When Cancer Attacked Me: 
A Personal Look at Role Reversal

RPCI Conference for Therapists and Dosimetrist
September 9, 2017

Lexie Smith-Raymond, MAdm, BS, RT(R)(T), CMD
A LITTLE ABOUT ME

- Radiologic Technologist
- Radiation Therapist
- Dosimetrist

- Lead Dosimetrist
- Technical Coordinator
- Radiation Therapy Program Manager
WHY AM I HERE TODAY?

I am a Dosimetrist
I am a Therapist
I am a Leader
I am an Educator
WHY AM I HERE TODAY?

Skills
Knowledgeable in the areas of anatomy, physiology, clinical oncology, radiobiology, radiation physics, and radiation safety. Expertise in the technical aspects of radiation oncology and medical physics to develop optimal treatment plans. Knowledgeable in health care informatics-including the resources, devices and methods to acquire, store and retrieve data. Tools include computers as well as clinical guidelines, current medical terminology, information and communication systems. Possess good communication and interpersonal skills to facilitate the exchange of information with patients, family members, the radiation oncology treatment team as well as outside entities. Has high level critical thinking and problem solving skills. Works independently, but in collaboration with the Radiation Oncologist and Medical Physicist. Has working knowledge of radiation safety principles and practices as well as current rules and regulations of the Nuclear Regulatory Commission and other regulatory agencies. Has the ability to interpret criteria and develop treatment plans as defined by relevant treatment protocols. Has mathematical skills including algebra, trigonometry, and introductory calculus.

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https://www.medicaldosimetry.org/about/medical-dosimetrist/
SO, WHY AM I REALLY HERE TODAY?

The Daughter Of A Cancer Patient
AND THEN, UNBELIEVABLY.....

The Wife Of A Cancer Patient
WHY AM I HERE TODAY?

- 2016 Estimated New Cancer Diagnosis
- 2008-2012 US Incidence Rates Per 100,000 people
- 4,500 Dosimetrists & 18,000 Radiation Therapists Nationally
- 225,000 Dosimetrists, Therapists & Those Closest To Them
- 1.7 Million
- All: 941.6
- Caner Will Strike 212
- Cancer Will Strike 10,060

COME ON MY WHIMSICAL JOURNEY

- At Times, Unbelievable
- Ups, Downs, Ins & Outs
- Questions, Confusion & Frustration
- Real Soul Searching Over My Career Path

Do I Really Make The Difference I Think I Do?
DECEMBER 3, 2010

- Nobody wants “that” call
- Think to yourself: “I got this”
  - I was so wrong
DECEMBER 6, 2010

- **Pathology Results Delivered by Surgeon**
  - *Triple negative- ER/PR/Her2neu (ERBB2)*

- **Only 15% of Breast Cancers Are Triple Negative**
  - *High Recurrence Rates & Inferior Survival Rates*
  - *Don’t Respond To Hormonal Therapy*
  - *Tend To Develop Distant Visceral Mets*

- **Plan of Attack: Chemotherapy Followed By Surgery**
  - *Possible Radiation*

I GET BY WITH A LITTLE HELP FROM MY FRIENDS

• First of the Favors....And of the Chaos
  • Rad Onc Consult on December 8, 2010
    • Confirmed No Radiation At This Time
  • Rad Onc Got Mom a Chemo Consult for THE NEXT DAY December 9, 2010
    • This Made Me REALLY Nervous
    • 12 Cycles of Chemo, Surgery (Double Mastectomy), Then More Chemo
  • December 10th Mom Watched Me Graduate....Again, For The Fourth Time
FAVORS, CHEMO AND CHAOS

• The Next Two Weeks Were Just Nutters
  – Favors Got Things Done Real Quick
  • Within Two Weeks:
    – Chemo Port Placed
    – Genetic Testing Done
      – Mom Carried BRCa2 Gene
    – PET Scan/MRI Completed
    – Chemo Appointments Set Up
    – Surgical Decisions Made

• The Problem With Favors.....
HIPAA

• Health Insurance Portability and Accountability Act of 1996
• Employees of Health Care Providers, Plans, or Clearinghouses
  – “Health care providers include all “providers of services” (e.g., institutional providers such as hospitals) and “providers of medical or health services” (e.g., non-institutional providers such as physicians, dentists and other practitioners) as defined by Medicare, and any other person or organization that furnishes, bills, or is paid for health care.”

