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Psychosocial Considerations Post-Hematopoietic Cell Transplantation

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OptumHealth Education

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Disclosures

- None

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Patient case

- 47-year-old Non-Hispanic White female: 6 years post C antigen mismatched unrelated donor peripheral blood hematopoietic cell transplant for AML
- Chronic GVHD of skin, fascia, joints- currently on treatment with prednisone, Sirolimus and Belumosudil
- Multiple complications
  - chronic non-healing ulcer of the left shin
  - left lower extremity deep vein thrombosis
  - chronic renal insufficiency
  - a history of left femur fracture due to osteoporosis with mycobacterial infection of the hip joint after surgery
- Got divorced one year after HCT and lost her job three years after the HCT
- Extremely depressed and was hospitalized recently for expressing suicidal intent

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Patient case

- 14-year-old Hispanic male who received a matched unrelated donor bone marrow transplant for Wiskott Aldrich syndrome at 10 months of age
- Parents were Mexican immigrants without extended family just before his transplant
- Medicaid coverage adequate with minimal out of pocket expenses, but having barely enough money for food and necessities
- Soon after the HCT, the father ran out of paid time off and was forced to take unpaid time off work
- Parents shared duties during and after transplant, often neglecting their own health care needs
- Lasting cognitive and academic deficits and behavioral problems

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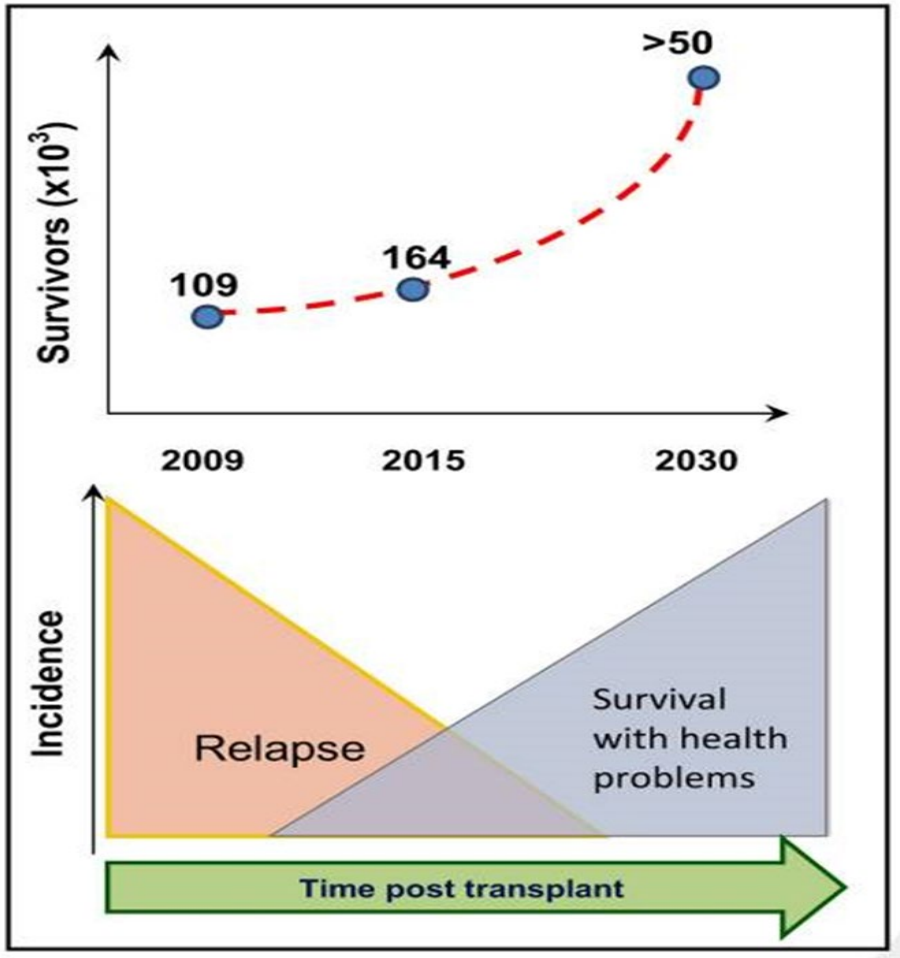
Projected numbers of HCT survivors and temporal course after HCT



Battiwalla et al. BBMT 2017

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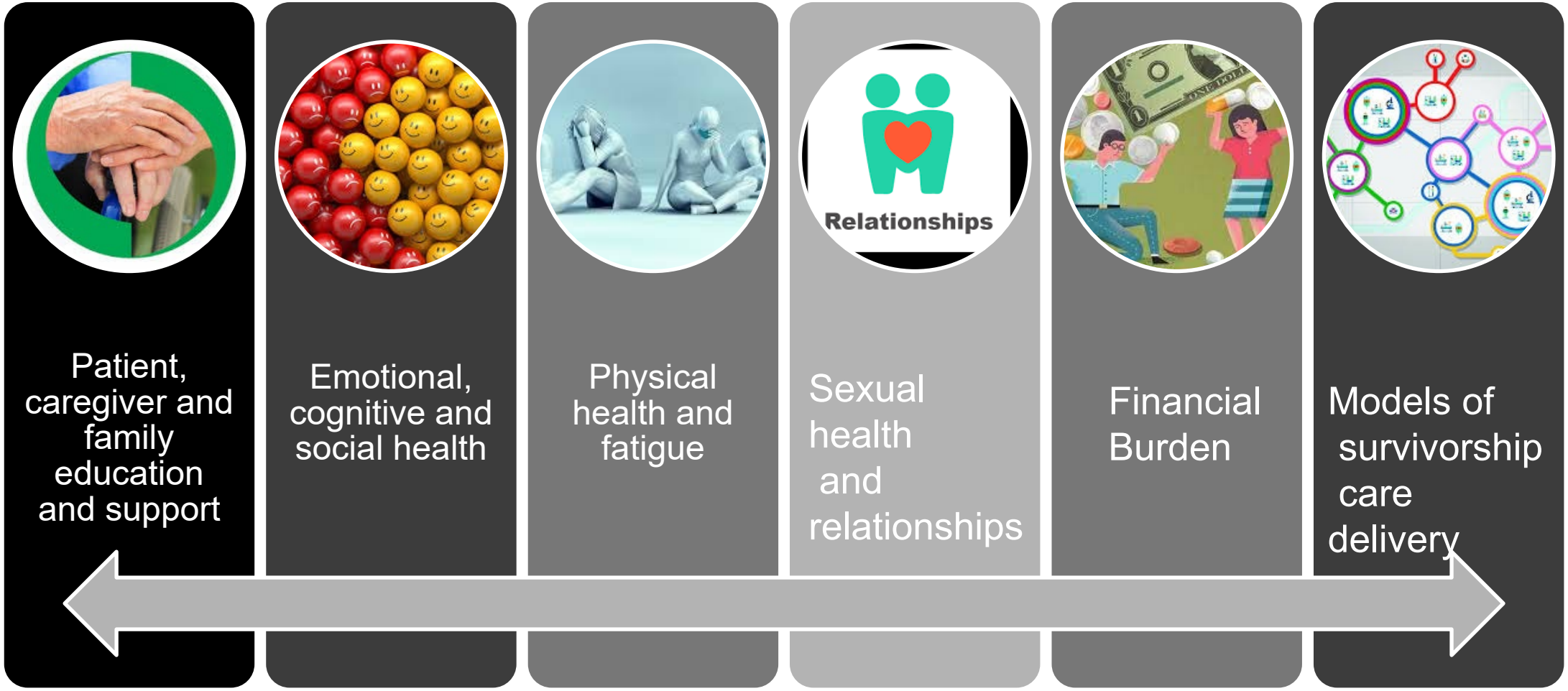
Engaging Patients in Setting a Patient-Centered Outcomes Research Agenda in HCT



