

Eduardo Bruera, MD, FAAHPM

Interview #95

Interview Navigation Materials

Date submitted: 12 December 2018

Interview Information:

Three sessions: 8 August 2018, 13 August 2018, 05 November 2018

Total approximate duration: 4 hours

Interviewer: Tacey A. Rosolowski, Ph.D.

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Interview Subject Snapshot:

Name: Eduardo Bruera, MD

Interviewed: 2018

Primary appt: Department of Palliative, Rehabilitation, and Integrative Medicine

Research: Control of cancer pain, physical symptoms, psychosocial, spiritual, and existential issues requiring holistic end-of-life care.

Admin: Chair, Department of Palliative, Rehabilitation, and Integrative Medicine (1999-present)

About the Interview Subject

Medical oncologist Eduardo Bruera, MD (b. 1955, Argentina) came to MD Anderson in 1999 to serve as Chair of the Department of Palliative, Rehabilitation, and Integrative Medicine in the Division of Medicine, a role he still serves. During this time, he has also served as Executive Director of the Palliative Research Group. He has a joint appointment in the University of Texas Graduate School of Biomedical Sciences. Dr. Bruera specializes in palliative care and symptom management: his department's research program focuses on the multi-disciplinary treatment and management of burdensome physical symptoms and/or psychological distress from cancer and/or the cancer treatment itself, with services offered to the patient and to the family. Dr. Bruera has

served as a principal or coinvestigator on randomized controlled trials of patients presenting with multi-dimensional problems, as well as various psychosocial, spiritual, and existential issues requiring holistic end-of-life care. He has extensive experience in conducting single-center and multicenter randomized control trials. He and his research teams have published research findings in over 550 peer-reviewed articles in the leading journals in oncology and supportive care. Dr. Bruera has been instrumental in broadening the acceptance of palliative care at MD Anderson and beyond through his work with external committees and organizations. He has also experimented in innovative ways with providing leadership support for wellness initiatives for his department's faculty and staff.

Major Topics Covered:

Personal background and education

Research: pain management; assessment of patient needs;

History of palliative care and its recognition by mainstream medicine; palliative care as a “fringe discipline”; strategies for promoting acceptance of the field; the importance of institutional structures and support; communicating with mainstream disciplines; developing a clinical service supported by research; relationship of palliative care to other care disciplines; the future of palliative care

Disease-centered patient care versus patient-centered care; MD Anderson's commitment to these approaches

Leadership practices: building a department; building teams; fostering collaborative leadership;

Burnout in palliative care; strategies to address it

Service to the World Health Organization and to the International Association for Hospice and Palliative Care

Spiritual dimensions of leadership and palliative care

About transcription, the transcript, and the views expressed

This interview had been transcribed according to oral history best practices to preserve the conversational quality of spoken language (rather than editing it to written standards).

The interview subject has been given the opportunity to review the transcript and make changes: any substantial departures from the audio file are indicated with brackets [].

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*The views expressed in this interview are solely the perspective of the interview subject.
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The University of Texas MD Anderson Cancer Center.*

Eduardo Bruera, MD, FAAHPM

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Committee Service: An Issue of Leadership and a Voice for Palliative Care
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Eduardo Bruera, MD, FAAHPM

Chapter Summaries

Interview Session One: 6 August 2018

Chapter 00A

Interview Identifier

about 1 minute

Chapter 01

Learning to See the Human Side of Medicine

A: Personal Background;

Codes

A: Personal Background;

A: Character, Values, Beliefs, Talents;

A: Personal Background;

A: Inspirations to Practice Science/Medicine;

A: Influences from People and Life Experiences;

A: Professional Values, Ethics, Purpose;

D: Understanding Cancer, the History of Science, Cancer Research;

Dr. Bruera begins this chapter by sketching his family background and experiences growing up in Rosario, Argentina. He talks about the impact of his father's work as a cardiologist. He explains his father's interest in both research and, most particularly, in clinical work. His father's discussions of interactions with patients and ethical issues enabled Dr. Bruera to see the "human side" of medicine very early.

Next, Dr. Bruera explains that cancer was "a big taboo" when he was in his early medical career. He talks about the fear of the disease, prohibitions against speaking about it, and his early commitment to contribute to addressing this challenge.

Next, he sketches his interest in sports in school. He talks about the importance of his interest in soccer, a team sport, and the "communist" attitude he took toward coaching children's soccer.

Chapter 02

Turning to the Human Side of Medicine: "An Impeccable Diagnosis is Not Sufficient"

A: Educational Path;

Codes

A: Personal Background;
A: Faith;
A: Character, Values, Beliefs, Talents;
A: Personal Background;
A: Inspirations to Practice Science/Medicine;
A: Influences from People and Life Experiences;
A: Professional Values, Ethics, Purpose;
C: Healing, Hope, and the Promise of Research;
C: Human Stories;
C: Offering Care, Compassion, Help;
C: Professional Practice; C: The Professional at Work;

In this chapter, Dr. Bruera begins to sketch his medical education. He begins by explaining his selection of a medical school and the education he received (MD conferred, 1979; Universidad de Rosario, Rosario, Argentina). He also speaks about professors who had a great impact on him and how he keeps their influence in mind through keepsakes in his office. He describes this as an important kind of ritual and symbolism he integrates into daily life.

Next he describes shifts in his interest in medicine. He began, he explains, with a fascination with disease and how it causes processes to break down in the body. However, as his clinical experience deepened, he became more interested in “the person around the problem.” He tells several anecdotes from his oncology training that inspired him to shift his focus (Certificate of Specialist, 1984 or 1982, Medical Oncology, Universidad del Salvador, Buenos Aires, Argentina). He explains that his director cautioned him against focusing on what was a “fringe area” at that time.

Chapter 03

Working “On the Fringe”: Establishing Palliative Care as a New Area of Service

A: Professional Path;

Codes

A: Overview;
A: The Researcher;
B: Survivors, Survivorship; C: Patients, Treatment, Survivors; Disc and success
C: Discovery and Success;
C: Leadership; D: On Leadership;
C: Mentoring; D: On Mentoring;
D: Understanding Cancer, the History of Science, Cancer Research;
D: The History of Health Care, Patient Care;
A: Inspirations to Practice Science/Medicine;
A: Influences from People and Life Experiences;
A: Professional Values, Ethics, Purpose;
A: The Researcher;

C: Professional Practice; C: The Professional at Work;

In this chapter, Dr. Bruera talks about his work at the Cross Cancer Institute in Edmonton, Canada. He talks about Dr. Neil MacDonald, the Institute Director, who brought him in on a fellowship to begin to establish palliative care.¹ He explains that Dr. MacDonald wanted to put patient experience at the center of the Institute's services. He then describes the situation on the ground with attention to patient experience and how, through surveys and research, he and a team began to establish evidence based approaches for addressing pain and other dimensions of the cancer experience. He also talks about the pushback against these efforts and how publications documenting evidence were effective in building acceptance. Next, Dr. Bruera discusses why it has taken so long to develop the "fringe area" of palliative care and to build acceptance for it.

He then discusses his team's most significant accomplishments during his 15 years at the Cross Cancer Institute. He talks about the development of the Edmonton Injector for delivery of pain medication, the discovery of how effective it is to shift a patient's pain medications, the discovering of methadone's effectiveness as a pain medication. He also talks about the value of discovering that team work is the best way to deliver care.

Chapter 04

Building Teams by Building Culture and Developing Collaborative Leadership

B: Building the Institution;

Codes

A: Overview;

C: Leadership; D: On Leadership;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

C: Collaborations;

A: Professional Values, Ethics, Purpose;

A: The Researcher;

In this chapter, Dr. Bruera talks about the lessons he learned about building teams at the Cross Cancer Institute, a model he brought to MD Anderson.

¹ Clinical Research Fellowship, Cross Cancer Institute, University of Alberta, Alberta, Edmonton, Canada, 7/1984-6/1985

Clinical Research Fellow, Cross Cancer Institute, 7/1985-6/1987

Rotating Internship, Grey Nuns Hospital, University of Alberta, Alberta, Canada, 7/1989-6/1990

Assistant Professor, Department of Medicine, University of Alberta, Edmonton, Canada, 1987-1990

Associate Professor, Department of Medicine, University of Alberta, Edmonton, Canada, 1/1990-1/1994

Alberta Cancer Foundation Chair in Palliative Medicine, University of Alberta, Alberta, Canada, 1/1994-1/1999

Director, Department of Oncology, Palliative Care Medicine, University of Alberta, Alberta, Canada, 1/1994-1/1999

He begins by describing the environment needed for a functioning team (a safe place where everyone has a voice and works for consensus) and uses the metaphor of a “symphonic concert” to characterize the working relationship that results.

Dr. Bruera then makes the connection to teams he has set up in the department at MD Anderson, saying that “we depend on people referring patients to us” and this kind of team ensures the quality of care that brings in new patients. He notes that the department makes operational changes eight to ten times per year, assessing the results. He describes how the department plans and manages these change processes and gives several examples, including a “failure” that required the department to return to a former procedure.

Next, Dr. Bruera talks about the stresses of palliative care and the support the department has created to address this. He shows two informative handbooks on self-care distributed to all department members.

Dr. Bruera then talks about his view that burnout and stress are linked to the “superstar model” of how resources and prestige are assigned in departments. He says that too much of medicine is geared toward supporting the individual. He talks about how Palliative Care balances expectations among the faculty to establish a more equitable and less ego-centered culture more geared to team work. He discusses how he has shaped his own persona as a leader to role-model this mentality.

Chapter 05

“Coming to MD Anderson Was Almost an Obligation”

A: Joining MD Anderson/Coming to Texas;

Codes

B: MD Anderson Culture;

C: Leadership; D: On Leadership;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

C: Collaborations;

A: Professional Values, Ethics, Purpose;

D: The History of Health Care, Patient Care;

B: Multi-disciplinary Approaches;

B: Multi-disciplinary Approaches;

B: MD Anderson Impact; C: MD Anderson Impact;

In this chapter, Dr. Bruera discusses how and why he left the Cross Cancer Institute to come to MD Anderson in 1999. He notes that twenty years ago there was not much understanding the United States about palliative care. He received a call from Andrew von Eschenbach inquiring whether he would bring the knowledge he had developed at Cross Institute to MD Anderson. Dr. Bruera describes his interactions with people at MD Anderson, the types of anxieties they expressed about bringing in this new perspective, and what he found exciting about the

opportunity. Dr. Bruera notes that, given MD Anderson's reputation, if he could establish palliative care, he would be able to have an impact on other institutions as well. As a result, he felt that it was "almost an obligation" to take the position at MD Anderson.

Chapter 06

Establishing Palliative Care at MD Anderson: First Challenges

B: Building the Institution;

Codes

A: Overview;

B: Institutional Politics;

B: MD Anderson Culture;

C: Leadership; D: On Leadership;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

A: The Researcher;

In this chapter, Dr. Bruera sketches what services existed at MD Anderson when he arrived in 1999. He notes that his mandate from Dr. John Mendelsohn [oral history interview] and Andrew von Eschenbach was to recreate what he had accomplished at Cross Cancer Institute on a "huge scale," including a research component as well as a clinical service. He explains that his own personal goal was to establish an intensive inpatient unit for care of suffering as well as an outpatient clinic for supportive care, a combination that was virtually non-existent in the United States at that time.

Next, Dr. Bruera discusses how some of his expectations for beginning this new enterprise were immediately compromised because of Andrew von Eschenbach left the institution and there were other leadership changes that eliminated the sources of administrative support he had expected.

Interview Session Two: 13 August 2018

Chapter 00B

Interview Identifier

Chapter 07

Starting a Palliative Care Service

B: Building the Institution;

Codes

B: Institutional Politics;
B: MD Anderson Culture;
C: Leadership; D: On Leadership;
C: Professional Practice; C: The Professional at Work;
B: MD Anderson Culture;
B: Working Environment;
A: The Researcher;

In this chapter, Dr. Bruera begins the story of how he set up an entirely new palliative care service upon arriving at MD Anderson. He begins by reviewing some of the context discussed at the end of the last session. He anticipated support from Dr. John Mendelsohn and Dr. David Callendar, but administrative shifts brought in new individuals for him to report to. He describes how this shifted perception of this new initiative to bring in palliative care from “the executive leadership wants it” to “this newcomer, Dr. Bruera wants it.” He describes a conversation with John Mendelsohn that resulted in transferring the Palliative Care Department to the Division of Cancer Medicine under Dr. Waun Ki Hong [oral history interview].

Dr. Bruera then describes how he began to operate in this situation and the importance of a very positive external review of the program conducted in 2003 or 2004, which enabled Dr. Bruera to go to Dr. Hong with concrete evidence of success. Dr. Hong authorized additional resources to build the program.

Next, Dr. Bruera talks about his strategies for assessing the institution’s need for palliative care and support services. He explains why he avoided giving presentations to introduce services.

Chapter 08

Growing Through Balance in Clinical and Research Activities

B: Building the Institution;

Codes

C: Leadership; D: On Leadership;
A: The Researcher;
B: Institutional Politics;
B: MD Anderson Culture;
D: On Research and Researchers;
A: Professional Values, Ethics, Purpose;
B: Fundraising, Philanthropy, Donations, Volunteers;
C: Professional Practice; C: The Professional at Work;
B: MD Anderson Culture;
B: Working Environment;
C: Collaborations;
B: Multi-disciplinary Approaches;

In this chapter, Dr. Bruera talks about the challenges his faculty face balancing research efforts with substantial clinical responsibilities. He notes that developing research was essential to

building the credibility of palliative care, but with few faculty, it was difficult to organize adequate time to conduct studies. Dr. Bruera explains a creative approach he took, establishing international partnerships to gather data. These studies then served as the foundation for two of the department's 3 RO-1 grants.

Next, he explains the department's growth pattern, noting that as a "fringe" department, he was never provided funds and resources in anticipation of growth. However, he notes, the department demonstrated it could sustain itself, which led to additional resources.

Dr. Bruera then discusses strategies the department instituted so faculty, fellows, and staff could support each other in this stressful environment. He notes that his department is one of the most successful and research-productive in the country. He comments on Dr. Waun Ki Hong, Division head, as a fair leader.

Dr. Bruera also sketches the egalitarian culture he has established in the department and shares his view that clinical work is an essential counterpart to conducting research in the field of palliative care.

Chapter 09

Shifting the Perception of Palliative Care and Related Services

B: Building the Institution;

Codes

A: Overview;

C: Leadership; D: On Leadership;

B: MD Anderson Culture;

A: The Researcher;

C: Professional Practice; C: The Professional at Work;

B: Working Environment;

C: Collaborations;

B: Multi-disciplinary Approaches;

B: Survivors, Survivorship; C: Patients, Treatment, Survivors;

B: Institutional Mission and Values;

Dr. Bruera notes that by 2008 and 2009, after a decade, the institution was more comfortable with palliative care. However, because the department had a perception problem, being known as a kind of "pre-hospice" with the result that clinicians were sending them patients too late in treatment. Dr. Bruera explains a survey the department conducted to assess the impact of the names "palliative care" versus "supportive care." Fewer than 30% said they would feel comfortable sending patients who were early in their treatment process to palliative care.

He explains that that he was able to obtain official approval to change the name of the patient center and the mobile teams, and within six months the services had grown by 41%.

Next, Dr. Bruera talks about the wide range of patient issues that supportive care addresses.

Dr. Bruera also explains that the Department's growth in business came exclusively from word of mouth referrals of patients and their success was totally unplanned by the institution. He notes that over the past eight years, the supportive care program has been the fastest growing program at MD Anderson, despite the resources that the institution has devoted to growing other areas.

Chapter 10

Palliative and Supportive Care in a Changing Institution

A: Overview;

Codes

C: Leadership; D: On Leadership;

A: Overview;

B: MD Anderson Culture;

A: The Researcher;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

C: Collaborations;

A: Professional Values, Ethics, Purpose;

B: Growth and/or Change;

B: Institutional Politics;

B: Institutional Mission and Values;

In this chapter, Dr. Bruera explores how attitudes toward palliative care reflect larger institutional priorities and focus on cancer. He begins by setting the institution's lack of support for palliative care despite its success, in context of what this says about institutions, the educational backgrounds of leadership, and the traditional disease-focus of cancer centers and other medical practices. He notes that Houston lags behind other cities in shifting this focus.

Dr. Bruera admits he is disappointed that a person-focus has not "exploded" over the course of his career at MD Anderson and that the institution has remained very disease focused. However he is hopeful, given some statements by new president, Peter Pisters, that this may be about to change and that Dr. Pisters may be shifting the focus away from cancer and the history of cancer to the person who has cancer.

Next, Dr. Bruera responds to a question about institutional changes under fourth president, Ronald DePinho and how they effected the view of clinical practice. Dr. Bruera responds that he saw no real change under Dr. DePinho, as the institution even under John Mendelsohn was very disease focused rather than person focused. He notes again that he has seen a change over the past 6 months, under Peter Pisters, in that palliative care is viewed as more mainstream and essential to treatment. He notes that Palliative Care has saved the institution millions in costs. He notes the work of Ben Nelson in using positive financial data to generate a more up to date

view that palliative care and support services are not simply “touchy feely” but useful for a vitally functioning institution.

Chapter 11

Creating a Department Culture of Support and Wellness

B: Building the Institution;

Codes

C: Leadership; D: On Leadership;

A: Overview;

B: MD Anderson Culture;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

C: Collaborations;

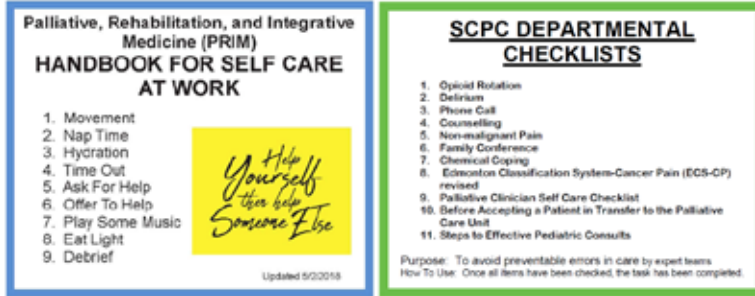
A: Professional Values, Ethics, Purpose;

A: The Researcher;

D: Ethics;

In this chapter, Dr. Bruera talks about the practices he has instituted to support faculty, fellows, and staff as the department has grown through very stressful times with challenging workloads. These include creating 100% transparency in decision-making about operations, workflow, and hiring. Dr. Bruera specifies that this is to provide department members with a sense of autonomy and control over their work environment. He also explains his own open-door policy, his views of serving as a role model for the rest of the department, and the use of anonymous surveys to assess the results of decisions and his own performance. He also discusses how the department has assembled a good team over the years, citing the fact that all the faculty have been fellows and trained through a rigorous monthly review process to perform according to the department's standards for excellence and emotional intelligence. Dr. Bruera shares an anecdote about a VIP patient and how he had full confidence that anyone on call on the supportive care service could provide the appropriate standard of care.

Next, Dr. Bruera talks about the high rates of burnout in palliative care. He also explains how the department has created a culture that values self-care and support among faculty and staff. He explains the department's self-care handbooks, how they were created and how the department is not reviewing them to make them even more effective. He notes that instituting this kind of self care is good ethical practice for the institution.



Interview Session Three: 5 November 2018

Chapter 00C

Interview Identifier

Chapter 12

Committee Service: An Issue of Leadership and a Voice for Palliative Care

A: Overview;

Codes

C: Leadership; D: On Leadership;

B: Obstacles, Challenges;

B: Research;

A: Overview;

B: Overview;

B: Research;

A: The Researcher;

B: Building/Transforming the Institution;

In this chapter, Dr. Bruera sketches his service on institutional committees. He notes some significant lessons he has learned from work as a board member of the MD Anderson Network Association: that organizations that seek to improve their operating systems value the opportunity to work with a highly credible state, not-for-profit institution like MD Anderson.

Next, Dr. Bruera discusses the significance of having palliative care represented on high-level committees and he talks about strategies he has used to build credibility with other committee members whose values and languages for discussing institutional issues are very different. Dr. Bruera stresses the strategy of discussing palliative care with data rather than soft rhetoric about the value of palliative care. He gives examples of what “irritates” administrators about introducing palliative care into the discussion of institutional processes, noting that palliative care’s patient centered approach threatens an administrator’s perception of his/her “area of control.” Another challenge, Dr. Bruera observes, is that there are no models in other institutions of well-established palliative care practices that administrators can look to.

Chapter 13

Building the IAHPC [International Association for Hospice and Palliative Care] and the Challenges of Cross-Cultural Care

A: Overview;

About 13 minutes

Codes

C: Leadership; D: On Leadership;

B: Beyond the Institution;

A: Activities Outside Institution;

C: Professional Practice; C: The Professional at Work;

A: Overview;

B: Overview;

B: Building/Transforming the Institution;

A: The Researcher;

D: Cultural/Social Influences;

D: Global Issues –Cancer, Health, Medicine;

D: Women and Diverse Populations;

D: Ethics;

In this chapter, Dr. Bruera talks about his work developing the IAHPC [International Association for Hospice and Palliative Care]. He explains that around 2000 he brought the headquarters of this organization to Houston to better manage its evolution and its ability to promote hospice and palliative care globally. He sketches some of the work done to foster regional organization of these care services.

Next, Dr. Bruera discusses the very significant issues that arise when adapting patient centered care to other cultures with different senses of family and social organization, meaning, and spirituality. He gives two main examples.

The first covers differences in practices about disclosing a cancer diagnosis to patients. He notes that in the West, the original practice was not to disclose a diagnosis to a patient/family because of fears surrounding the disease, a practice that changed with shifts in medical ethics.

The second example focuses on challenges in cultures where the family serves as the patient's advocate and sometimes comes to meet with the care team before the oncologists see the patient. He discusses challenges for Western physicians working in those contexts as well as clinicians from the culture who are educated in Western medicine, but need to adapt back to practicing in their own cultures.

Chapter 14

Committee Work, Care Guidelines, and ASCO Acceptance of Palliative Care

A: Overview;

Codes

A: Overview;

D: Understanding Cancer, the History of Science, Cancer Research;

D: The History of Health Care, Patient Care;

D: Ethics;

C: Offering Care, Compassion, Help;

B: Survivors, Survivorship; C: Patients, Treatment, Survivors;

Dr. Bruera begins this chapter by talking about his involvement in the WHO's Cancer Pain Management Committee. He describes the challenges and limitations of working with an intergovernmental organization, then talks about the committee's work in developing guidelines for both cancer pain management and palliative care, the latter expanding the scope of guidelines to other diseases. Dr. Bruera notes that palliative care was "born out of" cancer suffering, and the expansion of the guidelines underscores a focus on "personhood care" rather than disease based care.

He then discusses work on the EAPC [European Palliative Care Committee]. Dr. Bruera then discusses the importance of the Palliative Care Task Force convened by the American Society of Clinical Oncology [ASCO]. He notes that acceptance by ASCO around 2012 marked an important moment in the mainstreaming of palliative care.

CLIP He makes some final comments on the fact that palliative care is not exciting to organized medicine, which is fixated on cure.

Chapter 15

The Future of Palliative Care

A: Overview;

Codes

A: Definitions, Explanations, Translations;

A: Overview;

D: Understanding Cancer, the History of Science, Cancer Research;

D: The History of Health Care, Patient Care;

C: Offering Care, Compassion, Help;

B: Survivors, Survivorship; C: Patients, Treatment, Survivors;

C: Human Stories;

A: Post Retirement Activities;

B: Multi-disciplinary Approaches;

A: Personal Background;

Dr. Bruera first talks about his dream for the evolution of palliative care. He says he would like to large, centralized and multidisciplinary supportive care services available to all patients at

institutions, with care programs tailor made for each individual. He explains why the idea of multi-disciplinary supportive care is controversial for traditionally-trained clinicians. He acknowledges that medicine is far from reaching this dream.

Next, Dr. Bruera notes how proud he is of the many individuals he has mentored in the Department. He then talks about the challenges he sees as the field moves forward. First he talks about the danger of palliative care attempting to “be everything to everyone.” He explains the importance of staying focused on suffering brought about by cancer and other diseases. Next he talks about the challenge of convincing organized medicine and the healthcare system to embrace palliative care.

