



Psychosomatic Care in Cancer: Empathy, Understanding and Communication

First PAMEMMAZI Forum
Summary Report

October 2017

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1 INTRODUCTION

On October 20 and 21, 2017, PAMEMMAZI held its first two-day forum on the topic *Psychosomatic Care in Cancer: Empathy, Understanding and Communication*. The Forum was held at the American College of Greece.

PAMEMMAZI is a nonprofit organization that was set up by the family and friends of Emma Vernikou, an activist against the stigma of cancer in Greece and an advocate for young adults with cancer, who passed away on October 20, 2016. The PAMEMMAZI 2017 Forum was held honoring her memory and the memories of all people living with cancer.



PAMEMMAZI aims to improve the psychosocial health of oncology patients, the breakdown of taboos that surround cancer, the cultivation of empathy in health care providers, and in society as a whole, active support of the central role that patients themselves must play in their own therapy and care including managing symptoms and side effects, as well as overall decision making about their own live and health. The Forum was organized to explore the evidence demonstrating the links between physical and mental health and the beneficial contributions of empathy, understanding and communication on health outcomes—both therapeutic and quality of life—with special attention to issues faced by adolescent and young adult (AYA) patients.

PAMEMMAZI brought together respected American and Greek experts and leaders in the fields of oncology, psychiatry and psychology, as well as patients and families. The second day of the forum, the public participated in workshops demonstrating tools that facilitate difficult conversations about cancer that were developed and supported by the U.S. National Institutes of Health, explored in depth issues faced by young adult patients, and discussed strategies to address stress related to cancer. Exceptionally powerful were the voices of patients and families who sat side-by-side with clinicians and discussed a range of important issues such as the stigma cancer patients experience in Greece today, the need to access information about their cancer diagnosis and develop a better understanding of its potential trajectory and the importance of open and respectful communication with healthcare providers.

The PAMEMMAZI Forum was hosted by the American College of Greece (ACG) and sponsored by the ACG Alumni, Encompass LLC, PORTOBELLO's UOMO. The PAMEMMAZI Forum took place under the auspices of the Universities of Athens and Patras Medical Schools, who participated actively in the program.

The Forum plenary was attended by more than 300 participants and covered by ANT1 TV. The four workshops were full with 80 participants.



Photo 1 Participants in the first PAMEMMAZI Forum included Former Prime Minister and President of the Hellenic Academy Loukas Papademos, and Member of the Hellenic Academy and retired senior NASA Scientist Stamatias Krimigis with their spouses, seen here with Emma's uncle and retired IMF Board member Thanos Catsambas.

2 PROGRAM

2.1 OVERVIEW

The forum took place over Friday evening and on Saturday through the afternoon (see agenda in the next section). In the Friday plenary session, scientists, patients and families sat together on stage, and after two presentations, responded to questions, discussed and shared their experiences. It was very much the intent of PAMEMMAZI to have this peer discussion conveying the importance of including patient voices alongside clinicians.

2.1.1 Presenters

Prof. Michelle Riba, MD, MS



Prof. Riba studied chemistry in Queens College, (NY, USA), organic chemistry in St. John's University (NY, USA), and medicine in University of Connecticut School of Medicine (USA) to earn M.D. in 1985 and psychiatry residence in 1989.

Currently is a Professor and Associate Chair for Integrated Medicine and Psychiatric Services and Associate Director of the University of Michigan Comprehensive Depression Center, Director of the Psychoncology Program at the University of Michigan Comprehensive Cancer Center and Director of the Psychosomatic Fellowship Program.

Prof. Riba is Past President of the American Psychiatric Association (APA), the Association for Academic Psychiatry and American Association of Directors of Psychiatric Residency Training. She has served as the representative to the World Psychiatric Association (WPA) from the APA and is currently WPA Secretary for Scientific Publications.

Prof. Riba is the author or editor of over 100 scientific articles, books, chapters, scientific abstracts and has served on the editorial board of Psychiatric Services and Cancer News on the Net, Current Psychiatry and has served on the editorial advisory board of the American Psychiatric Press, Inc. She is a reviewer for Psycho-Oncology; Academic Psychiatry; Psychiatric Services; Journal of Psychiatric Practice; and Psychosomatic Medicine; Breast Cancer Research and Treatment. As a psychosomatic medicine psychiatrist, Dr. Riba's clinical and research interests include collaborative care, psychoncology, depression and cardiovascular disease and screening for distress in patients with medical illness.

Kristin Baird, MD



Dr. Kristin Baird is a pediatric hematologist-oncologist in Bethesda, Maryland. She received her medical degree from Temple University School of Medicine and completed Residency Training in Pediatrics at the University of California Los Angeles Medical Center in June 2000. She is a graduate of the Johns Hopkins University / National Cancer Institute Pediatric Hematology/Oncology/Fellowship Training Program.

Dr. Baird's research interests focused on the genetics and biology of pediatric sarcomas in the lab of Dr. Paul Meltzer. She had a clinical research interest in hematopoietic stem cell transplantation and chronic graft-versus-host disease. She served as the Pediatric Chair of the Natural History Study of Clinical and Biological Factors in Patients with Chronic Graft-Versus-Host Disease After Prior Allogeneic Hematopoietic Stem Cell Transplantation.

Prof. Alexandros Spyridonidis



Alexandros Spyridonidis is Professor of Haematology and Director of the Bone Marrow Transplantation Unit in University of Patras in Greece. After completing his medical studies in Aristotle University of Thessaloniki in Greece, he pursued postgraduate doctoral studies and completed his specialization in internal medicine and in Haematology/Oncology in the Dept. of Haematology/Oncology of University of Freiburg in Germany where he has been given the Venia Legendi (Assistant Professorship). In 2006, he was appointed at the University of Patras in Greece where he established from the scratch a fully accredited allogeneic bone marrow transplant program and an internationally recognized donor registry (CBMDP-“Xarise Zoi” Save a Life). He spent a research sabbatical in 2012 at the “National Institute of Health” in Washington D.C. working on the clinical establishment of multi-virus specific T-cells. On the national level, he is President of the BMT WP of the Hellenic Society of Haematology (HSH), founding member of the “Hellenic Society of Gene Therapy and Regenerative Medicine” and served as board member of the HSH and of various organizations dealing with stem cell donation. In International level, he is Hellenic Representative in European Union Commission for “Tissues and Cells”, board member of the “Centre of the Study of Haematological Malignancies” in Cyprus, Mentor of the “European Haematology Association” and inspector in the quality assessment agencies for BMT units in Europe. He has over 2 Million Euros in competitive research grants. He has more than 70 peer-reviewed original publications and more than 23 book chapters in international books. He has received 15 national and 11 international prizes.

Prof. Dimitris Dikeos



Dimitris Dikeos, MD, is Professor of Psychiatry at the 1st Department of Psychiatry of Athens University Medical School, Athens, Greece and Director of the Sleep Research Unit of Athens University at Eginition Hospital. He is currently: President of the Hellenic Sleep Research Society (HSRS); Immediate Past President of the International Neuropsychiatric Association (INA); Member of the Executive Committee (Treasurer) of the World Federation of Societies for Biological Psychiatry (WFSBP).

His research activities are focused on sleep medicine, psychiatric genetics, psychopathology and psychopharmacology. He has participated in various Multicentre Research Programmes in Europe and the U.S.A. such as: European Collaborative Studies of Affective Disorders, Johns Hopkins Genetic Epidemiology Schizophrenia Program, Meta-analysis of Sleep Laboratory Studies on Tolerance and Rebound Insomnia with Rapidly Eliminated Hypnotics, Maudsley Family Study, European Collaborative study by the Group

for the Study of Treatment Resistant Depression (TRD), International Multicentre Study “FACTOR”, International Study on the Genetics of Anorexia Nervosa, The Psychiatric Genetics Consortium (PGC), Neurobiology and Treatment of Adolescent Female Conduct Disorder: the Central Role of Emotion Processing (FemNAT-CD). He is or has been member of various scientific and professional Societies and Boards, as well as member of the Executive Committees of the Hellenic Sleep Research Society, the International Neuropsychiatric Association, the Athens Medical Society, the Hellenic Society for the Advancement of Psychiatry and Related Sciences, and others. Dr. Dikeos is co-editor of three English-language books, two of which have been published by the World Psychiatric Association, and he is author or co-author of more than 100 full publications.

Lori Wiener, PhD¹



Lori Wiener, PhD, is head of the Psychosocial Support and Research Program at the National Institutes of Health (NIH). As both a clinician and behavioral scientist, Dr. Wiener has dedicated her career to the fields of oncology and pediatric HIV/AIDS. Dr. Wiener provides counseling to the children, family members, siblings, donors, adolescents and young adults who are affected by NIH clinical trials and conducts research aimed at improving the cancer experience. For 30 years, Wiener has worked at the Pediatric Oncology Branch at NCI’s Center for Cancer Research, where she is a principal investigator and also provides therapeutic interventions to pediatric oncology patients and their families on ways to cope and adapt to their diagnosis and treatment.