Burns et al. BBMT 2018

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Psychosocial Sequelae of HCT

Physical Sequelae

- Fatigue
- Chronic pain
- Sexual dysfunction/ fertility issues
- Symptom burden
- Disability

Caregiver sequelae

- Depression/ Anxiety
- Perceived stress
- Adverse Coping
- Cognitive dysfunction (Chemo Brain)
- Role limitations

Patient

Psychological Sequalae

Social Sequalae

- Financial distress
- Social reintegration
- Return to work
- Marital problems

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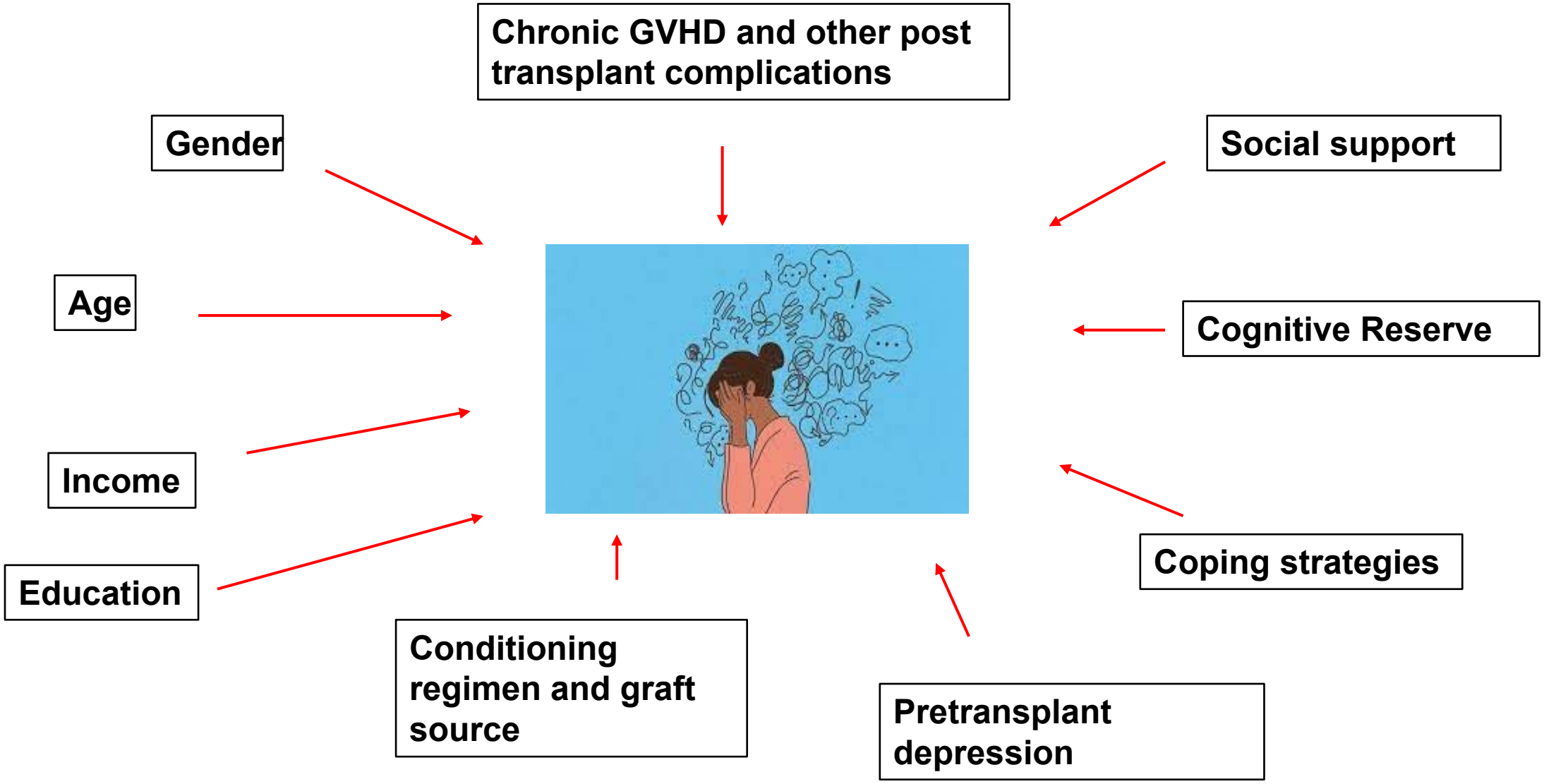
Factors affecting psychosocial sequelae



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Physical Sequelae after HCT

Outcome	Prevalence*	Risk Factors	Comments
Pain	21–25%	*Sociodemographic*: unknown *Clinical*: cGVHD, avascular necrosis, arthralgia, myalgia, muscle cramps	Syndromes not well defined but largely musculoskeletal
Fatigue	35–42%	*Sociodemographic*: female, younger age *Clinical*: chronic pain, cGVHD, inactivity	Widely measured, mechanisms unclear
Sleep Disturbance	14–51%	*Sociodemographic*: older age, female, divorced, unemployed *Clinical*: autologous HCT, depression, distress	Poorly defined, especially for pediatric survivors
Sexual dysfunction	Males: 6–46% Females: 33–80%	*Sociodemographic*: older age at HCT, female *Clinical*: depression, cGVHD, TBI (for men)	Clearly defined as prevalent though rates vary and risk factors not fully defined
Physical dysfunction	25% or greater	*Sociodemographic*: none consistent *Clinical*: active cGVHD, depression	Well defined as recovering overall by one year post-HCT for most survivors, not well defined for pediatric survivors