Next, Dr. Bruera explains how this process is connected to administrative structures in organizations. He also offers his evolutionary schema of how palliative care is accepted after processing through several stages he bases on Elizabeth Kubler-Ross’s phases of grief: denial; palli-phobia; palli-lalia (nonsense talk with no action); palli-active. He notes that most of the nation is in the stage of “palli-lalia”.

Dr. Bruera concludes the interview by saying he is optimistic about the future of palliative care and its acceptance.

Eduardo Bruera, MD, FAAHPM

Interview 95

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Interview Session One: August 6, 2018

Chapter 00A

Interview Identifier

Tacey A. Rosolowski, PhD

[00:00:02]

All right, and our counter is moving. Today is August 6, 2018, and I am on the fifth floor of Pickens Tower today, with Dr. Eduardo Bruera, and I'm saying that correctly?

[00:00:14]

Making Cancer History®

Interview Session: 01

Interview Date: August 6, 2018

Eduardo Bruera, MD

[00:00:14]

Perfect.

[00:00:14]

Tacey A. Rosolowski, PhD

[00:00:15]

Okay, good. The R after the B, those vowels can be a bit of a challenge for the anglophone mouth.

[00:00:23]

Eduardo Bruera, MD

[00:00:20]

It's not easy.

[00:00:21]

Tacey A. Rosolowski, PhD

[00:00:22]

But I got it, that's good. This is our first interview session together and the time, just for the record, is about 1:29. I'm Tacey Ann Rosolowski and I am conducting this interview for the Making Cancer History Voices Oral History Project, run by the Historical Resources Center at the Research Medical Library at MD Anderson Cancer Center in Houston, Texas. Just for the record, Dr. Bruera came to MD Anderson in 1999, and correct me if I have any of these details incorrect, to serve as chair of the Department of Palliative, Rehabilitation, and Integrative Medicine, in the Division of Medicine at MD Anderson, and that's a role he still serves. Similar record of service, in serving as executive director of the Palliative Research Group, is that correct as well?

[00:01:19]

Eduardo Bruera, MD

[00:01:18]

Mm-hmm.

[00:01:18]

Tacey A. Rosolowski, PhD

[00:01:19]

Okay. And you have a joint appointment with the Graduate School of Biomedical Sciences.

[00:01:23]

Making Cancer History®

Interview Session: 01

Interview Date: August 6, 2018

Eduardo Bruera, MD

[00:01:23]

Right.

[00:01:23]

Tacey A. Rosolowski, PhD

[00:01:24]

Okay. And we'll go into a lot of other details, because I know you've served other interesting roles. This session is being held in Dr. Bruera's office and thank you so much for making time.

[00:01:38]

Eduardo Bruera, MD

[00:01:39]

Thanks for coming, it's fine.

[00:01:40]

Making Cancer History™

Interview Session: 01

Interview Date: August 6, 2018

Chapter 01

Learning to See the Human Side of Medicine

A: Personal Background;

Codes

A: Personal Background;

A: Character, Values, Beliefs, Talents;

A: Personal Background;

A: Inspirations to Practice Science/Medicine;

A: Influences from People and Life Experiences;

A: Professional Values, Ethics, Purpose;

D: Understanding Cancer, the History of Science, Cancer Research;

Tacey A. Rosolowski, PhD

[00:01:40]

Yeah, I know how busy all of you folks are and it can be a real challenge. Well as I mentioned before we started, I want to just start in kind of the traditional place and ask you where you were born and when, and tell me a little bit about your family.

[00:01:55]

Eduardo Bruera, MD

[00:01:56]

Wonderful. I was born in a city named Rosario that is the third largest city in Argentina, in 1955. My dad was a cardiologist, who basically loved what he did. He loved patients, he did home visits with the patients on his own, and he also loved academics, he loved teaching and he did some research. So if you PubMed my name, you will see that the first two papers are not mine, they are Bruera, E., but they're my dad, and they were done in the '50s or something like that. And of course I could not publish that paper, being one year old.

[00:02:51]

Tacey A. Rosolowski, PhD

[00:02:52]

As much as you would have wanted to. [both laugh]

[00:02:54]

Eduardo Bruera, MD

[00:02:54]

Yes, I already had that.

[00:02:57]

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Tacey A. Rosolowski, PhD

[00:02:57]

Now you said he loved home visits and he went on his own. Was that unusual at the time, to do home visits?

[00:03:06]

Eduardo Bruera, MD

[00:03:06]

It was rather unusual, that a busy cardiologist would do quite a lot of visiting of his patients. It was perhaps more usual than now, but it was not that usual. I was surprised and I did not understand exactly why he would do that, but he sometimes would take me and my mom and my sister and leave us in the car, and then he would go into his visit and then take us somewhere else. Sometimes, I would accompany him in some of them, so I knew that patients loved the fact that their doctor would show up at their home and visit them.

[00:03:47]

Tacey A. Rosolowski, PhD

[00:03:48]

What did you observe about how he was with his patients and how did that affect you?

[00:03:52]

Eduardo Bruera, MD

[00:03:52]

I think he was a great listener. My dad was a great listener, at a time when nobody really was emphasizing listening so much, he was a great listener of the stories of the patients. And then later, in an anonymized way, he would tell some of those stories at dinnertime, so that we would understand some of the patients' experiences and what they liked to do and so on. So I found that the human side of his practice, it was very easy for me to perceive. He also had a great love for being rigorous and scientific. But of course in Argentina, getting to be an academic or a researcher was very, very hard, and so he basically did most of his practice as a clinician. That's what he did, he did clinical care. I learned a lot at the dinner table. So I learned stories, a lot of what he had learned, and the importance of being very ethical with patients and families, and the importance of trying to pitch in to knowledge. [00:05:11]

My mom, on the other side—my dad's side of the family was Italian and my mom's side of the family was Irish. My mom was very caring and wonderful. She was also very practical and she basically wanted me to become a banker, so she wanted me to go into finance and she thought that being particularly adult like my dad, who would never bill the patients and so it was not such a wonderful investment. So whenever I was riding my tricycle and telling—and people were asking, "Where are you going?" I said, "I'm going to the hospital." My mom would continuously say, "Okay, but after the hospital, you go to work at the bank," and she would

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redirect me continuously, to the bank.

[00:06:03]

Tacey A. Rosolowski, PhD

[00:06:04]

[laughs] That's really funny.

[00:06:05]

Eduardo Bruera, MD

[00:06:05]

Where she thought I should be really working.

[00:06:08]

Tacey A. Rosolowski, PhD

[00:06:08]

Now, am I correct in assuming that your father's first name is also Eduardo?

[00:06:13]

Eduardo Bruera, MD

[00:06:14]

Yes. Yes, yes.

[00:06:14]

Tacey A. Rosolowski, PhD

[00:06:15]

Okay. And your mom's name?

[00:06:15]

Eduardo Bruera, MD

[00:06:16]

My mom's was Beatrice, and they met actually, in Rosario, in a St. Patrick's Day party, where he and his friends attended the St. Patrick's Day party at the St. Patrick's Association in Rosario, and there they met. I don't know all the aspects of their courtship, but they had a very, very happy marriage and they did very well.

[00:06:49]

Tacey A. Rosolowski, PhD

[00:06:50]

Do you have brothers and sisters?

[00:06:51]

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Eduardo Bruera, MD

[00:06:51]

I have a sister who is two years younger than me, and she's in Argentina right now.

[00:06:56]

Tacey A. Rosolowski, PhD

[00:06:56]

And her name?

[00:06:56]

Eduardo Bruera, MD

[00:06:58]

Her name is Maria Beatrice, but everybody calls her Marichu, that is a Basque nickname for Maria. I don't exactly know why but that stuck with her.

[00:07:11]

Tacey A. Rosolowski, PhD

[00:07:11]

Marichu?

[00:07:11]

Eduardo Bruera, MD

[00:07:12]

Marichu, M-a-r-i-c-h-u.

[00:07:15]

Tacey A. Rosolowski, PhD

[00:07:16]

Huh. I've never heard that before either, yeah.

[00:07:19]

Eduardo Bruera, MD

[00:07:20]

That's a nickname for Maria in the Basque country of Spain.

[00:07:24]

Tacey A. Rosolowski, PhD

[00:07:24]

Yeah, interesting. Tell me about the impact of your dad's profession on you. Did you decide—you know, here you are, a doctor, banker. Were you riding your trike to the hospital because you

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had decided you wanted to be a doctor?

[00:07:41]

Eduardo Bruera, MD

[00:07:42]

I guess initially, I felt that my dad seemed to be really in love with his work. He basically died at seventy-nine and he was still going to his office, he still had some patients, and so he really loved what he did. I sensed that I could be comfortable in that, without knowing that much. And then I went to medical school, mostly I guess following what I had learned from here. I thought that I could be happy on this, but I wasn't sure I wanted to work one hundred percent by his side. I also felt that cardiology was not necessarily what I felt was the most exciting, maybe it was a very new area when he started doing it. In my time and age, the big taboo was cancer, the big thing that people were almost afraid to even mention. My mom would talk with her friends and they would ask, "Your boy, he's also a physician?" Yes, yes. What specialty is he training on, what specialty is he working on? She would say, "A bad disease." She wouldn't even like to name the word cancer at that time.

[00:09:12]

Tacey A. Rosolowski, PhD

[00:09:12]

Wow.

[00:09:12]

Eduardo Bruera, MD

[00:09:13]

I was telling my mom, "Mom they're going to think I'm into STDs or things like that, because..." So, you've got to learn how to call the name. At that time, especially when I was growing up in Argentina, cancer was such a taboo surrounding it. It was a disease that was perceived as being associated with so much suffering, that it was a terrible diagnosis to have, so I felt that to me it was a challenge and something that I would like to contribute to perhaps make it less of a taboo and make it more of a disease that people would be comfortable naming and of course living with.

[00:10:04]

Tacey A. Rosolowski, PhD

[00:10:05]

Let me ask you to kind of go back before medical school a bit and tell me a little bit about your educational path earlier. What were the things you were interested in, in school, and how did you find your own talents evolving?

[00:10:24]

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Eduardo Bruera, MD

[00:10:25]

I was very interested in sports and I was a soccer player, and I even went into college, but it didn't take me long to see that—well actually, I thought I was a very good soccer player. I thought I was a very talented soccer player, until one day we had the chance to play with two professional soccer players, who came to play a friendly game with us. I saw those two guys and I said oh, okay, that's soccer, that's a different thing. Now I understand that what I thought was completely wrong and I'm so glad that I'm going to college, because I can see that I could never ever in my life, do what these two people are doing in such an effortless way.

[00:11:18]

Tacey A. Rosolowski, PhD

[00:11:18]

What did you get out of playing soccer, that kind of made you start fantasizing about being a professional player?

[00:11:25]

Eduardo Bruera, MD

[00:11:25]

I think it was exciting, the game is exciting and is still exciting to me. My wife knows that whenever I see a television set and there's soccer being played, any place in the planet where I am, I will stop and watch for a while. I will just spend a few minutes watching and enjoying it, and then I'll move on. So it's still a passion I have, but I also understood that you could work very, very, very hard at it, but there's something else you had to have that is a very natural, special talent, that I clearly did not have, so that was a great lesson.

[00:12:06]

Tacey A. Rosolowski, PhD

[00:12:07]

It was. Well and also, how great that you were able to accept your own limitation and make a good decision around that.

[00:12:14]

Eduardo Bruera, MD

[00:12:15]

Yeah, yeah, I think you're right. The best decision I made was to understand that I wasn't good enough.

[00:12:20]

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Tacey A. Rosolowski, PhD

[00:12:20]

Yeah, and some people just, they don't do that. Well I'm also curious, because a game like that has a lot of things like teamwork and strategic thinking, and it also has body intelligence, and I'm wondering if there were elements of that, that also got you psyched about the game, because those are lasting gifts that go into other areas too.

[00:12:42]

Eduardo Bruera, MD

[00:12:42]

Oh, yes that's right. I learned a lot from that and I actually coached soccer for fifteen years thereafter. I coached all my kids into soccer and I spent fifteen years coaching soccer, until I took the job in Houston. So I did coach soccer for children for many, many years and I enjoyed coaching kids and seeing them grow from not knowing what to do with the ball to, at the end of the year, at the end of the season, playing. I also had a very communist approach in the sense that everybody got the same time of playing, as long as they came to practice, so I was not favoring the stars. During my fifteen years of coaching, I'm proud to say that we never won a single championship or anything, but everybody had a lot of fun and learned, and I thought that was the whole thing. I enjoyed the game, it teaches a lot of discipline, a lot of teamwork, a lot of harmony that is necessary, and also I enjoyed staying in touch as a coach. [00:13:55]

I also played bass, I played music, and I enjoyed that very much, and I also had a great love for bass playing, and that ended also when a real professional superstar needed somebody to do a job, a gig in a club and they hired me to go there that night, and I saw those two young kids, who were about six or seven years younger than me, who looked absolutely helpless, and they did such an extraordinary job with the music that I said okay, that's another one that I'm not good at. I've just seen what a good musician is like and I'm not one. So that was another wonderful lesson. It was fun, it was enjoyable, but then I had the chance to see extraordinary talent and say gee, well okay, I'm not that either.

[00:15:03]

Tacey A. Rosolowski, PhD

[00:15:03]

Reality check. [laughs]

[00:15:04]

Eduardo Bruera, MD

[00:15:05]

Yes. And then medicine came and I was good at it and I had fun doing it, and basically that, I stayed in, but having had the two other experiences in life helped me a lot, to understand that those are areas where I was not doing that great, and this seemed to be an area where I was really

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doing great, so it helped me stay the course.

[00:15:33]

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Chapter 02

Turning to the Human Side of Medicine: “An Impeccable Diagnosis is Not Sufficient”

A: Educational Path;

Codes

A: Personal Background;

A: Faith;

A: Character, Values, Beliefs, Talents;

A: Personal Background;

A: Inspirations to Practice Science/Medicine;

A: Influences from People and Life Experiences;

A: Professional Values, Ethics, Purpose;

C: Healing, Hope, and the Promise of Research;

C: Human Stories;

C: Offering Care, Compassion, Help;

C: Professional Practice; C: The Professional at Work;

Tacey A. Rosolowski, PhD

[00:15:33]

So tell me about your choice of medical school. Let's see, you got your MD in 1979, so tell me about going to the Universidad de Rosario, is that correct?

[00:15:48]

Eduardo Bruera, MD

[00:15:48]

Right. That was the only medical school really, so I had no other option and no other major choices.

[00:15:58]

Tacey A. Rosolowski, PhD

[00:15:59]

Was that where your dad went?

[00:16:00]

Eduardo Bruera, MD

[00:16:00]

That is where my dad went. The same place in the same town. It was the only medical school, and so basically I went there without having to make any choices. It was a six-year medical school, so you entered, it was combined with what the U.S. experience would be, the pre-med plus med all together. We had big classes, it was a public school, and as it usually happens, the

level of the teaching was quite variable. There were extraordinary teachers and then you had some that were not that great, but I had an amazing experience because I learned that there were some people out there who really were teachers who loved to teach and loved what they did, and I took advantage of a lot of these wonderful teachers, and they had a lifelong impression on me.
[00:17:04]

Tacey A. Rosolowski, PhD

[00:17:04]

How so?

[00:17:04]

Eduardo Bruera, MD

[00:17:05]

Well, I many times, find myself doing some things of the physical exam that I saw some of these people do, and it's like I'm carrying it now.

[00:17:20]

Tacey A. Rosolowski, PhD

[00:17:20]

Can you give me an example? I'm sorry to interrupt.

[00:17:23]

Eduardo Bruera, MD

[00:17:23]

Yes. There was a great internist that was at the beginning of my postgraduate training, Dr. Agrest, Alberto Agrest, who was an extraordinary internist, a brilliant internist in every possible way and he loved doing rounds, seeing patients and taking us around. He did his reflexes, putting the finger and hitting the finger with a hammer, and I still practice that way. He had a special way of also doing the liver exam, that is different from the way it's recommended nowadays, but I kept doing it like that because in a sense, first of all, I thought it's brilliant, and second, I think it's a way of remaining attached to that body of knowledge. So I find that there are some symbolic things, that if you do them, it's like a ritualistic way of putting you back in a sense of responsibility about what you do, why are you here and the things that you do. So I carry some ritualistic things, like this stethoscope that was given to me by the nurses in Canada, when I left, and that's a stethoscope that I used to steal from them whenever I went to the floor and they had no—and I did not bring my own stethoscope. Then, when I decided to leave, the nurses from that ward came to my office and brought me as a present, this thing that still says, "Station 30."

[00:19:04]

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Tacey A. Rosolowski, PhD

[00:19:04]

Oh yeah, there it is, Station 30.

[00:19:05]

Eduardo Bruera, MD

[00:11:05]

There were only two stations in our cancer center and I'm still carrying that with me all the time, and I also have my dad's picture, giving a talk, in front of my desk, because I think that helps me keep focused on how should I make decisions and how should I behave when I'm writing a paper, when I'm making decisions at the clinical level. I try to bring my medical school and my personal experiences to my daily world, and I think that helps keep me focused on what is right and what should be done.

[00:19:45]

Tacey A. Rosolowski, PhD

[00:19:46]

Does that have a kind of spiritual dimension for you?

[00:19:50]

Eduardo Bruera, MD

[00:19:50]

To me it is, to me it does. It does have an impact on saying, I am here because I am the product of the investment and work of a lot of people and I should not be letting them down. Some of them are around, some of them are not around anymore, but they all invested a lot in me being here, doing a right thing, and so I need to remind myself that all these people invested in me and I should not let them down.

[00:20:23]

Tacey A. Rosolowski, PhD

[00:20:25]

It does have an amazing keep you, kind of every moment of your day, connected with your past and your network of people.

[00:20:32]

Eduardo Bruera, MD

[00:20:32]

Yes, yes, yes, and it helps me whenever I have some difficult decisions or thoughts. I always anchor myself on the people that had impact on my life and I say well, if they were in my shoes what would they do in this case. Or if I'm in a fork of decisions, for me or for my career or for a

patient, what would they do in this case. That helps me.

[00:21:03]

Tacey A. Rosolowski, PhD

[00:21:04]

A very important dimension of life for sure.

[00:21:06]

Eduardo Bruera, MD

[00:21:06]

I guess so, yes.

[00:21:07]

Tacey A. Rosolowski, PhD

[00:21:07]

How did your sense of medicine as a practice and an intellectual body of knowledge, how did that evolve over the course of your medical school? What did you discover about your own abilities?

[00:21:22]

Eduardo Bruera, MD

[00:21:23]

I started really fascinated by disease, as many people do, by the process in which things break down in the body, by the process in which arteries don't work well and nerves don't work well, cells are invaded by tumors and viruses. I had that focus for several years and then, when I got into clinical practice, I found that in doing the technical things to diagnose and manage those kind of, we might call it biomechanical abnormalities, were still of interest, but I became progressively fascinated and concerned about the person bringing those problems. I found that what really concerned me was that we had this very limited understanding of how to deal with a person that brought us the tumor or the heart disease or the lung disease, and that that very strong focus on being impeccable in diagnosing and treating the problem was insufficient unless we're able to address the person. We had no training, no knowledge about how to do that. So, I progressively started getting more and more enthusiastic about helping the person. That's why slowly, within cancer, I noticed that it was the patient with cancer, rather than the type of cancer, that was concerning me, and how to help the person. [00:23:16]

So, when I was finishing my oncology training, my boss, I went to talk to my boss and I said, "I want to work in this area, palliative care, supportive care," and so on. Basically I want to do some of that work that is related to people that are suffering and not having a good time. He said, "Well, that doesn't happen here, we don't have anything like this. You can do one of the specialty tumor areas, you can do lung or you can do GI or you can do something like that but

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really, we don't have that here."

[00:23:58]

Tacey A. Rosolowski, PhD

[00:23:59]

Now where were you at this point?

[00:24:01]

Eduardo Bruera, MD

[00:24:01]

I was in Buenos Aires, in the capital city, doing my cancer training, my oncology training.

[00:24:06]

Tacey A. Rosolowski, PhD

[00:24:06]

Okay. So, immediately on graduating from medical school, you decided to go to the Universidad de Salvador in Buenos Aires, to be a specialist in medical oncology.

[00:24:19]

Eduardo Bruera, MD

[00:24:19]

That's correct.

[00:24:20]

Tacey A. Rosolowski, PhD

[00:24:20]

Okay. And you got that, finished that program in 1984, so why did you choose cancer to go, you know after medical school?

[00:24:32]

Eduardo Bruera, MD

[00:24:31]

To me it was the big barrier, it was the big taboo area, the big challenge, and I wanted something, a big challenge, it was a biological challenge. We were starting to understand how cancer behaves, and so I thought this was an extraordinary opportunity from the perspective of the pathology and the biology and so on, but I never really went into oncology thinking about the patients.

[00:25:02]

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Tacey A. Rosolowski, PhD

[00:25:03]

Right.

[00:25:03]

Eduardo Bruera, MD

[00:25:04]

I went thinking about the cancers. It was only after I started doing my clinical training, that I got the vision of the cancer patient, the person bringing the tumor.

[00:25:16]

Tacey A. Rosolowski, PhD

[00:25:16]

What were some of the things that began to strike you about the cancer experience for patients?

[00:25:22]

Eduardo Bruera, MD

[00:25:22]

I remember that we were telling patients that having pain was “normal,” because they had metastatic disease in their bones, that was said, when they said I have a lot of pain. Yes, well if you have an awful, awful lot of pain, you can get an IM shot, and that is quite painful in itself, over painkiller.

[00:25:43]

Tacey A. Rosolowski, PhD

[00:25:44]

IM meaning?

[00:25:44]

Eduardo Bruera, MD

[00:25:45]

Intramuscular. They got a shot into the—like when you get the shots of some of the vaccines, that can be quite painful, the shot itself. They were saying, well that’s normal, because you have a disease. Then well, the patients were—I remember a young woman who was telling me yes, doctor, it must be normal but I’m really hurting a lot. I had no words to respond to that. And then I sensed that people were having a lot of personal suffering from their disease. I remember a young mom who could not lift her child. She basically was telling me that she felt so guilty because her child was putting their little arms towards her, but she was so exhausted that she could not lift the child, and then the child would cry. I was seeing all that and I was saying all that is looked at as noise; the real problem is the cancer, we’re trying to treat the cancer, but the personal experience around it, we did not have a language to incorporate it into the medical

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record, to measure it, to treat it and so on. So I progressively drifted towards my concern about the person. [00:27:13]

I was doing very well indeed, training, but my boss was puzzled. My boss said, “Why are you going into these soft areas, why don’t you start with the hard sciences, why don’t you stay with the mainstream medicine? Why are you going to fringe areas?” I remember that conversation because that was a way of him telling me unless you are prepared to reason and go into mainstream, there are no jobs for you in our team. He was candid of saying that he really wanted me to stay there, but he wanted me to stay there to do mainstream cancer treatment. I basically felt that I wanted to focus on understanding how to help the patient. So then I had to send fifty-two letters, in the pre-Internet time, to different places in the world, to see if any of the big cancer centers in the United States or Europe or Canada, were having any interest in this area. [00:28:20]

Chapter 03

Working “On the Fringe”: Establishing Palliative Care as a New Area of Service

A: Professional Path;

Codes

A: Overview;

A: The Researcher;

B: Survivors, Survivorship; C: Patients, Treatment, Survivors; Disc and success

C: Discovery and Success;

C: Leadership; D: On Leadership;

C: Mentoring; D: On Mentoring;

D: Understanding Cancer, the History of Science, Cancer Research;

D: The History of Health Care, Patient Care;

A: Inspirations to Practice Science/Medicine;

A: Influences from People and Life Experiences;

A: Professional Values, Ethics, Purpose;

A: The Researcher;

C: Professional Practice; C: The Professional at Work;

Tacey A. Rosolowski, PhD

[00:28:20]

So let me ask you, was there—this was in the mid-’80s, so were people talking about palliative care, was that the language at the time?