Dr. Wiener focuses on quality of life for patients receiving treatment at the clinical center at the National Cancer Institute, where she carries out studies that look at how kids cope, with the goal of developing new materials, new resources and new interventions. She speaks with families whose children have been diagnosed with life-threatening conditions and are faced with the overwhelming challenges looking for treatment, coping with a big degree of uncertainty about available and appropriate treatments for their children, managing undergoing treatments and participating in protocols for their cancer, while also having to manage the high expense of these treatments. Dr. Wiener leads research for developing guidelines, solution-focused tools and strategies to help patients and families maintain the best mental and emotional strength to cope and manage the totality of their treatment and care under these challenging conditions.

2.1.2 Agenda

Friday, October 20, 2017 - Panel Presentation & Discussion

17:30 Registration

18:00 – 18:15 Commencement and Welcome speeches

¹ Although Dr. Wiener was unable to present her work due unexpected illness in the family, Dr. Baird presented her work, and she was later able to join her workshop by Skype.

18:15 – 18:45 **Keynote Speaker:** [Michelle Riba](#)

MD, MS, Professor and Associate Chair, University of Michigan, Department of Psychiatry and Depression Center, Director of PsychoOncology, University of Michigan Comprehensive Cancer Care
Title: *Emotional Aspects of Cancer*

18:45 – 19:05 [Kristin Baird](#)

MD, Pediatric Hematologist-Oncologist, Maryland, U.S.A.

Title: *Patient-centered communication and shared decision making in cancer care.*

19:05 – 19:25 [Lori Wiener](#)

PhD, Co-Director, Behavioral Health Core, Director, Psychosocial Support and Research Program, Pediatric Oncology Branch, Center for Cancer Research, National Cancer Institute, National Institute of Health U.S.A.

Title: *Psychosocial Therapeutic Interventions throughout the Adolescent and Young Adult (AYA) Cancer Trajectory.*

19:25 – 19:45 [Dimitris Dikeos](#)

MD, PhD, Professor of Psychiatry Athens University Medical School, Eginition Hospital.

Title: *Management of sleep disturbance and other neuropsychiatric issues in oncology patients.*

19:45 – 20:05 [Alexandros Spyridonidis](#)

MD, PhD, Professor of Hematology and Bone Marrow Transplantation, Director of the Bone Marrow and Transplantation Unit, Patras University Medical School and Hospital, Greece.

Title: *Particularities in young adult cancer patients.*

20:05 **Discussion**

*Upon completion of the discussion, panel speakers will be available to receive your questions and comments at the theatre's foyer until 9pm.

Saturday, October 21, 2017 - Workshops

All 4 workshops will be held simultaneously, so please select and **SIGN UP for ONLY ONE workshop.**

10:00 Registration

10:30 - 12:30 Workshops

12:30 - 13:10 Coffee Break

13:10 - 14:00 Conclusion

Panel speakers facilitated the following workshops in collaboration with the following experts:

- [Dr. Lambros Yiotis](#) MD, PhD, Psychiatrist
- [Mr. Yiannis Dinos](#) PhD, Clinical Psychologist, Oncology Hospital "Aghios Savvas"
- [Ms. Christina Fragiadakis](#) Systemic Psychotherapist, Dramatherapist

Workshop 1: [Communication and Management of Cancer in Young Adults and Their Families](#)

Facilitators: Y. Dinos, A. Spyridonidis

Workshop 2: [Strategies and tools for holding courageous conversations with cancer patients and their families](#)

Facilitators: L. Wiener, K. Baird

Workshop 3: [Cancer and distress – improving communication](#)

Facilitators: M. Riba, D. Dikeos

Workshop 4: [Drama therapy: “Without - a dramatherapy approach”](#)

Facilitators: L. Yiotis, C. Fragiadakis

2.2 PRESENTATIONS

2.2.1 Emotional Aspects of Cancer

Presenter: Michelle Riba, MD, MS, Professor and Associate Chair, University of Michigan, Department of Psychiatry and Depression Center, Director of PsychoOncology, University of Michigan Comprehensive Cancer Care

***Abstract:** A new cancer diagnosis or recurrence can result in various levels of depression or anxiety for adult, adolescent and child cancer patients, and their families. The distress can arise from a multitude of factors: from the diagnosis itself; potential or perceived disruptions to quality of life including family, work, school, finances, and relationships; responses from the social support system, including miscommunications, too little or too much information; direct or side effects from treatments, either primary or adjuvant; direct or indirect results of the cancer itself; current or past psychiatric history; etc.*

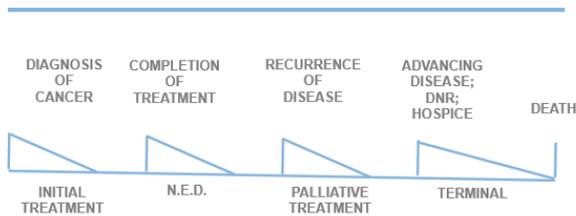
Since patients also often have cancer-related pain, fatigue, and symptoms from the cancer or its treatment that can mimic or look very much like depression and anxiety, the challenges for diagnosis and treatment are great. How do we increase awareness about the importance of recognizing depression and anxiety? How do we determine best ways to screen for distress and then provide treatments for these symptoms when they occur? How do we provide interventions for various types and stages of cancers, patients of different genders, ages, cultural backgrounds, past psychiatric histories?

This presentation will provide ways to address these very important and critical issues in psychooncology care. We will include one patient, one spouse and one sibling in the panel to receive their point of view and insights how our care can be improved, how communication can be enhanced and how we all can strive to improve the quality of care.

Cancer is not only a physical experience, but also an emotional, economic and spiritual one. What is the nature of the emotional aspect of cancer? There is significant impact on emotional well-being of patients and families, it influences patients’ and families’ decision-making processes, it increases health care costs, it may require prolonged medical treatment, and it contributes to adverse medical events. Thus, while all people live with a normal level of stress experiencing fears, worries and sadness, cancer patients

experience a severe level of stress that frequently involves anxiety and depression for the patient and the family, as cancer forces patients to face several existential crises, see figure below.

Existential Crises in Cancer



Adapted from McCormick & Conley, 1995

The work of the psychiatrist or psychologist in treating cancer patients is complex covering many factors in the psychological assessment and exploring many different kinds of symptoms and issues (see below).

Factors in Psychological Assessment

Many Psychiatric Symptoms/Issues

- Past psychiatric history
- Age at diagnosis
- Gender
- Type of cancer
- Stage of cancer
- Location of cancer
- How the cancer was diagnosed
- Substance use or abuse
- Pain
- Finances

- Types of cancer treatment
- Family coherence
- Marital/partner status
- Behavioral/previous coping strategies
- Religion/spirituality
- Job/employment status
- Medical/psychiatric insurance
- Genetic risks and testing
- Survivorship Resources

- Suicidal thoughts, feelings, intent
- Hopelessness
- Guilt
- Sexual problems
- Sleep disturbance
- Anhedonia
- Agitation
- Mood swings
- Worry
- Feelings of being a burden
- Pain
- Side effects of medications
- Insomnia
- Too much sleep
- Loss

- Loss of appetite
- Confusion
- Fatigue
- Self esteem
- Grief
- Anger
- Homicidal thoughts, feelings, intent
- Rage
- Regression
- Denial
- Irritability
- Fear
- Jitteriness
- Rumination

In addition, the care has to take into account several important variables including stage of life, stage of cancer and location of cancer, age, gender, type of surgery, side effects of medications, available support, socioeconomic status, psychiatric comorbidity, and disability/job status.

When cancer recurs, the prevalence of emotional distress in cancer patients increases. Twenty-five to thirty percent (25-30%) of all newly diagnosed and patients with recurrence experience significantly elevated levels of emotional distress, and up to 47% have a psychiatric diagnosis.² Common psychiatric conditions include depression, anxiety (panic, posttraumatic stress disorder [PTSD], phobias), adjustment disorders and delirium. Patients at increased risk for emotional issues are those with a history of psychiatric disorders/substance abuse, a history of depression/suicide attempts, cognitive impairment, communication barriers, severe comorbid illnesses, spiritual/religious concerns, and those with uncontrolled symptoms. In addition, several social challenges may result in emotional issues for patients such as family/caregiver conflicts, limited access to medical care, young or dependent children, younger age patients, women patients, those with a history of abuse (physical, sexual), and other stressors.

² Derogatis, et al. 1983; Farber, et al 1984; Stefanek et al 1987

It is important to assess cancer patients for psychological issues continually. Thirteen percent (13%) of cancer patients develop a major depressive disorder within two years of diagnosis.³ Many patients experience increased anxiety related to treatment decisions; worries about treatment failures; other issues-family, job, finances, transportation, medical costs; dependence, disability, disruption, death, disfigurement; pain; and side effects of medications. This anxiety can take the forms of panic, generalized anxiety, phobias, posttraumatic stress (PTSD) both acute and chronic, Obsessive Compulsive Disorder (OCD), anxiety due to medical conditions and medication. We see increased chances for PTSD in cancer patients with a reduced quality of life, those of younger age, lower income, lower social support, greater exposure to previous traumatic events, and more advanced disease at diagnosis.⁴



Photo 2: Participants discuss different aspects of stress related to cancer.