»Like a DOSIMETRIST or a THERAPIST

HIPAA

- **What Information Is Protected**
  - HIPAA protects all "individually identifiable health information"; electronic, paper, or oral, identifying it as protected health information (PHI).
    - Any records or information pertaining to patients past, present or future physical or mental health or condition
    - Any information that can be used to identify an individual patient

*Any information attendings, residents, physicists, dosimetrists or therapists put in a medical record*

HIPAA

• **How Is This Information Protected**
  – Employers have to institute safeguards to protect PHI.
  – Employers must have procedures in place to limit who can view and access PHI.
  – Employers must have implemented training programs for employees focusing on protecting PHI.

• **Do we really respect it all the time??**

HIPAA

NO, we don’t.
I SHOULD HAVE KNOWN BETTER

• PET Scan Done & Complete, Mom Was In Freakout Mode
  – Did I Access It Myself?
    • No
  – But Did I Ask The Resident?
    • Yes
    – Should I Have?
      » No

• Not Only HIPAA, But For Other Reasons
  – Scan Wasn’t Clear
CARRY THAT WEIGHT

- I Paid A Terrible Price That Day
  - 2nd Worst News I Would Ever Give My Mom
- That Day I Made The Decision To Step Away
  - Won’t Be Doing Plans, Won’t Be Treating
    - Mom Was Not Pleased
- Liver Biopsy Completed Within Days (Result of Another Favor)
  - Cells Determined To Be “Routinely Abnormal”
    » No Cancer—We Could Relax!
    » Bring On The Chemo
THE LONG AND WINDING ROAD

• Chemo Kicks In
  – She Got Sick Right On Schedule
  – Her Hair Disappeared Right On Time
  – Our BRCa2 Testing Completed

• After 10 Infusions; Time For More Imaging
  – PET, MRI Again To Prep For Surgery
THE LONG AND WINDING ROAD

• Week 11: Joy That The End Was Nearing
  – Instead Our News Was Devastating
  – Breast Tumor Was Bigger
    • The Non Cancerous Liver “Lesion” Was Bigger

• Remember The Nerves Over A Next Day Appointment?
  – Warning: VIP Treatment In Progress
    – VIP.....AKA.....Vast Ill-Contained Problem

  – “There Is Nothing More I Can Do For You”
    • As A Daughter & A Dosimetrist = RIDICULOUS
JUST LIKE STARTING OVER

• My Rad Onc Referred Us To Another Med Onc Out Of My Network
  – Me: Frustration & Confusion: Unfamiliarity
    • I Know Radiation, But Not Chemo
  – New Med Onc: Respect For What We Had Been Through; For What I Do

• Another Biopsy For Correct Diagnosis
  – There WAS Something He Could Do
  – Positive Moods Returned
ST. PATRICK'S DAY 2011

- For Us, The Gravity of Metastatic Disease Is Daily

- 5 Year Survival Rate for Metastatic Breast Cancer At Diagnosis is 23%
  - With All My Cancer Care Knowledge, How Do I Remain Hopeful For A Positive Outcome?

**IT’S ALL TOO MUCH**

- In A Few Short Weeks, Life Had Been Turned Upside Down
  - My Career Complicated Things
- Dosimetrists Like To Put Tallies In Little Boxes
  - There’s No Tally Box For This, No Constraint To Fix
  
  » It Just Is

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BACK ON...THE LONG AND WINDING ROAD

• Re-Consultation For Radiation (On A Weds At 3PM)
  – 4 Field Breast AND Liver SBRT

• “We’ll Sim You Tomorrow, Start You Monday”
  – “Ummmm, no we won’t”
    » Insurance......
    » Which Treatment Machine/Schedule
    » Planning Time For Two Separate Sites
    » Mom’s Work Schedule
    » Staff Concerns I Hadn’t Considered
RUN FOR YOUR LIFE

• Who Gets To Treat THIS Patient?
• Who Gets To Plan THIS Patient?

– Meeting With The Technical Staff
  • Update; Going To Find Out Anyway

– Offered Them All An Exit Opportunity
  • Right Or Wrong?