Bevans et al. BBMT 2017

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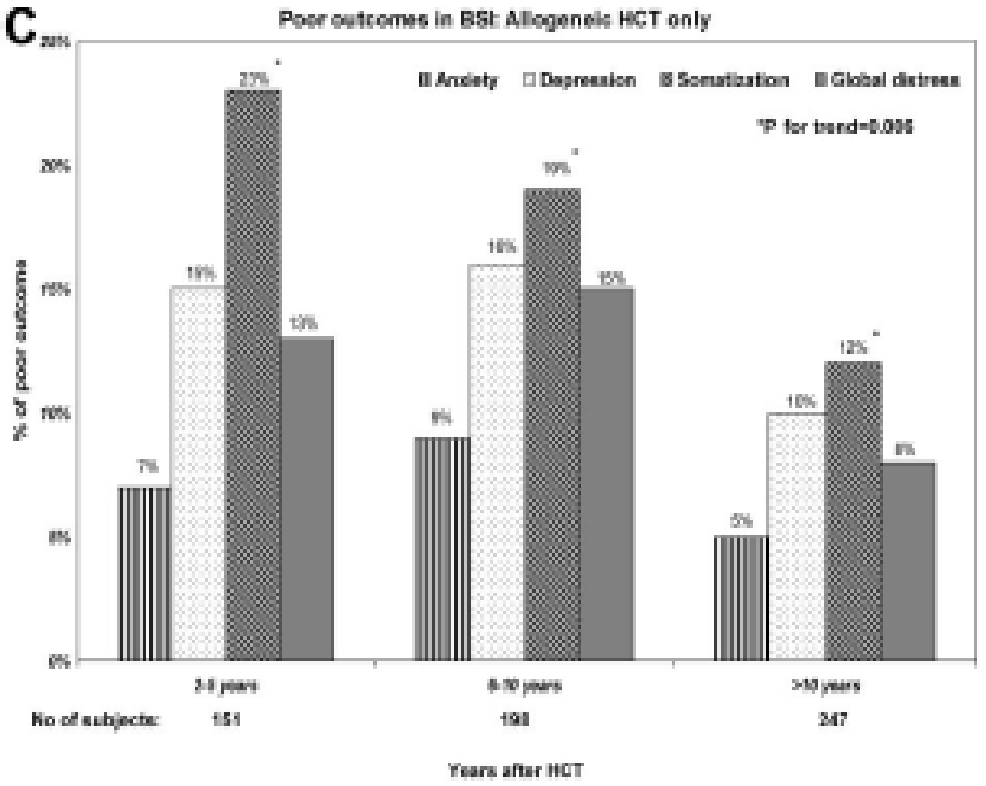
Psychological Sequelae after HCT

- **Prevalence:**
  - **Depression and Anxiety:12 to 40%**
  - **Post traumatic stress disorder:3 to 13%**
  - **Emotional distress: 22 to 43%**
  - **Neurocognitive dysfunction: 10 to 40% (though higher with self report)**



Seneviratne et al. Eur J Haematol 2021
Liang L et al. BBMT 2019
Jacobs et al. BBMT 2019
Sharafeldin N et al. JCO 2018
Sun et al. Blood 2015

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Financial Burden after HCT

- 20 to 70% of patients endorse financial burden
- Other financial stressors: employment and insurance challenges
- Two thirds of chronic GVHD patients experience financial hardship despite health insurance
  - likely to be patients with lower household income
- Consequences:
  - poor quality of life
  - non-adherence to treatment
  - higher symptom burden
  - higher perceived stress
  - low satisfaction with care
  - no impact on survival

Khera et al. BBMT 2014
Abel GA et al. BBMT 2016
Denzen et al. BMT 2016
Khera et al. BBMT 2018
Khera et al CEBP 2018

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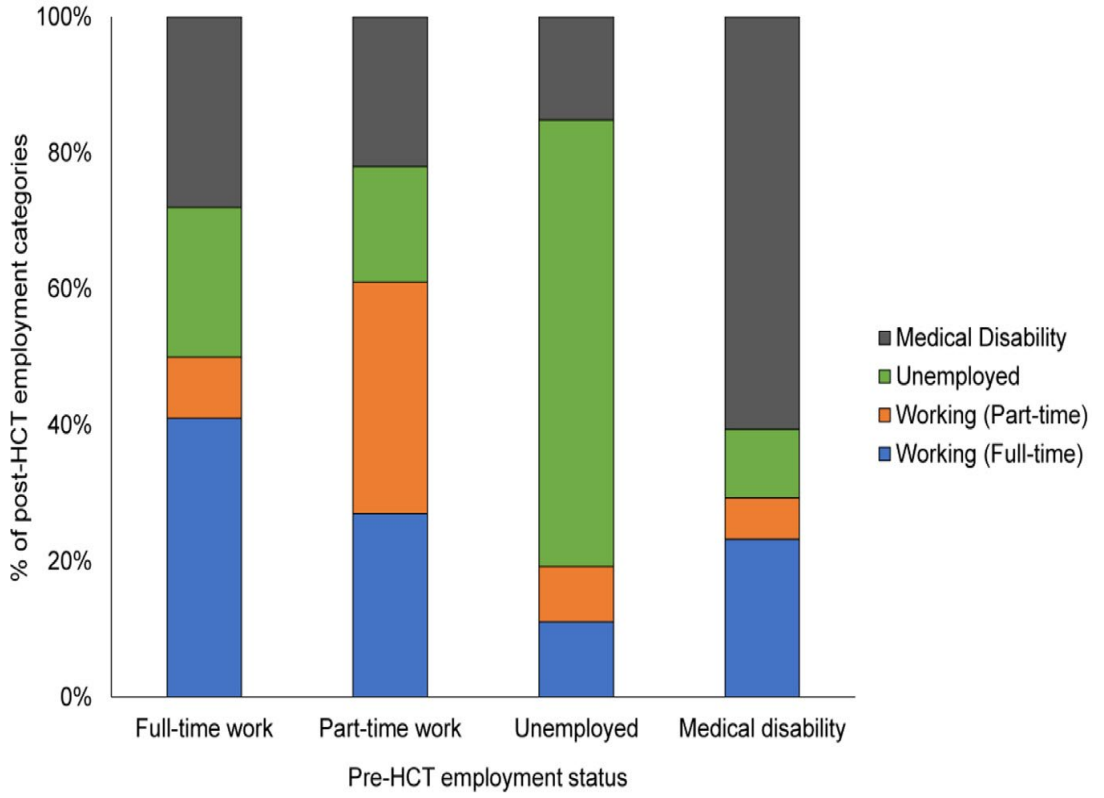
Return to work after allogeneic HCT

Risk factors for delayed RTW
Lower physical functioning
Multimorbidity (HCT-CI of>/=3)
Female gender
Use of PB for stem cell graft
Acute GVHD or relapse within 1 year of HCT
Pre HCT unemployment or disability
Lack of standard guidelines



Kirchhoff et al. Journal of cancer survivorship 2010
Lee SJ et al. JAMA Onc 2016
Salit et al. BBMT 2020
Bhatt et al. TCT Journal 2021