Unfortunately, depressive and anxiety disorders are underdiagnosed and undertreated. Cancer patients are discouraged from reaching out to mental health professionals because of stigma against mental health issues, fear, and overlapping symptoms that veil the mental aspects of health issues. For example, depression is often masked by anxiety symptoms or medical issues (medication, treatment, etc.). Cancer patients and their caregivers live in under the motto: Don't ask, don't tell! These barriers prevent cancer patients' access to beneficial therapeutic treatments.

Treatments for these frequent psychological challenges of cancer patients are many, see list below.

³ Arch Intern. Med 2005; 165

⁴ Cordova M, Riba MB, Spiegel: Post-traumatic stress disorder and cancer. The Lancet Psych-D-16-00490.

Psychosocial Therapies for Patients with Cancer

- Lifestyle
- Exercise
- Mind-body interventions (meditation, yoga)
- Expressive writing and journaling
- Art, Music
- Relaxation and guided imagery
- Group, Psychotherapy
- Cognitive-behavioral
- Supportive-expressive
- Family, and marital therapy
- Medication
- (alone or ideally combined with other approaches)

There is also evidence of the importance of religious support to enable better coping with cancer, i.e. patients make use of his/her religious beliefs to understand and adapt to stress. Patients with advanced cancer report religion and spirituality to be personally important in adjusting to their illness (Balboni, et al)⁵, and such coping informs medical decisions (Phelps, et al)⁶.

Psychological support is also important for survivors, as they have to adjust and cope with the cancer experience and its aftereffects. It is important to have long term follow-up in cancer centers and within primary care, to consider life style modifications, to consider being part of databases with periodic reporting for updates in treatment science, to make adjustments in relationships between patients and doctors, as well as patients and significant others, and to manage the emotional aspects of survivorship such as chronic trauma, anxiety about recurrence, anxiety about anniversaries, etc.

There are several obstacles to focusing on psychiatric issues. These obstacles may be patient centered, clinician centered, and institutional. Patients may be feeling distressed while needing to make decisions, they may not have access to new medical terminology and knowledge, they may be overwhelmed with worries about many issues including the future, family issues, job challenges, finances, insurance, nausea/pain, appearance, sexuality, marriage, etc. Clinicians need to disclose information to all patients, regardless of the wide variation in patient's reactions, but must have skills to recognize the patient's physical and psychological needs. Patients' reactions may range from arguing endlessly about options to refusing to discuss them and asking the doctor to make decisions for them. This places a significant strain on clinicians who must navigate these issues. Institutional issues may stem from lack of competence to fear of mental health concerns expressed in statements such as:

"We're here to treat disease - not psychosocial stuff."

"It's unscientific - we'll be criticized to focus on this."

"How can we evaluate - you can't measure feelings or outcome."

"It's too expensive and all they do is talk - how do we know it helps."

An additional dimension that is important in psychological support for cancer patients is to understand the dynamics of patients' families. Families are complicated and complex. Families start off with different stressors, different strengths, and different emotional problems. It is important to understand

⁵ Balboni TA, et al. J Clin Oncol: 2007;26(5):555-560.

⁶ Phelps AC, et al. JAMA, 2009; 301(11):1140-1147.

who is in the family, especially for the short and long-term issues. It is also important to distinguish between the old conflicts prior to diagnosis, and the current tensions. Cancer has an impact on families in many different ways including:

- Finances, jobs, transportation to medical appointments
- Taking care of the household, children, etc
- Communicating with others
- Getting rest, eating properly, keeping up with medical and dental appointments and other usual responsibilities.

Professional support becomes urgent when:

- Symptoms interfere with ability to function
- Symptoms out of proportion to actual threat
- Patients have suicidal thoughts or plans
- Patients engage in negatively affecting health behaviors (smoking, drinking, weight, etc.)
- Family or friends express concern
- There is any degree of emotional distress
- Patients have few supports or confidants.

It is important to encourage cancer patients and families to reach out for psychological assessment and support, and to reduce the stigma and fear that prevents from the beneficial and therapeutic strategies that can help them at this most stressful time.

2.2.2 Management of sleep disturbance and other neuropsychiatric issues in oncology patients

Presenter: Professor Dimitris Dikeos, MD, PhD, Professor of Psychiatry Athens University Medical School, Eginition Hospital

Abstract: Cancer is frequently accompanied by various neuropsychiatric problems, which may either be direct results of the illness itself or may result from the effect of medication on neural cells. These problems might either be neurological such as disorders of vision, hearing, balance, muscle strength, or psychiatric such as anxiety, depression or sleep disorders. While the latter may also result from neural damage, they are usually a consequence of psychological parameters associated with diagnosis, or with quality of life deterioration due to the disease and its treatment. This presentation addresses the need to recognize these neuropsychiatric problems and their causes, as well as the importance of their management, with a focus on sleep disorders.

2.2.3 Particularities in young adult cancer patients

Presenter: Alexandros Spyridonidis, MD, Ph.D., Professor of Hematology, Medical School of the University of Patras, Director of the Bone Marrow Transplant Unit, University Hospital of Patras

Abstract: *Though young adulthood is considered the healthiest time of life, many adolescents and late teens (15 - 24 years old) are diagnosed with certain types of cancer, such as Hodgkin lymphoma, melanoma, testicular cancer, thyroid cancer and sarcomas. Discussing the diagnosis of a cancer with young people with the added presence of the parents is challenging for all involved and unique age-appropriate communication processes are needed. Young adults (YA) are neither children nor adults. Though they are starting to take on responsibilities of adulthood, they are still emotionally and financially dependent from their parents and they have very specific concerns like forming intimate relationships, finishing school, beginning a career or starting families. A cancer diagnosis abruptly delays or derails the development and achievement of these important social processes and life plans. When communicating with young people about the diagnosis of cancer and cancer treatment, health professionals need to respond to each patient's level of maturity and independence. Good communication between patients, families, and doctors is very important in cancer care and improves the patient's well-being and quality of life. Psychosocial support services for YA's are limited.*

There is a rise in the number of adolescents and young adults who are diagnosed with cancer, and they represent a significant number. In Canada (2005), for example, AYAs represented 2,300 cancer cases (1.5% of all cases), and 300 deaths due to cancer. In fact, after homicides, suicides and accidents cancer is the commonest cause of death in the 15-39 years age group in industrialized societies.⁷

There are several distinguishing characteristics of AYAs as compared to children and adults:

- Independence: AYAs search for independence but are still emotional and financial dependent
- Future: AYAs are starting to think realistically about the future and develop goals
- Identity: AYAs have begun searching for intimate relationships, have begun to relate with others outside the school environment, and develop social skills and emotional intelligence
- Responsibility: AYAs have begun analyzing situations logically.

AYAs are not served well by the traditional dichotomy of the health care system, pediatric vs. adult, and are not even recognized as a distinct population with distinctive biology and unique medical and psychosocial needs. In the hospital, they do not have distinct spaces in part because they represent a small volume of the patient population.



Photo 3: Dr. Spyridonidis presents the issues surrounding AYAs living with cancer.

⁷ "We may be rare but we ARE still there" (Survivor, March 2010, AYA workshop)

A 2017 study⁸ found that there is not a consistent way to define AYAs. For example, in Belgium AYA definitions range from 10 to 16 years to 24 to 35 years; in Germany they have been defined to be between 10 and 18 years and other times between 22 and 39 years; and in Spain they have been defined to be between 14 and 30 years. This study also asked who treats AYAs. For patients with metastatic soft tissue sarcoma, 56% of respondents said that the lead clinician would have been trained in pediatrics, while for patients with acute lymphoblastic leukemia, 71% of respondents said the lead clinician would have training in pediatrics, and in the case of embryonal carcinoma of the testes only 44% expected training in pediatrics. Finally, AYAs were likely to have access to psychological support and physiotherapy (between 82 and 97 percent, they only fewer than half to a quarter of AYAs had access to an education or training mentor, age-specific nursing, or a support group of other young people.

It is really important to talk with AYAs about the cancer diagnosis, the treatment, adjusting after treatment, and cases when cancer will not go away. There are several important principles about communicating with AYAs. The clinician needs to convey the goal of treatment (curative or palliative), and the diagnosis and treatment plan. Not only the patient but the whole family is affected. Patients should be accompanied by at least one close person while at least two health professionals must be present. Health professionals must tailor the communication according to the age and educational status of the patient. Their goals should be to develop a successful relationship, overcome mistrust, and understand the AYA's special needs. To do this, they must engage with the patient, understand the patient's emotional effects and adaptive mechanisms – typically, denial (a mistake has been made), anger (why me?), sadness/depression, and acceptance.

