HealthCare Chaplaincy Network with funding by the John Templeton Foundation. The summaries of the research and keynotes presented at this conference will inspire you in your professional practice.

Be sure to share this OPEN ACCESS issue with your colleagues by forwarding this email.

From the Editor: A New Look and Looking Forward

Managing Editor Sue Wintz introduces the new site and design for PlainViews and the focus of this special open access issue.

# Articles

### It's a New Day

George Handzo on the background for and meaning of the landmark conference, Caring for the Human Spirit: Driving the Research Agenda for Spiritual Care in Health Care.

# "This was not Just a Conference. This was a transformative experience."

Jim Siegel, through quotes from participants, shares the flavor and learning experienced by conference attendees.

### Keynote Speakers Energize Conference

Highlights from the four keynote speakers who energized the participants, both present and virtual, of the conference.

### How Chaplain Care Influences Well-Being and Decision-Making for People Facing Serious Illness

A study by the Dana Farber Cancer Institute in Boston, Massachusetts focused on the presence and helpfulness of chaplaincy visits for advanced cancer patients.

### Understanding Pediatric Chaplaincy in Crisis Situations

Children's Mercy Hospital in Kansas City, Missouri's study demonstrated that, with the help of chaplains, their own relationship with God changed.

### Even Non-Religious Caregivers Feel Supported by Chaplains

The goal of a study by Duke University Medical Center in Durham, North Carolina was to conduct a pilot test of the feasibility and acceptability of the Caregiver Outlook Intervention.

## The Chaplain's Role Goes Beyond Spiritual Care When Treating the Seriously III

The goal of Emory University's study was to understand the impact of hospital chaplains on end-of-life (EOL) decision-making in a diverse urban population.

### UCSF Researchers Take "Spiritual AIM" at Advanced Cancer

The University of California San Francisco's study was designed to address a major gap in chaplaincy research: defining the nature of spiritual care.

### **Developing Taxonomy of Chaplain Activities**

A groundbreaking study to identify an inventory of chaplain activities done by Advocate Health Care in Chicago, Illinois provides an opportunity for chaplains to add to the process of developing a common taxonomy.

## Online Help Now Available for People in Spiritual Distress from Serious Illness, Trauma, or Grief

HealthCare Chaplaincy Network launches a new site for online health care chaplain services.

### From the Editor: A New Look and Looking Forward

| Next

#### With this issue, *PlainViews®* reveals its new design and website after several months of planning.

Our desire was to bring you a new, up-to-date look with a more customer-friendly site, and we believe that we have found the way in which to do so. While easier to use, you will likely find a small learning curve in navigating the site, so I hope you'll take the time to become familiar with the new features.

In the weeks ahead we will be navigating over the archives of issues, which will include a much easier-to-use search engine to guide you in finding topics and articles to strengthen you in your practice. They are still available for you to view <u>here</u>.

One of the capabilities of our new site is the ability to create a forum where readers will be able to discuss articles in more depth. Watch for the creation of this in the weeks to come.



This premier issue on our new site contains articles about last week's (March 31-April 3) landmark conference "Caring for the Human Spirit: Driving the Research Agenda for Spiritual Care in Health Care" sponsored by HealthCare Chaplaincy Network with funding by the John Templeton Foundation.

While unable to bring the full depth of information that was shared at the conference, including the unique opportunities for dialogue from presenters, researchers, and attendees representing an international audience, we believe that you will be excited as you read the articles. As George Handzo, who chaired and facilitated the conference writes in his piece, the result of the gathering is the beginning of a "new day" in building the evidence base for spiritual care and chaplaincy care.

Plans are not complete but we plan to make conference materials available to attendees and the general public in the near future. Watch the HeathCare Chaplaincy Network **website** for details.

To ensure that this information reaches the chaplaincy community, this entire issue is open access, so be sure to share it with your colleagues from both within chaplaincy, other disciplines, and administration.

We look forward to the future, and we invite you to be active in the journey:

Be bold in claiming the work that you do. Many chaplains think that they are not writers, however writing is like talking: put into words the work that you do, the challenges that you face, and the issues and topics that you would like colleagues to engage with you around.

Submit an article for PlainViews® about your professional work,

best practices, QI projects, research and other topics. (See the article submission guidelines for more information). Now more than ever there is interest in the work chaplains do to care for the human spirit and bring comfort to those in need.

Engage in dialogue with authors by sharing your comments; it is by sharing our knowledge that we all gain wisdom.

Sue Wintz is the Managing Editor of *PlainViews* and Director, Professional and Community Education, for HealthCare Chaplaincy Network. She is board certified by the Association of Professional Chaplains and is a past president of that organization. Follow her on Twitter at @SueWintz.

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Next

Back to top

### It's a New Day

Previous | Next

#### Editor's Note: George Handzo BCC CSSBB regularly blogs on his website.

This past week, HealthCare Chaplaincy Network (HCCN) with funding from the John Templeton Foundation hosted a landmark conference titled "Caring for the Human Spirit: Driving the Research Agenda for Spiritual Care in Health Care." The event was originally conceived as the capstone event for a three year grant from the John Templeton Foundation that funded six foundational studies which begin to lay the foundation for the workings of spiritual care and chaplaincy care in health care and begin to develop a cadre of health care chaplains engaged in this research.



Certainly, the event more than satisfied its original purpose. The six presentations from the research groups were extraordinary in both the sophistication and power of the results and in the rigor and professionalism with which they were presented. The question of whether professional chaplains can make significant contributions to research in the field and help advance the evidence base for chaplaincy care is now answered in the affirmative. The question of whether spiritual care can be researched productively is also answered in the affirmative.