[00:28:35]

Eduardo Bruera, MD

[00:28:36]

Not yet. The idea was, there was the beginning of the British hospice movement, and then I remember that there was an old Italian professor called Vittorio Ventafridda, who came once to Buenos Aires, to give a talk about all this area. Then a guy that then I was able to meet and befriend, a wonderful guy named Balfour Mount from Canada, had coined the name “palliative care.” That was the treatment of the suffering of the human being that was going to die of a disease. This guy, Vittorio Ventafridda, came to our city and I asked for another young resident to cover for my patients and I went downtown to the university, where he was lecturing, and he was giving --in a big conference hall, it was frozen, there was not even heating there. It was very cold and a winter day. He went out there to give the talk, and there were two or three people only to listen to him. Not even the people who invited him were listening to him. It was horrible. He stood up there, and there were probably three of us listening, and he gave the most extraordinary lecture about what this was all about and what could be done about that. I got out of that place saying, this is what I want to do, this is exactly what I want to do. I want to deal

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with the suffering of these patients, and we're doing it within cancer and I want to focus on this. That was very good for me, because we're talking at a time where social media did not exist, where we had no Internet, and where people had to learn from any sources possible, to gain information, so personal visits were important and lectures were important, more important than now. But it also taught me something that I kept with me all my life. That is when you're going to give a talk, you never know who's going to be listening, that you can really have an impact on, so I always did what he did, what this guy, Ventafridda did; that is whenever I am giving a talk in front of five thousand or five people, I will always put the same passion and energy, because you never know who's there, who can really be impacted by it and go out there and make a contribution.

[00:31:22]

Tacey A. Rosolowski, PhD

[00:31:23]

It's kind of making me wonder who are those other two people who showed up, because maybe they went off and did inspired things too.

[00:31:30]

Eduardo Bruera, MD

[00:31:28]

Yes. Maybe that's true, absolutely.

[00:31:32]

Tacey A. Rosolowski, PhD

[00:31:32]

I mean that was a pretty self-selected group that showed up.

[00:31:34]

Eduardo Bruera, MD

[00:31:35]

Exactly, so to go into a frozen auditorium, exactly, you're absolutely right.

[00:31:40]

Tacey A. Rosolowski, PhD

[00:31:41]

Yeah, no, that's an amazing story. I mean how telling, about not being mainstream at that time.

[00:31:47]

Eduardo Bruera, MD

[00:31:47]

Yeah, it was a real fringe work, and I have to say that it remained like that for many, many, many

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years. So, entering, I did not have any idea. My dad tried to warn me a little bit, that medicine is not forgiving for people who start kind of areas that are a bit in the fringe, and I was not aware of what he really said, and my first boss in Canada, who was the one who basically, only of the fifty-two CVs I sent around. Only two actually responded. One of them was in [Lyon?], France, to do something related to phase one chemotherapy, so probably the person did not read very well, what I said in my letter. The other one was in Edmonton, in Canada. This guy Neal MacDonald responded and said, you know I'm the director of the cancer center, I'm very interested in this, I haven't done it, but why don't you come down and see what we can do, come here for a year or two, and I will allow you to learn this area, I will help you in any way I can. So basically there we went, with my family. We moved up to Edmonton and what was supposed to be one year became fifteen. This is one of the handwritten letters I have from him, when I left to come here.

[00:33:23]

Tacey A. Rosolowski, PhD

[00:33:23]

And his name again?

[00:33:24]

Eduardo Bruera, MD

[00:33:24]

Neil MacDonald, with M-a-c. He's retired now, but he was instrumental in teaching me many, many things, and one of the things he said is, "Eduardo, administrative arrangements are important for anything in medicine," and I was trying to think about what does it mean, administrative arrangements are important, and I was saying oh yeah, yeah, yeah, and I didn't understand, I didn't care about that, I was so flustered. With the years, I understood that in medicine, it's all about administrative arrangements, it's all about departments, divisions, organizational arrangements and so on, and when those administrative arrangements do not exist, life is not easy. All the decision making and the power goes to the administrative arrangements. So at that time, going into an area that was a little bit of the fringe, was complex because you could not fit into the system. You could not fit easily into divisions, into departments, into hospitals. So the benchmarks that people used to measure achievement and productivity were always not measuring what we did. So, we were the ugly ducklings consistently, because the system had not evolved and you could not get a specialty in this area because there was not one. You could not have divisions or departments and you could not have teaching. So the creation of this area was more complex than other areas.

[00:35:18]

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Tacey A. Rosolowski, PhD

[00:35:18]

You were doing it, you were doing the creating.

[00:35:21]

Eduardo Bruera, MD

[00:35:21]

In a sense we were. A small group of people around were trying to navigate this world to make this happen.

[00:35:27]

Tacey A. Rosolowski, PhD

[00:35:28]

Now let me just make sure I get these things on the record, because I hadn't seen—how did this work, the movement to Canada? So, you were a clinical fellow, research fellow, at the Cross Cancer Institute, at the University of Alberta, in Canada, from '85 to '87.

[00:35:49]

Eduardo Bruera, MD

[00:35:50]

Yes. From '84 to '87.

[00:35:52]

Tacey A. Rosolowski, PhD

[00:35:52]

From '84 to '87. Were you doing what was effectively exploring palliative care at that time?

[00:35:58]

Eduardo Bruera, MD

[00:35:59]

Yes.

[00:35:59]

Tacey A. Rosolowski, PhD

[00:36:00]

You were, okay. Now so was that where Dr. MacDonald was?

[00:36:04]

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Eduardo Bruera, MD

[00:36:05]

Yes. He was the director there.

[00:36:06]

Tacey A. Rosolowski, PhD

[00:36:07]

Okay. So tell me, what were you doing, I mean how were you starting to explore this area?

[00:36:14]

Eduardo Bruera, MD

[00:36:15]

Well, we opened an outpatient pain and symptom control clinic that had not existed before, and it was kind of a revolutionary thing. We were seeing in consultations, some of the inpatients in the hospital, and I was doing research. I was trying to do research on how to treat symptoms, and well being and so on. Having Dr. MacDonald being the director of the cancer center, he basically got my back, because other people might see what I did as fringe, but they needed the director if you wanted to have new positions, new beds or something like that. So he would basically say okay, that's fine, I understand you need this, you need that, but why don't you send Eduardo some patients, or why don't you listen to Eduardo when he says this or that.

[00:37:10]

Tacey A. Rosolowski, PhD

[00:37:10]

Always good to have friends in high places.

[00:37:12]

Eduardo Bruera, MD

[00:37:13]

Exactly.

[00:37:14]

Tacey A. Rosolowski, PhD

[00:37:15]

Why do you think he was so interested in this?

[00:37:18]

Eduardo Bruera, MD

[00:37:19]

Well, I think Neil was a visionary. He saw that a cancer center was not really worth its name if it was not a center for cancer patients, not just for cancers. He really was concerned about the

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patient experience at a time when nobody spoke about the patient experience. So I think he felt that we had to put the patient at the center, and the cancer that the patient brought was secondary, the most important thing was the patient. And so he basically thought that I might help do that, and we also had to answer questions.

[00:38:00]

Tacey A. Rosolowski, PhD

[00:38:00]

I would love to know the thrill he got opening your letter, thinking oh my gosh, here's a person who can come and help me do this.

[00:38:07]

Eduardo Bruera, MD

[00:38:08]

Well, I'm not sure if he was completely sure that I could do it, but I think he probably felt that he could guide me, and that's what he did. He basically put me in the right direction and basically moved me to one side or the other when it was necessary. We had a very successful interaction because, well first of all, I never got in trouble, fortunately. I just did things reasonably the way he wanted. Also, I think we got into a stage in which so little was known, that we started making contributions and they started to become noticed. I just came back from the fiftieth anniversary of the Cross Center Institute, they had a little party in Edmonton about a month ago, and there was a good recollection of the contribution that the palliative care team did to the cancer center, because it was really pioneer work. But as usual, pioneer work can only exist in places where the senior leader is able to make space and to support the people doing that pioneer work. In many, many other areas there were efforts, but unfortunately they never took off or the people moved back to their background specialties and so on.

[00:39:39]

Tacey A. Rosolowski, PhD

[00:39:40]

It's tough.

[00:39:40]

Eduardo Bruera, MD

[00:39:40]

In my case it would have been going back to treating cancers, to doing medical oncology.

[00:39:44]

Tacey A. Rosolowski, PhD

[00:39:45]

You had started to talk about some of the landmark things that you did at Cross, and then I

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interrupted you with this sort of side thing on Dr. MacDonald. But continue with that story. So you put in the pain clinic, you started seeing patients. What were some of the other kind of innovative things you were starting to do to form this form of practice?

[00:40:08]

Eduardo Bruera, MD

[00:40:09]

Well the first thing we established is that nobody was asking the patients how they felt, and there were no real tools that could be used clinically, very rapidly, very simply. So we put together, from zero to ten, a number of little questions from pain, nausea, anxiety, and so on, and we started asking the patients how they felt, and we started collecting that information and saying this is useful because the patient can tell us how he or she feels and this can become part of the permanent medical record, and so we can now make it one of the reasons why we treat these patients. That was called that Edmonton Symptom Assessment System, the ESAS. The ESAS is currently being used in most palliative care and cancer centers around the world, including MD Anderson, we use it here. So very simply, people go to the ESAS but people don't remember that ESAS means Edmonton Symptom Assessment Scale, that is because we developed it in Edmonton.

[00:41:14]

Tacey A. Rosolowski, PhD

[00:41:15]

Now at the time, was there some pushback against making this part of the patient's permanent medical history?

[00:41:22]

Eduardo Bruera, MD

[00:41:22]

Oh, there was huge pushback.

[00:41:23]

Tacey A. Rosolowski, PhD

[00:41:23]

Was there?

[00:41:24]

Eduardo Bruera, MD

[00:41:24]

Enormous pushback.

[00:41:25]

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Tacey A. Rosolowski, PhD

[00:41:25]

Why so?

[00:41:25]

Eduardo Bruera, MD

[00:41:26]

First, because it was felt that patients could not really measure well their symptoms. That patients were not that good at being able to tell us what their experience is. Second, there were concerns that we were oversimplifying the complexity of the problems, and third, there was a concern that there might be liability issues. If you come and tell me that your pain is eight, your nausea is eight, your fatigue is eight, and your depression is eight, and I don't do much about it, would you then sue me about not having addressed your suffering, as compared to not having any record of it and then basically then if there is no record it didn't happen.

[00:42:14]

Tacey A. Rosolowski, PhD

[00:42:14]

Much better not to know. [laughs]

[00:42:17]

Eduardo Bruera, MD

[00:42:17]

So all of those had to be redirected and we had to do an awful lot of research and publications, to reassure the community and our colleagues. We found some things that were quite extraordinary about that, like patients repeat the way they score their symptoms over time. Then there are patterns from people who score everything ten or who score one ten and the rest like zero, and that patients are able to tolerate us failing to control their symptoms up to a level of three. So it's not that our patients expect their symptoms to go to zero, they're quite happy if their symptoms go to three. So, we learned an awful lot and we—I think slowly, it became more accepted that this was appropriate. But we're talking about '80s here, and there's been only a drive to put patient reported outcomes as a major component in healthcare in the last three or four years.

[00:43:19]

Tacey A. Rosolowski, PhD

[00:43:20]

Really?

[00:43:20]

Eduardo Bruera, MD

[00:43:21]

Really, it has been a very long process, and partially, I think why has it taken so long to develop palliative care and all the symptoms and all the things we did, well it is because of what my dad and Neil MacDonald warned me: that is when you're on the fringe, things get very difficult. Meanwhile, back at the ranch, medical oncology as a specialty is younger than palliative care, critical care medicine is younger, emergency medicine is younger, but they all are mainstream and fully organized and fully funded, and there's big congresses and everything else, and it was because they were mainstream medicine developments. The fringe movements have more difficulty getting adopted. So it took a long time for patient-centered care to become mainstream.

[00:44:29]

Tacey A. Rosolowski, PhD

[00:44:30]

What were some of your own kind of personal high points during those fifteen years at Cross?

[00:44:38]

Eduardo Bruera, MD

[00:44:38]

To me it was the development of new things. There were two things. One of them is findings. We found that we could put a little needle under the skin and give medications, and so we created something that was called the Edmonton Injector, that is used in many, many countries around the world, because it's so cheap. It costs nothing to give medications under the skin. We learned about opiate rotation, changing from one opiate to another when the patient did not do well. At that time, before, there was the belief that you always kept the painkiller higher and higher and higher. We learned that by changing from one painkiller to the other, patients tolerated their medications so much better. We learned that methadone could be used as a painkiller, and we started using it. We learned that methylphenidate could be used when people—as Ritalin-- could be used when people were very sleepy from the painkiller, and it woke them up and allowed them to function well. So, we did a number of discoveries that are still fully in practice today and to us, that really gave us a sense of hope and a sense that we could do little baby steps and people would feel better. That, to me was very important, that we were able to pitch in to the way patients were treated. We never copyrighted anything, a hundred percent of what we did was always for free, for anybody in the world to use, so the Edmonton Injector was used around the world for free, by anybody.

[00:46:20]

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Tacey A. Rosolowski, PhD

[00:46:20]

The communist in you coming out again. [both laugh]

[00:46:22]

Eduardo Bruera, MD

[00:46:23]

I guess that was again, back there. But the ESAS is also available for anybody who wants to download it, and we felt that that was part of the fun, to see that people could pick it up and start doing it tomorrow. So, we had all the designs and everything published in the common domain, so anybody could use it, and our drugs that we developed were all cheap drugs that could be used anywhere. So we had the goals of really trying to impact people in other places, and that to me was very enjoyable, was the real fun. The second thing that I found particularly attractive and fun was that we discovered the value of teamwork, that the patient was not helped by seeing the doctor but was helped a lot when a team came together; the physician, the nurse, the pharmacist, the counselor all worked together, also the same picture, all contributed to each other, and then everybody's day got shorter, got more fun, because we were operating as a team. That is the way we still work today at MD Anderson. So a lot of the things that I was able to bring here in 1999, were the result of what we had been doing for fifteen years in Edmonton, that then, I think was able to move them now, into a completely different stage, into now, the biggest cancer center in the world, but the fifteen years of learning how to do it in Edmonton were instrumental.

[00:48:09]

Tacey A. Rosolowski, PhD

[00:48:09]

Sure. Now, who are some of the other key people you worked with, because you, over and over you say we, I mean you were a team. Who were the other folks on your team in general, in Cross?

[00:48:21]

Eduardo Bruera, MD

[00:48:22]

Well, in addition to Neil MacDonald was my boss, then I was lucky to start getting a series of colleagues that came along and stayed. The first was Robin Fainsinger, who was my first fellow, who was a real true sacrificial lamb out there, because I had never trained anybody in my life and he agreed to be my fellow at moments when it was quite dubious, the outcome of everything we were doing. He became, of course, the leader there and he became a close friend for many years, and he's still there in Edmonton. And then we got more people joining us from different domains. Of course at that time there was no specialty, so they came from oncology, from family medicine, and we had a group of people that was really wonderful, because we had physicians who came to spend a year with us and then stayed longer, and they moved on into

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other areas of Canada. There was a time in which twelve of the—there were sixteen faculties of medicine in Canada and twelve of them had palliative care programs, and in almost all of them, we had either leaders or major [provosts?] that had worked in Edmonton.

[00:49:54]

Tacey A. Rosolowski, PhD

[00:49:54]

Wow.

[00:49:55]

Eduardo Bruera, MD

[00:49:55]

So we had some impact on the diaspora that moved on to work in different places and make a contribution in their areas. It was fun to work with them, but I have to say that it's almost as fun to see them move on and use the principles and have those principles work where they went, because in a sense, their ability to do things, they are validated what we were doing back home. It showed that our model was not just a model that could be done in Edmonton, but it could be done in many other places.

[00:50:34]

Chapter 04

Building Teams by Building Culture and Developing Collaborative Leadership

A: Overview;

Codes

A: Overview;

C: Leadership; D: On Leadership;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

C: Collaborations;

A: Professional Values, Ethics, Purpose;

A: The Researcher;

Tacey A. Rosolowski, PhD

[00:50:34]

Absolutely. Now, what were some of the kind of—I don't know if lessons is the right way to say it, but were there certain principles or guidelines that you learned about setting up teams, these multi-practice teams, or maybe I should say multi-specialty teams. What were the high points or key points from that?

[00:51:00]

Eduardo Bruera, MD

[00:51:00]

I think to me, it was extremely important to do what I learned from my dad and from Neil and from my experience in soccer, and other experiences, that was to really work as a team, everybody needs to feel safe and everybody has to have a voice. We need to try to vote on most of the things, we need to try to get consensus if possible, meaning by that, 80 percent agreeing on anything that we do, and we need to operate as a collaborative, and that collaborative needs all of us to relinquish positions. We need to operate as a group, as a team, and all my life we operated as team practice. At Anderson, for the last nineteen years, we always have operated as a team practice, and that means that I don't make decisions, we make decisions. What I do is I go there and fight, and I fight harder with my bosses when I know I am not there representing my own views, but the views of a lot of people working together, who have reached the conclusion that this is the way we have to do it. I think we learned, I learned, and all of us I think applied, the importance of team practice, as compared the more pyramidal CEO-based system.

[00:52:16]

Tacey A. Rosolowski, PhD

[00:52:17]

Right. What are some ways that you have discovered to overcome those gaps that can happen

between specializations, gaps in jargon, gaps in fundamental concerns, gaps in those kinds of—and gaps in workflow and perspective, I mean those sort of nitty-gritty. How do you help teams overcome those differences so they can move towards consensus and safety?

[00:52:47]

Eduardo Bruera, MD

[00:52:48]

We try to operate with a joint team approach, meaning by that, we operate like a symphonic orchestra, that's because we sound better as a team than any soloist. If anybody goes to hear the violin playing a lot, it might Itzhak Perlman but you're still going to be bored after forty minutes. But if you hear a symphony orchestra, you know that what they can do is something that the best violinist in the world cannot get through. And so we know that we need to complement each other to be harmonious. You're going to be dissonant, because if you decide to play your own way, you are not only not going to sound well, but you're going to hurt the sound of everybody else. So we do understand that we need to modify our clinical practices in consensus so that you're identifying those important gaps and you're identifying the importance of referring people --would depend forever, on people sending us their patients. Nobody comes from the street, to MD Anderson, saying, I want to get supportive care, I want to get palliative care. They come because they want to make their cancer history, so we depend on other clinicians saying this team is wonderful, we need them. We do not have an ownership of a body of knowledge that makes us unique. If you have a melanoma, you go to melanoma, if you have breast cancer, you go to breast. Those people receive the patients and that's it. We never receive anyone and therefore, we are an elective option, so we need to make ourselves highly desired by all those colleagues, as someone who can make their patients' lives better and their own lives better. The way we do it is by making sure that each time they call a member of our team, they get a product that is of similar quality. So we need to internalize in ourselves: that we need to change together by incorporating new treatments, by dropping other treatments. We need to operate as one symphonic orchestra. Then this has been as part of the way we've tried to convey to each other the importance of this, and that is done with the safety of being able to say, I found a new medicine, why don't we start using that one, or I believe that the way we're measuring the symptoms so far is not that good, let's change it. And then bring the evidence and discuss it, and then adopt it, and then change things. And we do change things about eight or ten times a year. About eight or ten times a year, we change the way we operate, but we do it in such a way that we all meet, we all discuss it, we all have the possibility to vet things, and whenever we change things, we change them for a period of two to three months. We never change things definitely. Everything is changed for a period of two to three months, during which we observe how it's working and if it's not working, nobody lost face, it was worthwhile, let's go back to the way we were doing it before. We've done it many times. We did it in a certain way for a few months, it didn't work, we go back.

[00:56:11]

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Tacey A. Rosolowski, PhD

[00:56:12]

Can you give me an example?

[00:56:13]

Eduardo Bruera, MD

[00:56:14]

For example, we adopt sometimes, a new way of giving medications that we believe is going to shorten the time for pain control. But sometimes those medications are either not always available, or they take too long to come from the pharmacy, or the patients don't like them, and then we say, well that system is not effective, let's go back to the way we were doing it. Other times, we have a system in which we are operating in our mobile teams, seeing patients in the floors, and when we find a patient who needs to be transferred to the Palliative Care Unit, we transfer the patient, but we find that if you're going to transfer that patient, it will take you forty-five minutes extra work. So you get punished for doing the right thing and then, what we identify is that if you find a second team whose job is to transfer patients. Now, that second team gets notified by you and you go ahead and do your work, and that team will come with the specific goal of organizing transfer for the day, and so, of course it takes a lot of coordination to do that. [00:57:30]

Another thing is sometimes we have two, three, four patients in the clinic, and we have two or three, four doctors being called to see those patients, and we learned quickly that when we asked two hundred—because we do that, most of that we do it in research based. So we asked more than two hundred patients the following question: Sir, would you like to be seen today, even though you might be seen by another doctor, or would you like to come tomorrow and see Dr. Bruera? Eighty five percent of them said no, I'd like to be seen today by whoever, because if I have to come tomorrow, I have to drive again, I have to pay fifteen dollars parking, and on top of that, I'm not feeling very well today. So if you can guarantee to me that the person who is going to see me will operate in a similar way as Dr. Bruera, I prefer to be seen today. So we went from a doctor-based clinic to a team-based clinic. So we emphasized access more than continuity, with the understanding that if somebody is really interested in seeing Dr. Bruera, they can always come on Thursday and see Dr. Bruera, but if they want to be seen rapidly, they will see one of the colleagues. Our satisfaction rates have consistently been the highest at MD Anderson, even though our patients are very, very ill. And the reason for that is that we try to adapt to what we thought the patients' experiences were at MD Anderson. Of course that could not easily be done by another primary team, because they might want to see the oncologist for decisions, but when they're not feeling well, they want to be seen by someone today, rather than in three days, five days, six days. All those changes in the way we operate took, first to observe, then to decide what could we do different, then try to get consensus by all the players, you know this is not the way we've been doing it, but I am willing to give it a try and see what happens. I am not so sure

about this. And then say well, okay, let's try it for two months and then we'll come back.
[00:59:58]

Putting music in our center, in our Palliative Care Unit, was regarded as really bad by our own faculty and some of our nurses. They said, my goodness, we're going to make mistakes here, we're going to get distracted, we're going to write the wrong orders, and the patients might not like it, and the families might not like it. So we basically had to do it again three months later, an anonymous survey, and I always emphasize anonymity because it's not easy for an assistant professor to vote against Bruera, because I happen to be the professor, I'm the chief. So we emphasize a lot of anonymity, in which people will vote to one of our research assistants, for yes or no. Although there was very, very heated arguments against, when we asked patients and families and staff members, the negativity went down from about 60 to 70 percent openly, to 9 percent in the anonymous. Everybody loved the music and then we kept the music. But putting the music was a shock. [01:01:08]

Abolishing the waiting room was another thing that we wanted to do and again, the waiting room to us is not good, because you have people who are suffering. Especially in palliative care, having a lot of people who are suffering sitting in front of each other, they don't look good. It required us to reengineer the patient floor, and a lot of our doctors said and our nurses said, my goodness, this is going to be crazy, because I'm going to have all my rooms full, and how am I going to flow the patients, and how are we going to keep the appointments and how are we going to keep those rooms open? We had to put big boards with all the names of the patients, and the rooms, like if it was an emergency room, to see which room was open and which room was not open. Instead of having three rooms per doctor, we had every room for every doctor, and we had to reengineer things. Again, it took thinking, can we do it differently? Yes. Okay, well, convincing some people, being reluctant, and then ask them, and they overwhelmingly loved it. So we've introduced over time, a lot of changes. But we require building consensus, and then evaluating, and then some of them were failures. We embedded a doctor into the Thoracic Medical Oncology Clinic, to do palliative care there, to get the first patients and then move them later on, to the Supportive Care Center; it was a failure. It did not have the resources, it did not have the numbers of patients, and so on. We did that for three or four months, five months, and then we went back and said it didn't work, let's move back. And I think when people know that it's going to be for a time period and then if it doesn't work we go back, they have a trend to say let's give it a try.

[01:03:01]

Tacey A. Rosolowski, PhD

[01:03:01]

Right. Well, it's the trust thing: it isn't going to be forever, it's not a top down, this is the way it is, suck it up kind of thing.

[01:03:07]

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Eduardo Bruera, MD

[01:03:08]

Yeah, exactly. We all made the decision together, we all agreed, there was consensus, and now we'll move on. We do the same thing with anonymous surveys about workload. Are you finding that the workload is too bad for you? I've always felt that it was extremely important for the patients and families, that they are seeing a doctor who is confident, comfortable within their own job, within their own skin, and that they're comfortable with their working conditions. So we implemented measures for self-care, that actually everybody carries them in our department. I personally feel very nice, but this is what everybody cares here, about what you are supposed to do. You are supposed to take a nap. You're supposed to drink a lot of water. You are supposed to take some time out and listen to music. You are supposed to ask for help, you are supposed to eat, and you're supposed to debrief when you have a bad case.