Health professionals need to develop strategies to respond to each patient's level of maturity and independency to ensure the basic rights of the patient are being met, including:

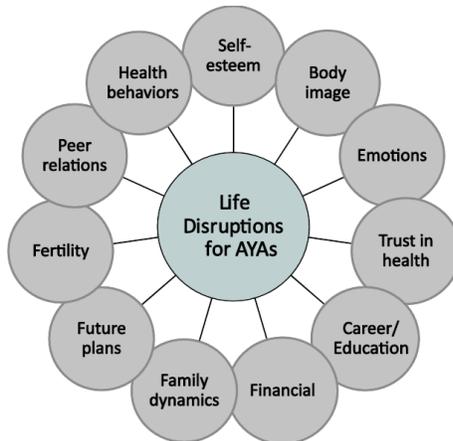
- understand their illness
- understand their treatment
- understand the possible implications of treatment
- understand any choices they may have
- have their personal choices acted upon

In the case of AYAs, health professionals need to understand their age-specific needs and their particular perspectives, as well as the family dynamics. AYAs diagnosed with cancer face a paradox: AYA age is the physically healthiest time of life. A patient expressed it best:

I was diagnosed with Advanced Stage Hodgkin Lymphoma, a form of Lymphatic Cancer in 2007. I was 21. I couldn't believe it. Up until that point I had always been more worried about getting hit by an asteroid than been diagnosed with Cancer, it just seemed more likely.

AYAs diagnosed with cancer are concerned with many issues such as:

⁸ Saloustros, E. et al, "The Care of adolescents and young adults with cancer: results of the ESMO/SIOPE survey" in ESMO Open, September 2017.



- Emotional effects (anger, sadness/depression, anxiety, stress, fear of recurrence and death)
 - Concerns about fatigue and pain
 - Concerns about body image and its effects on intimacy/sexuality
 - Concerns of self esteem/social isolation
 - Changes in relationships with family, friends, co-workers, dating (new, current)
 - Difficulty working due to physical or emotional effects
 - Financial stress
 - Uncertainty about the future (Employment discrimination, Vocational goals)
 - Stress syndrome especially in parents
- Concerns about late effects (secondary cancers, infertility etc)

Many don't even begin to process their cancer experience until later. Some have positive late effects: greater appreciation for life, Increased life satisfaction, improved self-acceptance & self-awareness, strengthened relationships with significant others). Health professionals must employ effective strategies to:

- Communicate effectively with AYAs diagnosed with cancer
- Support AYA relationships
- Address aspects of physical wellbeing related to psychosocial health
- Address the psychosocial wellbeing of the patient
- Keep the young person connected with life outside their cancer treatment
- Provide age-appropriate clinical management
- Address the palliative care needs of AYA patients.

Some good practices in communicating with AYAs are:

- Be honest and open, balance hope with reality
- Tell what to expect, don't make promises you can't keep
- Address misunderstandings (was it my fault?)
- Involve other (school, close persons)
- Explain treatment (side effects, hospital visits) and answer questions (does it hurt, will my hair come back?)
- Show your love and emotion
- Maintain discipline.

Dr. Spyridonidis' recommendation for the future in Greece is to build teenage cancer support hubs. In these spaces, there would be a professional who would act as a named point of contact on a day-to-day basis. In that space, AYAs can find help to cope with the physical, social and emotional effect of cancer and its treatment. Health professionals would work together to develop tools specific to AYA needs. In that space and online, AYAs would find someone who would listen to their views (website, Facebook, twitter accounts), and find support for making decisions, while supporting AYAs' independence. If needed, that support would extend to communicating with your school/college/university to support the AYA

through his or her education, work with community teams to arrange support at home, and also visit the AYA at home, hospital or in a place of the AYA's choice. In addition, the AYA would have access to advice on work, finances and other aspects of life that might be affected by cancer.

2.2.4 Psychosocial Therapeutic Interventions throughout the Adolescent and Young Adult (AYA) Cancer Trajectory

Presented by Dr. Kristin Baird on behalf of Dr. Lori Wiener, PhD, Co-Director, Behavioral Health Core, Director, Psychosocial Support and Research Program, Pediatric Oncology Branch, Center for Cancer Research, National Cancer Institute, National Institute of Health U.S.A.

Abstract: Adolescents and young adults engage in a myriad of development tasks. These tasks are disrupted when a diagnosis of cancer is made. Psychosocial stressors will be reviewed and assessment domains for psychosocial adjustment described. Ways to improve coping and adaptation will be provided, including educational, family and peer interventions. Tools to support AYAs during cancer treatment, survivorship and when cure is not possible will be presented.

AYAs engage in a myriad of developmental tasks. They are in the process of establishing autonomy from parents, developing personal set of values and identity, establishing, reinforcing peer relationships, and forming intimate relationships, and preparing to join the workforce. At this time, the prevalence of mental health disorders is highest, while AYAs lack a range of coping tools, life experiences, vulnerable to emotional distress.

Thus, while healthy peers experience 'typical' adolescence, AYAs with cancer are hospitalized or homebound under the watchful eyes of hypervigilant parents, they lack privacy, and they are isolated from their peers. The reality they face, includes many challenges such as:

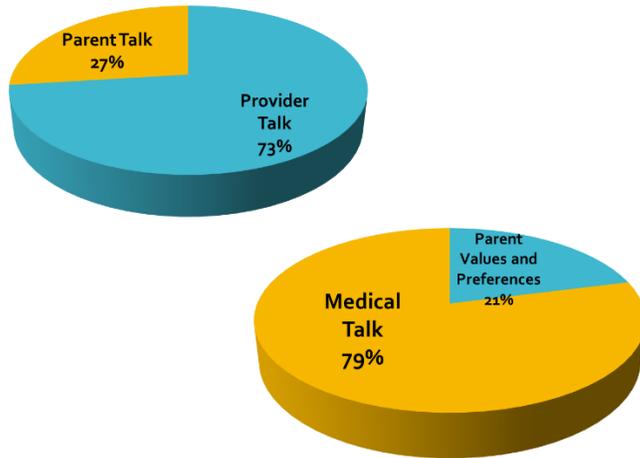
- Concerns related to identity, independence, appearance, peer/dating acceptance, intimacy, reproduction
- Difficulties losing control and managing forced dependence
- School/work absence
- Disruption of plans for the future
- Symptom control (nausea, pain, fatigue)
- Premature confrontation with mortality.

The goal of psychotherapeutic interventions is to promote positive outcomes for AYAs living with cancer increasing their potential to promote maturity, psychosocial development, be exposed to new people and ideas, engage in identity transformation, increase knowledge about their body, develop empathy for others.

Assessment of psychosocial adjustment is critical and should be routine and obtained throughout treatment. In a study⁹ of physician's patient-centered communication patterns and parental satisfaction during decision-making family conferences in a pediatric ICU, the following patterns were identified after observing 11 providers in several dozen family meetings. First in the graph on top, the physician spoke for the majority of the time (73%), and in the bottom chart you'll see the majority of the physicians'

⁹ October, et al, PCCM 2016

conversation was specifically medical “jargon” or talk. By being aware of this imbalance, providers can try to focus on changing components of the patient-care conferences to allow the family to talk more, and to bring other relevant, non-medical aspects into the discussion.



It is not enough to communicate, however. It is important to ensure that what is being communicated is, in fact, understood.¹⁰ A good practice is to ask patients: “How would you like to receive information (verbal, written, audiovisual)?” for different types of relevant information such as cancer, treatments, side effects, decision-making, diet, fertility, complementary approaches, etc. Healthcare professionals need to use understandable language, allow time for patients and families to process information. Furthermore, professionals should expect concerns to differ between the AYA and the parent, and to listen to each one separately. We should anticipate some knowledge will be obtained online, and be prepared and open to address all questions and concerns. Chronically ill adolescents may be more equipped for medical decision-making, because they have had a long experience with their own condition, they have familiarity with the health care system, and they have watched friends grow progressively sick and die.¹¹

So, how should medical staff approach AYA patients? The first step is to set the agenda of the conversation. We begin this by asking permission to discuss the relevant topic, for example: “I wonder if it would be ok with you if we talked about your overall weight loss.” Then explain that you will not insist



Photo 4: Participants explore games to help initiate difficult conversations with cancer patients.

on immediate action, saying for example, “I’d like to get a better idea of how you feel about how your eating, don’t worry, I’m not going to lecture you.” The goal here is not to give advice or guidance at this time, but rather to invite the AYA to talk and become part of the conversation.

There are processes and tools that help with coping and communication. These include: music, art, aromatherapy, tactile activities (knitting, handheld video games), journal, books, photographs, comfort foods, blanket, pillows, phone apps (e.g. breathing, relaxation,

¹⁰ www.nowwhat.org.au

¹¹ Fleischman, www.ippcweb.org

mindfulness), and others. The purpose is to offer patients a personal, tailored tool box. If a patient has known areas of concern, such as anxiety before re-staging, nausea with treatments, he or she can identify those items that help reduce those symptoms and provide support and utilize them in times of need.