However, the event turned out to be much more than simply a reporting out of six research groups- as ground breaking as that reporting was. When HCCN issued its call for proposals on this project, we really didn't know what the quality and quantity of the response was going to be. One guess was twenty proposals would be generated and this guess was generally thought to be optimistic. The call generated 72 responses of which 56 were judged of high enough quality to be presented to the review panel as finalists. Thus, it became immediately clear that there is a tremendous interest in this kind of research, much of it from highly sophisticated research groups.

Given this beginning to the project, it should not have been a surprise that the conference also drew a response far beyond what many would have guessed. Despite a very short lead time for the publicity and the costs of coming to a conference in New York City, the conference drew close to 250 attendees from all over the US and several other countries with another significant audience attending though live streaming video. Anecdotally, the response of those attendees was overwhelmingly positive.

So what does this all mean? History will provide the best answer to this question of course but I am impressed by the similarities to integrating spiritual care in health care. Almost every survey published to date is clear that a majority of patients and family care givers want their spiritual and religious needs integrated into their health care- especially as they make decisions about how that care is to proceed. An increasing number of directives and guidelines including from such prestigious bodies as the World Health Organization promote the universal availability of palliative care and with it the inclusion of spiritual care. And yet, many people who could benefit from palliative care, including in the US, do not get it and many who get something billed as palliative care do not get good spiritual care as part of that care.

So we clearly have a lack of alignment between what many patients and many health care authorities think ought to happen and what is happening. Why? One issue has to do with available workforce. Even hospitals that are looking to hire a physician board certified in palliative care often have trouble finding one. One influential palliative care guidelines panel lists a board certified chaplain as "preferred" rather than required because they were aware that it is currently impossible for many palliative care teams to find a board certified chaplain with the proper training. One initiative that is needed here is to continue to educate palliative care providers about the special contributions of palliative care trained, board certified chaplains so they give preference in hiring to those with these credentials which should result in more chaplains seeking those credentials. Hopefully the

conference results can help in that regard.

But the other issue is developing the evidence base for spiritual care in palliative care. This conference made a huge contribution but the body of evidence is still very small and not yet at a level that should be considered persuasive. Getting over this barrier is a "chicken and egg" problem. Many funders, especially federal funders,

want to see some "evidence" that this line of research is worthwhile but funding is needed to develop that evidence. We need to find courageous funders who will follow the lead of the John Templeton Foundation in building this field.

So is this a new day? Absolutely! Have we achieved our goals of developing the work force and the evidence base for spiritual care and chaplaincy care? No. However, I believe we have now answered the question of whether these goals can be attained. We need to push on because the progress will not happen of its own momentum. But I think we now have a committed community to develop the evidence and the practice models and we have encouraged a lot of chaplains and researchers that this journey is



important and worthwhile. Hopefully, we have also persuaded a few more funders and regulators to join the effort.

The Rev. George Handzo MDiv CSSBB is a board certified chaplain, and President, Handzo Consulting. He is also Director of Health Services Research & Quality at HealthCare Chaplaincy. George is a past president of the Association of Professional Chaplains.

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Back to top

### "This Was Not Just a Conference. This was a Transformative Experience"

Previous | Next

The headline is a direct quote from one participant and is the consensus of the 325 chaplains and other health care professionals who attended in person or by webcast the first global research conference on spiritual care in health care - "Caring for the Human Spirit: Driving the Research Agenda in Spiritual Care in Health Care."

The conference, sponsored by HealthCare Chaplaincy Network, was held March 31-April 3 at the New York Academy of Medicine and culminated a three-year long research and education effort funded by the John Templeton Foundation.



Participants were from throughout the United States, the United Kingdom, Australia, Belgium, India, Ireland, Canada, Kenya, and Namibia.

Announced at the conference were the results of six research studies from major academic centers across the United States on the role of chaplaincy care interventions. The studies represent the first collection of empirical data on the contributions of chaplains in health care.

"The presentations, dialogue, and energy at the conference were extraordinary," said Rev. Eric J. Hall, president and CEO of HealthCare Chaplaincy Network. "For many years, chaplains have done their work with a well-trained basis of knowledge which has, with experience, become intuitive. But the health care world demands data. These six research studies are a huge step forward in describing what chaplains do so that these interventions can be tested, measured, refined, and applied to better patient care."

"The conference also marked the birth of a global research consortium on the impact of spiritual care in health care," added Rev. Hall. "We have begun to establish collaborative relationships with organizations and individuals who are committed to quantifying and defining best practices. Something truly big has begun."

#### **Other Conference Participants Agree**

"The conference is a landmark in the progress of health care. The majority of Americans think their spiritual care is as important as their medical care when they are ill. That means we should be as careful and thorough in spiritual care as we are in medical care. This conference sets the field in the right direction." "The whole thrust of the scientific method is to move us from 'I think this is right' to 'I know this is right'. After 5000 years of medical care, the introduction of the scientific method to medicine in the early 20th century led to the extraordinary advances we enjoy today. Now, with the introduction of that method to spiritual care, I think we can expect a similar trajectory. I predict that, in the future, we will look back on this conference as a watershed moment in the same way we look back at the Flexner Report and its effect on physicians." - Charles F. von Gunten, MD, PhD, vice president of Medical Affairs, Hospice and Palliative Care for the Ohio Health System

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"Some colleagues and I recently completed a survey of over 700 chaplains. These chaplains reported strong support for an evidence-based approach to chaplaincy care. The number of chaplains who attended the conference this week, in person and virtually, and their enthusiasm, is further evidence of the emergence of a research-informed, evidence-based approach to chaplaincy. This is an exciting new paradigm for our profession." - George Fitchett, BCC, DMin, PhD, Professor and Director of Research, Department of Religion,