[01:04:06]

Tacey A. Rosolowski, PhD

[01:04:09]

Wow.

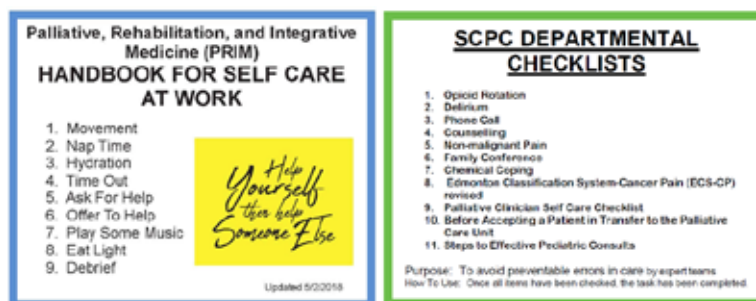
[01:04:09]

Eduardo Bruera, MD

[01:04:09]

In our interdepartmental guidelines, that have all the things that we're supposed to do, we have one that is it a weekly self-care checklist that tells you things that you can achieve to take care of yourself. This is on work and this is on your week self-care.

[01:04:29]



[Contact the Research Medical Library for copies of these materials.]

Tacey A. Rosolowski, PhD

[01:04:27]

Wow. Would you have copies of this, because I can put things into your transcript or connect

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them to your interview, so people could see that.

[01:04:37]

Eduardo Bruera, MD

[01:04:37]

Oh yes, absolutely, we can give you those.

[01:04:38]

Tacey A. Rosolowski, PhD

[01:04:38]

Yeah, that would be great, yeah I'll make a note about that.

[01:04:41]

Eduardo Bruera, MD

[01:04:41]

I know our faculty and our staff have these, so we have the feeling that if you create an environment where people feel safe to say things, to raise things, feel comfortable and reasonably supported, then they're more likely to go there and do a better job. I think they're also going to do a good job for an institution, with everybody who comes to see us.

[01:05:09]

Tacey A. Rosolowski, PhD

[01:05:10]

Well, I'm really struck too, I mean I did some work connected up with the burnout symposium last year, and one of the things that came out over and over is how the traditional culture of medicine is basically designed to put people into a state of burnout, because it's always work alone, never admit you need any help, you have to do more and more and more and never complain because you're a super-person. All those things that basically set people up.

[01:05:39]

Eduardo Bruera, MD

[01:05:40]

Yes.

[01:05:40]

Tacey A. Rosolowski, PhD

[01:05:41]

And by creating handbooks like this, in a culture in which it's expected, I mean you're creating a culture in which it's okay for people to say, wait a minute, dealing with a tough case, that is tough and I may need to speak with someone, that's part of community building. So I mean

you're shifting the culture, in at least this corner of the institution.

[01:06:01]

Eduardo Bruera, MD

[01:06:01]

Yes, you're absolutely right, that's what we perceived. We see dying people all the time, so our practice is particularly stressful, because we don't have those balances between the patient that you are seeing who is doing bad, and then three patients that are doing good, and then a couple who are cured. We don't see those that are cured or are doing well, we see the ones that are doing bad, so for us it's particularly important that we take care of the team. So I personally -- probably because of my years as a coach-- I always made the point that I was not there to support the stars. Too much of medicine has been wrongly construed on support the superstar and the rest should do the scud work and should not be treated well. That is not very smart because the overwhelming majority of the work is done by the ones who do the scud work. So by emphasizing that superstar and having them only do clinical care one day a week, and giving them all the research time and all the glory and all the papers, all you are creating is resentment by a lot of the other people that are having to do the clinical work. It happens to be that the clinical work is done by those people that you do not particularly respect. So we created exactly the opposite: that is an emphasis on the importance of the people who see the patients every day. And then there are some people who will do less number of days of clinic a week, because they will bring grants and so on, but there's nothing among those individuals that will be more meritorious or different than the rest. In fact, I take call and come on weekends exactly the same as any other clinical faculty that is 80 percent clinical, and so all my tenured faculty have to do exactly the same amount, because if I am doing this at sixty-three, then it's understood that the younger tenured professors should be coming here and doing clinical call. That's a message to everybody: that we all have to keep a low profile, be involved in helping each other, and that ultimately, it's about the patients. That helps break some of that barrier between the so-called superstar and the rest, that I think is, my impression is that leads a lot to burnout. So in my soccer times, if you came for practice, you would get your playing time and ultimately, if you look at happiness as an outcome, we were the happiest team of all. And happiest means happiness by all the players, not happiness by one player and unhappiness by the rest.

[01:08:55]

Tacey A. Rosolowski, PhD

[01:08:56]

Right, right. I'm thinking too, I mean the superstar model is very much, there are only particular types of achievement or a particular type of personal talent that we respect and reward. But just because somebody's really great at giving grants, doesn't mean that they're very good at sitting down and listening and diagnosing the question behind the question, and a person that's got an emotional issue at work. This is a model that really balances and acknowledges that people

bring a whole array of abilities to a team. Very, very interesting.

[01:09:33]

Eduardo Bruera, MD

[01:09:33]

And you know, we have been finding that the productivity of our team is one of the largest in the institution, even though we have much less tenured positions, much less protected time. If you look by a citation index and our H-index and our publication record, it's very, very high. That means that you do not need the superstars to do very good work. A whole bunch of mediocre people helping each other can do extraordinary things. You can have all these people helping each other and publishing and publishing in the best journals and doing a lot of work, because it's not that you need extraordinary achievements. If we all pitch in, at the end of the year, we've done good academic work. So, I personally do not agree with a model of having a superstar and giving that person everything, and then the rest working, because I think burnout, to a great degree, is linked to that model of medicine. To me, it's the collective governance, that really works, but it requires that we assume that we're going to behave in that way. That means I need to swallow a lot of my pride about the way I think things should be done, and be patient, and sometimes know that no, I'm not going to be able to do this, we're going to have to wait two more weeks, during the faculty meetings happens, until the staff meeting happens. We need to be patient because by decree, I can make this happen tomorrow. But I'm going to hurt a lot of people's morale if I do it. So the patients and the bringing it for everybody to discuss and listening to the arguments of those who are not in favor and making all the necessary modifications, I think that's something that sometimes it is felt as not productive. People perceive that that is not productive. I think it's a bad concept, because it's productive in building a team.

[01:11:51]

Tacey A. Rosolowski, PhD

[01:11:51]

Absolutely. Well it's not the traditional model of leadership, you know the lone leader that makes the decree, as you said, and then we move on. It's a different model, it's collaborative leadership.

[01:12:02]

Eduardo Bruera, MD

[01:12:02]

Yes, that's our—I think our understanding is that that's what we do, and that we bring somebody in here and I don't remember having ever appointed anyone alone. A hundred percent of the appointments that we've always made here, have been collective appointments. I make a point that that's the way we operate in our team and that is very important, because if you had a role in bringing someone to the team, then you are going to be vested in the success of this person.

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You're going to be welcoming them and trying to make them feel good and support them. While if you've got somebody who parachuted next door to you and says hi, I'm coming here to work as of today, you're going to be puzzled and you're not necessarily going to be that welcoming. So we find that even for the new person that is coming, it is so important to be welcomed by consensus.

[01:13:05]

Tacey A. Rosolowski, PhD

[01:13:06]

Well, and a collective interview and selection process also builds bridges with that new person coming in, so there's a basis for conversation afterwards. It's not like they're parachuting onto an island.

[01:13:20]

Eduardo Bruera, MD

[01:13:20]

Exactly, exactly.

[01:13:22]

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Chapter 05

“Coming to MD Anderson Was Almost an Obligation”

A: Joining MD Anderson/Coming to Texas;

Codes

B: MD Anderson Culture;

C: Leadership; D: On Leadership;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

C: Collaborations;

A: Professional Values, Ethics, Purpose;

D: The History of Health Care, Patient Care;

B: Multi-disciplinary Approaches;

B: Multi-disciplinary Approaches;

B: MD Anderson Impact; C: MD Anderson Impact;

Tacey A. Rosolowski, PhD

[01:13:22]

Well, we've started talking a lot about what you've done here at MD Anderson, based on that learning process, long learning process at Cross. How did you make the move from Cross to MD Anderson and why did you choose to make the move when you did, which was 1999. Tell me how that happened.

[01:13:45]

Eduardo Bruera, MD

[01:13:44]

Right. Well, I got a phone call from Andy von Eschenbach, who was the chief academic officer at that time, together with John Mendelsohn [oral history interview], and basically he said we've heard that you are doing this thing in Canada. We have nothing in palliative care at MD Anderson, we think we're a little bit behind where we would like to be, and would you be interested in coming down to MD Anderson and do it here? And so they asked me to come and meet some members of their faculty and meet with them, and then they offered me the job.

[01:14:25]

Tacey A. Rosolowski, PhD

[01:14:26]

So who did you meet with and what were those conversations like, what were those first impressions?

[01:14:31]

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Eduardo Bruera, MD

[01:14:32]

Well the first meetings were with different department chairs who were working at that time, and the idea is to understand what I was going to bring, because there was not much understanding in the United States twenty years ago, about what all this was. And so they wanted to understand what could I do for patients and families and what could I do for a research driven clinical environment as MD Anderson. Part of my time was spent, or a large proportion of my time, was spent calming anxieties of colleagues, that we were not just going to come to talk about death, but we're going to help people live well and get treatments. It did help me that as a background, I am a medical oncologist. So they could not feel that I was in a way against cancer treatment or anything else. A lot of the time, I think I had to spend calming down people's concerns that I might be coming to do something that might be not aligned with the culture of the house.

[01:15:46]

Tacey A. Rosolowski, PhD

[01:15:46]

What did they imagine might happen?

[01:15:49]

Eduardo Bruera, MD

[01:15:50]

Well, one of the concerns was that one might come and talk to the patients so they can stop their treatment and go to hospice or go back home, or not get involved in any experimental cancer treatments, or basically get a referral from a patient and make all kind of comments that the way they are being treated for the pain or the nausea or the depression or the anxiety before, had not been very good. So there is this natural concern that all these doctors --who have never seen a palliative care doctor, have never trained in this area in medical school-- had about this practice. So part of my challenge was to tell them that the idea was that their patients were going to be doing great and that their day might even get a bit shorter if I came and brought some people and hired some people, but it was a very difficult process. It was a very, very difficult process, to get this graft, get adopted.

[01:16:53]

Tacey A. Rosolowski, PhD

[01:16:54]

Now, I imagine that some of these anxieties, you had confronted already, in Edmonton. Were there certain dimensions, because of MD Anderson being what it is, that were unexpected to you? Surprises that you had to address? I'm talking here about early in the process, not kind of down the line, but wow, I'm just visiting, here I am, interviewing, this was a surprise to me.

[01:17:22]

Eduardo Bruera, MD

[01:17:24]

One of the things that I have found exciting about MD Anderson is that it was in a sense the cancer capital of the world. So in a sense people, it was the phase one, phase two capital of the world at that time, and it has remained having a major role in that since then. This was a place where every leader of a cancer program in the world did a pilgrimage, to see what was new and what was happening at MD Anderson. So if I could make palliative care happen here, it would have global impact, because a lot of people, coming from all countries around the world, would come here. I'm not talking about palliative care people, I'm talking about administrators of cancer centers, directors of cancer programs, would come here and say wow, look, MD Anderson has a Palliative Care Unit on the twelfth floor, I think we should have one. MD Anderson has a Supportive Care Center, I think we should have one. Well, they never went to Edmonton. What we did in Edmonton was wonderful. But it rarely could become a template for the planet, simply because it was not even the largest in Canada, but, having the largest cancer center in the world starting to do these, would offer a nice template. What I perhaps was surprised, was by the amount of concern that this raised among cancer specialists. The idea that bringing the human dimension and putting it in the center, would be a threat to the way cancer care was being delivered. It truly had not—I had not experienced that to that degree. I had not experienced that concern that this program might be perceived as a threat by so many colleagues.

[01:19:23]

Tacey A. Rosolowski, PhD

[01:19:23]

Now that's one of those gaps, right? To what do you attribute that, you know these folks looking at you across that chasm. What is their value system and training making them see in what you're bringing?

[01:19:41]

Eduardo Bruera, MD

[01:19:42]

I think the way I reflected on this is they are a product of all those hours of training that were invested in them, and all those scientific meetings that are attended, and those journalists that read. And so unfortunately, they are the product of a flawed system. I happen to be a fringe character who somehow saw the picture from a different color. These are good people, they're great people, they went to medical school with me. They took training, they read the journals, they do the best they can, they reflect the state of the art. I am the one who is an outlier. Therefore, I need to respect their views and their practice, align and try to have them make me part of their repertoire with patients and with time, because these are good people doing good work, they are not good or bad in this story, it's all the fact that we are in a system that did not change, did not adapt, and they are the products of that system. So the opportunity and the

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challenge lies on making them slowly and progressively see that there is an opportunity here.
[01:21:04]

Tacey A. Rosolowski, PhD

[01:21:05]

Now was taking that opportunity, as you mentioned, to be able to get palliative care accepted here at MD Anderson, would have this ripple effect throughout cancer care. Was that the main reason you chose to leave Edmonton, because it sounds like you were pretty happy there.

[01:21:25]

Eduardo Bruera, MD

[01:21:25]

I was very happy, I was profoundly comfortable and happy. I think at a certain point, the offer was to come here and create a model that might have global impact, and I really liked that very much. Ventafridda, this old Italian guy who gave that lecture in that auditorium, and I kept meeting for conferences once in a while. He always said, "Eduardo, you've got to go to the United States. That's where everything happens in medicine. Until you go to the United States, you can't get things changed here, you have to go to the U.S. and change things there." And so he continuously harassed me with this business of you've got to go to the U.S., because that's where things happen. So I think it had that pressure also, that said you can make a contribution to other places by being where everything happens. In medicine, still today, where everything happens is in the United States. So basically, coming here in a sense was almost an obligation. If they call you from the director of a cancer center that is the best in the world and tell you, would you like to come here and do this type of work here, it was very difficult to say no. Because the challenge was very, very big, but the opportunity to make a contribution was such that nobody in Canada had any problem. When I announced they said of course, of course, I mean you're going to MD Anderson. If I had gone to a private clinic somewhere else, they may have said wow, why would you somehow betray your academic principles and so on. But coming to work at MD Anderson was, for a hundred percent of the people I talked to, they said of course you have to go, that was the answer.

[01:23:26]

Tacey A. Rosolowski, PhD

[01:23:26]

Oh, so that's lovely too. [laughs]

[01:23:28]

Eduardo Bruera, MD

[01:23:30]

That was the response.

[01:23:32]



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Chapter 06

Establishing Palliative Care at MD Anderson: First Challenges

B: Building the Institution;

Codes

A: Overview;

B: Institutional Politics;

B: MD Anderson Culture;

C: Leadership; D: On Leadership;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

A: The Researcher;

Tacey A. Rosolowski, PhD

[01:23:32]

So tell me about when you arrived here in 1999. I mean you said palliative care basically didn't exist. Was there anything related that was in place at all, that you could build on?

[01:23:49]

Eduardo Bruera, MD

[01:23:50]

There was a pain clinic, there were some pain doctors, and there was a process of organizing them into—some of them wanted to do palliative care and stay with us, and some of them did not. They wanted to do pain, only do pain. Another time, pain and anesthesiology was doing a lot of the cancer pain. Now they're doing more procedures and things like that and we are doing the cancer pain at MD Anderson, but at that time they were doing more of the pain procedures and so on. It was almost nothing else in terms of medical care of these very advanced cancer patients. So I found that refreshing, I have to say, because that gave me the opportunity to try to start a process of creating a department.

[01:24:46]

Tacey A. Rosolowski, PhD

[01:24:47]

Now let me ask you kind of two related questions. The first is, what was your official mandate from the institution, what did the leadership want you to do? And then the second question is what did you want to do? [both laugh]

[01:25:04]

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Eduardo Bruera, MD

[01:25:06]

That was a hidden agenda there.

[01:25:07]

Tacey A. Rosolowski, PhD

[01:25:07]

Well, you know, what personal goals or vision, whatever that might be.

[01:25:12]

Eduardo Bruera, MD

[01:25:13]

The initial agenda from when I was interviewed by Andy von Eschenbach and John Mendelsohn at that time was bring this new area called palliative care, do a little bit of what you've done in Edmonton. Of course of a dimension that is about ten times larger than what you've been doing there, to MD Anderson. And build both a clinical and an academic program, a research program, an education program. So making sure that you're not just seeing patients well, but you are contributing to the body of knowledge. So that's what their agenda was. My personal agenda was to really bring, from the clinical perspective, two things that I strongly believe in: the Palliative Care Unit as a unit, the Intensive Unit for the care of suffering, and the Outpatient Center that we used to call the Pain and Symptom Clinic in Canada but now became the Supportive Care Center. Actually, we changed the name from Palliative Care to Supportive Care Center here at Anderson. Now it has become the name that is used in most of the centers in the world, because palliative care was a little bit too close to hospice and end of life, so we thought if we changed the name into supportive care, people are not going to be so worried about sending us patients. We did a study with a couple hundred patients, a couple hundred doctors at MD Anderson, doctors and midlevel providers, and effectively they said, in an anonymous survey, that they were much more likely to send a patient to a center called Supportive Care Center, than a center called palliative care, so we brought that name. But when I arrived, in Edmonton we called it the Pain and Symptom Clinic. The idea was that we should be able to do the outpatient center and the Inpatient Unit. Those were almost nonexistent in the United States at that time, so my goal was to bring those two, and there were some hiccups in the process because about a month before I was to land in Houston, so I had already sold our home and being ready to move, I received a call from John Mendelsohn, saying that Andy von Eschenbach has stepped down as chief academic officer and that David Callendar was now going to be the Chief Medical Officer, and Margaret Kripke was going to be the chief academic officer, and that his job had been split in two pieces, done by two different individuals, none of them I had met. Basically, I landed to report in a way that was new. So, part of the challenge of bringing a new and kind of fringe program to bosses that never heard about it was that they really did not really know how that fit into MD Anderson very well, because it really had not been one of their babies.

[01:28:30]

Tacey A. Rosolowski, PhD

[01:28:30]

Yeah.

[01:28:31]

Eduardo Bruera, MD

[01:28:31]

So that brought an extra challenge for the adoption and it delayed, a little bit, the program. Because my arrival to Houston, in a sense was with a feeling that if the chief academic officer had my back the same as Neil MacDonald had my back initially in Edmonton, things were going to be okay, because there was no doubt that there was going to be great resistance. And I expected that I was going to hear the administration say, we want this and we want that unit, and we want the center and we want research, and because we want this, we got this little guy, Bruera, who is coming to technically do it, but it's as we want. Instead of that, what became more of (inaudible), Bruera wants a unit, Bruera wants an outpatient center, Bruera wants to do research on that. And then people felt that it was very easy to throw a rock at Bruera, because he was nothing. It was very hard to throw a rock at a big boss, because the big boss said, I want this done. It was very hard, because you needed to be boss for other things. So the initial development was complex and more delayed, because I arrived coming from the tundra, with no real understanding of who I was, and wanting all these new things that had not happened before. So it took a longer time to get this kind of graft being accepted by the place.

[01:30:24]

Tacey A. Rosolowski, PhD

[01:30:24]

Sure. Well, we're almost at three and that sounds like a really good cliffhanger place to leave it.

[01:30:30]

Eduardo Bruera, MD

[01:30:30]

Perfect. [both laugh] Wonderful.

[01:30:32]

Tacey A. Rosolowski, PhD

[01:30:32]

No, I mean that's an amazing story, it kind of goes back to that initial lesson you learned from Neil MacDonald; how important the administrative structure is, like bang, there it is.

[01:30:44]

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Eduardo Bruera, MD

[01:30:44]

Yes. Yes. Years after, I'd been banging my head, saying, I should have listened to him, but as you always do, you know it, but you don't really understand what he's saying.

[01:30:55]

Tacey A. Rosolowski, PhD

[01:30:55]

Well, I mean how could you have predicted this? You did everything right and then bang, MD Anderson did it smoke and mirrors with organization like it does.

[01:31:03]

Eduardo Bruera, MD

[01:31:04]

As it does, yes, that's right.

[01:31:06]

Tacey A. Rosolowski, PhD

[01:31:07]

Well, I look forward to our next conversation.

[01:31:09]

Eduardo Bruera, MD

[01:31:09]

Wonderful. Well, thanks so much for coming and spending so much time listening to all this.

[01:31:12]

Tacey A. Rosolowski, PhD

[01:31:11]

Sure. Oh no, it's lovely.

[01:31:13]

Eduardo Bruera, MD

[01:31:14]

To me it's nice because it's reminiscing on old history that is fun.

[01:31:18]

Tacey A. Rosolowski, PhD

[01:31:18]

Well, I mean it's really important to get a window into these corners of how things happen, so I

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thank you for your candor and your information.

[01:31:28]

Eduardo Bruera, MD

[01:31:28]

Wonderful. Well, thanks.

[01:31:30]

Tacey A. Rosolowski, PhD

[01:31:30]

And I wanted to say for the record, I am turning off the recorder at 3:00 p.m.

[01:31:35]

Eduardo Bruera, MD, FAAHPM

Interview Session Two: August 13, 2018

Chapter 00B

Interview Identifier

Tacey A. Rosolowski, PhD

[00:00:01]

Today is August 13, 2018, and today I'm in Pickens Tower, on the fifth floor, for our second session with Dr. Eduardo Bruera, and I want to thank you for taking the time again today.

[00:00:15]

Eduardo Bruera, MD

[00:00:15]

Thank you, thank you very much.

[00:00:16]

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Chapter 07

Starting a Palliative Care Service

B: Building the Institution;

Codes

B: Institutional Politics;

B: MD Anderson Culture;

C: Leadership; D: On Leadership;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

A: The Researcher;

Tacey A. Rosolowski, PhD

[00:00:18]

We ended up last time, where you had come to MD Anderson and were talking a bit about your personal vision for what could be accomplished here, between setting up an inpatient service and also setting up an outpatient service, and some of the challenges that you realized you were going to have to confront. So, I wanted to just ask you to start telling that story, of how you began to implement what your vision was for developing this department.

[00:00:47]

Eduardo Bruera, MD

[00:00:48]

Wonderful. Well, I learned a lot about transitions and to which point transitions are extremely dangerous for academic physicians, because you're moving from a state of certain balance, certain stability, to a world of extreme uncertainty. My uncertainty level increased very dramatically, because a month before I moved, John Mendelsohn phoned me and said Eduardo, Andy von Eschenbach, who is the one who had most of the conversations with you about your transition, has now moved back to GU oncology and we have split his job in two parts; one is going to be run by Margaret Kripke [oral history interview], the other one is going to be run by David Callendar, and then you are going to be reporting partially through them. So basically, I arrived at MD Anderson to report, in a sense, to a senior leadership that had not been able to hear the story and had not been able to say that they really were aware. It didn't mean that they were necessarily against, but certainly, it had not been one of their priorities, it was not one of the things that they thought was important for MD Anderson. I was arriving from Edmonton with a series of needs, and unfortunately, what I hoped was going to happen, is what happened to me when I was in Canada: that is that Neil MacDonald was the director of the center, would go and say I would like to have a Palliative Care Unit and I have asked Bruera to do it for me, I would like to have an outpatient clinic and I would like Bruera to do it. So that he would in a sense have my back. And because of his enormous reach within the institution, people would say well,

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I'm going to say yes to this or I'm going to support this, because I still need the good side of Neil to allow me to buy a new radiotherapy machine or to hire three doctors, et cetera. So people in the position of administrative clout can really negotiate getting things done. But of course the language wasn't that. The language was, Bruera wants to have a unit, Bruera wants to have an outpatient center. Bruera wants to have this or that. Bruera is concerned about the opioid use in the institution. What happened is people started asking, who is Bruera? Well, a guy who is coming from Canada, up north, and of course people who were in my business knew me well, but the oncologists, radiation therapists and surgeons here, had no idea who I was. Of course, their first reaction was no, we're not going to give him this, we're not going to give him that, because it's not something we really care for and we believe in and so on. And who is this guy anyway? So it was a big task, to bring back progressively, some understanding from senior leadership that this was good, this was important. In the process, it required moving from the Division of Anesthesia and Clinical Care, all our department to the Division of Cancer Medicine. That was done by Dr. Mendelsohn, when I went to talk to him and said you know, this is unfortunately not going to succeed where it is because we are reaching a ceiling and we can't get to the patients. To his credit, John Mendelsohn immediately caught the idea that the program was getting a bit stuck.