In the United States, hospitals provide psychosocial interventions such as education support groups, relaxed visitation, peer-to-peer sharing, “feel good, look good” workshops, pet therapy, massage, art therapy, music therapy, and other activities. In addition to what hospitals offer, social support is incredibly important during this time. And although many friends and family members may have difficulty reaching out or feel unsure how to communicate or what to say, it is important to stay engaged. At this time, young patients can connect with friends using of Skype and FaceTime, AYA programming/space and blogging, or through organized support groups (hospital or community).

During this time, AYA’s experience profound fear of cancer recurrence. They ask, “Would one more cycle of chemotherapy make sure it [cancer] will really not come back?” Approximately one-third of survivors report high fear of cancer recurrence. Psychologists and psychiatrists can help with psychoeducation, blended cognitive behavior therapy, or other approaches, as patients are encouraged to develop their own “toolbox” for managing this anxiety.

Most adolescents and young adults adapt to extraordinary life changes and embrace their futures after cancer. Long-term follow-up care is recommended, as it is important to detect and treat health problems related to treatment. We must continually assess for psychosocial difficulties: academic achievement, employment, social and family relationships, affective distress, PTSS, suicidality, tobacco and heavy alcohol use.¹² At the root of identifying and addressing these important issues is communication.

Sadly, each year, more than 11,000 adolescents and young adults, ages 15-34, die from cancer and other life-threatening conditions. So how do we address situations when cure is not possible? Advance care planning (ACP) is now regarded as the gold standard in the care of patients with life-limiting illnesses. Clinicians should develop a systematic approach to discussing end of life issues and develop a standardized message to implement consistently. A team approach is essential and the topics should be introduced by a member of the healthcare team who has a trusting relationship with the AYA and their family to talk frankly about end of life without it being portrayed as loss of hope. This is extremely difficult for healthcare staff. There are, however, tools that can help facilitate these conversations, for example, tools available on-line at www.agingwithdignity.com.

¹² Lown et al., PBC, 2015



Finally, it is important to also keep in mind the toll on healthcare providers. The cumulative effect of professional stress can be severe. Staff witness the anguish of threatened separation and loss along with the harsh physical ravages of disease which can be draining and can lead to “compassion fatigue.” Programs to help reduce stress include: annual pediatric bereavement service for staff, ‘Good grief and chocolate’ at noon every quarter, counseling sessions such as “Harnessing the energy: Bereavement debriefing team,” and Wellness Series¹³. Healthcare staff need additional medical education focused on skills for communicating end-of-life planning, engaging youth in decision-making, and use of tools to help health professionals reduce the burden of stress.

2.2.5 Patient-centered communication and shared decision making in cancer care¹⁴

Presenter: Dr. Kristin Baird, pediatric hematologist-oncologist in Bethesda, Maryland.

Abstract: *There is growing recognition throughout the medical and scientific research community that an interdisciplinary approach to cancer treatment and care should incorporate patient-centered communication to maximize the benefit of current medical practices and treatment. Communication between physicians and patients is a multidimensional concept and involves several key components including both verbal and non-verbal communication. The goals of effective communication include establishing trust and rapport between the physician and patient, information gathering about the patient, and effectively providing information about the illness and treatment. Additionally, eliciting patient’s concerns and addressing these concerns is essential. Effective and supportive communication can assist the patient and his or her family in navigating their way through the complicated course of cancer treatment from informed consent, access to health care information and compassionate care, and when warranted, a successful transition to palliative care. Topics to be addressed include:*

- *What is the responsibility of the physician in charge regarding engaging the family?*
- *Ways to best engage the patient and the family in discussion and decision making?*

The scientific study of communication skills in oncology is in its infancy. However, three key concepts have emerged in defining the importance of interpersonal and communication skills in the interaction of

¹³ Zadeh S, Gamba N, Hudson C., Wiener L, JPON, 29 (5), 294 - 299.

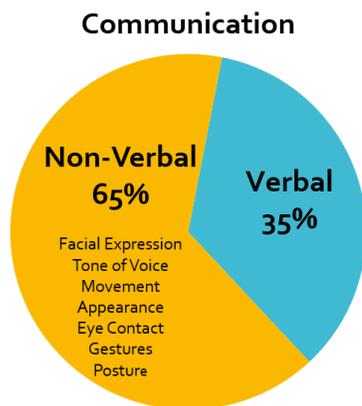
¹⁴ Kristin Baird, MD

providers with cancer patients and their families. A patient-centered approach best describes the most effective way of providing comprehensive cancer care and communication skills training can no longer be considered as optional skill. The communication between the oncology clinician, patient, and patient’s family is associated with important outcomes of care. Communication skills are not innate, do not necessarily improve with clinical experience, but can be taught and learned.

Clinicians, patients, relationships (clinical and social), and health services are all integral to patient-centered care. The interactions among these elements are complex and deficits in any one area can significantly decrease the quality of patient care. In order for communication to contribute to healing and reduced suffering all members of this dynamic must be involved and capable of effective communication, which has been shown to improve health outcomes. In oncology, communication skills are a key to achieving the important goals of the clinical encounter:

- Establishing trust and rapport.
- Gathering information from the patient and the patient’s family.
- Giving bad news and other information about the illness.
- Addressing patient emotions.
- Eliciting concerns.

Communication between physicians and patients is a multidimensional concept and involves several key components including both verbal and non-verbal communication.



Components of effective communication include the following:

Nonverbal behaviors such as maintaining eye contact; forward lean to indicate attentiveness; nodding to indicate understanding; absence of distracting movements (e.g., fidgeting)

Verbal behaviors such as avoiding interruptions, establishing purpose of the visit, encouraging patient participation, soliciting the patient’s beliefs, values, and preferences, eliciting and validating the patient’s

emotions, asking about family and social context, providing sufficient information, providing clear, jargon-free explanations, checking for patient understanding, offering reassurance, offering encouragement and support.

Imparting information to the patient can serve the following key functions:

- Grant patients a sense of control
- Reduce anxiety
- Improve compliance
- Create realistic expectations
- Promote self-care and participation
- Generate feelings of safety and security.

Every patient has different needs and expectations. Although many patients have high information needs, some patients want less information about their cancer. Research increasingly supports clinical experience in clarifying that patients differ in the amount of information they want and need about their cancer care. Participation can range from the patient actively engaging in the decision-making process, to the patient wanting the doctor to make the ultimate decision. One study¹⁵ categorized patients with early-stage breast cancer into the following groups:

- Delayers, who consider at least two options, but their deliberation is perfunctory and they immediately prefer one option.
- Deferrers, who accept their doctors' recommendations without a significant degree of reflection.
- Deliberators, who weigh the pros and cons of each treatment and do not make a choice until they have considered all the relevant information and have found an alternative with which they are satisfied.

A study of cancer patients¹⁶ seen at a large cancer center elicited patient communication preferences. The highest rated elements included:

- The doctor being up-to-date on the latest research on the patient's cancer.
- The doctor informing the patient about the best treatment options and taking time to answer all patient questions.
- The doctor being honest about the severity of the condition.
- The doctor using simple and clear language, giving the news directly, and giving full attention to the patient.

The need for truly informed consent and the patient's right to health care information and compassionate care create ethical, legal, and humanistic mandates for competency in oncology communication. Interventions to improve the informed consent process show that having a study team member or educator spend more time talking one-on-one with the patient to improve understanding of clinical trials are more successful than the use of multimedia or enhanced consent forms. One study using a staged approach in which parents or guardians consented to more limited segments of treatment showed promise. The informed consent process is not a one-time encounter, it requires continual communication and education.

Many factors affect communication including age, race, ethnicity, and language; socioeconomic status; the patient's family; and other communication barriers. There are some patterns—for example, younger and more educated patients are most likely to take an active role in medical decision making. It is always important to tailor the physician's approach. Using culturally appropriate approaches to communicating about cancer may lessen levels of distress for the patient and/or members of the patient's family.