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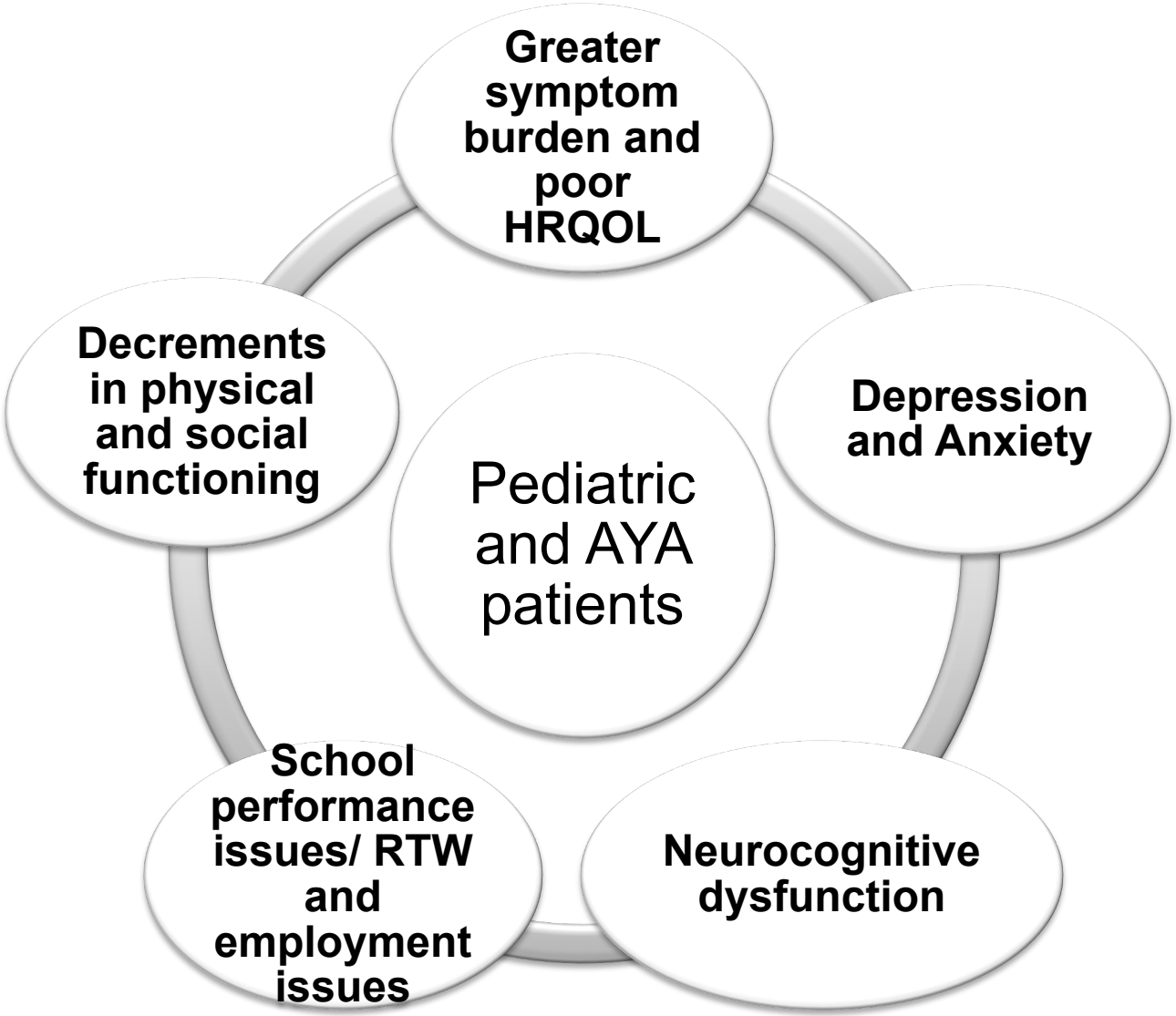
Psychosocial needs of pediatric and AYA population



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Challenges for the HCT Caregiver

Physical

Fatigue

Sleep issues

Sexual dysfunction

Psychological

Depression

Distress

Cognitive dysfunction

Social

Lack of social support

Role conflict

Financial/ employment issues

Caregiver Burden and poor Quality of Life

Bishop et al.JCO 2007
Jamani et al. BBMT 2018

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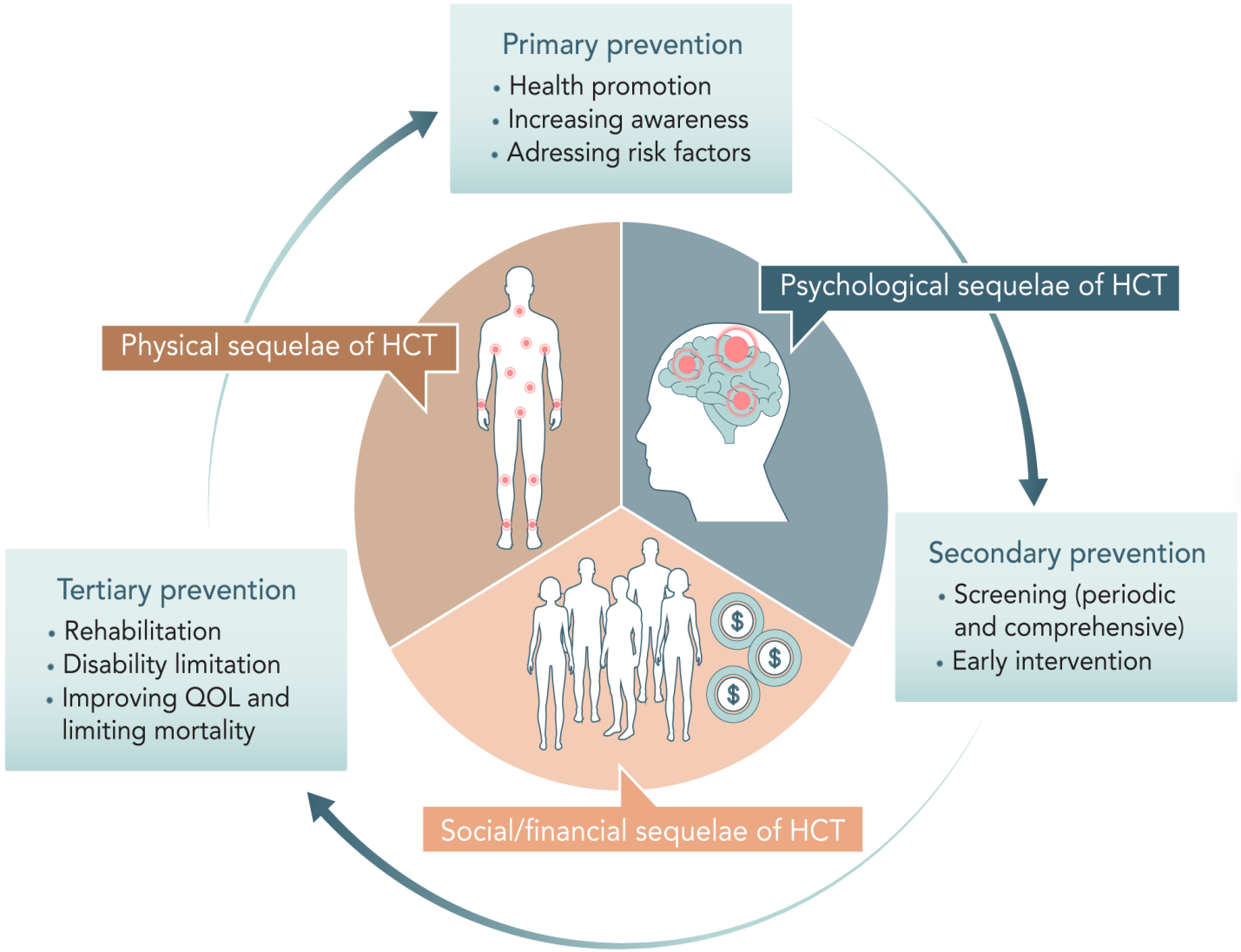
Addressing Psychosocial sequelae of allogeneic HCT