Health, and Human Values, Rush University Medical Center

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"I felt as though history was being made with this conference." - Margo Heda, Staff Chaplain, Department of Pastoral Care, Hospital for Special Surgery

"Our field must develop a robust, collaborative research base if we are to respond to and plan for the rapidly changing contexts in which we serve." - Trace Haythorn, Executive Director, Association for Clinical Pastoral Education

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"Rigorous research and its evidence based outcomes are the quantitative data needed to legitimize the qualitative benefits of

professional spiritual care. This conference brought together individuals from around the world and highlighted the outcomes of the six significant research projects funded by the John Templeton Foundation. The conference was the impetus for the formation a global research consortium which can only lead to better care of individuals. All of this leads to creating a caring community of which we are all committed." - Cecille Allman Asekoff, Executive Vice President, National Association of Jewish Chaplains

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"The conference was momentous, inspirational, and encouraging. It started right with the opening day which aptly rooted the value and validity of chaplaincy research in the global context with Dr. Kathleen Foley and effectively provided the call to professional persistence with long view of Dr. Jimmie C. Holland." "The presentations by the research team of the six funded projects were very instructive and promising. Witnessing researchers, physicians, other clinicians, and chaplains teaming together to improve the patient experience and outcomes was remarkable, encouraging, and inspiring." "Bravo to all involved whose inspiration, dedication, and commitment to chaplaincy research have resulted in a monumental step forward to ensure the highest quality care for the human spirit of those seeking health care today. Onward together!" - David A. Lichter, DMin, Executive Director, National Association of Catholic Chaplains

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"Regarding patient-centered care I think it's very important that chaplaincy is both spiritually-based and research-based. This conference contributes to that very much in a sense that if we are not research-based we are missing out on fundamental ground to stand on in contemporary health care. Chaplaincy will then be marginalized in a few years, and that does not help patients in spiritual pain and seeking spiritual wholeness." "We owe it to patients to not only deepen our spirituality as chaplains but to develop our professionalism. To do that we must know what people expect of us. We have to know what we offer. We have to be able to express and communicate it what we offer. The research findings presented at this conference have made a huge difference in starting to accomplish all that." "To me essential in the research that must be done is the unbreakable link between assessment, intervention, and outcomes. I'm very happy that several of the research studies presented at the conference respect this link across all three. That's one of the added values of this conference. Not only does it make chaplains hungry to do more research, as you can notice from the reactions of the people here at the conference, it shows the value of these first six research studies. This is the beginning and a pretty good start." - Anne Vandenhoeck, Coordinator of the European Council for Pastoral Care and Counseling, Chair of the Academic Center for Practical Theology Katholieke Universiteit Leuven (Belgium)

"Connecting with the global family of health care chaplains at this conference has been very valuable. As a

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researcher the importance of interdisciplinary research is a very strong theme coming out of it. That's very good, and I would like to see more research globally." - The Rev. Daniel Nuzum, Healthcare Chaplain (Ireland), Marymount



University Hospice, Bon Secours Hospital Cork, Diocesan Coordinator of Healthcare Chaplains in the Diocese of Cork, Cloyne, and Ross

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"What I've been trying to do in my practice is get changes to our curriculum to better prepare chaplaincy residents for professional chaplaincy. All of the research projects presented at the conference have implications for training. One of the issues has always been where's the proof if I get my students to do X, Y, and Z it will mean something different for the patient. So you start to see more projects that look at the outcomes of activities that chaplains participate in. That gives me more to work with as to determining what should be the curriculum to become a competent professional and board certified chaplain." "In CPE we've always had a tension between personal development and integration and professional practice. Because we haven't had a lot of evidence

on the professional practice side, we tend to stay on the personal development. We say that if people are self-aware and listen very carefully they will build the tools they need for their professional practice. We try to teach them to be learners. I try to build in practice elements, too." "We need to look at verbatim not only in terms of what you do as a professional chaplain but in terms of what would be helpful with the patient." "I'm hopeful we will know increasingly more and with greater confidence what is helpful in what we do." - Janet MacLean, ACPE Supervisor & Staff Chaplain, Advocate Christ Medical Center, Oak Lawn, Illinois

"When I first started my work in bioethics I had a fuzzy notion of what chaplaincy was all about. At this conference I have come to appreciate and respect all the work that chaplains do in all its dimensions. I have begun to see how crucial is the multidimensional role of the chaplain for communication with patients, families, the other members of the care team." - Dr. Michael McDuffie, Chair, Philosophy Department, California State University San Marcos

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"I came to the conference to gain statistics information to grow the program at the hospital in a suburban, rural setting where I work in central Washington State. So far I have gotten so much information. I feel well equipped to take information back. The investment was so well worth it in what I learned and the so many people I've met who are in similar situations as I and different situations. It's been well beyond any value that I could have imagined in advance." "I am already scheduling meetings with the vice presidents at the organizations where I work. I will meet with oncologists and other executives. We are a 226 bed facility and I am the sole full-time chaplain." - Laurie Oswalt, MDiv, Director of Spiritual Care, Chaplain, Certified Grief Recovery Specialist, Yakima Valley Memorial Hospital, Yakima, Washington

## "The conference was simply fantastic and hopefully a seminal meeting that will take us forward collectively to even greater heights." - Tony Powell, BA, MA, MSc, Researcher in Global Health, Nairobi, Kenya