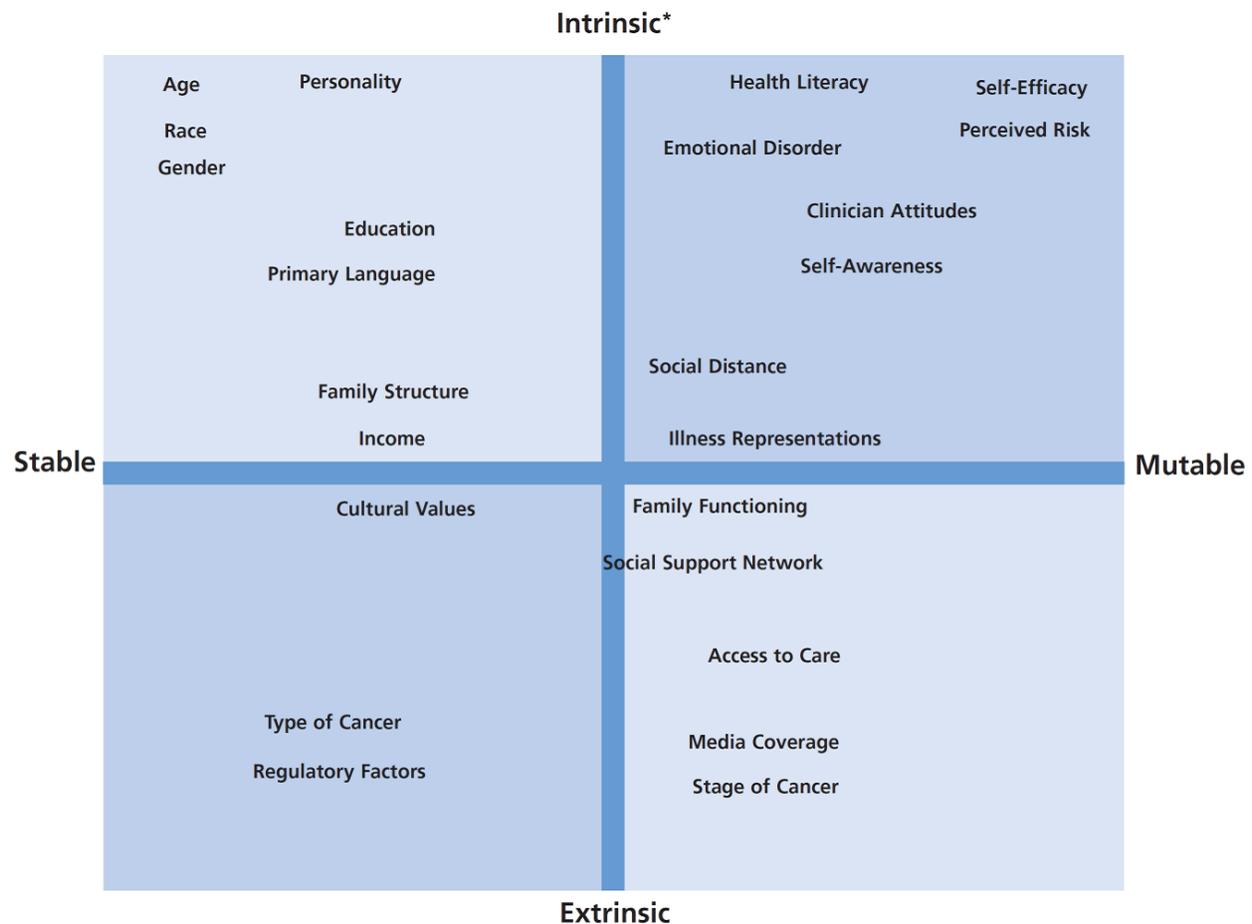
In a two-dimensional model¹⁷ of moderation of the communication-outcome relationships in cancer, moderators along one dimension are related to the degree to which the factor is intrinsic or extrinsic to clinicians, patients, and their relationship. The other dimension represents the degree to which the

¹⁵ Pierce PF. Nurs Res 42 (1): 22-8, 1993 Jan-Feb.

¹⁶ Parker PA, Baile WF, de Moor C, et al.: Breaking bad news about cancer: patients' preferences for communication. J Clin Oncol 19 (7): 2049-56, 2001.

¹⁷ Epstein RM, Street RL, Jr. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD, 2007.

moderator is mutable. By knowing which areas are more mutable, this can help identify areas where interventions can be made to help improve patient communication. See below:



A team approach between physicians, nursing staff, patient educators, social workers, psychologists, and others allows the following:

- A supportive and comprehensive approach to all aspects of patient care
- Distributes the emotional burden among care givers
- Gives the patient more time to address needs, which is often limited by physician schedules
- Allow the patient to hear different “voices” or perspectives on important issues (such as engaging others in the informed consent process for treatment, and educating the patient at the time of diagnosis, and recognizing that some patients may be willing to ask questions to nurses that they are afraid may be “simple”, obvious or even “stupid” to the physician.

A multidisciplinary team approach that engages the entire care team in the discussion is critical. Nurses play a vital role on the treatment team, advocating for patients and acting as intermediaries for patient requests or concerns. Thus, teamwork between physicians and nurses is essential. Clinic and inpatient nurses are frequently the first clinical contacts for patients and family members and, through their initial interactions, set the tone for the support the patient will receive throughout his or her care. In general, nurses spend more time with patients than their physician counterparts.

In conclusion, a patient-centered approach is the most effective way of providing comprehensive cancer care. Communication between the oncology clinician, patient, and patient's family is associated with improvement in important outcomes of care. Every patient has different needs and expectations from their care providers. Truly informed consent is a patient's right. Finally, engaging with multiple disciplines for a team approach between physicians, nursing staff, patient educators, social workers, child development experts, psychologists, psychiatrists, and others allows for optimal care delivery.

3 WORKSHOPS

Four two-hour workshops took place in different rooms of the ACG. In the workshops, physicians, psychiatrists, psychologists, families and people living with cancer had open discussions on the nature of living with cancer, explored tools for having difficult conversations, and discussed strategies for managing stress.

3.1 WORKSHOP 1: COMMUNICATION AND MANAGEMENT OF CANCER IN YOUNG ADULTS AND THEIR FAMILIES

3.1.1 Overview and structure of the workshop

***Abstract:** Young-adult oncology patients as a group have special needs, because in many ways they are still children who are treated by the health system as adults and have to be treated in adult hospitals. Unlike children, young-adults understand exactly what is going on, and typically have more extreme reactions to their diagnosis, treatment and prognosis, e.g. greater anger, conflicts, and depression. In other words, they face intense psychosocial challenges. At the same time, their families play a significant role in the whole trajectory of the disease and treatment. This is why it is essential to have a psychologist involved in the medical team treating young-adults and their families.*

In addition, it is also important to provide psychological support and guidance for physicians and nurses caring for young-adults. Frequently, doctors experience an emotional charge when caring for young adults which, especially in cases where there is no cure, leaves them at a loss for how to communicate with these patient, lead them to hide behind their medical teams. This strong emotional charge on doctors of young-adult patients, combined with continuing pressure from patients' families, is further complicated by the evolving psychological maturity of young adults, making the guidance and support of these doctors a necessity.

This workshop explored the issues and challenges that arise throughout the trajectory of the illness between the medical team and patients, as well as with their families. We will then discuss communication strategies that are supported by research, the experience in other countries and their relevance and applicability in Greece, as well as the conditions and contributing factors for their successful application. Our goal is to put forth promising ideas for how to improve and facilitate communication with young-adult oncology patients and their families, in order to help them be appropriately informed, reduce stress, and contribute to better quality of life and health outcomes.

Dr. Spyridonidis and Mr Dinos hosted three men in their 20s, all three survivors, who had gone through cancer in their teens that required multi-year treatment and were now living normal lives. They spoke of their experience with cancer as AYAs, and participants engaged in a broader discussion on the issues of the workshop.



Photo 5 Dr. Spyridonidis and Mr. Dinos facilitate a discussion with three young adults discussing the AYA experience in the cancer trajectory.

3.1.2 Discussion

The three cancer survivors told their stories of diagnosis, therapy and life after cancer.

The first issue raised the confusion of the diagnosis. One young man, V., did not understand his diagnosis initially and thought he had mononucleosis, while A. thought he had a type of infection and kept asking when he would be cured.

When A. became the patient of Dr. Spyridonidis, he received a clear briefing about his situation. He went through emotional ups and downs, and it was helpful that he had been informed about what to expect. He had to make significant adjustments in his everyday life to receive a long-term treatment during which he experienced a range of complications.

A medical school student told the story of a friend who was diagnosed with melanoma, which the speaker already suspected because of her training. The physician who made the diagnosis told her friend and his family, “Here we will address the fever you are experiencing, and the rest, you will discuss with your dermatologist.” The same medical school student mentioned that there is no appreciation of the importance of empathy in medical school, and it is not part of any class. In fact, caring about empathy is stigmatized; there is a sense that if a doctor cares about empathy, it is because he or she must not be good at the scientific part of medicine. She said that she has been fortunate to participate in a nonprofit organization where she is learning a lot about empathy. She wishes that empathy and client-centered care were part of her studies and valued in medical schools in Greece. She said she is here and wants to be part of that change.

Dr. Spyridonidis invited the group to contemplate what it must feel like for a young person to enter the health system for the first time with a serious condition. He underscored the importance of having many discussions and making sure the AYA understand the severity of the situation, and the importance of working together in therapy. V. said that it made a big difference for him that his doctor checked up on him after painful procedures, asked how he was doing, and told him he was sorry that it was painful; this empathetic behavior made it so much easier to endure the painful or uncomfortable therapy.

Participants agreed that everything is about how you approach the young patient. In addition, it is critical to educate and support the family of the young person, because they will be critical in making decisions and managing the therapy. Dr. Spyronidis agreed, and added that when he first meets a patient, he tries to assess the patient's level of maturity, so he can adjust how he addresses them.