[00:04:44]

Tacey A. Rosolowski, PhD

[00:04:45]

Now, so the Division of Anesthesia and Clinical Care, that was the original department that you were put in?

[00:04:51]

Eduardo Bruera, MD

[00:04:51]

My department was established there initially, in that area, but it became clear that it wasn't a good fit at that point, because they were not so understanding of what it was that we did. When I went to John Mendelsohn, I said you know, I'm quite happy to resign and to move on. I just want to tell you that regrettably, the arrangements are not allowing us to do this. He thought about it and said, "Well, give me a week or two, Eduardo." He called me back and said, yes, we're going to move you under Dr. Waun Ki Hong [oral history interview], who was the head of the Division of Cancer Medicine at that time.

[00:05:27]

Tacey A. Rosolowski, PhD

[00:05:27]

Now let me ask you, how soon after your arrival did you have this conversation with Dr. Mendelsohn?

[00:05:34]

Eduardo Bruera, MD

[00:05:35]

Two and a half years, more than two years.

[00:05:37]

Tacey A. Rosolowski, PhD

[00:05:36]

Oh, okay, so you kind of bashed your head against the wall for quite a while.

[00:05:41]

Eduardo Bruera, MD

[00:05:42]

Oh yeah. Two or three years it was. Two and a half years about that, two or three years in which we were kind of banging our head on the wall, because we were desperately trying to get the unit going, to get the Outpatient Center going, to get the growth in referrals and so on, and also to get some of the research going. But when the division does not really understand what you are about, it cannot be supportive, because it would be kind of failing to their own values. So we had to go to a place where they could understand what we were doing. Then to his credit, Dr. Hong took us and he basically honored some of the commitments that were made before I arrived, that we already delayed by about three years. He looked at my letter of offer, he looked at what he were doing, and he banged his hand on the table and said, "We're MD Anderson, we're going to honor our commitments, we're going to get the unit going," and basically that's what he did.

[00:06:44]

Tacey A. Rosolowski, PhD

[00:06:45]

Wow.

[00:06:45]

Eduardo Bruera, MD

[00:06:45]

He went up to Dr. Callendar and he went to other people and said, "We're going to get this unit done because we said we were going to get this unit done."

[00:06:53]

Tacey A. Rosolowski, PhD

[00:06:53]

Now, the division, Dr. Hong's Division of Cancer Medicine?

[00:06:57]

Eduardo Bruera, MD

[00:06:58]

Yes.

[00:06:58]

Tacey A. Rosolowski, PhD

[00:06:58]

Right, okay, just making sure.

[00:07:00]

Eduardo Bruera, MD

[00:07:00]

He was the one who finally said, we are going to do this, we're going to do an external review. When the moment came to do an external review --and our department was the first department to undergo an external review of all the departments in the Division of Cancer Medicine-- and we fortunately passed that external review with great recognition from the reviewers from Harvard and from Memorial Sloan Kettering. So we had reviewers from our competitors that came to review our program. After the review, he felt reassured that the support he had given us was worth it. Then he also supported us further, to allow us to get more positions and to start creating an environment where oncologists and other people would really start seeing us walking the corridors and seeing patients.

[00:08:12]

Tacey A. Rosolowski, PhD

[00:08:13]

What was the year, if you can recall, where you went through that external review?

[00:08:19]

Eduardo Bruera, MD

[00:08:20]

Well, the year in which we moved might have been 2002, and the external review may have been 2004, 2003, 2004, so it was a year or two after the move.

[00:08:31]

Tacey A. Rosolowski, PhD

[00:08:34]

Now, tell me a little bit more about once you got the support of Dr. Hong, what were the steps you took to develop things, because I'm sure in the process, you also began to look around the institution and say oh, I hadn't thought of that, I hadn't thought of that.

[00:08:51]

Eduardo Bruera, MD

[00:08:52]

I had already gone through the strategy, before we moved to Cancer Medicine, of meeting with a small group of leaders that were busy clinical leaders from the institution, and have breakfast with them, pay them for breakfast and ask them for their thoughts, their advice. And also in the process of doing that, sell them the type of work we did, and ask them to send us some patients and see if that works for you.

[00:09:23]

Tacey A. Rosolowski, PhD

[00:09:24]

Who were some of these folks that you met with?

[00:09:26]

Eduardo Bruera, MD

[00:09:26]

We met with physicians from Cancer Medicine, the majority, but also some gynecological surgeons, GYN oncologists, and I think they were mostly Medical Oncology and GYN oncologists, because those are physicians that, especially at that time, had a lot of continuity with the care of the patients. The surgeons and radiation therapists are more episodic care. They get involved but they do their treatment, and sometimes the patient doesn't follow with them. Oncologists and GYN oncologists continue very much on the care, and so we thought that those might be an easy target and we started getting some initial referrals from them, and then what we did is we avoided going into any presentation, any auditorium or any presentation in public, about our program, because in absence of data, all opinions are good, and we knew that in general, opinions about person centered care and palliative care at that time, were seen in a very unfavorable way. And so people with great prestige in the house might be very negative or very derogatory of our comments about what we wanted to do, so we kept a very low profile until we had seen a couple of hundred patients. [00:10:50]

Then, once we had data from a couple of hundred patients, then we were able to start doing some presentations in auditoriums and grand rounds, because what we were doing was not just showing that the patients were referred to us, that nothing went wrong, that the patients were feeling better, that the referring doctor was going home earlier. We were doing some publications and papers and by the way, some of the ones who have been sending patients are here in the audience and if you want to ask them, you can now ask them. Those presentations started, in a sense opening the field a little bit more for us. Now, colleagues that had never referred a patient before started saying, well, I'm going to give these people a trial. We made a policy of being very, very available. We started covering the service twenty-four hours, seven days a week. Our center, from the very inception, started taking patients on the same day. So if

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a doctor had a patient who was uncomfortable or having a bad time, they could send the patient, that same day to our center. We still have that policy right now. That also made us very nice for them, as compared to other clinics in the hospital, that were a bit harder to get a patient to. We were very, very accessible, both in the inpatient service and in the outpatient service.

[00:12:32]

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Chapter 08

Growing Through Balance in Clinical and Research Activities

B: Building the Institution;

Codes

C: Leadership; D: On Leadership;

A: The Researcher;

B: Institutional Politics;

B: MD Anderson Culture;

D: On Research and Researchers;

A: Professional Values, Ethics, Purpose;

B: Fundraising, Philanthropy, Donations, Volunteers;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

C: Collaborations;

B: Multi-disciplinary Approaches;

Tacey A. Rosolowski, PhD

[00:12:33]

Can I ask you, how many people did you have involved in the department at that time, in different categories of roles?

[00:12:40]

Eduardo Bruera, MD

[00:12:41]

At the very beginning four.

[00:12:41]

Tacey A. Rosolowski, PhD

[00:12:42]

Wow.

[00:12:42]

Eduardo Bruera, MD

[00:12:42]

It was only four.

[00:12:43]

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Tacey A. Rosolowski, PhD

[00:12:43]

Tiny shop.

[00:12:44]

Eduardo Bruera, MD

[00:12:44]

Yeah, and we were here all the time, because we were on call one out of every four days, one out of every four weekends, so we were working clinical hours in addition to research hours, a long time.

[00:12:58]

Tacey A. Rosolowski, PhD

[00:12:59]

So this is four faculty members?

[00:13:01]

Eduardo Bruera, MD

[00:13:01]

Four faculty members.

[00:13:02]

Tacey A. Rosolowski, PhD

[00:13:02]

And who were the other folks involved?

[00:13:03]

Eduardo Bruera, MD

[00:13:04]

The other folks, at that point were Donna Zhukovsky, Paul Walker, Mike Fisch [oral history interview], who later left to go to AIM healthcare, and me. There were four of us. That initial team was very, very busy and it was long hours, and for a while it looked quite hopeless.

[00:13:30]

Tacey A. Rosolowski, PhD

[00:13:32]

What did you mean, hopeless?

[00:13:33]

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Eduardo Bruera, MD

[00:13:34]

Because there was a lot of hard work, there was not a clear idea that resources might be coming, and that the institution might buy our product, but also that we would be able to do anything with our academic careers, that we would be able to get some publications and get promoted and so on.

[00:13:51]

Tacey A. Rosolowski, PhD

[00:13:51]

Right. Because you were just putting in the hours in the clinic at that point.

[00:13:54]

Eduardo Bruera, MD

[00:13:55]

A lot of hours in the clinic and of course, what really gets you promoted are the papers, so getting that balance between the hours in the clinic and the papers, was always a big challenge.

[00:14:07]

Tacey A. Rosolowski, PhD

[00:14:08]

Now did you focus it down and kind of strategize, or how did you approach that clinical research balance? Did you kind of figure out papers that could come naturally out of the clinical work you were doing? How did you approach that question, to help support your colleagues?

[00:14:29]

Eduardo Bruera, MD

[00:14:30]

Well at the very beginning, we went into real survival mode. We knew that we had to build the clinical practice to be able to then do the academic practice. Then we had very limited ability to do academic work because of the clinical demands.

[00:14:50]

Tacey A. Rosolowski, PhD

[00:14:50]

And that was one of the original mission areas that John Mendelsohn had wanted you to develop, I remember you telling me, is to build the research piece.

[00:14:58]

Eduardo Bruera, MD

[00:14:58]

Yes. And so unless the clinical care, the patients are safe, then it gets hard to build the other part. So I was able to build some preliminary data and I did it in a way that was kind of unusual. I was not given a lot of establishment monies, and I had to use some of that to hire doctors to do clinical care. So some of my establishment package was used to pay some doctors, because I had no positions. Then, I did that preliminary data with international centers. I had built a little bit of a reputation when I was in Canada, as somebody who could get research done, and so I got people from Denmark, Australia, and some other centers in Canada, and we established an international kind of research group. I was able to send them a little bit of money. It wasn't that much, but enough to help them collect data that we needed. We passed a couple of protocols through the IRB and we started collecting data. That data was very, very useful because that data was what allowed us to write our first R01s with the NIH, because we were doing a lot of clinical work. We did not have too many patients, but I was extremely lucky that --or fortunate and grateful-- that several international colleagues, we brought them here to Houston. We spent two days discussing clinical studies, specific clinical studies that they were going to do. They went back home and they basically got the studies, the data collected for us. So at a time when our clinical programs were not working very well, they were in a sense, they were trusting that at some point we were going to be okay, and they participated in the studies. That data was what we really used for two of our three R01s, of the three R01s I got, and I used that data as the pillar, the preliminary data was used for the application.

[00:17:12]

Tacey A. Rosolowski, PhD

[00:17:12]

Wow.

[00:17:13]

Eduardo Bruera, MD

[00:17:14]

So as we were growing clinically, I was continuously going after --we had saturated the clinical practice to the point of exceeding ourselves by one full position. Then I made the case, and we got one more, and then we got another more, and then we got another more, as the clinical. But of course each growth was very painful for us. It meant that first we had to grow the clinical activity to the point that would justify one more faculty position, then ask for the faculty position, then wait until the faculty position was hired. And at that point the burden came down a little bit and then that job started again. So, we were not one of the departments that were lucky enough to get upfront support. We knew that—and I knew that from every aspect of where I've been, it's always very hard to grow a program that is not right in the main highway of what an institution does. So if an institution is in the area of heart care, like the Texas Heart Institute, you know that what will give you a lot of work, prestige and resources, is to be a

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cardiologist or a cardiothoracic surgeon. If you're an ophthalmologist working there, or an internist, you are not in the mainstream. Of course palliative care is never in the mainstream, because there are no big palliative care hospitals. Actually, there is one in New York, but there's almost none anywhere else. [00:18:56]

So, we knew that we were not going to ever be given resources in anticipation of growth. It was always going to have to be the opposite procedure. That is, you first grow, you show the growth, then you ask for the resources to cover. But of course, you're always at the edge of burnout, because you're having big demands. So what we did is we, every year consorted ourselves and said are we able to grow the business? Yes. Okay, how many positions do we ask for? One more or two more? That's what we did, and we continuously started asking for that growth. As the decompression started to happen for weekends and vacation and so on, then writing became a little bit easier, because now we had more time. Even if it was weekend time, we had more time to allocate to the nonclinical part of the operation. And those grants that we obtained helped us, because then Dr. Hong and the rest of the institution saw that we could be independently funded. Regrettably, there are many things that we never got. So we never got development monies really. We never got a Moon Shot. We never got proposed by the institution to be separate, and so we knew that we were going to have to pay our own way into all this. [00:20:30]

Tacey A. Rosolowski, PhD

[00:20:29]

Right. Now when you said you never got development monies, are you meaning that from the Development Office?

[00:20:37]

Eduardo Bruera, MD

[00:20:37]

Yes, yes.

[00:20:38]

Tacey A. Rosolowski, PhD

[00:20:38]

Okay, so philanthropic dollars were not coming.

[00:20:40]

Eduardo Bruera, MD

[00:20:40]

Yes. Yes.

[00:20:41]

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Tacey A. Rosolowski, PhD

[00:20:41]

Which actually surprises me, that surprises me.

[00:20:44]

Eduardo Bruera, MD

[00:20:44]

Well, yeah, it's a list, that I don't know how they're going to do it now with Peter Pisters and Steve Hahn, but historically, it was a list of people who are designated by the senior leadership, to be in the list of recipients of arriving monies and therefore, the institution made a strategy for development.

[00:21:05]

Tacey A. Rosolowski, PhD

[00:21:05]

Right.

[00:21:05]

Eduardo Bruera, MD

[00:21:06]

Our programs was not one of the ones that were high on that list, the same as we're not high or low, we're just not there.

[00:21:15]

Tacey A. Rosolowski, PhD

[00:21:15]

Right. I mean, as they draw up the institutional priorities and then they assigned based on that, right?

[00:21:19]

Eduardo Bruera, MD

[00:21:20]

Yes, that's right. The same happened with getting separate grants, and being one of the institutional grants for those. The same happened with the Moon Shots and being highlighted for that. So we knew that we had to basically pay our way into other academic activities, but we developed a strategy within our team, to support each other and to basically help each other be productive. We were, I think, fortunate in the sense that the team, the members that were arriving, were willing to put a little bit of time --because we didn't have an awful lot of time-- but a little bit of time into writing, into doing papers. My job was to provide them with the infrastructure, to get the research nurses, the statisticians, the people who would make their life easy, so that our clinically busy faculty would not have to be running around trying to get

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money. The money was my job, and they got to work on the ideas and the projects, and write them and so on, and that helped us. Over the years, we have been one, I think by far, of the most productive academic teams in palliative care in the United States.

[00:22:37]

Tacey A. Rosolowski, PhD

[00:22:37]

Wow.

[00:22:37]

Eduardo Bruera, MD

[00:22:39]

The reason for that was not because we had particularly geniuses that were hired for hundreds of millions of dollars; we just had a group of people who, we were all mediocre, but we all got together and we pitched in together, and I think we managed to get those studies finished. So we managed to get some discoveries and to make some contributions. Then that is very nice because once people find --once a faculty member finds that their name is in the paper and that they made a contribution, that becomes addictive. Now they really want to do the second one and they really want to do the third one. The first one is horribly painful, the second is as painful, and third is probably a little bit easier, and once you got six or seven or eight papers, you say I can ride this bicycle, I can do this. Then more of them started taking the challenge of writing grants. Then we were able to move our first faculty to a tenure track position several years after that. The first one we were able to move was Sriram Yennu, who was working on fatigue.

[00:23:53]

Tacey A. Rosolowski, PhD

[00:23:54]

And the last name is spelled?

[00:23:56]

Eduardo Bruera, MD

[00:23:56]

It's Y-e-n-n-u. Sriram. He was one of our fellows that we hired. He was wonderful and very interesting in fatigue. Finally, we got for him, a mentor, American Cancer Society Scholarship, and so we went to Dr. Hong and said, we have this grant but it requires him to have a lot of protected time and we're having a lot of patients. I would love to give him the time, but then we would need to hire a clinical position to cover for that. He looked at the numbers, he looked at us, and he said, "That's fine, do it," because Dr. Hong was not in this area, but he was an incredibly fair and data oriented leader. If he could see the papers, the publications, he could see the grants, and he could see the clinical encounters, then he would be fair in the allocation of

resources, he would not be biased. That was an extraordinarily good thing for us to have.
[00:25:09]

The second one was David Hui, who came and trained with me, from Canada, as a research fellow. David was able to get again, a scholarship, and also to get an R01 grant reasonably early, and we were able to then switch him to the tenured track, and so now we had a core team of three tenured track faculty, both of them and me. Then we were able to now keep more grants going and get more monies so that all the non-tenured track people were able to get some research done. We always operated as a cooperative effort, meaning by that, that we did not have any difference between the tenure or tenured track, and the non-tenure, with regards to for example, weekend call, holiday call and everything else. Everybody was pitching in the same way. The only difference is during the working hours, the tenured people were doing more research papers and the clinical people were seeing more patients. But we never found that it was important to establish this pyramidal thing in which the tenure people got all the time, all the money and then didn't do call or did almost no clinical work. We felt, and I personally felt, that being clinically good was essential to the research work, particularly in our field. We don't do any laboratory research, we don't do any of those things of basic research and basically, even if you do that, I believe that you can be dangerous to patients and families if you don't keep a good clinical practice. So we had to make sure that everybody practiced clinically, and so then it became easier, because now the team was larger and we had people working in different areas, and then we started getting advanced practice practitioners. [00:27:27]

Chapter 09

Shifting the Perception of Palliative Care and Related Services

B: Building the Institution;

Codes

A: Overview;

C: Leadership; D: On Leadership;

B: MD Anderson Culture;

A: The Researcher;

C: Professional Practice; C: The Professional at Work;

B: Working Environment;

C: Collaborations;

B: Multi-disciplinary Approaches;

B: Survivors, Survivorship; C: Patients, Treatment, Survivors;

B: Institutional Mission and Values;

Eduardo Bruera, MD

[00:27:27]

By this time, the institution had gotten much more comfortable with us being around. What we noticed by the year 2008, 2009, was that still, we had a problem with getting the patients to us too late. We were perceived as a service that was a pre-hospice, pre-end of life. So what we did with a young faculty member we had --who then went out to become an endocrinologist somewhere else-- we did a survey of oncologists and nurses, an anonymous survey, at MD Anderson, of two hundred oncologists and advanced practice providers. We asked them how would you feel about a service named palliative care and a service named supportive care, to refer your patients? Close to the end of life, 92 percent of them said they would send us those patients. That to us was very reassuring because if we had done that survey ten years before, we would have found that 10 percent would have said they would send us a patient, because they were not entrusting us their patients. But by 2008, 2009, about nine years or ten years of me being here, that battle had been completely won. For people who had advanced cancer, who were not candidates for treatment, the vast majority of the doctors and nurses at Anderson would send us a patient. However, as the disease became earlier and earlier, fewer and fewer doctors and nurses were willing to refer to us a patient to a service named palliative care. For those with an early diagnosis, less than 30 percent were willing to send us a patient. On the other hand, when the name of that service—and that's the only thing we asked them, the name. When the name was supportive care, the numbers increased dramatically for early patients, they were way more likely to send us earlier patients. [00:29:43]

So, we had to go to our Chief Medical Officer, who at that point was Dr. [Thomas A.] Burke [oral history interview] already, and tell him we've got a problem here, of perception. We are perceived as—we asked them, why is it, because 44 percent of them felt that the name palliative

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decreased hope for the patient and family. We're not asking the patient, we were asking the referring doctors, but those were our real customers. So we went to him and said, listen, we need to change the name of the Outpatient Center, we need to call it the Supportive Care Center. We also need to change the name of our mobile teams, the consult teams. We need to call them supportive care teams. And then he said, "Well, who else is doing this," and we said well, nobody yet but we are MD Anderson, we're supposed to be leading things and we're not supposed to do things only because other people are doing them." He had a bit of a chuckle and then he said, "Well that's okay, we'll do that, okay." So they sent us the authorization to change the name of our center and to change the name of our mobile teams. Our Palliative Care Unit remained Palliative Care Unit, because there was zero problem with people who were facing end of life care. Our survey clearly said that. The problem was with earlier patients.

[00:31:06]

Tacey A. Rosolowski, PhD

[00:31:05]

Right.

[00:31:06]

Eduardo Bruera, MD

[00:31:07]

Within six months of changing the name, our business grew by 41 percent and so it was an explosion of referrals within six months of getting the name changed. It unleashed a lot of people who really felt that they needed help with those patients, but they were reluctant. They suddenly opened up and they started sending us more patients.

[00:31:35]

Tacey A. Rosolowski, PhD

[00:31:35]

Now here may be a good time to ask, because I haven't really asked to this point, what is the array of services that you provide, provided at that time and continue to provide, for this area of supportive care for people early in the disease process?

[00:31:56]

Eduardo Bruera, MD

[00:31:56]

Well, for example, of course the main problem in this stage is physical and psychosocial symptoms; people who have pain, fatigue, nausea, lack of appetite, but also people who feel depressed, anxious, poor sensation of well-being, cannot sleep well. People who have family distress, people who are ill and they have young children who are distressed, or who have a spouse who is either unable to address their needs or distress, people who have spiritual distress. This is God's punishment, or I used to believe in God but God could not do this to me, now I

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don't believe in God any more. People who have financial distress; I am doing this for myself and I'm being so selfish because I'm spending the college education of my children in treating my cancer. So people who had multiple reasons to feel really bad, that was the number one priority, but also there were issues of organizing their care. Who will take care of me, who will drive me to places, who will get me back? When families were not always aware of what was going on, aware of how they could help the patient, the primary teams felt kind of a bit lost about what to do. They also frequently sent us patients. Also, somebody might be really starting treatment and have a really good short-term prognosis but a really bad long-term prognosis. So then they might send them to us to establish a relationship, because they knew that the ending was not going to be good, but things are not looking bad right now. Establishing a relationship early might prevent these patients from being in worse distress later on.

[00:33:55]

Tacey A. Rosolowski, PhD

[00:33:55]

Right.

[00:33:55]

Eduardo Bruera, MD

[00:33:56]

So those would be the packages, I think, about the overall services that we provided.

[00:34:03]

Tacey A. Rosolowski, PhD

[00:34:03]

Now how did you go about communicating this array of services to people within the institution?

[00:34:09]

Eduardo Bruera, MD

[00:34:10]

It had to be word of mouth. We were never depicted by the institution in any internal advertising, in any internal promotion, absolutely nowhere in the institution. Actually, most of the time we were not even announced that we existed.

[00:34:29]

Tacey A. Rosolowski, PhD

[00:34:30]

Why do you think that was? I'm sorry, I didn't mean to interrupt you.

[00:34:32]

Eduardo Bruera, MD

[00:34:33]

Well partially, I guess it was not a major focus of what the institution was all about. It was making cancer history, it was basically treating cancer aggressively. The cancer was brought to the institution by a person and the person frequently suffered, physically and emotionally, but there was not a lot of interest in making this a centerpiece. Some people might be afraid that if we were to acknowledge that people suffered and that people died, the institution might lose credibility or might lose resources. I was personally convinced that that was going to be exactly the opposite, because what people fear more than death is pain and suffering. And an institution that will be welcoming and embracing you, and telling you don't fear coming here, we will deal with your cancer but we'll deal with you and your family --to me, that was a great sales pitch. But for that reason --I am not a wealthy person-- I have never been able to sell anything very well, so I don't know. Other people who were into the business area thought that maybe it wasn't that cool. Therefore, because we had no power in any element, we were not really visible in the institution. So, a hundred percent of our growth, a hundred percent was word of mouth. If a physician saw a patient and sent them to us and they did very well, then they would send us another, and then they would meet a colleague and say you know what, I'm using these guys, Bruera and his team, and they're doing a good job with me. Oh, okay that's good. So, something happened that was totally unplanned for the institution, that is for the last eight years in a row, eight or nine years in a row, since we changed the name to supportive care in 2010, so for eight years in a row, the Supportive Care Program has been the fastest growing program at MD Anderson, more than any other program, every single year for the last eight years.