"What I've gained at this conference has made the long air journey from Australia to come here, and traveling in 'Cattle Class' as my CPE colleague describes it, very well worth it. I was anticipating that there would be much learning. I've learned how research will help to further validate that chaplains do. My expectations have been met and exceeded. The diversity in what has been presented and the caliber of the presenters has been terrific." - Marie-Therese Daly, Chaplain, St. Vincent's Hospital, Sydney, Australia

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"The conference has been really exciting. It has been the first time to me to see the importance of research data on what we're doing. We must have the empirical data. But we cannot lose the sense of mystery, the

sense of mysticism, the sense of 'The Great Other' that by its definition transcends empirical science. We must

hold those two things together and make sure we keep the tension between the two. "It's been repeated so many times at this conference: we have to ask the right questions. So whatever we're doing in research in trying to understand what is the patient-chaplain interaction that we don't reduce it only to objective indicators and multivariate analysis. We need to be aware of the sense of mystery but that's alone is not enough, because that will keep us estranged from the others on the interdisciplinary health care team. The AIM research project (editor's note: The Spiritual Assessment and Intervention Model in Outpatient Palliative Care for Patients with Advanced Cancer by the University of California San Francisco team) seemed to keep the two pieces together – the things that can't easily be described such as reconciliation and the need for meaning but in a way that they can be



described. I think they got it." - Father Richard W. Bauer, MM, LCSW, Maryknoll Missioners, Windhoek, Namibia

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"The conference exceeded my expectations. The excitement and enthusiasm of the attendees was palpable. The presentations were very well received, and the feedback our (UCSF research) team received was uniformly positive and affirming - motivating me even more to move forward with further research." "Chaplains and other attendees got the message that research can enhance their practice and inform others of the importance and value of chaplaincy." - Laura B. Dunn, M.D., Professor, Department of Psychiatry, Gloria Hubner Endowed Chair in Psycho-Oncology, Director of Psycho-Oncology, UCSF Helen Diller Family Comprehensive Cancer Center, University of California, San Francisco

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"The conference exceeded my expectations, too. The physician speakers tied their comments directly to chaplaincy care, and tied our history with fascinating history of new movements in health care broadly." "An implications for improved patient care was that the conference introduced attendees to a taxonomy that is open for wider use (Advocate/Chicago), a CPE-specialty program for non-chaplain health care providers and chaplaincy care within a larger cancer study (Dana Farber/Boston); Spiritual AIM – a chaplain-specific spiritual assessment tool (University of California/San Francisco); the value of case-studies in pediatrics(Children's Mercy/Kansas City); and, consideration of both open (Emory/Atlanta) and semi-structured manualized (Duke/Durham) interviewing processes to study both chaplains and family caregivers." - Rev. Annette Olsen, M Div, BSSW, IHC, BCC-Board Certified Chaplain, Senior Clinical & Administrative Chaplain, Cancer Center/Oncology, Surgery, Trauma, and Neurology , Dept. Coordinator, Spiritual Health Programming & Community Spiritual Care Referral Network Pastoral Services Department, Duke University Medical Center, Durham, NC

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"I am very inspired and very hopeful. The conference content has been substantial as has been the opportunity to meet and speak with a lot of people that I normally would never get to encounter." - Ann Satterfield, Making a career change and about to take her first CPE Unit

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"In addition to helping people plan for end-of-life, I am also a creative arts therapist. As with the case with chaplains, it's common for people not to know what a creative arts therapists do, how we help patients, and how to value us. People can be

fascinated by our work, but they don't understand it, and it's wrapped in mystery. So learning about how chaplaincy is looking to address this through research is very instructive." "I've learned about 'meaning-making'

and I've already started to apply that tool to my work. After being here at the conference I had a conversation with a client, and keeping in mind the distress that Dr. Jimmie Holland had discussed in her talk, and how to help the client, who was dying, cope better with his fear. This client said felt like he had failed in some way, because he was now in hospice, and his oncologist had dropped him as a patient." - Pam Edgar, End-of-Life Care Manager, Compassion & Choices

#### It Wouldn't Be a Research Conference Without Survey Data

The online survey sent to attendees revealed the following responses to the conference evaluation:

Rating: Excellent/Very Good

Overall how would you rate the conference: 93%

How would you rate the conference content: 96%

The conference met my expectations: 99%

As a result of the conference my practice will change: 83%

I am likely to come to this conference again in the future: 88%

#### **Conclusions from the Two Co-Principal Investigators**

The Rev. George Handzo, BCC, CSSB and Linda Emanuel, MD, PhD were the co-principal investigators for HealthCare Chaplaincy Network. They oversaw the complex grant that funded the research, meetings and collaboration among researchers, and finally this conference.

Dr. Emanuel said: "In the evolution of living things, including collective thought, there are phase transitions. There is incubation, birth, development, maturation, impact and so on. The conference 'Caring for the Human Spirit' made a transition out of its three year gestation, and a new field was born. People who did not previously share a common language, culture or core assumptions came together with six groups who had worked for the last three years, creating as they went a common language and a new collective culture.

"Hundreds came from far and wide, and we streamed and tweeted and included questions and comments from yet more.

"We shared a model for the workings of human spirituality the group had worked on that used a mathematical formula and visual depictions. Chaplains and researchers alike had wonderful comments and a deep appreciation for its potential to help generate research questions.

"We shared research findings from the six groups. It was like an extended family caring for newborn sextuplets.

"Everyone seemed to have something special to offer; this new community was investing in the future success of each of its investigators! We shared the stories about how we got to know one another and laughed. We shared a vision for the future. Could anyone have imagined a conference being a sublime experience? Well, no need for those of us present to imagine it, we experienced it!"