Psychosocial/QOL and sexual function clinical assessment recommended at 6 months, 1 year and annually thereafter

Majhail et al. BBMT 2012

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Psychosocial & Financial Screening Tools

Scale	Description
Psychosocial Assessment of Candidates for Transplant (PACT)	Describes psychosocial functioning before HCT
Transplant Evaluation Rating Scale (TERS)	Describes psychosocial functioning before HCT
Psychosocial Assessment Tool - Hematopoietic Cell Transplantation (PAT-HCT)	Describes the family psychosocial risk for families of a child undergoing HCT
Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT)	Measures psychosocial readiness for transplant
COmprehensive Score for financial Toxicity (COST FACIT)	Describes the financial distress experienced by cancer patients 18 years of age and older during the past seven days

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Ferrata Storti Foundation

Randomized controlled trial of individualized treatment summary and survivorship care plans for hematopoietic cell transplantation survivors

Navneet S. Majhail,[1] Elizabeth Murphy,[2] Purushottam Laud,[3] Jaime M. Preussler,[2,4] Ellen M. Denzen,[2,4] Beatrice Abetti,[5] Alexia Adams,[4] RaeAnne Besser,[4] Linda J. Burns,[2,4] Jan Cerny,[6] Rebecca Drexler,[4] Theresa Hahn,[7] Lensa Idossa,[2] Balkrishna Jahagirdar,[8] Naynesh Kamani,[9] Alison Loren,[10] Deborah Mattila,[4] Joseph McGuirk,[11] Heather Moore,[2] Jana Reynolds,[12] Wael Saber,[3,13] Lizette Salazar,[14] Barry Schatz,[15] Patrick Stiff,[15] John R. Wingard,[16] Karen L Syrjala[17] and K. Scott Baker[17]

Haematologica 2019
Volume 104(5):1084-1092

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Individualized Care plans in HCT survivors

- Studied impact of survivorship care plans in adult HCT survivors 1-5 years out from HCT on PROs at 6 months
- Participants on the care plan arm reported
  - significantly lower distress scores
  - increase in mental functioning

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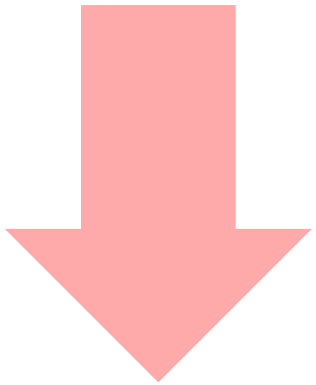
Treatments for Psychosocial concerns: pharmacologic agents for depression/ anxiety/fatigue/insomnia/pain

- **Antidepressants/ anti-anxiety**
- **Psychostimulants (Methylphenidate, Modafinil)**
- **Sleeping meds**
- **Analgesics (Opioid and non-opioid)**
- **Hormone replacement**



