



SPECTRUM OF SURVIVORSHIP CARE: SURVIVORSHIP STORY

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Two-time Cancer Survivor

Outline

- **Lessons from the Past**
 - Survivorship as an Adolescent/Young Adult (AYA) with Re-occurrence
- **Integration in the Present**
 - Professionally
 - Community
- **Vision for the Future**
 - What worked well
 - Improvements needed within community/policy
 - Collaborations needed to improve the work within the community
- **Summary**

Lessons from the Past: A Tale of Three Systems

First Episode – 29 y/o female

Primary Care Provider (PCP) – Identifier and Navigator

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- PCP had 5-year history with patient prior to identification in routine physical
- Clearly defined treatment plan for thyroid cancer
- Seamless communication across testing, treatment, and follow-up care
- Well-established treatment protocol with high success rate
- Insurance company attempted to decline coverage for treatment declaring a “pre-existing condition”
- Coverage was through a friend’s father’s company and personally appealed case

PAST

Lessons from the Past: A Tale of Three Systems

Second Episode – 34 y/o Female

Specialty Care System – No Longer Fits a Protocol, A Zebra (Phase I)

- Over-utilization of testing
- Lack of coordination and plan for 6-8 months
- “We’ll let the cancer grow and return visit in 3-6 months”
- Proposed most drastic and expensive measures with estimated minimal success

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Lessons from the Past: A Tale of Three Systems

Second Episode – 34 y/o Female Integrated Care System – Resolution (Phase II)

- + Serendipitous meeting on a plane in rural Wisconsin that ended Phase I
- + Testing, full diagnosis and treatment team gathered within 12 hours of arrival
- + Seamless and rapid communication across all levels of care
- Appeal for in-network coverage declined by medical director

Ref - Ian D. Hay & J. William Charboneau, "The Coming of Age of Ultrasound-Guided Percutaneous Ethanol Ablation of Selected Neck Nodal Metastases in Well-Differentiated Thyroid Carcinoma." *The Journal of Clinical Endocrinology & Metabolism*, 96(9), pp. 2717-2720

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Integration in the Present: Stimulating Action in Policy and the Community

Transitioned to national and international mental health policy and advocacy post-Episode I

Keys to Propelling Forward

I. Power of unlikely partners in propelling issues

- Media (e.g. Rosalynn Carter Fellows)
- Big Business (e.g. Local project working with Fortune 500 companies and large businesses)
- Entertainment Industry (e.g. TV series, VIPs)

II. Responsive to “hot” policies in public debate to push agenda

- ACA implementation (e.g. Bundled care)

III. Connect to broader policy movement focused on integrated/collaborative care

- Mental health



Vision for the Future: Fusing Lessons from the Past & Present to Drive Reform & Collaboration

I. Whole Health in Survivorship – “Go and Live Your Life”

Collaboration: PCPs, specialists, employers, faith community, psychiatrist/counselors, and health policy

Community resources for survivors to address social/relational, career/ vocational, financial, and mental health needs for full re-integration.

- Disease driven system drops recovered survivors at the curb
- Mental Health needs post-treatment and years into survivorship



FUTURE

Vision for the Future: Fusing Lessons from the Past & Present to Drive Reform & Collaboration

II. Rapid Penetration of Research Across All Systems to End Users

- **Collaboration:** Researchers, health systems, specialists, treatment teams/navigators, insurance plans, and health policy
- Remove perverse incentives to encourage widespread adoption
 - Unnecessary/duplicative testing
 - Turf battles
 - Profit driven costly treatments over highly effective but less profitable treatments



FUTURE

Vision for the Future: Fusing Lessons from the Past & Present to Drive Reform & Collaboration

III. Unique Needs of Adolescent/ Young Adult Survivors (AYA)

Collaboration: Researchers, Insurance, Health Systems, Education Systems, Employers, Fertility Specialists, Dentists, Boys/Girls Clubs, Faith Community and Psychiatrists/Counselors

Living decades post-cancer treatment have unique health and mental health needs – currently not well-researched

- Pro-active approach to side-effects and morbidity issues
 - Fertility
 - Dental
 - Mental Health



FUTURE

Summary

- Unlikely partners can propel integration into new and bold terrain.
- Hitching survivorship to the “Whole Health” and “Integration” movements may provide new opportunities for collaboration.
- Addressing the mental health of cancer survivors is critical.
- Rapid penetration of new research should be a priority.
- AYA reoccurrence survivors have unique needs and the dearth of research in this area should be addressed.