[00:36:40]

Tacey A. Rosolowski, PhD

[00:36:41]

Wow.

[00:36:41]

Eduardo Bruera, MD

[00:36:42]

We have had more referrals than any other program, and that was—even though the institution, during that time, made big promotions of other services and other programs and so on. They never once mentioned us in any documentation or any advertisement. One of the challenges for us was to keep our growth possible, because many of our administrators and leaders had trouble accepting that we were growing at the rate we were growing, because we were not intended to grow. There were other things that were intended to grow, we were not. The doctors and nurses from MD Anderson knew better. The ones that were not powerful but were seeing most of the patients said, these people are helping my patients and my patients feel better when they go to see them, so I am going to send the patients. They were basically sending us the patients.

[00:37:45]

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Chapter 10

Palliative and Supportive Care in a Changing Institution

B: Overview;

Codes

C: Leadership; D: On Leadership;

A: Overview;

B: MD Anderson Culture;

A: The Researcher;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

C: Collaborations;

A: Professional Values, Ethics, Purpose;

B: Growth and/or Change;

B: Institutional Politics;

B: Institutional Mission and Values;

Tacey A. Rosolowski, PhD

[00:37:45]

Now I'm curious if you've reflected at all on what that says about leadership, and kind of the way leadership sees an institution or makes those— [phone rings] Shall I pause the recorder?

[00:38:03]

Eduardo Bruera, MD

[00:38:03]

No that's fine, that's fine, it's my wife so it is no problem.

[00:38:09]

Tacey A. Rosolowski, PhD

[00:38:12]

Just a reflection on what that says about institutions and leadership, that something like that can happen.

[00:38:19]

Eduardo Bruera, MD

[00:38:20]

I think it tells us that institutions and leadership in medicine are disease-oriented, not person-oriented. I never hold it against the institutions or the leaders, that they make those decisions about what I do. It would be easy for me to personalize and to say that there are good people and bad people, but that would be kind of naïve. These people went to medical school with me, these

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people took training, these people are trying to do the best within the tools of what they know. That's a heart institute, this is a cancer center, people are disease-oriented, and then a group that is person-oriented had no real fit. It was not seen as to fit. None of these colleagues, none of the ones that are my age or even twenty years younger, ever learned about palliative care. They did not learn in medical school, they did not learn in residency, they did not learn in fellowship, and so basically, they have a natural kind of resistance. They're a bit cynical about anything that they haven't learned. They may have thought that we were quacks. They may have thought that we had nothing to offer. In fact, many people who are in a leadership position at the institution right now have said to me that there's nothing we do that is special and so on, even though there are now thousands of papers, more than two thousand by our group, but hundreds and hundreds of papers in the literature every day that clearly show that there is a body of knowledge.

[00:40:05]

Tacey A. Rosolowski, PhD

[00:40:05]

Interesting.

[00:40:05]

Eduardo Bruera, MD

[00:40:06]

But since people have not been educated on it and they arrive into a position of leadership and the whole administrative structure is disease-oriented. A person-oriented program doesn't fit. So the two medical schools in Houston have no department of supportive and palliative care. The Methodist Hospital, as big as you see it, only has four doctors. Saint Luke's doesn't have one doctor, and the UT Health Sciences Building has three or four doctors only. Memorial Hermann does better. It has ten or eleven. Houston particularly, has been a little bit behind, and the understanding that personal care is important has not always been there. So I think that we owe our existence here, I owe my life, my career, to first, the vision of Neil MacDonald who, in the '80s, when this was thought to be almost esoteric things, he saw that there was an opportunity for this, for patients and families. Upon my arrival here, it was John Mendelsohn resuscitating a program that was moribund by people not knowing what we were doing here and so on. And picking us up again and then saying, you know what, I'm going to put you guys here and I'm going to support you. And then Dr. Hong, who basically took us and said, I'm not a hundred percent sure what you guys do every day, but show me the data, show me your achievements, show me the numbers, and then I will fairly react to that and put the resources. So, really, it's not surprising to me that this area received very, very little attention. [00:42:10]

It is a little bit disappointing to me, that as I'm getting to the last years of my career, I have not seen yet, the explosion of person interest in medicine. I think it's getting better. I think it's improving every year. And for the first time in the history of this institution, I heard a president say that patients die of cancer. So, Dr. Pisters, for the first time in the history of this institution,

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mentioned that end of life care is one of the priorities. I was incredibly thrilled to hear him say that, I was emotionally affected. It took me to a very emotional level, to hear a president of MD Anderson saying that end of life care was a priority. So it's a tribute to him and it's a tribute to Dr. Hong, who have both said that this is important. But I also heard him say something that is striking: that is MD Anderson is person-focused, patient-focused cancer care. This sounds naïve. But for the first time, I have heard a leader say that we're focused on the person, we're focused on the patient, we're not focused on your cancer. We're not just focusing on the history of cancer or anything, we're focused on the person. It's great to see that, I am not very surprised that it took so long for the person to be put in the center of the action. In a sense, hopefully, I'm going to end up my career seeing that --looking at the personal suffering discipline,,and measuring it, and treating it and supporting it, will finally make it to mainstream medicine, will finally become an important part, and that with doctors and advanced practice providers will feel proud of the patient being the center of what we're saying. Because the patient being the center has been given a tremendous amount of talk. But the same as we were discussing before about leadership, it's not what you say it's what you do, are the actions that depict it. [00:44:44]

Now, in the case of our current leadership, who have been here for six months, the fact that they make these very strong statements has been unprecedented, it's never happened before. I'm not sure what people who have been so disease-oriented feel about this, they might not like it. From what I know, they might say, where is this taking our institution? I personally believe, as an oncologist who has been in this all my life, I believe that this is taking an institution to greatness. This is taking an institution to making Texans proud, and to make Americans proud that you can do both: that you can treat a cancer, but you can treat it in an environment where the person is honored, where the person is cherished and embraced, and you don't have to do one or the other, that you can balance both. So I think that to me, this is a call for greatness. [00:45:51]

Tacey A. Rosolowski, PhD

[00:45:53]

That's very inspiring. I'm also thinking about how this shift in attention that Dr. Pisters is exemplifying, in really striking ways, I mean it is amazing, some of the statements that he makes and the way he's presenting himself as a leader, to everyone within the institution. He was obviously a stark contrast to Dr. DePinho and the research focus that Dr. DePinho brought, and I mean that certainly sent the institution into a very turbulent time. There were a lot of reflections on what was happening to MD Anderson culture and focus during that time. I'm wondering what your read was on that, I mean Dr. DePinho bringing in a very specific vision for how research might be conducted. But it began to have an impact, in some people's minds, on that balance between research and clinical work. What's your impression on what happened during those years?

[00:47:00]

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Eduardo Bruera, MD

[00:47:01]

You know, my impression is since 1999, including all the Mendelsohn years and all the DePinho years, MD Anderson was a very, very strongly disease-oriented institution. MD Anderson was not a person-oriented institution, and so nobody said that you had to be bad to patients, but nobody made a lot of emphasis on the interdisciplinary assessment of suffering and management and so on. So in a sense, I'm not sure that there was such an enormous change in the focus. From our perspective, we were kind of used to the fact that we were underground and that we were going to remain in that role, but that was, in a sense what happened also in other institutions in the nation. And so basically we considered ourselves lucky to get some support at the local level, and we never intended and we don't believe it's necessary, for us to ever be a prime program. We are what we do and we serve the patients and families, the primary teams, so we did not sense, we certainly did not sense that we were interesting to the institution, or at least to the senior leadership. But you know, we were very happy with the fact that the people who are actually seeing the patients and doing the clinical care, really found us very useful. And so that was what I feel kept us going and kept us being useful, the fact that the people working at the trench greatly valued our presence there. We wish we could have done more, because we didn't have the resources to be able to do as much as we could do for those people who are sending us patients, and we still have a deficit in that area, but that was very useful for us. [00:49:12]

The change into becoming now mainstream --and I'm not saying us, myself, but what we do becoming mainstream-- has been the last six months, or I would say the last four or five months, in which the institution finally, in the last nineteen years I've been here, we've started hearing that what we do might end up being cool at the end, that being the nerds in the front of the bus. We also don't want to go to the back of the bus and be the naughty people, but we would like to be right in the middle, and I think it looks like that's where we're heading.

[00:49:56]

Tacey A. Rosolowski, PhD

[00:49:57]

What are some of the other signs you're picking up, that there's that sea change within the institution? There's the explicit comments that Dr. Pisters makes and Dr. Hong. Are there other kind of reads that you're getting?

[00:50:11]

Eduardo Bruera, MD

[00:50:13]

I think it's a little bit early to see if that's, what are the changes are going to happen, but I sense that the patient is starting to be emphasized much more than procedures, practices and the research. They're not incompatible. Actually, I think in a place where patients are taking care of with great compassion and with great care, I think research becomes much easier, so I think it's

not one or the other. I think that what we do actually is financially positive for any institution. We generate tens of millions of dollars every year in saved costs for things that insurance will not pay, that might be done; unnecessary MRIs, chemo, ICU, that cause sometimes patients to be in more discomfort and the insurance won't pay. So, the financial data have been around for many years, but now I think it's finally taking advantage of and the institution is seeing this as something that is worth it. For a long time, the feeling was that investing on us was a loss of money. That was a wrong concept, based on a very historical concept of the '80s, that is if you do more things, you bill for more things and you bring more money in. But that's not always true, because if you do more things, bill more things, but only 20 percent of what you do gets paid, you actually are a big liability. There were many, many institutional historical issues with some targeted therapies that never got paid, with implantable pain pumps that did not get paid, with a lot of things that the institution was thinking that doing was good procedure, was actually a loss of money. That old concept fortunately has been replaced, and I think Ben Nelson has to be credited with having had a much more complex concept of what is financially or economically advantageous and what isn't. He has clearly the idea that if you happen to be a program that avoids non-reimbursable costs, you are a great asset to an institution, and so that helped us because it was impossible to sustain that investing in whole patient care was a loss of money. It suddenly became that investing was wise, was not a touchy-feely decision with poor financial discipline. It was actually a financially wise decision, but it took financial leadership to be able to say would you guys—it's okay, what you guys are doing is okay. You don't need someone to come and bill a lot of money, only to find that only half of that is reimbursed. You guys actually make that person's job feasible, because you guys, when that person is going to do one more of those and you tell the patient no, that's okay let's go home, that's it. Then that person doesn't do that, and then the institution doesn't lose the money.

[00:53:55]

Tacey A. Rosolowski, PhD

[00:53:56]

And that individual who is doing the prescribing and the other side of the care can actually use their resources of time for another patient that can benefit better from it.

[00:54:06]

Eduardo Bruera, MD

[00:54:06]

Exactly. Especially in a place like MD Anderson, where the patients are not—it's not like we lack patients. We actually don't have enough space to see enough patients, so you're absolutely correct. What you are saying is perfectly right: is you can invest your skills and your talent on someone who really has a big chance to benefit.

[00:54:31]

Chapter 11

Creating a Department Culture of Support and Wellness

B: Building the Institution;

Codes

C: Leadership; D: On Leadership;

A: Overview;

B: MD Anderson Culture;

C: Professional Practice; C: The Professional at Work;

B: MD Anderson Culture;

B: Working Environment;

C: Collaborations;

A: Professional Values, Ethics, Purpose;

A: The Researcher;

D: Ethics;

Tacey A. Rosolowski, PhD

[00:54:34]

I wanted to kind of go back a little bit and ask you some more about the practices that you instituted as a department. You talked about how that was really tough to build the clinical then get the resources, build the clinical, get the resources. Always this retroactive filling in the people that you need, and you said that you began to do a lot of things to support one another. What were those in-house initiatives that you took to kind of save people's necks during all this?

[00:55:11]

Eduardo Bruera, MD

[00:55:13]

Well, we started saying that first the area of governance was the most important one. At times where it was not always possible for us to understand what was going on, where was the money going, where were the decisions being made, we said well, in the area where we can have access, there will be one hundred percent transparency on anything. So the number of hours that each person worked, the number of patients that each person saw, the number of money that each one got paid, the number of weekends on call and evenings on call, were all transparent and actually the decision of allocation was done by an open committee in the auditorium, where everybody could show up and decide how we were going to organize. We usually do it three times a year for four months each time and then we basically have everybody show up and say what their needs are, and to review the process, so that there was completely transparency on those things. Whatever I learned, I would share with everybody in the team and occasionally, I would warn people that I was going to share that with my faculty, that I was not going to not share with my faculty when it affected them, so that they would feel that they were completely aware of what

was going on, and we knew. We didn't know a lot of other things, but we thought the transparency was a very important value. [00:56:51]

Decision making became one hundred percent collective, and that meant that you were going to hire someone, one hundred percent of the faculty sitting around the table says yes or no, and finally we get literally voting on hiring a new faculty. And so it's not me hiring the faculty, it's me hiring the faculty on behalf of our faculty team. If one of our members is going to ask for another 20 percent more protected time, and that's going to have impact on the rest, that's discussed by everybody. So we have everybody saying, yes, David might bring another grant and this might help all of us, let's have that protected time and let's do it this way, and so on. It takes more time. It's more time consuming for me, but it does ensure that people feel that they have autonomy, that they have a certain amount of control of their working environment, control of the decision making, that they can opine on how things are going and how people are doing. We also emphasized a lot the open-door policy, so the door is always open for anyone who wants to show up with a problem or a need. They can email, they can page, or they can just walk in, and I made it a point that everybody could walk in at any time and interrupt me, to the point that when I need to do something, I sometimes have to leave the office, because I need to hide somewhere where I can do some work, either in the library or the coffee shop or whatever, because that way I can focus on something in an uninterrupted way. Otherwise, the door was always open. But that I think provides a little bit of guidance for other ones to be available too, because then if I am making myself one hundred percent open, well the rest should also be open to others, right? I think that promoted a bit more of collaboration, sharing ideas. That is my idea board where I have all kind of ideas, but one hundred percent, I give away. So, when I have an idea of a new study, I just find someone who wants to do it and coach them into getting it done, rather than doing it myself, and so that way, that person starts to learn how to ride a bike and becomes more independent. [00:59:21]

We started doing anonymous surveys about workload. How is the workload this month or the last three or four months. Which is the area that you find more difficult? And then bringing those to our business meetings allows us to reallocate people to different places, based on how they express things. We try to do anonymous because I have a bigger microphone than an assistant professor, and if we say let's do it at an open table, then that assistant professor might try to please me, instead of expressing their dissent. I have to say with great pride, that when we have our business meetings, people feel totally confident about dissenting with me on anything and I find that that's an incredibly good thing, because that means that they feel free, they feel that they are not going to be paying any consequences for speaking their mind. [01:00:22]

Tacey A. Rosolowski, PhD

[01:00:23]

Has there ever been an instance where you were genuinely surprised about something that

someone brought to your attention in one of these contexts?

[01:00:31]

Eduardo Bruera, MD

[01:00:32]

You mean surprised about something that was wrong?

[01:00:37]

Tacey A. Rosolowski, PhD

[01:00:38]

Whatever it might be. I mean because you obviously, you have an intimate knowledge of this department, but things go on. Was there ever a time when somebody brought something to your attention, and you had really been surprised that this was there?

[01:00:52]

Eduardo Bruera, MD

[01:00:53]

There have been instances in which people, for example noticed that some of the medical procedures that we had established for a long time were not being honored as much as two or three years before, and then some of the assessments of the patients that we thought were part of a routine, were not being done as much. Some of them had been abandoned because of time constraints or because of people feeling that it was not so important, and then that allowed us to have a conversation collectively and say what do we need to change so that the patients benefit from these assessments and they don't get the short end of the stick. That was brought up to my attention once in a while. I have to say that I don't really deal too much with personal issues. I deal with things and concepts and ideas and so on, so I'm usually the last to learn when there are kind of personal difficulties, but they have been once in a while. When it's non-faculty, they all go to [Natalie?], who is my business manager and firm director, when it's a faculty issue I might learn, but I have to say that we've been extremely lucky because when I hear what happens in other areas and our program, my goodness, we have so few in the process of nineteen years, so few situations where we had a major ethical issue or a major personal issue that involved a faculty member. That, I think has been so easy from that perspective. It might be because we focus on playing the game together. We don't have to be one single burg, but we focus on playing the game together and I think we've been lucky in the hirings too. We perhaps brought onboard, people who were positive characters, who were sensitive people, and I also wonder, I always wondered, if partially, this might not be related to our specialty. When you are dealing with dying people all the time, there is less time for petty problems or conflict, because you are seeing what real problems are, and then when you're exposed to real problems, I suspect that you don't want to generate a lot of little problems. I don't know that as a fact, but I have this suspicion that our personhood-based practice permeates into our life, has an impact on our lives.

[01:03:49]

Tacey A. Rosolowski, PhD

[01:03:49]

Yeah, that may very well. Well then also, I mean you have stressed and you've said it's luck, and I'm sure some of it is luck that you've gotten good people, but as we've discussed in earlier conversations, you've been very clear that one has to search for individuals who have those qualities of emotional intelligence. So part of it is you as a department, have made a commitment to look for people like that and too, in your collaborative decision making, intentionally select for those individuals to join your group. How do you go about, in a hiring process, finding people with those qualities? How do you assess people so that you know you're making a good decision in that arena?

[01:04:37]

Eduardo Bruera, MD

[01:04:38]

Well, almost one hundred percent, one hundred percent of our faculty for the last fifteen years or sixteen years, one hundred percent of them have been our fellows before. So we got to know them for a whole year, we knew which ones had all those qualities, which ones could learn, and then our fellowship is funny. Suresh Reddy has been running our fellowship for many years and I've been working very, very close with him, extremely close, and our fellowship assessment is every month, all the faculty meet and discuss each one of the fellows. Each one of the fellows is discussed in great depth, so that if somebody is finding any warning signs, those are brought back to the fellow immediately and we also put together the puzzle of how is that fellow.

[01:05:35]

Tacey A. Rosolowski, PhD

[01:05:37]

Can I ask just quickly, what might be some issues that would arise, kind of warning signs that you need to jump on?

[01:05:44]

Eduardo Bruera, MD

[01:05:44]

Well, a fellow that does not have enough emotional intelligence when they go to see a patient and a family member, a fellow that does not display the empathy that might be necessary, a fellow that is not willing to help the other fellows, a fellow that does not show respect or team effort with the nurses and the counselors. We, for many years, have had representation of our nurses and representation of our counselors in the fellows evaluation meeting, so the nurses at the center and the nurses of the Palliative Care Unit, as well as the counselors, all come to the meeting, and they do their evaluation of our fellows.

[01:06:28]

Tacey A. Rosolowski, PhD

[01:06:29]

Wow.

[01:06:29]

Eduardo Bruera, MD

[01:06:30]

We do a very thorough evaluation of all our fellows. Many of them are shocked, because they've gone through residency and sometimes from another fellowship, and they never had that thorough level of evaluation, but we reassure them that the idea is that they play the game better, that they become better persons, better professionals, and they usually are happy at the end. In the beginning, they are not happy when they see the amount of scrutiny that has taken place, that results in their monthly evaluation, and so at the end of a year, we've got a very good understanding of who is who, and I credit our hiring from our fellowship for 90 percent of the success in having harmony and team operations. We also have people that we hire who have had similar training. Our training, we believe is the best in the nation and therefore, these people land already running and they are able to do things the way we do them. They have bought our model, our model of counseling, our model of medications, our model of assessment. We prime access to service for patients, we are proud of that. We get a call at four-thirty in the afternoon that we know is going to be an hour and a half and we say that's fine, there we go, we'll see that patient, no problem. We don't leave it until tomorrow, we'll see them today. We pride on taking phone calls and addressing them, so these people who are fellows have internalized that and they've demonstrated that they are feeling good with that. So I think we hire, in a sense, the best fellows that we have here. Sometimes we don't hire any because we didn't have any openings unfortunately, like the last group had two or three extraordinary fellows but we couldn't hire them because we had no openings. We have wonderful fellows this year, I hope we'll be able to keep one or two of them, because we do a very thorough job of assessing them for those qualities and I think that a lot of our success in the institution is that. [01:08:55]

I had an extremely VIP come on Saturday. They phoned me, what was it on Saturday? No, it was on Friday evening. I was in Galveston, and I got a call from this extreme VIP from one of the doctors that was sending this extreme VIP to the emergency center. They said, "What are you going to do, Eduardo?" And I said well, "I'm going to send them to whoever is on call," and they said, "Well, watch out, this is a big, big VIP and how can you be sure?" They said, "Who's on call?" I said, "I don't know." They said, "Well, this is a big, big, big VIP and you've got to be careful about who you send." I told that colleague, I don't know how you guys operate, but I want to reassure you about something. There's none of the doctors who work on my team, I would not have them treat my daughter, my wife, or me. If one of them was someone I would not trust—I mean, they may have slightly different styles-- but if I did not trust them, I'm not sure I could possibly go to Galveston, I would probably stay in Houston, camping there and

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trying to see what holes are there. So, they have slightly different styles but... And of course they did an extraordinary job. I sent an email there, this person is going out of there, who can see them? In about fifteen seconds, I had a response from one, "I'm heading out there right now." And then the person who was on call for the weekend, I contacted her and basically there she was, in another person in the ER and they fixed the problem and that was it. My experiences with the worst possible cases of VIPs that you could imagine, has been a variation of our regular product for those people is zero.

[01:11:05]

Tacey A. Rosolowski, PhD

[01:11:06]

Wow.

[01:11:06]

Eduardo Bruera, MD

[01:11:07]

Nothing. They are just seen by the member of our team who is seeing the patients that day, and I feel personally, very proud of that, because what that means is that huge VIP does not need different care from the poorest Medicaid patient we see, because they are all kind of—the people we deploy out there are so good, they're so extraordinarily good, that basically they show up on any floor, they show up in any area, and they will fix the problem, they will take care. They also know that they can call me at any time, they know that if they get stuck, and maybe eight or ten times a year they will call me and they said, I'm really stuck here, let me tell you about a problem I'm having. Sure, tell me. And then I have to tell you, 90 percent of the time, it's reassurance, then 10 percent of the time I find something that I might do different, and I tell them oh, why don't you try this, try that, and so on. But 90 percent of the time is so wonderful, there's nothing to add. I have no comments.

[01:12:20]

Tacey A. Rosolowski, PhD

[01:12:20]

That's wonderful testimony to the entire group, the strength of the group. I was going to say the flipside is, that the VIP deserves exactly the same treatment as the poorest patient, you know they're both ends of the spectrum and there's no difference, I mean that's quite lovely.

[01:12:36]

Eduardo Bruera, MD

[01:12:35]

Yes, yes. But you know programs that are erratic, they know that if you get one of the real jockeys or one of the people who published a lot of papers but are not clinically very solid, and you get a very, very big VIP, they're going to kindly remove that one because that one is not that

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good at dealing with the clinical issues. They might need to bring another one to do that type of work. Or, if somebody is on call that is not very reliable, they will call someone else, we've never had to do that. It just never, ever happened. I don't remember one single time. We have had cases in which a very unreasonable patient became very aggressive with one of our faculty and one hundred percent of the time, that faculty is removed from the trench and another faculty goes in place. I remove them myself, but that's for protection of the faculty, because sometimes that clash occurs and then that is hurtful.

[01:13:44]

Tacey A. Rosolowski, PhD

[01:13:44]

It damages that rapport and it's hard to rebuild it. Absolutely.

[01:13:47]

Eduardo Bruera, MD

[01:13:47]

Completely. And for the benefit of the patient and for the benefit of the faculty, I always make the point of changing them. I go with them, most of the time I end up going with them to that room where the conflict is happening, to try to understand what is going on. Then what I usually says is, that's fine, that's fine, and then I stay with the patient and say we're going to change the doctor who is seeing you and so on. It again, happens very rarely. Very, very rarely. Not once a year. Less than once a year it happens. But when it happens, I make a point of relieving that. But in terms of me ever feeling that someone else should be deployed to see a patient, we've been very, very lucky because we don't have that problem.

[01:14:37]

Tacey A. Rosolowski, PhD

[01:14:39]

Now, we had occasion a bit last time, and then we happened to be at a meeting on Friday and you were talking about the issue of burnout, which has become a topic within the institution. So, I wondered if—you know, we have a few minutes remaining today. I wondered if you'd say a little bit about that issue of burnout within the department, and some of the things that you've done to kind of address that reality.