-Small studies

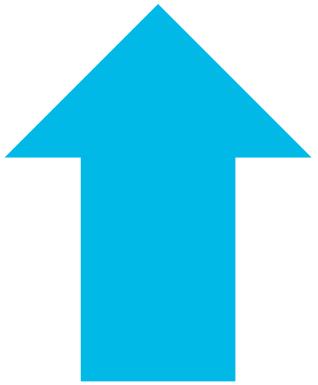
-Extrapolated from cancer literature

-Side effects and drug interactions

-Risk for dependence/ addiction

-Validation of symptom experience

-Symptom management



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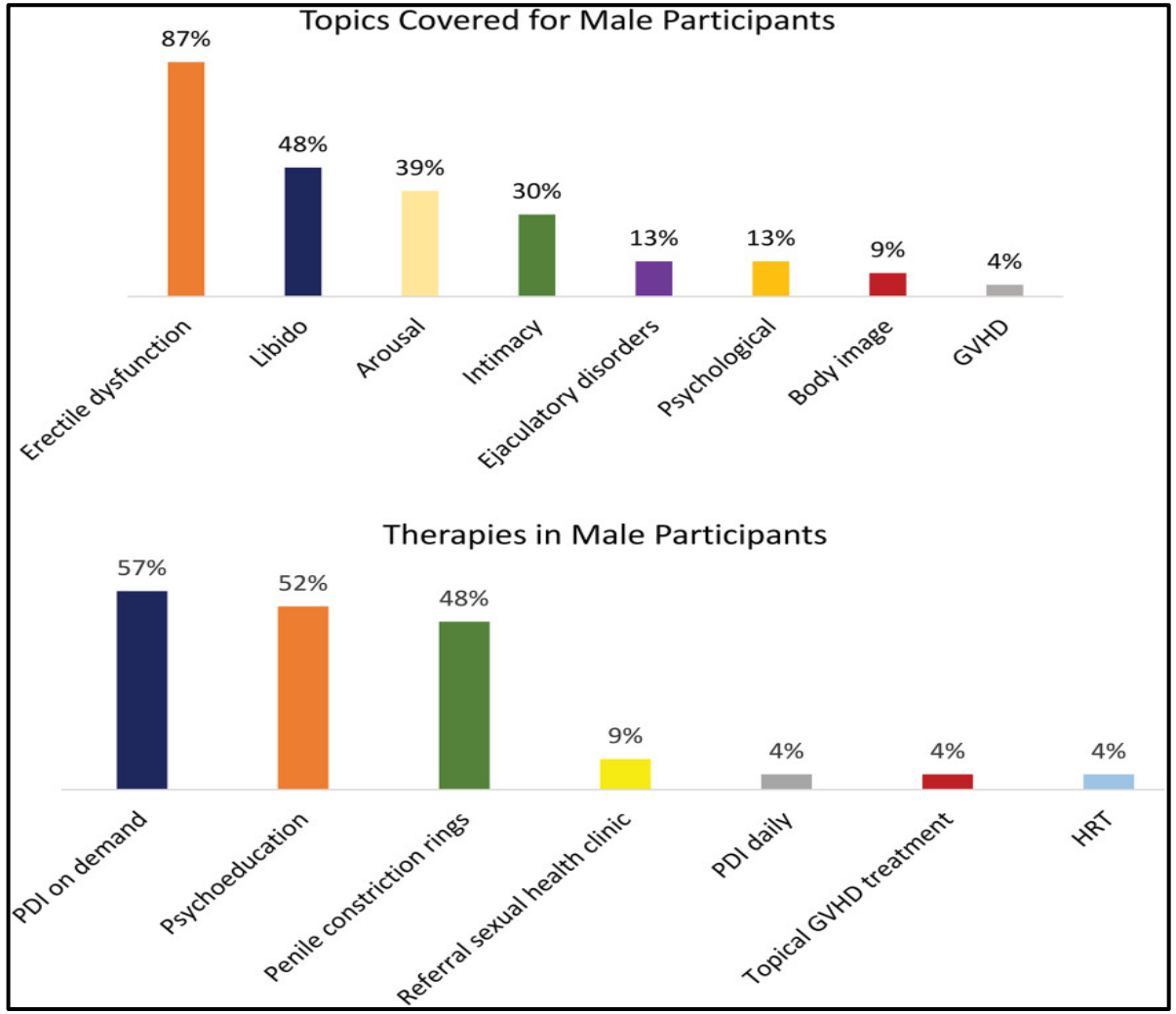
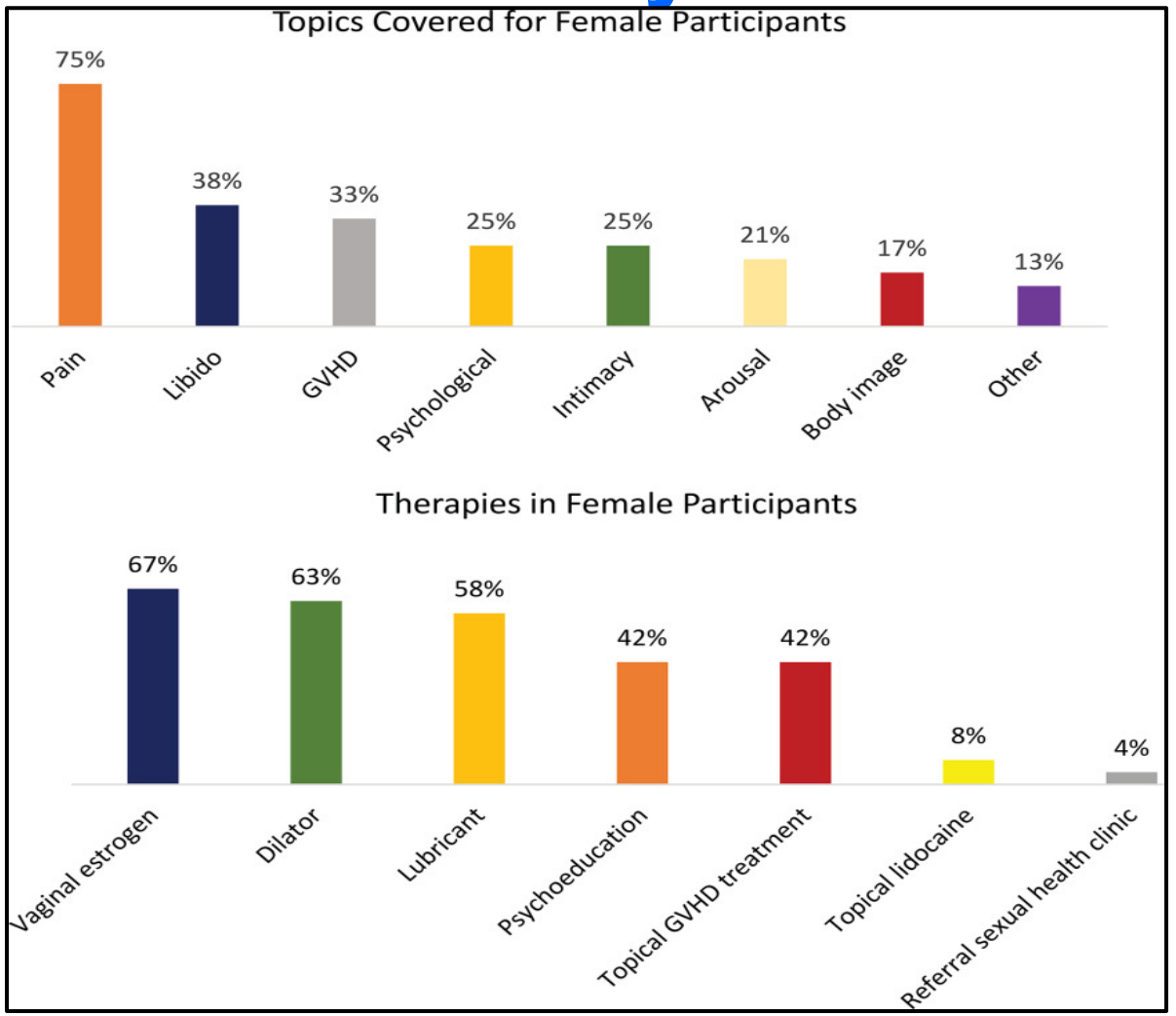
Treatments for Psychosocial concerns: multimodal intervention for sexual dysfunction





El-Jawahari et al. Cancer 2018

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Treatments for Psychosocial concerns: Other modalities for fatigue, insomnia, depression, cognitive deficits

- Exercise
- Psychotherapy
  - Cognitive behavioral therapy
- Neuropsychological evaluation/ recommendations
- Other Integrative therapies
  - Yoga/meditation
  - Mindfulness based techniques
  - Supportive expressive therapies

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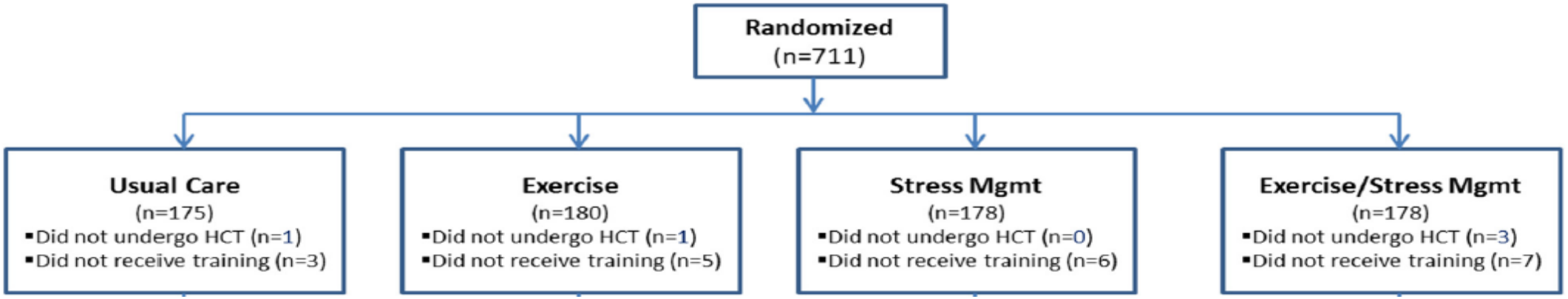
Exercise and Stress Management Training Prior to Hematopoietic Cell Transplantation: Blood and Marrow Transplant Clinical Trials Network (BMT CTN) 0902

Paul B. Jacobsen [1], Jennifer Le-Rademacher [2], Heather Jim [1], Karen Syrjala [3], John R. Wingard [4], Brent Logan [2], Juan Wu [5], Navneet S. Majhail [6], William Wood [7], J. Douglas Rizzo [8], Nancy L. Geller [9], Carrie Kitko [10], Edward Faber [11], Muneer H. Abidi [12], Susan Slater [13], Mary M. Horowitz [8], Stephanie J. Lee [3,*]



- **No differences in**
  - **physical and mental functioning at day +100**
  - **overall survival**
  - **days of hospitalization through day +100 post-HCT**
  - **other patient-reported outcomes: treatment-related distress, sleep quality, pain and nausea**