The Rev. Handzo said as he closed the conference: "This is a day a lot of us hoped for and dreamed about and





thought it would never come. We're not there yet. But we're on the journey and we're not turning back.

"People call and email me to asking what can they tell administrators what chaplains do and how to do spiritual assessment. Now we have a start, thanks to the John Templeton Foundation and the six research teams who are the heroes and heroines today.

"It's a new day.



"Now we've got to do more.

"I am convinced that because of what has been set in motion here more people will have their spiritual suffering reduced and

their lives improved."

Jim Siegel, Executive Vice President at HealthCare Chaplaincy Network, has more than 35 years' experience in the private and nonprofit sectors. Jim serves on the Board of Directors of Inwood Academy for Leadership Charter School in Upper Manhattan, and has been an active congregant volunteer at Central Synagogue in Manhattan. Jim holds an MBA degree from Boston University. He joined HealthCare Chaplaincy in 2008. Follow Jim on Twitter on behalf of HealthCare Chaplaincy Network with @MeaningComfort.

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Back to top

# Keynote Speakers Energize the Conference, "Driving the Agenda for Spiritual Care in Health Care"

Previous | Next

# Four nationally known experts brought key focus and enthusiasm to the recent landmark conference on spirituality research in health care.



**Kathleen Foley, MD**, holder of the Society of Memorial Sloan-Kettering Cancer Center Chair in Pain Research, Attending Neurologist, Pain and Palliative Care Service, Memorial Sloan-Kettering Cancer Center, Professor of neurology, neuroscience and clinical pharmacology, Weill Medical College of Cornell University talked about "Research in Spiritual Care and Palliative Care: A Global Perspective." Dr. Foley is identified as one of the 30 most influential leaders in hospice and palliative care today.

She outlined the global issues which generate the current need for spiritual care in palliative care, discussed the major challenges and opportunities for spiritual care globally, and identified research questions for work both locally and globally.

#### **Highlights included:**

• It is extraordinary that spiritual is included in the World Health Organization (WHO) definition of palliative care: Palliative Care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is

achievement of the best quality of life for patients and their families.

• Palliative care is a public health issue. There is no question that it affects all people and has a potential to prevent suffering. If palliative care is a public health issue then so is spirituality as we seek to prevent and reduce suffering.

• Approximately 25 million world-wide need palliative care - and therefore spiritual care too.

• There is great importance in professionalizing those who provide spiritual care in addressing this essential part of palliative care.

**Jimmie C. Holland, MD**, Wayne E. Chapman Chair in Psychiatric Oncology, Attending Psychiatrist , Department of Psychiatry & Behavioral Sciences, Memorial Sloan-Kettering Cancer Center.

Dr. Holland focused on the challenges of developing a research program and evidence base for interventions that depend on patient-reported outcomes of their symptoms. Medicine has long favored physician observations as being more accurate. The barriers are difficult in areas that are regarded as "too soft for real data," and research in spirituality faces these issues. In her talk, Dr. Holland helped the audience navigate through ways to gain knowledge about the development of a research base in psycho-oncology,



learning the common barriers and supports for "soft science" areas, and how to apply practical suggestions for future efforts in research.

#### **Highlights included:**

• The stigma in early end of life psychosocial research was similar to what is seen in research on spirituality in health care now.

 Distress, including spiritual distress, should be identified, documented, and treated according to clinical practice guidelines.

 Patient distress should be considered the 6th Vital Sign that is assessed and treated. The human side of cancer care - addressing distress - must be part of the future.

 There are many creative ways to modify a distress scale to be included in electronic medical records. Try them and share results.

Charles von Gunten, MD, PhD, Vice President, Medical Affairs, Hospice and Palliative Medicine for



OhioHealth, Chairman, Test Committee, Hospice & Palliative Medicine, American Board of Medical Specialties.

Dr. von Gunten used case studies and video clips to engage the audience in an interactive conversation about the "Emerging Horizons in Palliative Care Research: Special Focus on Spiritual Aspects of Care." In doing so, he included the history of hospice care as developed by Dame Cicely Saunders, MD who emphasized the importance of "total pain" management: physical, emotional, practical, and spiritual.

#### **Highlights included:**

 Two big fear myths continue in pain management: medication tolerance and medication dependence. What are the spiritual components of pain management, and how can chaplains claim their role in addressing them?

 Spiritual care has been in the weakest in the palliative care disciplines: we need to change this.

 Spiritual assessment and care are essential to effective pain management in order to identify sources of spiritual pain.

 We don't want physicians and nurses to be weaker; we want chaplains and social workers to be stronger as members of one team.

 Many palliative and hospice programs have enough chaplains on team to work with the large number of spiritual issues experienced.

Linda Emanuel, MD, Director, Buehler Center on Aging, Health & Society, Institute for Public Health and Medicine, Buehler Professor of Geriatric, PhDMedicine, Northwestern University, and Senior Vice President for Research and Education, HealthCare Chaplaincy Network spoke on "Working of the Human Spirit in Palliative Care Situations: a Consensus Model."

She outlined the 10 features of the model, the definition of spirituality for palliative care chaplaincy research, explored ways in which researchers model the "physiology" of spirituality, and identified potential physiological measures of spiritual interventions.

#### **Highlights included:**

2 of 3

 The time is right to bring together disciplines that have traditionally been separate.



http://plainviews.live.subhub.com/articles/keynote\_speak...

• We are here to help patients benefit from empirically guided chaplaincy care.

• People will benefit from the spiritual care research presented at this conference.



• Spirituality is human experience and can be studied. If we can feel it we can measure it.

