

Long Term Survivors and Bone Marrow Transplants: The Risks, the Rewards and What You Should Know

A Panel Discussion with:

James L. Gajewski, MD, MACP, AAMDSIF Board of Directors

John F. DiPersio, MD, PhD, Washington University School of Medicine at St. Louis

Kyle Rocheleau, Bone Marrow Transplant Survivor

Frank Schiro, Bone Marrow Transplant Survivor

July 19, 2020



Conflicts of Interest:

Gajewski: None

DiPersio: Magenta Therapeutics
Advisory Board
WUGEN

The transition from being in cancer treatment to being a survivor is not easy. The hope by all is that cancer and transplant can just be in the rearview mirror, but it never is.

- Psychological
 - Survivor's guilt
 - Transitioning out of sick mode
 - Repairing and transforming relationships
 - With caregivers
 - With children, parents and spouses
- Financial
 - Trying to work again for patient and caregiver
 - Disability
 - Health insurance access

The transition from being in cancer treatment to being a survivor is not easy. The hope by all is that cancer and transplant can just be in the rearview mirror, but it never is.

- Medical problems continue
 - Accelerated metabolism with new chronic diseases
 - Chronic GVHD
 - Chronic pain care
 - Second cancer and relapse remain as problems
- Access to medical care
 - Transplant centers are measured on new transplants they do, not on survivorship management
 - Community physicians are scared of transplant survivor patients
 - Because they don't understand the technology and problems patients can have
 - Community hematology-oncology physicians are measured on treating new cancer patients not survivors.
 - Value based care metrics do not adjust for acuity and hence are creating new access to care barriers

Psychological Issues

- Existential questions-why was I lucky enough to survive? Who do I live for and why?
- Relationship transitions
 - Caregiving can alter parent child relationship and this needs to be returned to normal afterwards but it cannot.
 - Caregivers get burnt out and exhausted especially if protracted debilitating chronic GVHD
 - Somebody needs to work
- Acute then Chronic PTSD-treatment options are not as good we would like
- Cognitive problems add to frustration and woe
- Everyone wants to get back to the way they were before they got sick but can't - everyone going through this is older after they are done and significantly debilitated

Financial

- Patients and families lose jobs and homes to pay for transplant and long-term care
- Relocation to BMT center is not usually just 100 days but can last 6 months to one year or more
- Caregivers need to work and maintain health insurance.
- HCT survivors other family members do get sick and sometimes with catastrophic illnesses
- Health insurance access is a problem-Medicare, Medicaid and SSI help but never replace what patients had before. Temptation for Medicare is to choose a Medadvantage plans but these function like a HMO and limit care options
- Transplant physicians now having own specialty designation may help access as Medicare advantage plans must provide access to every type of specialist

Financial

- Bills and bankruptcy occur frequently
- Philanthropic support focuses on newly diagnosed and treated patients, not the “lucky” long term survivors who “should be able to totally care for themselves”
- Expectation is to get care in community. While some transplant centers have survivors clinics these are for annual assessments not true care coordination and management. Long term access to such centers is insurance carrier dependent.

Survivor Medical Issues

Please tell all medical providers that you are a survivor of HCT!

- Accelerated metabolism means certain chronic diseases are more likely to happen with greater severity
 - Medical literature lacks good studies in how to screen survivors
 - Should we do screening testing like cardiac stress tests more frequently?
 - Should we give aspirin prophylaxis to groups because of increased risk?
 - Relapse and second cancers remain a risk. Is the second cancer in donor or recipient cell line?
 - Long term problems: eye disease, thyroid disease, sexual function and intimacy
- Pain management during treatment is to relieve pain, but when we switch to survivorship, we sometimes must deal with addiction and emphasize non-opioid options

Access to Care

- Primary care clinics normally do a 10 – 20 minute single problem assessment visit
- Transplant survivors are accustomed to prolonged transplant clinic visits with providers of 30 – 60 minutes as the normal and the focus is on every problem
- Primary care physicians, Hospitalists, and Community practice hematology-oncology physicians are not given training and teaching on treating survivors
- Performance metrics for providers are becoming the biggest access to care barrier.
 - Per MACRA legislation passed in 2015, CMS in 2020 will publish cost of care per year per beneficiary.
 - Providers are now more likely to be employed physicians.
 - Providers are being fired for poor satisfaction scores and will even be more likely to be fired when cost of care per beneficiary is higher.
 - Proper acuity adjustment for complexity of disease for HCT survivors does not exist, so providers will be loath to accept HCT survivors as patients

Advice

- Take long term health seriously. Don't neglect problems!
- Ask for screening for chronic disease
- Tell your provider you are a HCT survivor
- Be your own advocate for access to care
- Be an advocate on national healthcare access to care
- There are policy statements that sound good on 20 second soundbites like “let's pay for value in healthcare”, yet the nuts and bolts of implementation will be a problem for access to care for patients whose disease is high cost and high acuity.

Thank you!