[01:15:07]

Eduardo Bruera, MD

[01:15:07]

Right. Well, burnout in palliative care is rampant, it's the specialty that I know of, that has reported the highest level of burnout in medicine. That is not surprising, because of all the things we said. Faculties of medicine do not have palliative and supportive care departments. The specialty is not really well recognized, there are not very good solid clinical programs. The patients are very ill. So in that situation of not having a tremendous amount of credibility and

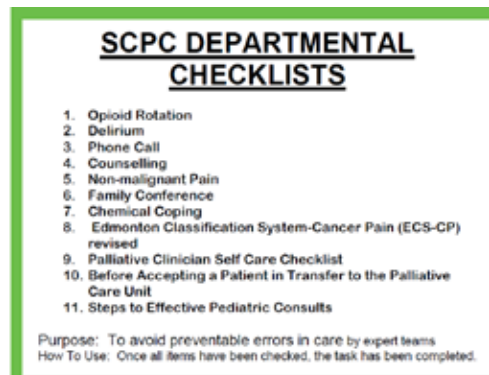
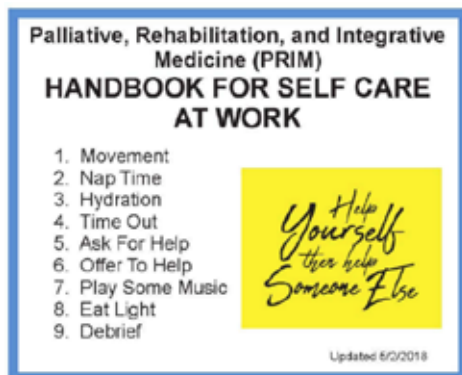
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respect and having big demands, is a position of great responsibility, dealing with ill patients and so on, and lack of autonomy to run things. The combination of high responsibility with no autonomy is what essentially leads to burnout, and basically, palliative care would be almost a picture-perfect case for that. So we early recognized that support was important and we implemented a lot of those previously mentioned institutional --institutional meaning our own team --department self-support strategies. But also, we implemented a whole series of measures for self-care, and actually they are part of our departmental protocol for many years now.
[01:16:26]

So, when you open our little department protocol of things, you see what you do in terms of opiate rotation, delirium, phone call counseling, nonmalignant pain, family conference, but you also see the palliative clinician self-care checklist, and that is something that tells us a series of measures. There are thirteen different measures that you can apply every week to take care of yourself, anywhere from exercise, healthy food, meditation, yoga or mindfulness, literature reading, no junk reading, art, movie, theater, no junk movie, watch visual arts, meet with family members in person, meet with friends in person, participate in spiritual religious activities, palliative care professional education activities, avoid noise most days, TV sponsored Web or work telephone, when you're at home. Avoid at least one personal item of maladaptive coping that you know, nobody else needs to know, and achieve one personalized self-care goal. When you get more than eight of those, you are completely successful, between four and seven, partial success, and then when you get less than four of those, there's always next week. So that's our goal.
[01:17:50]



[Contact the Research Medical Library for these documents]

Tacey A. Rosolowski, PhD

[01:17:51]

Now, can I ask how you use this as a group. I mean obviously, people have this little booklet in their pockets, they can refer to it at any time, but is there—you know, do people come together to

talk about what they've done, or is there kind of community support? How does that piece work?

[01:18:10]

Eduardo Bruera, MD

[01:18:11]

Yes. We have, every Wednesday morning, a fellows round, where a case is presented, a complex patient case that is very important because it's a palliative care education activity, where we present difficult cases that have been there before problems. In the middle of the round there's something called the commercial break, and the commercial break is a moment in which we announce a clinical research protocol. Or if there is no clinical research protocol that needs to be advertised, and then I bring naptime or I bring the importance of timeout, or we have a meditation five minute video that everybody takes into the screen. That was done by Ale [Alejandro] Chaoul for us, and then we take that video of meditation. So, the different aspects of self-care are emphasized every week when there is no—so we would say at least twice a month, those aspects are emphasized specifically in that five-minute commercial break. And then we are now doing some anonymous surveys about which aspects of that are people using and which aspects are they not using, and which aspects do they find particularly useful. We are trying to learn, from our faculty and our APPs, what they are finding. [01:19:53]

We also have a second booklet, there is a whole booklet about self-care at work, that is basically what things can you do for yourself during your working day that will make your day a little bit less painful, that is anywhere from offer to help when you are not busy, that improves your immune system and your well-being, but also ask for help when you are overwhelmed. Play some music, take your headphones and listen to music. Eat not too heavy. Take your time out and choose where you are going to take your time out. Drink water, because most Americans in the workplace are dehydrated. Take a nap. Move. And so those are things that we are—and then when you have a really bad thing, debrief, you know come to my office or some to somebody else's office and debrief about a traumatic situation, don't go home carrying it, debrief, and debrief if possible, immediately after.

[01:20:55]

Tacey A. Rosolowski, PhD

[01:20:55]

When did you decide to create these booklets for the benefit of your faculty and the team's self-care?

[01:21:02]

Eduardo Bruera, MD

[01:21:03]

The first one must be about three or four years ago, about four years ago, five years ago, when

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things were getting difficult at MD Anderson, especially for teams like ours, that were getting a lot of hard work and not always resources to get the work done, et cetera. We felt that it was necessary to make sure that people took advantage. I spent my life coaching soccer and basically, I felt that coaching people was something that I liked to do, but I also wanted to learn a bit more about the area, because I did not want to coach people wrong. So I had to do some reading about this and then find what are the practices that appear to be more successful and I put those into that weekly self-care checklist. [01:21:52]

The other one was probably about a year ago, a year and a half ago, and the other one was because what you do on a weekly basis to take care of yourself, it's okay, it's your lifestyle modification, but we sensed that you have to take advantage of what you can do for yourself here, during your working hours. It's not what you do only when you are home, but it's what do you do during your working hours at MD Anderson that can make you feel better. About a year, a year and a half ago, I came up with this other one, and Aimee [Anderson] and I have been working at helping people use it and also tell us which parts work and which parts don't. The feedback we received generally has been very positive, that faculty and APPs feel that being reminded of the things that they can do for themselves, make you feel less helpless. If you feel that there are some things you can do for your distress yourself, you feel in a sense more empowered.

[01:23:10]

Tacey A. Rosolowski, PhD

[01:23:10]

I'm also thinking too, I mean the very fact that you've written these things down and it's an official department little publication, it's giving people permission. It's not saying no, do this when you can sneak it in, don't let us know about it. It's saying no, we want you to do this. It is part of your working day.

[01:23:31]

Eduardo Bruera, MD

[01:23:31]

Yes.

[01:23:31]

Tacey A. Rosolowski, PhD

[01:23:32]

That's an enormously important message.

[01:23:34]

Eduardo Bruera, MD

[01:23:34]

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Yeah, we made that a point, you're absolutely correct, because I also told our people that's why I'm putting it in writing, because if someone from any department or from any other area, brings it to your attention, show them this and send them to me. Whether it is the president of the institution or the head of Human Resources, or the director of another service, send them to me. I will assume personal responsibility for people really being upset about the fact that you are taking of yourself, because in my view, this is what is good ethical practice for the institution. You cannot go and see a suffering patient and a family in a state of distress. You cannot serve the institution well if you are feeling really bad within yourself. So if you take care of yourself, then you can take care of others, but there's no need for self-neglect to be helpful to others. So, I think you're absolutely correct. Maybe some of the reasons the feedback is positive is not so much because there's anything original there that they may not have read or thought, but it's because in a sense it's an official welcoming of those things as ways in which you can take care of yourself. I heard some people say, you know there are some days where I could barely keep my eyes open, but I felt so embarrassed about taking a fifteen minute nap, and since you said that, I'm going to my desk, I put on my facemask. I slept exactly ten minutes, fifteen minutes, then I went and had a wonderful day.

[01:25:16]

Tacey A. Rosolowski, PhD

[01:25:17]

It made all the difference.

[01:25:17]

Eduardo Bruera, MD

[01:25:18]

So, it was just that short period, or you know, people who want to walk from here to there, they walked outside, they went by the trees and so on. They crossed the street, then they went in again, and that minimal time off, of walking among the trees and crossing the street and being outside, brought them back to the real world and now they were ready to go back. So, I think there is great value in small things. People overemphasize the big picture and we try to emphasize the little things.

[01:25:55]

Tacey A. Rosolowski, PhD

[01:25:57]

Well I know we're a bit over time, so I wanted to thank you for that and for your time this morning.

[01:26:03]

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Eduardo Bruera, MD

[01:26:02]

Oh, thank you so much for your patience and your time, listening to all these stories.

[01:26:05]

Tacey A. Rosolowski, PhD

[01:26:05]

No, no. No, I'm delighted, and I actually do have a few more questions, so if you're amenable, I'll ask Carlos to work with your schedule.

[01:26:13]

Eduardo Bruera, MD

[01:26:10]

Oh sure, sure. Wonderful.

[01:26:14]

Tacey A. Rosolowski, PhD

[01:26:14]

All right. Well, I want to thank you again, for taking the time today, Dr. Bruera.

[01:26:18]

Eduardo Bruera, MD

[01:26:17]

Oh thanks for coming, it was wonderful.

[01:26:18]

Tacey A. Rosolowski, PhD

[01:26:19]

And for the record, I'm turning off the recorder at five minutes after three.

[01:26:24]

Eduardo Bruera, MD, FAAHPM

Interview Session Three: November 5, 2018

Chapter 00C

Interview Identifier

Tacey A. Rosolowski, PhD

[00:00:01]

Today is November 5, 2018, and I'm on the fifth floor of Pickens Tower, in the office of Dr. Eduardo Bruera, for our third session. I wanted to thank you for quickly recognizing things so that we could meet today.

[00:00:17]

Eduardo Bruera, MD

[00:00:17]

Thank you very much, I'm delighted to be here.

[00:00:20]

Tacey A. Rosolowski, PhD

[00:00:20]

It's really a pleasure. I wanted to also say for the record, that it is one thirty-five in the afternoon, and I kind of had my list of things to go through, as I indicated, and I wanted to start and talk about really, what were some of the most important committees that you served on, first within the institution.

[00:00:42]

Chapter 12

Committee Service: An Issue of Leadership and a Voice for Palliative Care

A: Overview;

Codes

C: Leadership; D: On Leadership;

B: Obstacles, Challenges;

B: Research;

A: Overview;

B: Overview;

B: Research;

A: The Researcher;

B: Building/Transforming the Institution;

Eduardo Bruera, MD

[00:00:44]

Over the years, I had the chance to become involved with, I would daresay most of the institutional committees, certainly from the research aspect, the CRC, the Clinical Research Committee, the [PBH-SRC?] there is a Social Sciences Research Committee, the IRB [Institutional Review Board] Committee. I also had the chance to participate on the Promotions and Tenure Committee, I had the chance to participate on the Pharmacy and Therapeutics Committee, and of course in the Executive Council of the Division of Cancer Medicine, for a number of years.

[00:01:31]

Tacey A. Rosolowski, PhD

[00:01:32]

What do you feel were the most significant ones, I mean maybe the ones that you felt gave you the chance to have the most impact, or the ones that taught you the most about the institution.

[00:01:42]

Eduardo Bruera, MD

[00:01:43]

I think that second aspect is probably the one that I recall the most. That is I think I participated as a member of the committee, but I think what I mostly gained from that was understanding; understanding of how MD Anderson operates, the relationship between MD Anderson and the University of Texas, the relationship between MD Anderson and other cancer centers in the nation, the state community and so on. So I think it was very useful to be part of it. I still am part of some committees, like the Executive Council of the Division of Cancer Medicine. I'm a member of the board of the MD Anderson Network Association. So there is almost an independent company that MD Anderson owns, that is called the MD Anderson Network, and

I'm a member of the board of it and that has taught me a lot about what happens with global distribution of oncology services and so on.

[00:02:54]

Tacey A. Rosolowski, PhD

[00:02:55]

What are some of the things that you learned from that perspective?

[00:02:58]

Eduardo Bruera, MD

[00:02:59]

I think I learned that there is an enormous need for smaller organizations to take advantage of the way we have learned how to do things, and they are avid to establish a relationship. Something that normally one would say, well, why would they be paying or transferring money to MD Anderson to learn how to operate? They're avid about doing that because they know that over time, we have managed to do two things that are nice. One of them is to operate as an effective institution, but the second one is to do it in a way that was highly ethical, in the sense that we generally have the patient and the family's well-being as an important aspect. So, organizations, both private and public organizations, that are looking at improving their systems, find it attractive to work with a state institute, a not-for-profit institution, and an institution that has high credibility like MD Anderson. So I learned a lot from those participations and I had a chance to participate at the national and international level in many organizations, that taught me a lot and I think I was able to work with them. I had multiple roles at ASCO, the American Society of Clinical Oncology, over the years.

[00:04:32]

Tacey A. Rosolowski, PhD

[00:04:33]

I wanted to ask you, I did want to ask you about some of those specific experiences, but before we move into those, I wanted to ask you what's the significance of having someone from Palliative Care on these committees?

[00:04:49]

Eduardo Bruera, MD

[00:04:50]

I think it has some value in the sense that we sponsor patient care, rather than disease care, or comorbidity care. The institution has quite a few departments and quite a few centers that aim at the management of different diseases, and also some of the comorbidities that accompany those diseases, but we're one of the few that has faculty that is looking at the person, the person care. So from that perspective, we're able to contribute some of that.

[00:05:26]

Tacey A. Rosolowski, PhD

[00:05:28]

Do you find that that's a new perspective, or an unusual perspective?

[00:05:32]

Eduardo Bruera, MD

[00:05:33]

It is a completely unusual and new perspective in the vast majority of disease-based care and it's still very, very significantly underrepresented in the institution. So it is not something that has reached the level of administrative recognition that would make it clearly a priority, not just for us but for the majority of centers in the nation.

[00:06:03]

Tacey A. Rosolowski, PhD

[00:06:03]

Now, I know we'd spoken at length, in the other sessions, about some of your strategies for basically getting palliative care recognized within the institution, and how you set up working relationships with other departments, with clinicians that may have been very unfamiliar. What are some of the strategies that you've used, when you work at that different administrative level, on committees? Is there a different approach that you take? How do you communicate with those folks?

[00:06:34]

Eduardo Bruera, MD

[00:06:36]

Well, it is very hard when the language is totally different, to communicate with teams from the perspective of what we do, and for that reason, patient-centered care is profoundly irritating to many committees and administrative structures, because we value aspects of care that other groups do not really understand. It's not their fault, it's just that they are based on the liver or the breast or the melanoma, or the heart failure, and that's what they do. But we are emphasizing on the personal experience: on the lighting on the ceiling and the medications for making people comfortable, and spending time with the family, talking. So, our need for structures and processes, that is what is basically directed by those committees. Our need for structures and processes happens to be different from many of the other entities and therefore, while it is not an issue that one can discuss very successfully with rhetoric, I think it's more successful to discuss it with data. So our challenge was always to bring, to our requests, more and better data than other groups, because we knew that a lot of our issues were not going to find kind of an intuitive concordance with the way other people saw it, with the way physicians, nurses, pharmacists, saw the operation. So we made it a point to try to bring data, and data meant how do patients perceive the music? How do patients perceive the computer in the room, how do patients

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perceive having a full bed instead of an examining table? How do patients perceive no waiting room? It forced us to generate data on things that we thought were very important but other teams and administrative leadership did not necessarily feel that way.

[00:08:41]

Tacey A. Rosolowski, PhD

[00:08:42]

Now, you've used the word irritating. [laughs]

[00:08:44]

Eduardo Bruera, MD

[00:08:44]

Yes, yes.

[00:08:45]

Tacey A. Rosolowski, PhD

[00:08:45]

Why did you use that word, I mean that's a telling word, that they found it irritating. How would they respond?

[00:08:52]

Eduardo Bruera, MD

[00:08:52]

Well, the problem is that it changes the way an administrative leader sees their area of control. So if I am running the facilities and every outpatient center has a waiting room and a front desk, and then people go in and somebody says we don't like to use waiting rooms, because we don't like people who are very ill and who have body image problems and suffering, to be sitting in front of each other waiting to be called in, we want to move them directly. If you're running a nursing structure in which nurses can be deployed freely, from one area to another, and a group says for patient-centered care, you need a special type of training in the nurse, and the nurse cannot be the same one that did push chemotherapy last Monday and who is going to be helping in postoperative Tuesday, because this is personhood care and requires a slightly different operation. When you talk to social services or chaplains and you say these are very suffering people, and when you allocate your people according to number of beds, it's probably not helping us because a hundred percent of our patients are suffering, and in the other areas, maybe 10 or 15 percent of the patients are suffering, so how do you reallocate resources to serve these suffering people? Those things, unfortunately have a trend to be a bit frustrating, because I run my operation in a certain way and now these people come and tell me that they have slightly different needs for the patients. Of course our argument was always we bring, to our setting, patients that are not our patients, patients that are your patients. We never get anybody coming from the street coming to see us. One hundred percent of the people who receive supportive and

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palliative care are people who are already part of our patient family. And because we move to our care those who are having more difficulty, our needs are a little bit different. That is always frustrating to administrators, especially when what we are trying to do is widely available somewhere else. So it's not that we could say well, look at how big they are at Memorial Sloan Kettering, how big they are at Dana Farber, how big they are in Methodist Hospital, because unfortunately, those programs weren't and still are not that well developed there. So part of our goal was to convince that we needed those elements, and to do it not only with the idea that it made face, it had face value good, that we were able to generate data, especially patient-based data, that supported their use. And so that's why the participation in committees was always a situation where you had to be aware that we had to justify ourselves a little bit more than what are called mainstream hospital programs.

[00:12:10]

Chapter 13

Building the IAHPC [International Association for Hospice and Palliative Care] and the Challenges of Cross-Cultural Care

A: Overview;

Codes

C: Leadership; D: On Leadership;

B: Beyond the Institution;

A: Activities Outside Institution;

C: Professional Practice; C: The Professional at Work;

A: Overview;

B: Overview;

B: Building/Transforming the Institution;

A: The Researcher;

D: Cultural/Social Influences;

D: Global Issues –Cancer, Health, Medicine;

D: Women and Diverse Populations;

D: Ethics;

Tacey A. Rosolowski, PhD

[00:12:12]

I can imagine that. Now you were about to tell me about some of the external committees you worked on. I have the Palliative Care Committee for Latin America, via the World Health Organization, and a number of others. What were some of the most important ones for you and what were your roles on those committees?

[00:12:33]

Eduardo Bruera, MD

[00:12:34]

One of the things that I thought was nice, is that soon after I arrived, I was offered to become the president of the International Association for Hospice and Palliative Care, the IAHPC. I basically discussed that with the leadership, because the leadership was in Australia, and I told them, I can only do this if we bring the organization to Houston, because I would need to work very closely with an executive director. The board agreed that we could relocate IAHPC to Houston, and I believe that was around the year 2000. And so we brought IAHPC here and actually, nineteen years later it's still in Houston, and I hired the executive director, who became the person running the organization.

[00:13:29]

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Tacey A. Rosolowski, PhD

[00:13:30]

Who is that?

[00:13:30]

Eduardo Bruera, MD

[00:13:31]

Her name is Liliana De Lima. She had been running a hospice initially, in Columbia, but she had relocated, with her husband, to Houston, and basically I said also to the board, I'll do it with two conditions. First, I'll move it to Houston, second, I'll hire Liliana, because I knew she was very, very good. And then, I was able to hire her and actually, she's retiring later this year, so she was running it for nineteen years. I only was the president for four years and then I stayed at the board for another eight or nine years, but during that time, I think we were able to help promote the model of hospice and palliative care with a global perspective, and that was very attractive because we started using online programs, we started organizing meetings. We helped organize regional organizations, both in Latin America, India, Africa, and those organizations, we believed were very, very important, because now they could discuss their own problems with a very original, independent perspective.

[00:14:52]

Tacey A. Rosolowski, PhD

[00:14:53]

Are there cross-cultural differences in palliative care needs?

[00:14:57]

Eduardo Bruera, MD

[00:14:58]

Yes.

[00:14:58]

Tacey A. Rosolowski, PhD

[00:14:59]

Tell me a bit about that.

[00:15:00]

Eduardo Bruera, MD

[00:15:00]

I think those are way more significant than those that you find in other areas of cancer care, because the prostate is the prostate, the liver is the liver. The differences are absolutely minimal. But my approach to my life, my end of life, my family, my spirituality, even things like just my entertainment and my food, are dramatically different in different areas of the world and

therefore, integrating palliative care needs to respect how things are done in each of those cultures. How the patient and the family communicate with the doctor, with the nurse, with each other, what are their values. So it requires, I think much more adaptation to the societal values than other areas that are a bit more genetic with medicine and cancer care.

[00:15:56]

Tacey A. Rosolowski, PhD

[00:15:56]

Just to kind of make it more alive for me and for the listener, can you give me an example of something you discovered in one of these cross-cultural interactions that really surprised you?

[00:16:11]

Eduardo Bruera, MD

[00:16:12]

Yes, there were several issues that were very attractive to study and to understand. One of them was, for example, the disclosure of cancer and the disclosure of end of life, something that was accepted universally in North America, both in Canada, where I worked for fifteen years, and in the United States. It did not happen in a large majority of the patients in developing countries and therefore, palliative care had to be inserting itself into a disease model and a communication model, where upfront, telling a patient you have cancer or upfront, telling a patient I cannot cure your cancer and the cancer is likely to be the cause while you will die, were not the norm. And so if one was to reach those patients and families and help them, one had to—one could not bulldoze the way things were done. One had to kindly and gently integrate into that model, and then slowly from inside change it and increase frank and honest communication, and empower those clinicians with a way to change their own system, because coming with the assumption that universal disclosure was the appropriate way, would have caused a cultural clash that would have been devastating for the careers of those doing palliative care. They would not get any more referrals, nobody would want to have them see a patient.

[00:17:46]

Tacey A. Rosolowski, PhD

[00:17:47]

What would be some of the reasons within the culture, that there would not be a kind of stark, upfront disclosure of cancer, because there's always a reason, why that mechanism is there.

[00:18:00]

Eduardo Bruera, MD

[00:17:58]

Right. I think it's very likely, purely evolutionary. During the 1960s in the United States, disclosure of the diagnosis and the prognosis was also very minimal. Most doctors did not tell the patients they had cancer, they were going to die. Emperor Hirohito from Japan was never

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told that he had prostatic cancer, and he was dying of prostatic cancer. Also Franco, the dictator from Spain, was also having prostatic cancer and also was not told. So it was not just what we might call the patients who are disadvantaged. It was actually very powerful people were not told, and that was due to the feeling that there was so much terror and fear around the word cancer and the end of life, that it was not compassionate to share, with a patient and family, those terrible news. So patients were frequently not told what happened to them. The grandfather of Queen Elizabeth in the UK, also had lung cancer, and initially, he had a pneumonectomy and was not informed of the diagnosis of cancer, and so he was mistaken in thinking that things were going to get better, and then he started having symptoms again and finally, his doctor was having to tell him. So, initially, people feel that it's cultural, but it's not really cultural, I think it's more evolutionary, and within a decade, between '60 and '70, in the United States, patients went from 10 percent knowing the diagnosis to 90 percent. Then, in the '90s, the same things happened in Japan, and I could say that this model is happening now worldwide. I don't think it's just the work of palliative care, because it would not be fair. I think it's just the understanding of what is in the best interest of a patient and family, in a sense, the understanding of medical ethics has evolved a little bit. We were, of course, we were very much part of those changes globally, and so that was one of the issues that we felt was important. [00:20:24]

The other kind of cultural change relates to the communication between the patient and the family and the doctor and the medical team. That is, in many countries, patients and families, patients prefer their family to be their advocate, and so in the decision of palliative care issues, contrary to what happens in the United States, where the patient arrives either alone or with one person, in many developing countries, the family arrives first and two or three relatives arrive first, to discuss with the doctor, the patient's care and what happens, before the patient enters the room or before the patient enters the realm of care.

[00:21:10]

Tacey A. Rosolowski, PhD

[00:21:11]

That's kind of interesting. I've read how either --differences in cultures, is it an individualist—do people think of themselves as individuals first, or do they think of themselves as part of a corporate entity first.

[00:21:23]

Eduardo Bruera, MD

[00:21:24]

Yes.