– Normally Therapists and Dosimetrists Don’t Get This Option
HERE COMES THE SUN

• Like All Our Patients, Consent Covered Skin Redness
  – Skin Reaction Was Decent, Especially Near End
    • “Do You Do This To All Your Patients?”
    – “Of Course Mom, Everyone”

• So, Now, We Will Revisit That Magical Tour
  – Attending Was Unnerved
    • By The Skin & By Me
    • Care That Wasn’t Awesome
MAGICAL MYSTERY TOUR REVISITED

• Prepare Yourselves
  – Whole Breast Tangents: 46.8 Gy in 26 Fx
  – Boost: 18Gy in 9 Fx
• Due To Skin: Stop Tangs At
  – Go To 3D Boost
  – After 3 Of Those 9 Fx
  • Change One Beam By 8 Degrees
  • Back To TWO Day of Tangs + REPLAN
  – You Heard Me: 2 Fractions
• Daughter In Me vs Dosimetrist In Me
  • Logic Sided With Dosimetry
MAGICAL MYSTERY TOUR REVISITED

• OTVs Were Often Missed
  – Most Of The Time, Residents Covered
    • But I Know My Mom; I Could Sense It
      – Eventually She Cornered Him

• His Response Was This....
  – Sure Lucy And Her Sky Diamonds Were In My Coffee

• After The Shock Was Gone; I Thought About Other Patients
  – Do They Get Excuses Like This???
MAGICAL MYSTERY TOUR REVISITED

- Nothing Tops The "Vacation Situation"
  - Set To Leave For A Conference
- Over The Last 3 Days Of Treatment
  - Yes, Same 3 Days Of The 2 Day SC/PAB Replan
  - Dosimetry Already Scrambling
- 8AM Friday, Page To Machine
  - I Knew Something Was Awry
- "Have You Spoken To Him?"
  - "No. Why?"
  - This Story Goes Like This...
AND IN THE END

• Mom Finished Treatment January 18th, 2012
  — Moist Desquamation
    • It Did Heal In About A Month & Chemo Resumed

• I Reeled For A Lot Longer
  — Professional Relationships
    • Once Fractured, They Are Slow To Heal

  — Questions About My Career
    • Wondering...Did I Miss Something?
TOMORROW NEVER KNOWS

• She Reminded Me I Should Be Proud
  • What I Do Makes A Difference To Someone’s Mom

• My Mom Told Me Shortly After Her Diagnosis “Metastatic Doesn’t Mean Dead”
  • Her Chemo Will Never Stop
  • Her Scans Will Never Stop

— She Still Had Things To Do

No One Knows When The Other Shoe Is Going To Drop….
TOMORROW NEVER KNOWS

• Both My Shoes Fell Off On January 7, 2013

• “Honey I Need You To Sit Down For A Minute So I Can Talk To You”
  – Lump....... 
  – Ultrasound at 8 Tomorrow....
I GET BY WITH A LITTLE HELP FROM MY FRIENDS

- **Favors & Chaos: Round Two**
  - Within Two Weeks A Consultation With Surgical Oncology, An Ultrasound Read & A Scheduled Surgery Date of January 18

- My Life Had Again Been Turned Upside Down......
  - But to my surprise after EVERYTHING she had been through....there was my Mom
I GET BY WITH A LITTLE HELP FROM MY FRIENDS

- Ended Up With A pT2NXMX Mixed Germ Cell Tumor
NOT A SECOND TIME

- So We Proceed With Life For The Next Two Months....Planning Upcoming Grad School, High School, 8th Grade, & Kindergarten Graduations....
- But Then, On March 24th...Another Shoe Didn’t Drop; Every Pair I Own Came Fling Out Of The Closet At Me
HELP....I NEED SOMEBODY

• First And Hardest Thing Was Deciding To Hold Chemo Until After All Our “Happy” Events

• Then There Was The Paperwork....
  • I Was Totally New At This
HELP....I NEED SOMEBODY

• First And Hardest Thing Was Deciding To Hold Chemo Until After All Our “Happy” Events

• Then There Was The Paperwork....
  • I Was Totally New At This

• Then The Real Fun Started.....The Chemo Regimine

• I Ended Up Taking Almost 7 Weeks Off
TWO OF US

• As Horrible As It Was....At The Same Time It Was Amazing
  • Mom & Hubby Bonded In A Way I Will Never Understand
    • They Spoke Their Own Confusing Language
      • JUST LIKE OUR PATIENTS