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INSPIRE Study

- Tailored webpage with topics
  1) lift mood, reduce fatigue, boost health
  2) Self-care tips and tools
  3) Tailored care guidelines
  4) Forum for posting experiences and for input
  5) Resource list
- Problem Solving intervention- with psychologists
- Outcomes: CTXD, SCL-90-R Depression Scale, SF-36, FSI

Syrjala et al. J Cancer Survivorship 2018
Syrjala et al. BBMT 2018

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Results of INSPIRE study

- Survivors age ≥40 years, females, and those who underwent previous HCT >10 years earlier were most engaged
- INSPIRE+ problem solving training more likely to improvement in distress than controls, specially those who viewed the website and those >40 years of age
- Engagement did not differ by race, education, income, rural/urban residence, computer experience, donor type, or presence of depression

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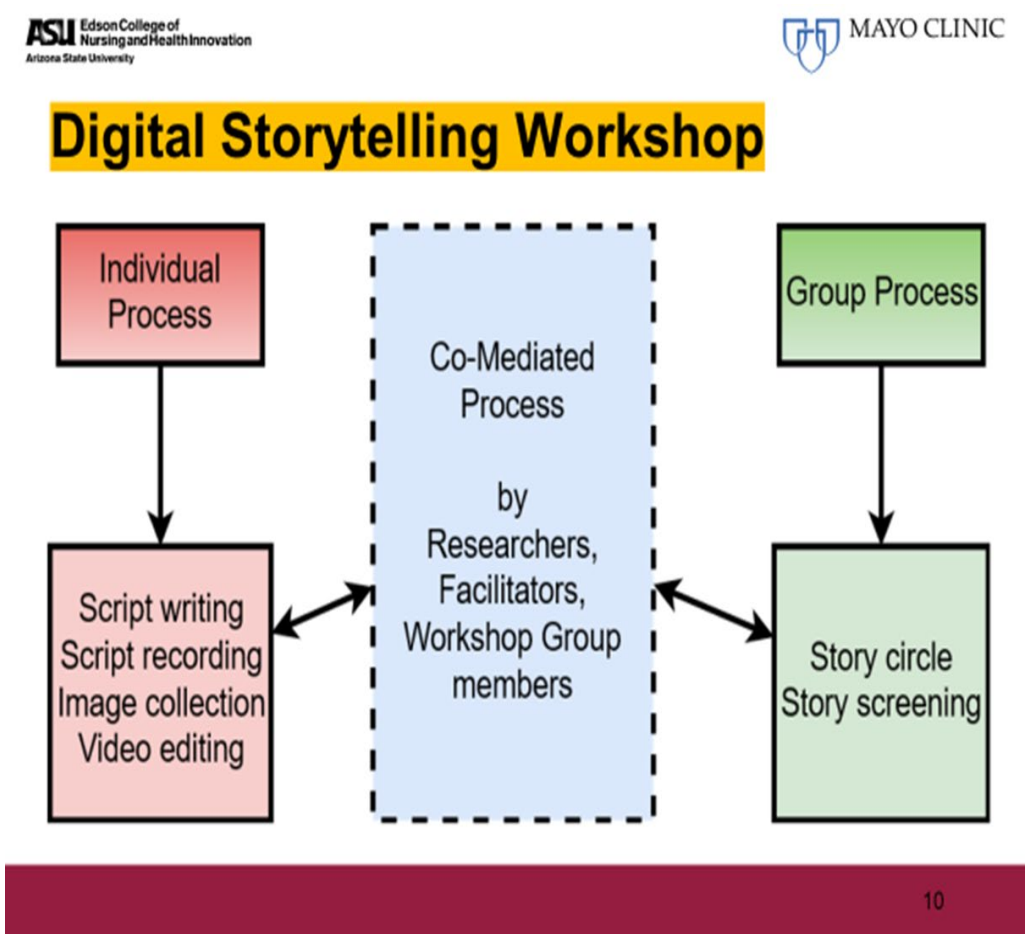
Digital storytelling for HCT patients and caregivers



Workshop participants' comments...

"It was so nice to meet other patients who have gone through what you've gone through and hear what other people have gone through. It was more than talking and having a support group; it was very therapeutic for me". ."

"I was surprised at how much emotional I was when I went over my real story. I never thought of once any of the feelings that I was having. This workshop opens me up to realize the value of talking and sharing emotions. Now I am sharing my emotions with my family.".

"Hearing it from all of us is going to be much more powerful for other HCT patients instead of support groups. We all need tremendous support to get through this. These stories will be unique, helpful, and inspirational"

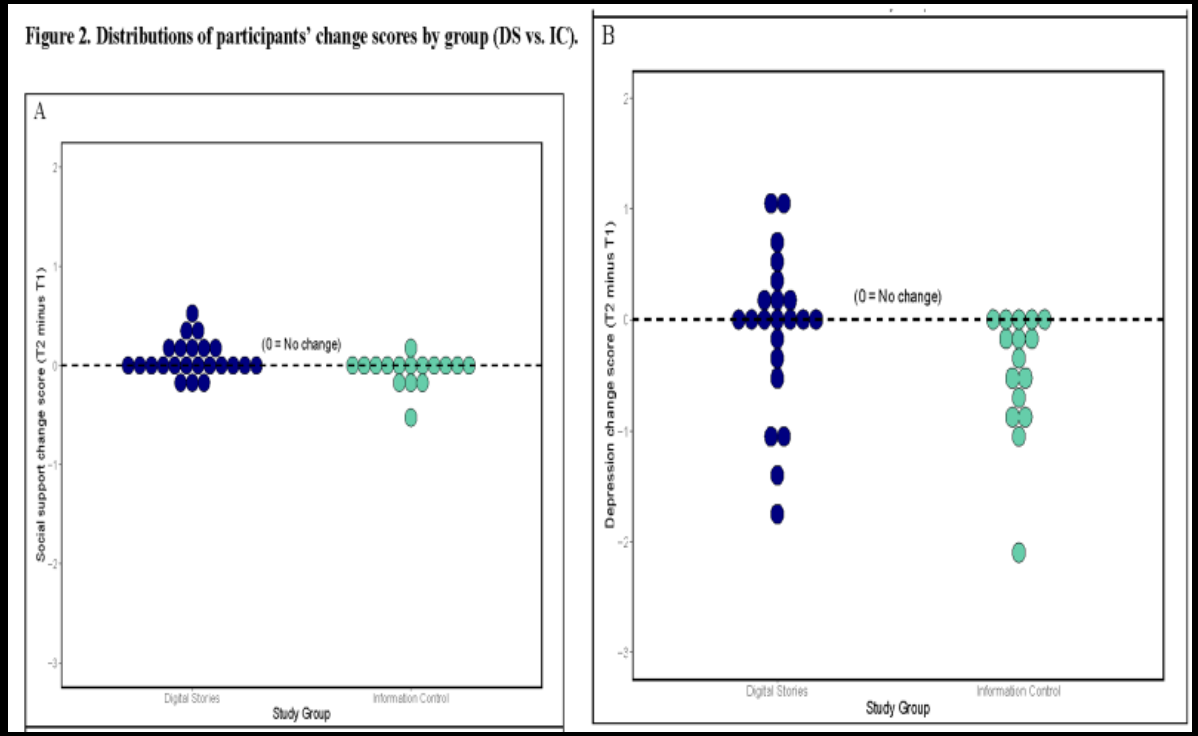
Kim et al. BBMT 2019

Journal of Cancer Education
https://doi.org/10.1007/s13187-020-01948-2

Feasibility of a Digital Storytelling Intervention for Hematopoietic Cell Transplant Patients