[00:21:24]

Tacey A. Rosolowski, PhD

[00:21:25]

You know, and those are cultures that you're part of a group, that's your first notion of your identity. How interesting. So I'm sorry, I interrupted you.

[00:21:32]

Eduardo Bruera, MD

[00:21:32]

Oh no, that's exactly, I completely agree with that. Those, I think were two important things, the disclosure, but on the other hand, how you communicate as the disease progresses and so on. So there were major cultural issues and it was very nice to see that palliative care was successful in those environments also, and there was great support and gratefulness from patients and families, for having received palliative care in those environments.

[00:22:03]

Tacey A. Rosolowski, PhD

[00:22:03]

So, I can imagine that for a western doctor, for example, arriving on a scenario like that, it would be very disorienting to have family arrive first. What are some of the communication challenges that they would confront in that scenario? How would their communication strategy be different if the family comes first as the advocating body?

[00:22:25]

Eduardo Bruera, MD

[00:22:26]

There would be significant differences in the sense that the initial reaction from the family is we can learn anything that is going wrong with dad or with mom, and so on, and we can discuss it with you, and we can discuss the possible treatments and we can discuss the medications, but we would not like you to discuss that with the patient, with mom or with dad. Then, one of the challenges for that clinician is that this idea of collective decision making about their care was -- well, for somebody trained in the west it was foreign. For somebody trained in those countries, they have difficulty incorporating the principles of palliative care to the way they were supposed to practice, so we had to help them understand how the principles of multidimensional care, of your physical, emotional, social and spiritual suffering could be addressed in that environment and yet, because it was creating an enormous amount of distress and cognitive dissonance from those doctors who were coming here and training, or those nurses who were training here, and so one level of communication, and then they had to go back home and apply that in an environment where the communication was totally different. So it was nice to make them feel good about themselves, to understand that we are there to reduce suffering, not to turn end of life into a picnic, that is not possible, and that they should not put that burden on themselves, and they should also not try to change society. They were not there to change the social rules, they

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were there to help very ill and dying patients and their grieving families through a very difficult time, and in the meantime, things might evolve, things hopefully will evolve, but at this point, you are doing, one at a time, building those relationships and helping patients and families. They did it and we enjoyed seeing them grow and develop. Communication has improved a lot now in many countries, so it's much more open that it has ever been before.

[00:25:00]

Tacey A. Rosolowski, PhD

[00:25:01]

Wow, that's amazing. So, these are some of the success stories that you had with this organization you were working with, the one that you brought to Houston, I'm sorry, the IAHBC.

[00:25:14]

Eduardo Bruera, MD

[00:25:15]

Perfect.

[00:25:15]

Tacey A. Rosolowski, PhD

[00:25:16]

Yeah. And for the record, I'll just confess, I had to read that, I did not remember it!

[00:25:21]

Eduardo Bruera, MD

[00:25:21]

That's all right, good, good.

[00:25:23]

Tacey A. Rosolowski, PhD

[00:25:25]

Does that describe what you feel you accomplished with that particular organization?

[00:25:30]

Eduardo Bruera, MD

[00:25:30]

Oh yes, yes, perfectly well.

[00:25:32]

Chapter 14

Committee Work, Care Guidelines, and ASCO Acceptance of Palliative Care

A: Overview;

Codes

A: Overview;

D: Understanding Cancer, the History of Science, Cancer Research;

D: The History of Health Care, Patient Care;

D: Ethics;

C: Offering Care, Compassion, Help;

B: Survivors, Survivorship; C: Patients, Treatment, Survivors;

Tacey A. Rosolowski, PhD

[00:25:32]

And there were others that you were involved with as well. Were there others that you felt had a significant impact?

[00:25:38]

Eduardo Bruera, MD

[00:25:39]

I worked quite a bit with the World Health Organization, and I continue to do some roles, because I just finished with them, the guidelines for cancer pain management, worldwide. I chaired that committee. I worked with them for many years. WHO was a complex organization to work with, because it's an intergovernmental organization and therefore, it has a much lower level of independence. It depends on getting consensus from all country members and therefore, it is a very, very difficult organization to bring change into. It's more about doing what we're doing the best possible, rather than doing new things. So it was—it would not have been enjoyable if that was all I did, but because I was able to contribute to WHO over time, we made some progress, for example, in the development of palliative care guidelines, in the development of cancer pain guidelines, that was enjoyable. They have the organization for the Americas, called the Pan American Health Organization. The WHO headquarters are in Geneva. The Pan American Health Organization is based in Washington, and basically, the two are intergovernmental organizations. So we collaborated with them, and I was part of several committees over the years, trying to bring palliative care. My focus always was cancer, but we also tried to bring palliative care to the conditions of which patients died frequently in developing countries, such as malaria, tuberculosis, rabies. Conditions that were barely seen in our side of the world were still very prevalent causes of end of life in developing worlds, so we made a point that it's important to remember that we are personhood care, we're not disease care. So it's not a big difference for me to see a patient dying of cancer or a patient dying from congestive heart failure or lung failure or renal failure, because our focus is on persons, and so suffering associated with dying of disease can be addressed. We made a point of trying to

empower those teams to deliver palliative care to whatever people were dying of. Of course, that clashed for a while, against medical organizations, and hospitals, and many medical organizations got very angry because they said well, you know, in the middle of the AIDS epidemic, in the middle a tuberculosis epidemic in many countries, malaria, what they said is this is immoral, people should not die of these diseases, we're there to treat these diseases. Our position was always it's fantastic, what you're saying, but the reality is millions of people are dying of these diseases every year. When nobody else dies of these diseases, there will be no need for palliative care for these diseases, but as long as this continues to happen, it's very nice to be present and to learn how to decrease the suffering of the patient and the family, so we're going to plug ahead. Basically, we tried to tell those teams, you don't need to have one palliative care for malaria, another for tuberculosis, another for AIDS, another for cancer; you need to have palliative care for the patients, for the people. Then, many of those groups adopted the palliative care principles that we developed for cancer. There's no doubt that palliative care was borne out of cancer suffering, and it was borne out of cancer suffering because it was so much the suffering associated with cancer, especially pain and other symptoms, that it was a taboo word, people didn't even want to say they had cancer, because it was so, so scary. And then that knowledge -- we worked at transferring that knowledge to other disease models, that in a sense it was a little bit easier, because there were less taboo diseases than cancer. So that was part of the global effort. [00:30:15]

I worked with the European association also. I was lucky to be part of the committee that organized the European palliative care association, so the European Association of Palliative Care, EAPC, I was able to participate in the initial discussions that led to that organization and that's very healthy now. I was able to be part of the discussions that led to organization of the Latin American Palliative Care Association, that also did not exist at that time, and it also has been very successful. So over the years, then of course I was very much part of the American Society of Clinical Oncology that, for many, many years, had great difficulty accepting palliative care and finally they embraced it and they have an annual ASCO Palliative Conference that will take place in the next two or three weeks, and that is a great development because it had brought palliative care to the forefront. Whatever the American Society of Clinical Oncology does, the world follows. It is the leading organization in the planet, and so the moment ASCO embraced palliative care, it meant palliative care was now embraced by the cancer world fully. [00:31:46]

Tacey A. Rosolowski, PhD

[00:31:48]

So that must feel like a real landmark moment.

[00:31:50]

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Eduardo Bruera, MD

[00:31:51]

That was a wonderful time.

[00:31:52]

Tacey A. Rosolowski, PhD

[00:31:52]

And what year was that, when you felt it had been accepted by ASCO?

[00:31:56]

Eduardo Bruera, MD

[00:31:58]

It must have been six years ago approximately, but no more than six or seven years ago. So, it was the moment in which finally, I would say six years ago, in about 2012 or so, that ASCO finally said this is important, patients need to have access to this, and our organization needs to sponsor and facilitate that palliative care knowledge be imparted to oncologists and to cancer organizations.

[00:32:32]

Tacey A. Rosolowski, PhD

[00:32:32]

I'm remembering some of our first conversations, when you were talking about getting interested in this outlier field, being a real non-mainstream person, and this has been a long time coming.

[00:32:47]

Eduardo Bruera, MD

[00:32:48]

It's been a huge time, I agree with you. I never thought it was going to be so difficult. I mean I always thought that this made—to me, it made so much sense, that I thought that full integration between the person and the cancer, the person and the tumor, the person and the disease, was something that it was absolutely obviously something that was going to be adopted very quickly. Whenever we came out with a new care model, like the Palliative Care Unit or the Supportive Care Center, we thought that that was going to be rapidly adopted everywhere and it took decades for things to be adopted. Obviously, first we did not do the sales job that we should have done, we didn't do it very well. And second, there's no doubt that person-centered care, personhood care, is not exciting, or was not exciting. I think it's getting much better, but it was never exciting to organized medicine, this issue. It's fascinating, because before the antibiotic era, there was very little doctors could do other than alleviating suffering in their patients and doing prognosis. Then, as medicine moved into this curative stage, almost nothing else mattered. Only curing mattered. That in itself is such a self-defeating attitude, because one hundred percent of humans are going to die. So to assume that medicine could have the luxury of turning

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its back on those who were suffering before they died, was actually, from the clinical perspective it was just stupid, because a hundred percent of those people that you're curing today are going to die after that, of another cancer, of another disease. So for medicine to keep a harmonious approach between the technological knowledge, the biomedical knowledge, and the personhood knowledge, would have been very wise, but medicine moved away from it. Fortunately, it's coming back and the new generation seems to be embracing it, so I'm glad to see that in the last years of my career, I will see person centered care become much more important than ever before.

[00:35:19]

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Chapter 15

The Future of Palliative Care

A: Overview;

Codes

A: Definitions, Explanations, Translations;

A: Overview;

D: Understanding Cancer, the History of Science, Cancer Research;

D: The History of Health Care, Patient Care;

C: Offering Care, Compassion, Help;

B: Survivors, Survivorship; C: Patients, Treatment, Survivors;

C: Human Stories;

A: Post Retirement Activities;

B: Multi-disciplinary Approaches;

A: Personal Background;

Tacey A. Rosolowski, PhD

[00:35:20]

What is next for you in terms of research and what you would like to do in the department?

[00:35:26]

Eduardo Bruera, MD

[00:35:28]

I think, I personally have decided some time ago, that I will end up my career staying in this field. Many people use, unfortunately—palliative care was never very hard, but some people have used palliative care as a springboard, to become deans of medicine, hospital medical directors, people who have administrative roles. I was never interested in that. I'm only interested in what I've been doing all my career and I want to end up doing that. But my dream would be that when you are hit by the hammer of getting a diagnosis of cancer, you are given the opportunity to receive supportive care from the moment you are hit by that hammer. You might be suffering more than someone else, some people are hit by a diagnosis of cancer, they are very pragmatic, they go to Google, they see this is my type of cancer, this is my type of treatment, it will be a disruption in my life for six months and I am going to be okay. Maybe that person doesn't need me. Other people get that same diagnosis and they are absolutely devastated. They are devastated because they're different and they just take it in a different way. That person might need me. If the diagnosis for that patient is one that is not likely to be a very positive one, that person probably needs me, even if they don't know they need me, and as the disease progresses, that person probably needs me. [00:37:09]

So, my dream would be that we'll have a big supportive care access available for everybody diagnosed with cancer, and then, that access could differ. In some cases, it might be one or two

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or three visits and then you will move on with your life, you don't need us anymore and you are perfect. In other cases, you know where we are, you can get to us at any time. You don't need to actually make an appointment, just drop in. Drop in, come in and say, hey, I'm not having a good time, can you guys help me? And then we will chase you, we will phone you, we will Facetime you and contact you and see how you are doing, and keep in touch with you. In the process of doing those things, we will do all the necessary research to document that models that work, the models that don't work, so that we can put that in the literature, so that other people can then take advantage and change the way their hospitals operate. It is my dream that there will never be a hospital that has an Intensive Care Unit, that does not have also, a Palliative Care Unit, that every hospital in the nation --and we're having nine big hospitals here, all of them with multiple ICUs and not one single PCU. Therefore, Methodist doesn't have one, Saint Luke's doesn't have one, Hermann Hospital doesn't have one, Texas Children doesn't have one. So, having a Palliative Care Unit wherever you have an Intensive Care Unit is a personal dream of mine. That nowhere where you see people with serious illnesses as outpatients, you will not also have a Supportive Care Center. So that if you treat cancer, if you treat heart failure, if you treat other diseases that can potentially cause suffering, you will have a center for the human suffering, a center where you can say, our institution doesn't just treat heart like that one, our institution treats people, and then the Supportive Care Center is where person centered care is expressed. Other institutions will have that Supportive Care Center and everything that happens inside will be our problem. You cannot have people being referred to a pain center, a psychiatrist center, a social worker center, a nutrition center, a fatigue center, this center. Personhood care should be the business of the supportive care team. Those of us working inside will distribute our workload, but we cannot burden that patient, and we should also not burden that oncologist, with deciding which of the services are there. So my dream is that we will have this universal access, these big programs, and that in the process of having them, we'll do the science to document what works and what doesn't work, so that other people will take advantage.

[00:40:28]

Tacey A. Rosolowski, PhD

[00:40:29]

It's that analog of the multidisciplinary care and the disease centered arm of treatment, and now you've got the multidisciplinary arm of the supportive care.

[00:40:39]

Eduardo Bruera, MD

[00:40:40]

Exactly, exactly.

[00:40:41]

Tacey A. Rosolowski, PhD

[00:40:40]

Yeah, it makes perfect sense.

[00:40:42]

Eduardo Bruera, MD

[00:40:42]

And really, when we think about that, should we have disease specialists? Should there be have palliative care for leukemia, palliative care for breast cancer, palliative care for lung cancer? My answer is that's really stupid, because it's about the person, not about the disease. That is assuming that if you get lung cancer, you have a different family, a different way of seeing life, a different way of approaching your suffering and a different way of wiring from your nerves to the periphery, as compared to if you get melanoma or breast cancer. What might be disease specific would be palliative care for extreme anxiety, palliative care for existential distress, palliative care for fatigue, palliative care for pain. That would be specialized. So if you want disease specific, I would say spiritual suffering oriented, grief related to the loss of a child oriented, fatigue oriented, pain oriented. That would be saying the personhood, care is what matters. What we need to do is to, you are going to have disease specific, is the person problem, not the diagnosis, but you know doctors are doctors and they see diseases as the goal, and they have sometimes this a little bit simplistic approach to the suffering component, and they say well suffering is suffering and you just do it that way. My answer to them frequently is that you know—and they frequently say this—think about bone marrow transplantation. What is bone marrow transplantation? I put a needle here, remove a little bit of your bone marrow, put it in the freezer, throw your chemotherapy to levels that are capable of killing an elephant, then ten or twelve days later, I load you up with antibiotics capable of killing every single virus, fungus, and bacteria in the world, do that for two or three weeks, then I take that from the freezer, I thaw it and I inject it back in your and off you go. Anybody can do that. So, of course saying that would be terribly ignorant, because I know that there is a lot of complexity in removing your bone marrow, in freezing it, in giving you the super lethal chemotherapy, in keeping you not infected to death, and then injecting it back to you and helping you go. What happens is there's very limited understanding of the complexity of human suffering, that what we try to do with these people is very, very complex and requires a certain level of expertise. But a bone marrow transplantation is part of mainstream medicine, while person centered care is not. So those colleagues don't really understand that there is a certain level of complexity, and so I sympathize with them because they never learned about it. On the other hand, I need to make sure that they understand that some of the way people conceive suffering as so easy. My reply to them is so, if it's so easy, how come you cannot fix it? If you were unable to fix the cancer and now you're calling me, so why are you calling me if you can fix that suffering? It's got to be very easy. And so I never will hold anybody responsible for not having cured the cancer. I know they've done their best. I'm an oncologist myself and I know they used the best of their wisdom to help that

patient and it didn't work. But then they need to respect the fact that the suffering is complex and it requires structures and it requires processes to do with suffering. [00:44:45]

So I am happy to see that there is more awareness than there has been, but we're still far from getting to what would be my dream. Well, we're still far from getting there. I don't know if I'll see it before I'm gone. I for sure will keep chugging away for another few years, but I think I'm leaving a generation of good people, and the one thing that makes me the proudest is all this new generation of people that I've mentored over the years. We have penetrated many organizations, we have people who are in the younger generation, my children, who will basically keep hammering away. So they are not going anywhere, they are very committed, they're very passionate, and I think that ultimately, person centered care will succeed, not because of what our generation did, but because of what the next generation will end up doing.

[00:45:47]

Tacey A. Rosolowski, PhD

[00:45:48]

Where do you think the field is going, you know kind of what are the big—are there intellectual challenges or practical research challenges? What's holding things back, what's going to make things move?

[00:46:05]

Eduardo Bruera, MD

[00:46:05]

I think the big challenge of person-centered care is not to dislocate it too much into becoming everything to everybody. So, we are fantastic with somebody who is going to die. We're good with somebody who is ill and is not dying yet. We're not that good with somebody who --we don't know how well we can be with somebody who is a chronic survivor of cancer. They may have a significant burden of suffering, but how do we address that? So, I think the intellectual challenge in our field is that we cannot be everything to everybody forever. There are some of us who have had a very difficult existence, and they do not have cancer and they do not have any disease. And the same as we told people in the developing countries many years ago, do what you do well, do it the best you can, don't try to change society, don't try to change the world, because then you're going to get burned out, and then you're going to get frustrated. If we embrace every aspect of suffering associated with famine, with political neglect, with personality issues and so on, we will become burnt out. So the challenge is to stay focused on the suffering that is brought to you by cancer or by other medical diseases. I can see that many people, particularly armchair type of lecturers who don't really see patients, I find that patients are very important. This weekend, I saw twenty-two patients, and that gives me a strong—or twenty-three patients, and that gives me a strong reality sense of what can be done and what cannot be done, by being on the field and delivering the care myself. But I think many people have this idealistic view that palliative and supportive care will resolve human suffering. That is a big

problem. Human suffering is ever going to be there. So I think the challenges for the future are to make sure that we stay focused on what we might call unnecessary human suffering, but not to put ourselves as the people who can achieve what is not possible to be achieved. [00:48:24]

The second, to me, big, big challenge for palliative care and supportive care, is to be finally embraced by what we might call organized medicine and healthcare. It takes big roles, that there has to be professorships in supportive and palliative care and whole person care. It cannot be seen as, in our case, not cancer medicine, not even medical oncology, supportive care is now there. They will have to have major administrative roles in organizations, so that the center, the patient-centered care, sits with the president and with the dean, and with the people who make decisions, as a very important role of what we are. Only by having those changes in the structures in power in medicine, in academia, will then the voice of those who are interested in the patient experience get them the space, the positions, the resources they need to deliver care. As long as they remain as a small part of the operation on the side, it's nobody's fault. It's nobody's fault, but when the big names are sitting at the table distributing space and positions and philanthropy, that group is never there, and so it doesn't have a voice. It cannot say, me too. It cannot say why don't you add this component. The same thing happens in medical schools and in nursing schools. The curriculum discussion about how much time they spend in cardiology or nephrology or family medicine, there is no one representing person-centered care. The problem then is that they will get the crumbs. It will trickle down into something down the line, but if that person is not any less than family medicine, internal medicine, cardiology, is sitting there and arguing with a dean, we need the time of the students, we need them to learn about this, and maybe holding retractors another four hours is not going to educate them as much as learning about person suffering. But if we do not have the people in those levels, if we do not have the people in those decision making levels, then we're not going to change the culture, the culture will remain what we call pallialia, that is where it is right now. [00:51:10]

Many years ago, I was asked to develop some paper and I did something that was developing the level of development of palliative care, understanding in society or in medical schools and in hospitals. I did something on the Kubler-Ross type of acceptance of death, so I said that there were four stages. One of them was denial, and some institutions might be now in denial. Saint Luke's is in denial. They feel that they don't need to address suffering. Their patients are taken care of by hospice and there's not much suffering in that place. And then the way you fight denial is you go and ask a hundred people in that place how happy are you that you're dying, how well is your suffering treated, and I'm sure there's no suffering in you isn't it? So, denial is replaced with palliphobia, and palliphobia is basically panic whenever the palliative word is pronounced, because they're afraid that you're going to scare the patients away, that they're not going to accept your treatments, that it will show that people might die of cancer or heart failure, and also that you're competing. So palliphobia occurs among, of course, deans of medicine and hospital presidents, but also among people who feel threatened; social workers, doctors, nurses, other people who are doing their little thing and they are afraid that palliative care might infringe

on it. The way you alleviate the palliphobia, mostly on the leaders, is you don't go and talk. What you do is you do what we did, you treat patients on the underground. [00:52:55]

The third stage, where a lot of the world is right now, is pallilalia, that will be repetitive nonsense talking about palliative without doing anything about it. This is so important, let's do a study to demonstrate it, we should do something about it, but not changing the structures to open the range and allow them in. That's why there is so much burnout, because teams are finding that now, contrary to the palliphobia stage, when they were not getting those patients referred to them or they were not getting pressure, they are getting pressure but they're not getting resources. So finally, after the pallilalia, you get the final stage, that would be palliative, and palliative means basically, you set up the structures and you put the money, and as we say in Texas, money talks and BS walks, and that palliative needs to not. Need that institutions reflect on where in the administrative structure of the institution, be it the hospital, the faculty of medicine, the cancer center, is person centered care necessary, and that they give it the resources it needs. So, I think it's starting to happen in some areas. Most of the nation is still in the pallilalia stage, some areas of the nation are palliphobic, and regrettably, some areas are still in denial. So, I hope that by the time I'm gone, most of the nation will be palliative. I had a lot of fun doing what I've done for all these years, and I would not change it for anything else. I know it was much harder in some areas and certainly, money was much worse than what was in other areas. [00:54:54]

My wife bought me a bottle of champagne, the first time she counted and said—and I said, “Why are you doing that?” She said, “Oh, this is the first time you've donated a million dollars to your hospital.” So the time she calculated that, as compared to the other medical oncologists, I had donated a million dollars to the hospital. She said, here, let's celebrate your first philanthropic donation of a million dollars, because if I had pushed chemo, my income would have been much better than doing palliative care. So, the reality is some things are easier, some things are more difficult. I personally would not change it. I think it was nice and I am very optimistic that the future looks good for us, for palliative care, for all the people doing person-centered care, I think we are over the hump and things look much better. Of course, I'm not going to be here too many years to enjoy it, but I am so happy that the people who are getting into the field now, are going to have a much better life, a much better professional life than we did. [00:56:07]

Tacey A. Rosolowski, PhD

[00:56:07]

Sure, sure. Do you have plans for retirement?

[00:56:10]

Eduardo Bruera, MD

[00:56:11]

At some point I will. I don't know, maybe six, seven years more and then I'm going to be gone,

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I don't think I'm going to be staying in this forever, my wife would not allow me. Basically, I think that's the plan.

[00:56:25]

Tacey A. Rosolowski, PhD

[00:56:26]

Well we are at two-thirty and I know you're very, very busy, so I'll just ask you if there's anything else you would like to add at this point.

[00:56:33]

Eduardo Bruera, MD

[00:56:34]

No. First of all, thank you very much for having taken the time and for having decided to cover this. I've never discussed all the things I discussed with you before, so I think it's all new.

[00:56:48]

Tacey A. Rosolowski, PhD

[00:56:48]

Oh, good.

[00:56:49]

Eduardo Bruera, MD

[00:56:50]

I hope somebody decides to take advantage, because I'm certainly not one to write my memoirs in any way, so this is the closest thing they're ever going to see to that.

[00:57:03]

Tacey A. Rosolowski, PhD

[00:57:03]

Well, I think it's not a bad memoir then. Well, it was really a pleasure talking to you.

[00:57:08]

Eduardo Bruera, MD

[00:57:08]

Wonderful.

[00:57:08]

Tacey A. Rosolowski, PhD

[00:57:09]

This is really interesting conversation.

[00:57:10]

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Eduardo Bruera, MD

[00:57:10]

Thank you so much, it was wonderful.

[00:57:12]

Tacey A. Rosolowski, PhD

[00:57:12]

Thank you for your time, Dr. Bruera.

[00:57:14]

Eduardo Bruera, MD

[00:57:14]

Thank you.

[00:57:14]

Tacey A. Rosolowski, PhD

[00:57:15]

And I just want to say for the record, I am turning off the recorder at two thirty-two.

[00:57:20]