• Chemo Ended On August 2, 2013
OB-LA-DI OB-LA-DA LIFE GOES ON

• For 4 Blessed Months...... My Family Was Left Alone
• My Husband Healed
• Mom’s Maintenance Chemo Was Going Well
• My Baby Sister Divorced My Favorite Ex-Brother-In-Law
• My Family Spent Christmas TOGETHER For The First Time Since 2000
• But In Reality, I Knew Something Was Off, I Sensed & Felt It.....But Did Everything In My Power To Ignore It
DO YOU WANT TO KNOW A SECRET

• Ever Hear That Saying….Denial Isn’t Just A River In Egypt

• January 3, 2014: FU With Med Onc

• January 6, 2014: Bone Marrow Biopsy

• This Is When I Knew For Sure Something Was Wrong..........Really Wrong
TELL ME WHY

- January 8, 2014
  - Day My Mom Was Diagnosed With Leukemia
    - AML m5 Specifically
    - Caused By Her Massive Doses Of Chemotherapy To Keep Her Breast Cancer At Bay
  - January 10, 2014 Diagnosis Confirmed By BMT Med Onc
  - January 15, 2014 Mom Entered The Hospital To Start Chemo Again....
I JUST DON’T UNDERSTAND

• The Next 18 Days Were A Torture No One Should Ever Have To Endure

• Thursday January 30, 2014 2nd Bone Marrow Biopsy

• Super Bowl Sunday February 2, 2014 I Gave My Mom The Worst News Of My Life
  • Chemo Didn’t Work
    • Leukemic Condition Was Worsening
I’M SO TIRED
FEBRUARY 9, 2014
AND IN THE END

• **Here I Sit, In 2017**
  • My Mom Is Gone and I Am Still Reeling From That Reality
  
  • My Husband Still Isn’t “Cured”

• My Then 36 Year Old BRCa2+ Sister Underwent Prophylactic Bilateral Mastectomy & Oophorectomy in August 2015

• I Worry **Constantly**
AND IN THE END

• I Still Whole Heartedly Believe In Cancer Fighting; But NOT Curing Cancer In Everyone
  – Everyday What We Do Makes A Difference To Someone, Even If WE Don’t See It
• Different Take On Replanning & Scheduling
  – Frustrations As A Dosimetrist & A Therapist
    • To Them It’s Going Above And Beyond
• I Am Again Content In My Career Path
  – Dedicated Staff Are Responsible For Great Patient Care
AND IN THE END

• Journey On The “Other Side” Has Educated Me
  – Made Me Better
    • Care Giver
    • Dosimetrist
    • Leader
    • Educator
      • Resident Class On Patient Relations
      • RAD101 Class For Patients
WHY AM I HERE TODAY?

Skills
Knowledgeable in the areas of anatomy, physiology, clinical oncology, radiobiology, radiation physics, and radiation safety.
Expertise in the technical aspects of radiation oncology and medical physics to develop optimal treatment plans.
Knowledgeable in health care informatics-including the resources, devices and methods to acquire, store and retrieve data.
Tools include computers as well as clinical guidelines, current medical terminology, information and communication systems.
Possess good communication and interpersonal skills to facilitate the exchange of information with patients, family members, the radiation oncology treatment team as well as outside entities.
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Has working knowledge of radiation safety principles and practices as well as current rules and regulations of the Nuclear Regulatory Commission and other regulatory agencies.
Has the ability to interpret criteria and develop treatment plans as defined by relevant treatment protocols.
Has mathematical skills including algebra, trigonometry, and introductory calculus.
WHY AM I HERE TODAY?

• Just Like All of You Here....I Got Into This Field For a Reason

  • We All Want To Make A Difference; To Help Our Patients

  • We Are All Compassionate And We Care About Those Bodies That Come Across Our Computer Screens & Lay On Our Tables

  • And Try As We Might...We All Have That One Patient....And They Got Us...Right Where It Hurts....In The Soul
WHY AM I HERE TODAY?

• I Want You To Know It’s Ok That Everything Doesn’t Fit Into A Constraint Box; Not Everything Can Be Compartmentalized
  
  • Because We Are Human....And That Is What Makes Us Good At What We Do
  
  • Because Cancer Care Is Not Perfect