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Back to top

### **Developing a Taxonomy of Chaplaincy Activities**

Previous | Next

A groundbreaking study, "What Do I Do? Developing a Taxonomy of Chaplaincy Activities and Spiritual Care in ICU Palliative Care Patients," was undertaken by Advocate Health Care in Chicago, Illinois. The research undertook a new approach to identify an inventory of chaplain activities through conducting a mixed-method exploration of chaplain thought and language. As a result, it created a new taxonomy of chaplain interventions, methods and intended effects.

The Rev. Kevin Massey, BCC, was project director. The Rev. Marilyn Barnes, BCC, and William Thomas Summerfelt, PhD were co-principal investigators.

Study steps included:

1. Using a purposeful sequence of steps to generate and evaluate a comprehensive pool of items

2. Identifying a core set of chaplain activities and interventions aimed at meeting the spiritual needs of patients, significant others, and health care staff within palliative care provided in the ICU



3. Forming a standardized chaplaincy language geared towards:

- Serving as a common frame of reference for chaplains to communicate actions with each other and inter-disciplinary care teams
- Providing the utility of uniformly portraying those actions for research and evaluation purposes

The study team used a variety of methods through its process, including literature review, retrospective chart review, focus groups, self-observation, experience sampling, concept mapping, reliability testing, and case studies.

Terms emerged during the Literature Review phase and continued in the Focus Group phase. These included:

- Intended Effect: the desired purpose, goal, and outcome of chaplain action(s).
- Method: the manner by which a specific gesture, action or activity supports a purpose, goal, and outcome.
- Intervention: any ministry gesture, action, or activity by a chaplain.
- **Pathway:** the assemblage of an Intended Effect Method Intervention.

• **Spiritual Care Plan (SCP)**: the intended effects, interventions, and methods selected in response to the identified spiritual care needs surfaced in the spiritual care assessment.

The taxonomy enhances the Advocate chaplaincy team's Patient Centered Spiritual Care Model, which begins with spiritual assessment and is followed to enhance meeting the identified needs of the patient or family.

This study is groundbreaking because it has begun a process of putting words to what chaplains do. The study team has presented the work at 3rd Annual Medicine and Religion Conference held March 2014 in Chicago, and will also present at the 2014 conference of the Association of Professional Chaplains in June and the 6th Annual Spirituality and Health Summer Institute at George Washington University in July.

The Advocate team has generously made the Taxonomy available at the link <u>here</u> for readers to read, use, test, discuss, and give feedback to them on. Note that will be asked to provide an email address so that the Advocate team is able to alert you to any changes or updates related to the taxonomy.

It is respectfully asked by the study team that you not use the taxonomy without the expressed, written permission of <u>Rev. Kevin Massey</u>. This request is so that the team is able to support and to work collaboratively with others in using the taxonomy reliably. They have developed a training procedure effective in generating consistency among chaplaincy users (>90%).

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Back to top

### How Chaplain Care Influences Well-Being and Decision-Making for People Facing Serious Illness

Previous | Next

The data collected for the study by the Dana Farber Cancer Institute in Boston, "Hospital Chaplaincy and Medical Outcomes at the End of Life," focused on the presence and helpfulness of chaplaincy visits for advanced cancer patients. Project director was Tracy Balboni, MD, MPH and Angelika Zollfrank, BCC was the project chaplain.



Over half (52.4 percent) of the 250 respondents reported not being visited by a chaplain. Of those who were visited by chaplains, 88 percent of patients said the chaplaincy visit was at least helpful to a small extent. The study also collected qualitative data in response to the question: "Please explain why your time with the chaplain was helpful or not helpful." Several patients said that the chaplain was "comforting," noting that the discussion, support, and prayer with the chaplain were helpful. Though this data is still in the process of being collected, some preliminary conclusions indicate that though chaplaincy visits may not be as frequent as desired, when they do occur, they are generally helpful to patients.

One dramatic outcome on the chaplaincy end of the research involved the clinical pastoral education for health care providers at Massachusetts General Hospital, led by Angelika Zollfrank and other members of the research team. They have created one potential educational method designed to develop health care providers' expertise in spiritual caregiving. The findings show that clinical pastoral education for health care providers is an effective educational method to help caregivers gain confidence in addressing patients' religious or spiritual needs. The increase in health care providers' self-reported ability to provide religious/spiritual support was significant with both patients of concordant and discordant beliefs. This team has several journal articles in submission or press.

The majority of the research focused on the provision of spiritual care at the end of life, but the project began with the goal of supporting field-advancing research aimed at furthering the understanding of chaplaincy care within palliative care.

The study achieved its set goals by first, advancing the understanding of the relationships between the content and degree of involvement of chaplaincy services to key end-of-life outcomes. These results aid in defining chaplaincy spiritual care within palliative cancer care.

The research is expected to aid in furthering the understanding of how chaplaincy spiritual care influences patient well-being and their medical decision making at the end of life. In light of these important potential research advances, the study findings hold key implications for improving the availability of chaplaincy services to patients and to deepen chaplaincy's involvement on medical teams, particularly in the setting of end of life care.

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### **Understanding Pediatric Chaplaincy** in Crisis Situations

Previous

For many families, their child's critical illness was a time of spiritual crisis. Many of the parents in a study led by John Lantos, MD, and with Chaplain Dane Sommer, BCC, of Children's Mercy Hospital in Kansas City, reported that, with the help of the chaplains, their own relationship with god changed. Most of these changes were for the better - or, at least, the parents were grateful. A few parents were alienated from god and church as a result of their child's illness. This study describes and documents what chaplains do, which will allow testing for the first time of chaplaincy interventions.