Mr. Yiannis Dinos initially underscored that the potential for empathy in a professional setting becomes complicated by the gender dimension—the relationship between men and women. The skills required to exercise empathy—patience, acceptance of the feelings of others, the effort it takes to understand others, the minding and care of others—are socially connected with the “female nature.” On the other hand, the socially-accepted ideal requires men to demonstrate strength, courage, and daring. It is interesting that professions that require empathy and care for others are dominated by women. Even participation in seminars with psychosocial content on cancer are dominated by women.

Yiannis Dinos highlighted the critical importance of adolescence and the particularities it implies in shaping the therapeutic relationship, which differs greatly when dealing with adult patients. The adolescent approaches the physician along with his or her parents, with who he or she has a complex relationship frequently characterized by an ambivalent “love-hate” aspect, an aspect that is necessary for the formation of the adolescent's personality. In spite of the serious challenges caused by the illness, it is important for parents and the therapeutic team to recognize and support this ambivalence. The adolescent cannot make decisions without the parents' consent, and parents must not only understand the difficulties of the illness, but also orient the adolescent in the decision-making process of therapeutic choices. At the same time, however, the adolescent is not a child, and must be informed in order to understand his or her health status.

Yiannis Dinos also emphasized that breaking the news of a diagnosis is one of the most difficult responsibilities of the oncologist, and is much more than simply reciting, the unfortunate news from a piece of paper. In most instances, parents' anxiety intrudes in the therapeutic relationship; for example, parents make statements such as: “You will not say anything to my child (about the diagnosis), else we will not get along.” Or: “Do not say anything to my child. I cannot handle speaking to my child about this horrible diagnosis.” In the face of such tense expressions, which are not at all infrequent, the role of the therapeutic team can be decisive and supportive, so as not to leave the lead physician alone to face the resulting anxiety and stress. The role of the psychologist then proves to be catalytic to enable understanding and address these challenges.

3.2 WORKSHOP 2: STRATEGIES AND TOOLS FOR HOLDING COURAGEOUS CONVERSATIONS WITH CANCER PATIENTS AND FAMILIES

3.2.1 Overview and structure

Abstract: Including adolescents and young adults (AYA) in difficult conversations and advance care planning has been identified by the Institute of Medicine as a standard designed to promote patient-centered care. Unfortunately, adolescents do not always participate in these discussions. This exclusion often occurs because providers are uncomfortable and unprepared to initiate these important discussions, AYA may want to protect their parents, and parents are often hesitant to talk about death with their child. We know from our research, and that of other scientists, that adolescents want to engage in these conversations and they can participate. Also, parents report less decisional regret and psychosocial long-term outcomes when their child participated in advanced care planning decisions.

This workshop introduced four tools designed to engage adolescent patients and caregiving staff in having difficult conversations.

- 1. ShopTalk: a therapeutic game, created to help youth living with cancer talk about their illness in a non-threatening way with a health care provider.*
- 2. Jenga: a game that uses stacked wood blocks inscribed with thought provoking questions that encourage discussion.*
- 3. My Gift of Grace (now called Hello): a conversation card game. 74% of people who played My Gift of Grace went on to perform an advance care planning activity following the game.*
- 4. Voicing My Choices: an advance care planning guide developed following extensive research with adolescents and young adults.*

The tools were first introduced, and then participants were invited to practice in a small group, rotating through the different tools. A discussion followed.

This workshop was attended by professional psychologists and counselling staff including in nutrition.

3.2.2 Presenting the tools

Hospitals in the United States use a range of tools to help clinicians engage with difficult conversations about cancer with their patients and families. The National Institutes of Health (NIH) has introduced and tested several additional ones that are available to professionals. PAMEMMAZI translated several of these tools in preparation for this session, and they were presented and discussed at the workshop.

ShopTalk

ShopTalk is a therapeutic game designed for children living with cancer or another serious illness. It was created by Drs. Cindy Mamalian (an artist and psychologist) and Lori Wiener to help therapists lead conversations with pediatric patients about difficult emotional issues related to the illness that has affected their lives (ages 7 to 16 years). ShopTalk players visit 10 different “shops” around the board, choosing one of 6 “gifts” from each store to place in their individual shopping bag when they choose to answer the question. The shops are named according to different themes: The Ball’s in Your Court sports store, for example, allows players to explore how they would respond to various social scenarios during treatment.



ShopTalk is available in three versions, one for pediatric cancer patients, one for their siblings, and one for children whose parent have cancer. All questions in both versions of the game are written in Spanish as well as in English. Therapists who are interested in obtaining a copy of the game should contact Dr. Wiener directly at wienel@mail.nih.gov(link sends e-mail).

Jenga

In Jenga, players take turns removing one block at a time from a tower. Each block removed has a question that encourages the player to discuss feelings, concerns, hopes, expectations. It is then placed on top of the tower, creating a progressively taller structured.

There is a version of Jenga for patients, and another one for nursing and caregiving staff. The stress from the challenges of caring and sometimes loosing cancer patients is high for caregiving professionals and families, and it is important to offer them opportunities to discuss the issues openly and share the burden with colleagues and psychologists.



My Gift of Grace (now called Hello)

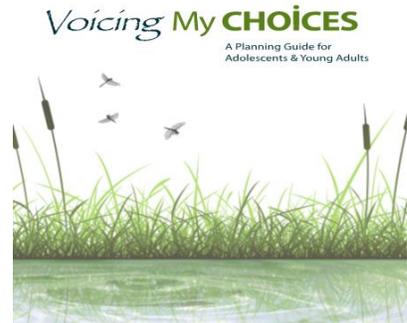
This is a conversation game. Forty-seven (47) *Question Cards*, and twenty-four (24) *Thank You* chips. During each turn, all the players have a chance to share their answers to the same question, trading chips as part of the game play. You can find more information here: www.mygiftofgrace.com



Voicing My Choices

Enlisting the advice of adolescents and young adults with serious illness, researchers at the National Institutes of Health have developed a guide to help young people and their families address issues surrounding end-of-life care.

[Voicing My CHOICES](#) is the first guide designed to help adolescents and young adults express how they would like to be comforted, supported, and cared for in the course of serious illness, and how they would like to be remembered if they do not survive. The guide is aimed at helping families and health professionals open difficult conversations, and was written, using language and questions tailored to the particular needs and preferences of young people.



A paper in the November 2012 issue of the journal *Pediatrics* reported on a study in which young people with serious illnesses read and commented on pages from two existing advance care planning guides. The study found that adolescents and young adults do want to be involved in end-of-life planning. Almost all of the 52 participants in the study felt that having such a guide was helpful and important. Their comments on specific questions shaped the content of *Voicing My CHOICES*.

Lori Wiener, Ph.D., director of the pediatric psychosocial support and research program at the National Cancer Institute, is lead author of the *Pediatrics* study and developed the prototype for *Voicing My CHOICES* that the young participants evaluated. She collaborated with Maryland Pao, M.D., clinical director of the National Institute of Mental Health, whose staff provides psychiatric consultation at NIH's research hospital for patients of all ages with serious illness.

3.2.3 Discussion

Participants easily saw the value and potential use of the tools presented and spent some time taking photos of the tools and the questions they posed. In the conversation that followed, these professionals expressed their anxiety at the prospect of having such difficult and raw conversations and sought to exchange ideas and hear from their American colleagues about good practices in managing different kinds of responses and patient needs. Another part of the discussion focused on how doctors, nurses and counselling staff deal with the loss of beloved patients. Drs. Wiener and Baird shared a practice they have experienced at the NIH where every quarter they get together and light candles, tell stories and have a ceremony of remembrance of departed patients. The key to managing end of life discussions and loss is to name it, voice how hard it is, share with others, show and experience empathy, and focus on those things that are in our control even in the worst of circumstances.

3.3 WORKSHOP 3: CANCER AND DISTRESS-IMPROVING COMMUNICATION

3.3.1 Overview and structure

Abstract: *A new cancer diagnosis or recurrence can result in various levels of depression or anxiety for adult, adolescent and child cancer patients, and their families. The distress can arise from a multitude of factors: from the diagnosis itself; potential or perceived disruptions to quality of life including family, work, school, finances, and relationships; responses from the social support system, including*

miscommunications, too little or too much information; direct or side effects from treatments, either primary or adjuvant; direct or indirect result of the cancer itself; current or past psychiatric history; etc. Since patients also often have cancer related pain, fatigue, and symptoms from the cancer or its treatment that can mimic or look very much like depression and anxiety, the challenges for diagnosis and treatment are great. How do we increase awareness about the importance of recognizing depression and anxiety? How do we determine best ways to screen for distress and then provide treatments for these symptoms when they occur? How do we provide interventions for various types and stages of cancers, patients of different genders, ages, cultural backgrounds, past psychiatric histories? This presentation will provide ways to address these very important and critical issues in psycho-oncologic care. We will include patients and families in the workshop to receive their point of view and insights how our care can be improved, how communication can be enhanced and how we all can strive to improve the quality of care.

Drs. Riba and Dikeos facilitated this workshop that included group discussions and individual reflection of participants. Several participants had been living with cancer themselves and some had lost loved ones. Several clinicians also participated.



Photo 6 Dr. Michelle Riba joined by Dr. Dimitri Dikeos facilitated this highly interactive workshop.