Wonsun (Sunny) Kim[1] · Shelby Langer[1] · Michael Todd[1] · Linda Larkey[1] · Soojung Jo[1] · Lauren R. Bangerter[2] · Nandita Khera[3]

- 40 adult HCT patients randomized to Digital storytelling (DS) intervention and information control (IC) to compare depression and perceived social support
- 74% completed the intervention
- Assessments done at baseline and after completion of the intervention



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Multi level barriers to psychosocial care delivery

- Lack of awareness
- Socioeconomic barriers
- Logistical challenges

- Lack of resources/tools
- Lack of interest
- Lack of awareness of guidelines
- Inadequate communication

- Lack of reimbursement
- Poor care coordination
- Competing priorities
- Lack of resources/ specialists
- Inadequate quality assurance

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Areas of Focus for Future Research Priorities & Clinical Practice

Study design and measures

- Proactive longitudinal data collection with standardized time points
- Validated PRO measures
- Focus on special populations

Screening and assessment

- Evidence based recommendations
- Leverage technology to incorporate PRO data in EMRs

Rehabilitation and Interventions

- Develop and test interventions
- Novel delivery platforms

Education and awareness

- Raise awareness
- Develop metrics

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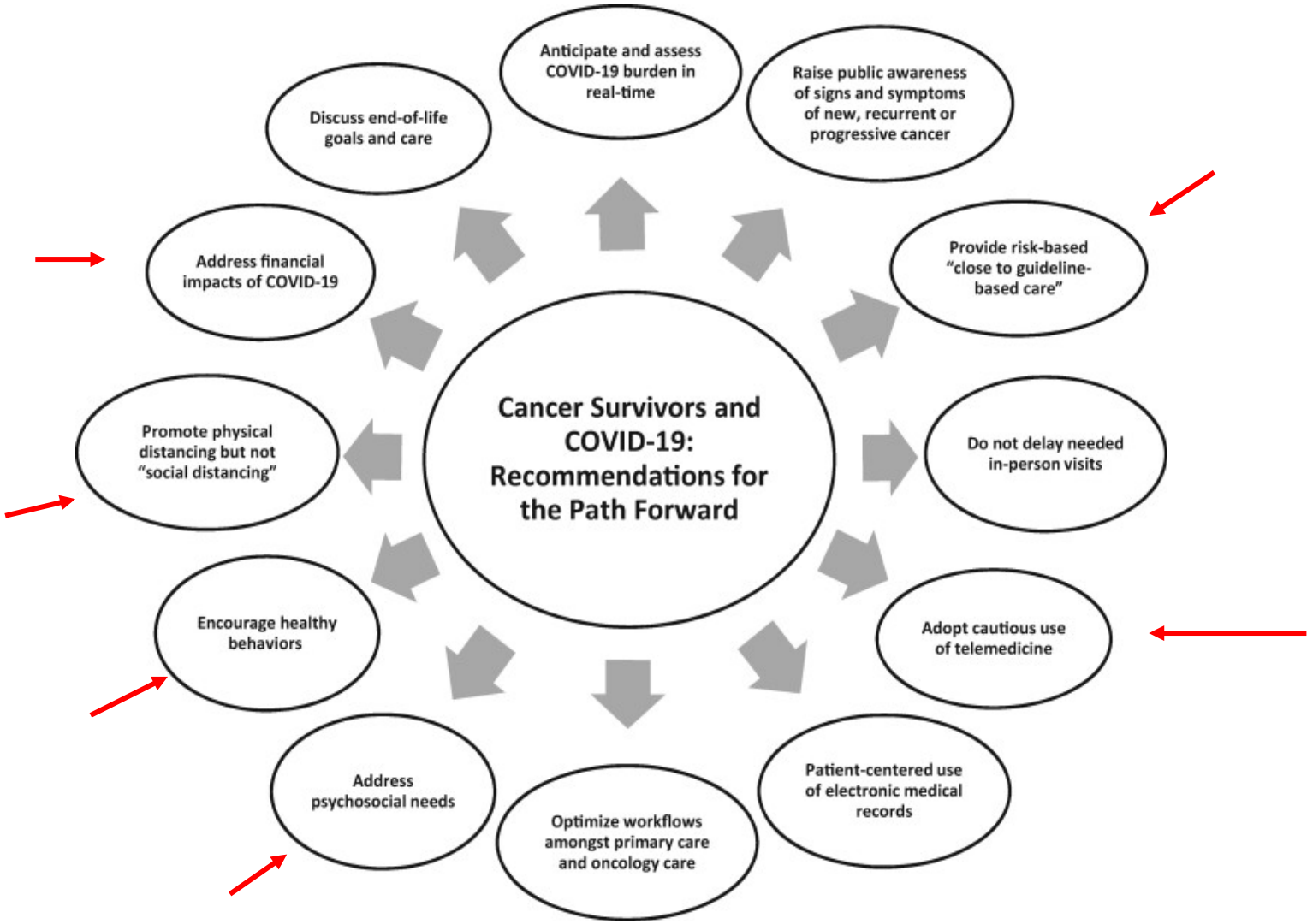
Survivorship care during COVID-19



Jones et al. JNCI 2021

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Patient case

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- Chronic GVHD of skin, fascia, joints- currently on treatment with prednisone, Sirolimus and belumosudil
- Multiple other medical complications
- Got divorced one year after HCT and lost her job three years after the HCT
- Extremely depressed and was hospitalized recently for expressing suicidal intent

- Coordinated care by a multi-disciplinary team including her transplant physician and nurse, social worker, patient financial services, providers from palliative medicine and psychiatry/psychology
- Frequent touch points using virtual visits
- Getting grants for financial support
- Support group for chronic GVHD patients for emotional support

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Patient case

- 14-year-old Hispanic male who received a matched unrelated donor BMT for Wiskott Aldrich syndrome at 10 months of age
- Parents were Mexican immigrants without extended family just before his transplant
- Medicaid coverage adequate with minimal out of pocket expenses, but having barely enough money for food and necessities
- Soon after the HCT, the father ran out of paid time off and was forced to take unpaid time off work
- Parents shared duties during and after transplant, often neglecting their own health care needs
- Lasting cognitive and academic deficits and behavioral problems in the patient

- A local charitable organization for grant funds for rent and food assistance
- Frequent meetings with social workers for support
- Formal neuropsychological evaluation following which the HCT clinical team and parents worked closely with the child's school including teachers and administration to develop an appropriate Individualized Education Plan

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Thank you!