Chaplains are often caught in the middle - they are both representatives of the hospital to the family and representatives of the family to the hospital. Thus their work takes place in a limited space - in the doorway, as it were, from where they look in both directions.

This place in the doorway leads the chaplains to think seriously about the notion of hospitality. They think about in two ways. First, they see themselves as offering hospitality to patients, welcoming them to the hospital environment and serving as their guide and chaperone in the emotionally and spiritually troubling world of tertiary care pediatrics. Second, they are quests in the family's space and, as such, effectively convey to the families that the hospital is now, at least temporarily, the family's home, and the chaplains are visitors or guests there only with



the permission and through the hospitality of the families.

The research team presented the results of this observational study of pediatric chaplain interaction with families of critically ill children. It focused on the ways chaplains introduce themselves to families in crisis; on ways they help families find solace in prayer and the ways in which chaplains minister to members of the health care team.

- Assessed the challenges chaplains face when intervening in crisis situations
- Analyzed the role of prayer, penitence, and psychology in discussion about the meaning of a child's illness
- Considered the ways in which chaplains balanced their conflicting obligations—to themselves, to other patients and families and to different members of a child's family.

The researchers completed seven detailed case studies of chaplain interactions with parents of children admitted to the hospital with life-threatening illnesses. They learned that most health professionals have little or no understanding of what chaplains do. They fly under the radar. When asked about specifics of what chaplains do, or whether it was beneficial, most professionals were utterly at a loss to provide any detailed responses.

Their project didn't focus on palliative care, per se, but on children with life-threatening illnesses.

### **Even Non-Religious Caregivers Feel Supported by Chaplains**

Previous | Next

The goal of "Caregiver Outlook: An Evidence-Based Intervention for the Chaplain Toolkit" from Duke University Medical Center (Durham, NC) with project director, Karen Steinhauser, PhD and project chaplain, Annette Olsen, BCC, was to conduct a pilot test of the feasibility and acceptability of the Caregiver Outlook intervention. Since this was a feasibility trial, it doesn't show whether it works. It shows that The Caregiver Outlook intervention is feasible (doable) and acceptable to caregivers of those with advanced life-limiting illness. The study demonstrates the acceptability of the first chaplain-led intervention from a manual.

Both religious and non-religious participants found conversations with the chaplain meaningful and without an agenda. Non-religious participants did not feel that there was a religious or spiritual agenda. Religious participants found that they were supported in their worldview. This is very important for chaplaincy. This study establishes that patients and families can benefit from a low-cost, standardized chaplaincy intervention by phone, is measurable and can be taught.

Research shows that caregivers with a higher sense of meaning report lower subjective caregiver burden. In palliative care, two important tasks of the caregiver role are preparation and completion, which include reviewing one's life, addressing relationship conflicts and forgiveness and identifying wisdom gained and future



goals. These tasks are crucial to patient and family definitions of quality and central to the goals and skills of health care chaplaincy.

- Analyze the feasibility and acceptability of a manual intervention to improve the well-being of caregivers
- Analýze the feasibility and acceptability of a manual intervention for chaplains
- Integrate such an intervention with spiritual assessment and other approaches to chaplaincy and spiritual care.

Unexpectedly, a lot of caregivers of those with ALS were enrolled in the study. The burden of care is enormous and represented a group not frequently written about within palliative care. Not absent, but not at the forefront.

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Back to top

### The Chaplain's Role Goes Beyond Spiritual Care When Testing the Seriously III

Previous | Next

The goal of the study from Emory University in Atlanta, "Impact of Hospital-Based Chaplain Support on Decision-Making During Serious Illness in a Diverse Urban Palliative Care Population," was to understand the impact of hospital chaplains on end-of –life (EOL) decision-making in a diverse urban population. Findings showed that a chaplain's primary role was to relieve spiritual distress, ease guilt and provide comfort. Key barriers to EOL planning were low health literacy and misperceptions about palliative care and hospice care.



Tammie Quest, MD, was Project director, with The Rev. George Grant, PhD, ACPE, and Karen Steinhauser, PhD, as co-investigators.

The Emory study focused on the use of palliative and hospice care in the African-American community, which is well documented to underutilizing these services and also the largest population served in the project area.

Chaplains provided data on nearly 500 hours of visits with more than 700 patients across 1,100 visits just during the 10-month data collection period. This represents only a proportion of their work during this period, as many visits with less seriously ill patients were not recorded for the study.

More than half of chaplain visits did not focus on specifically on spiritual issues, but were concerned instead with physical symptoms, existential and emotional matters, family concerns, life reviews, medical issues and advance directives.

Health literacy and understanding of their disease was remarkably low among patients that were interviewed.

A majority of chaplain encounters resulted in the patients and families relaxing and expressing positive emotions. In about 9 percent of cases the patient developed new coping skills.

The chaplains rated the patient's familial support as problematic in only 8.7 percent, so the chaplains perceived families to be overwhelmingly supportive.

The spokesperson at the conference for this study was Ellen L. Idler, PhD, the Samuel Candler Dobbs Professor of Sociology, Director, Religion and Public Health Collaborative in the Department of Epidemiology at the Rollins School fo Public Health.

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Back to top

# UCSF Researchers Take "Spiritual AIM" at Advanced Cancer

Previous | Next

"Spiritual Assessment and Intervention Model (AIM) in Outpatient Palliative Care for Patients with Advanced Cancer" is one of very few studies to provide an in-depth picture of what chaplains do in their work with patients. The study at University of California, San Francisco was designed to address a major gap in chaplaincy research: defining the nature of spiritual care.