3.3.2 Discussion

Dr. Riba introduced the workshop by saying that we hope that cancer will become a chronic illness, and for many cancer patients, it is a chronic illness. Even in the worse of circumstances, we want to meet people where they are, and try to help them be in charge of what they want to do at each phase of care.

Participants were asked to reflect what good things have come out of their cancer. They also explored the challenges they had in their interactions with healthcare professionals. The biggest challenges patients had faced the reluctance or inability of healthcare professionals to help them understand their situation

and answer their questions. Patients wanted to understand their options, and they were unable to do so. In those interactions, patients reported that the way they were treated by healthcare professionals made them feel that it was not an equal relationship. Physicians did not seem comfortable with questions from patients and did not seem accustomed to patients who wanted to take an active role in decisions about their cancer.

Dr. Riba presented a framework called SPIKES¹⁸ developed by Baile and Buckman in 2000 as a process to share bad news. Let's just consider the first step—setting the stage for the conversation. At this step, it is important for the psychologist or psychiatrist to read the chart and be prepared. Then you want to make sure the patient is awake and there is privacy, maybe tell the nurse you are there. When you enter, you need to ask permission; the patient might have just taken medication, be sleepy, and say this is not a good time. You also want to ask

SPIKES - The Six-Step Protocol for Delivering Bad News

STEP 1: SETTING UP the Interview

STEP 2: Assessing the Patient's PERCEPTION

STEP 3: Obtaining the Patient's INVITATION

STEP 4: Giving KNOWLEDGE and Information to the Patient

STEP 5: Addressing the Patient's EMOTIONS with empathic responses

STEP 6: Strategy and Summary

permission of how much information you want to give them. Let's look at step 5—addressing the patient's emotions. You always need to give patients hope, not false hope—you will not promise a prolonged life, but you want to give patients options and areas where they have control. When you approach a patient, you must be prepared for a relationship that you are beginning now and will evolve over time. All this is taught in medical school in the United States—all types of physicians have to learn how to communicate in this way. Dr. Dikeos said it is not included in Greek medical texts.

Cancer can make people face some very difficult decisions. A useful strategy is to invite other family members in the conversation, so the family is on board, and can help the patient make these decisions. Patients' preferences vary a great deal; some patients want to join new clinical trials in another city or country for new and novel treatments, and others want to be home, and not be so sick anymore from the treatments and be available to their families. The idea is that we the physicians' team is supportive of them in any decision they make.

We also want to make sure we diagnose any more serious mental health side effects. Many cancer patients have thoughts of suicide, not because they want to die, but because they do not want to be in pain anymore. Then, they feel guilty about those thoughts. In her practice, Dr. Riba asks cancer patients if they have had thoughts of suicide, and it is freeing for them to talk about it.

Another issue we have in Greece is the stigma against pain management, because it falls under palliative care, which is seen as just preparing to die. There is also stigma against referrals to psychiatrists, and physicians might be reluctant to do so. Dr. Dikeos suggested connecting the referral to an ongoing conversation, for example, "I noticed that you get anxious every time you come back from getting your bloodwork. You might consider speaking to a psychiatrist about that anxiety." The other issue raised is

¹⁸ http://www.cetl.org.uk/learning/feedback_opportunities/data/downloads/breaking_bad_news.pdf

the ethics of referrals and making sure that we do not send people to our friends. We can also ask patients for a referral.

Message to doctors in Greece from a woman living with cancer: “Don’t underestimate the patient. Don’t underestimate my mind, just because I am not an oncologist. I have a mind. Doctors have a superiority as if they are gods, and they are not god. And tell me the truth. If I have three months to live, tell me. I have the right to know. I want to prepare my son. I want to prepare my testimony.”

Dr. Dikeos underscored the importance of not infantilizing the patient.

What does good communication look like? See below what participants said:

- Successful treatment
- Trustworthiness
- Patient and explanatory (preparing patients to work on the upcoming level of disability during treatment)
- Continued interest and follow up
- Professional, caring, simple and direct communication
- Setting a framework
- Eye contact, doctor’s presence, undistracted
- Giving time and space to the patients to express themselves
- Written guidelines and instructions
- Be available
- Doctor presence (not just dealing with the doctor’s assistant)
- Interest in family members
- Intra-doctor cooperation and communication
- Having a humorous approach
- The importance of the patient being acknowledged

3.4 WORKSHOP 4: DRAMA THERAPY

This was an experiential workshop.



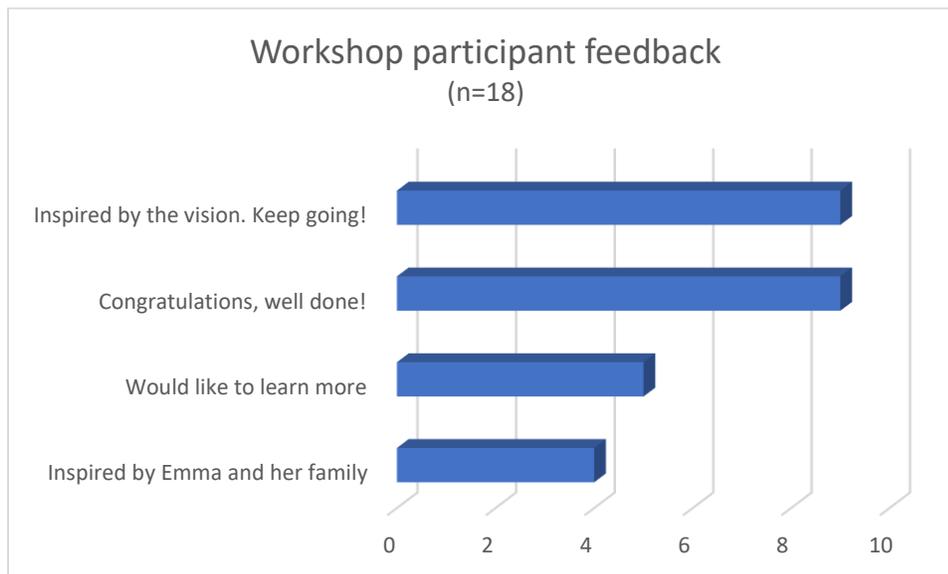
4 EVALUATION

PAMEMMAZI solicited feedback on the Forum in two ways:

- An exit survey was distributed to participants after the workshops
- A summary reflection was facilitated in a one-hour plenary session to listen to highlights and lessons from participants and presenters.

4.1 EXIT SURVEY FEEDBACK

Overall, participants had positive feedback for the workshops. Comments are summarized below.



Participants found the workshops and Forum well organized and useful. Those who were inspired by the vision wished to see changes in the healthcare system in Greece. Several participants wished for more learning either by longer workshops, a chance to attend more than one workshop, or follow-up workshops with practical tips and strategies. A few participants who knew Emma and the family were touched by the way a sad and traumatic experience can become an inspiration for great works.

Feedback on specific workshops follows.

Exhibit 1: Participants appreciated most, and found most useful in the workshops they attended

1: The needs of young adults	2: Tools for difficult conversations	3: Managing stress	Drama therapy
<ul style="list-style-type: none"> •The stories of survivors and their openness in sharing their experiences •Approaching the topic from different perspectives: patient, physician, psychologist •The message that cancer can be managed, and can be an invitation to make life better •Appreciating the importance of collaboration patient-family-doctor-nurse-psychologist 	<ul style="list-style-type: none"> •The honest, personal stories of the presenter •Use of therapeutic games as a tool for communication •The collaboration of young people, experts from overseas and colleagues in Greece •The nature of the questions to get at difficult topics •The importance of psychological support during cancer, and the contribution it can make 	<ul style="list-style-type: none"> •The interaction and equality of voice between scientists and patients and families •The honesty in the stories of participants •The strategies for how to approach patients respectfully and honestly •Exploring differences between Greece and the United States •Approaching cancer patients appropriately •Learning how patients feel 	<ul style="list-style-type: none"> •The experiential nature of the workshop •Tackling the challenge of communication experientially •Using art to catalyze communication •(Some participants felt uncomfortable in this workshop)

4.2 FUTURE TOPICS

Participants expressed a wish for more workshops in the future in the following topics.

Managing cancer holistically including people with other specialties, managing pain, collaboration between doctor, nursing staff and psychologists, strategies for nutrition in cancer, understanding how to stay current in research related to one’s cancer. Exploring people’s experience with cancer from different angles: the patient, the physician and the challenges she faces, parents, and understanding it from all sides.

Mental health in cancer, managing stress, strategies and tools for supporting families, training physicians to offer supportive care, innovative techniques for counselling and psychotherapy, increasing patients’ and families’ quality of life during cancer, tailored psychological approaches for cancer patients, mourning strategies for professionals. Understand the nature of stigma against cancer, fears about cancer, and strategies for acceptance.

Communication during cancer, talking without stigma, strategies for friends of cancer patients and volunteers in cancer care. Relevance of strategies and potential application in Greece. Approaching families in Greece about managing challenges with cancer.