Laura Dunn, MD, was the project director. Allison Kestenbaum, BCC ACPE, and Michele Shields, DMin, BCC, ACPE, were the Project Chaplains and Lead Investigators.

Spiritual AIM posits that individuals have core spiritual needs in the areas of meaning and direction, self-worth and belonging to community, and reconciliation (to love and be loved).

The study was able to characterize in detail, using both qualitative (audio taped, transcribed sessions) methods, the nature, process, and outcomes of chaplains' spiritual assessments and interventions with patients with advanced cancer.

This is one of the few studies to provide this in-depth picture of what chaplains do in their work with patients. While this has been described in case reports and overviews, having verbatim transcripts of



chaplains' sessions with patients is providing a wealth of information about the important and unique contributions of chaplains to the care of patients with serious illness.

A remarkable outcome of the project was that even three sessions with a chaplain seemed to have important effects for patients. In other words, this research raises the possibility that chaplain interventions should be studied as a potentially powerful, yet brief, intervention for patients with various serious illnesses, not just cancer. Anyone facing a life threatening or chronic illness has spiritual needs, and chaplains are uniquely positioned and qualified to address these. More research is needed that uses in-depth, rigorous methods to examine the content, process, and outcomes of chaplains' provision of spiritual care.

Even those patients who did not describe themselves as religious or spiritual found that they had important spiritual concerns and that they benefitted from meeting several times with a chaplain. Many expressed surprised at learning that the chaplain was a resource who could provide a novel perspective and unique insights.

This study raises the possibility that chaplain interventions should be studied as a potentially powerful, yet brief, intervention for patients with various serious illnesses, not just cancer. Anyone facing a life-threatening or chronic illness has spiritual needs, and chaplains are uniquely positioned and qualified to address these.

Patients were, on the whole, quite welcoming and appreciate of their meetings with chaplains. Even patients who did not describe themselves as religious or spiritual found that they had important spiritual concerns and that they benefited from meeting several times with a chaplain. Many expressed surprise at learning that the chaplains was a resource who could provide a novel perspective and unique insights. The chaplains provided are that was unique from other providers, serving—in the words of the AIM assessment model, as a "guide" or "valuer" or "truth-teller" for patients, depending on the patient's core spiritual need. Some patients reached new self-awareness, found a deeper sense of purpose of meaning, or made important steps toward reconciling with important people in their lives.

While palliative care has long been committed to providing interdisciplinary care, evidence has been limited for the feasibility and added value of board-certified chaplains as uniquely important, vitally necessary members of the palliative care team. This research demonstrates the key contributions of chaplains to the care of outpatients facing advanced cancer.

Chaplaincy's perspective is vital to a full understanding of patients receiving palliative care and enables the team to provide truly comprehensive care.

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Back to top

# Online Help Now Available for People in Spiritual Distress from Serious Illness, Trauma, or Grief

Previous | Next

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HealthCare Chaplaincy Network Launches ChaplainsOnHand.org and Chat With A Chaplain



Help from professional health care chaplains for everyone — *whoever* you are, *whatever* you believe.

HealthCare Chaplaincy Network has introduced a new website for online health care chaplain services. The new resources of *ChaplainsOnHand.org* provide counseling to anyone seeking help – regardless of religion or beliefs. To the best of our knowledge, this the first service of its kind specifically geared to health care.

"Serious illness, trauma, or grief can create the distress that arises when one struggles with thoughts such as 'Why is this happening to me?' 'What do I have to live for?' 'Has God abandoned me?' 'What should I do now?'" said the Rev. Eric J. Hall, HealthCare Chaplaincy Network president and CEO. "We want to help everyone in spiritual distress, whatever they believe and wherever they are."

Professional health care chaplains created the content for *ChaplainsOnHand* to respond to the big issues people in spiritual distress face due to illness and grief. The counseling, information and resources provided come from first-hand chaplain experience and can significantly help in the healing process.

The site includes the *ChatWithAChaplain* feature where people can connect by <u>email</u> or phone at 844-CHAPLAIN (844-242-7524) with a professional health care chaplain who will listen and offer spiritual comfort and support. While hospitals and other institutions have professional chaplains on staff who are trained to help those in spiritual distress, countless others in the community need help. Until now, they have not had easy access to professional health care chaplains.



Chaplains, physicians, and social workers say that ChaplainsOnHand meets a large and important need, and people who have chatted with a chaplain have welcomed the help.

Already ChaplainsOnHand has generated 14,000 visits from 88 countries. One third have come from smart phones and tablets, which is higher than average for most nonprofits and reflects the work done to make the site user-friendly across device types. **Download here a flyer to tell others about ChaplainsOnHand.** 

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Back to top





## Find free spiritual comfort online at *ChaplainsOnHand.org*. And chat for free with a professionally-trained health care chaplain by phone or email.

Serious illness, trauma, or grief can create the spiritual distress that arises when one struggles with thoughts such as "Why is this happening to me?" 'What do I have to live for?' "Has God abandoned me?" "What now?"

Spiritual distress can affect anyone – whoever you are, whatever you believe, wherever you are.

Find information and resources to help at <u>www.chaplainsonhand.org</u>.

*ChaplainsOnHand<sup>TM</sup>* includes the *ChatWithAChaplain* feature where you can connect by email or phone with a professional chaplain who is trained to listen well and offer spiritual comfort and support to everyone regardless of religion or beliefs.

*ChaplainsOnHand* and *ChatWithAChaplain* are a free service of HealthCare Chaplaincy Network, a national health care organization dedicated to helping people faced with the distress of illness and suffering find comfort and meaning. Learn more at <u>www.healthcarechaplaincy.org</u>.

