

Survivorship Care Plans: Are They Effective?

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Disclosures

The following faculty and planning committee staff have no financial disclosures:

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Learning Objectives

At the conclusion of this session, attendees will be able to:

- Apply Commission on Cancer requirements for survivorship care plans (SCPs) for all transplant patients at their center
- Synthesize findings from the Individualized SCPs for hematopoietic cell transplant (HCT) Survivors study
- Discover the patient and provider experience with using the SCP as part of the study

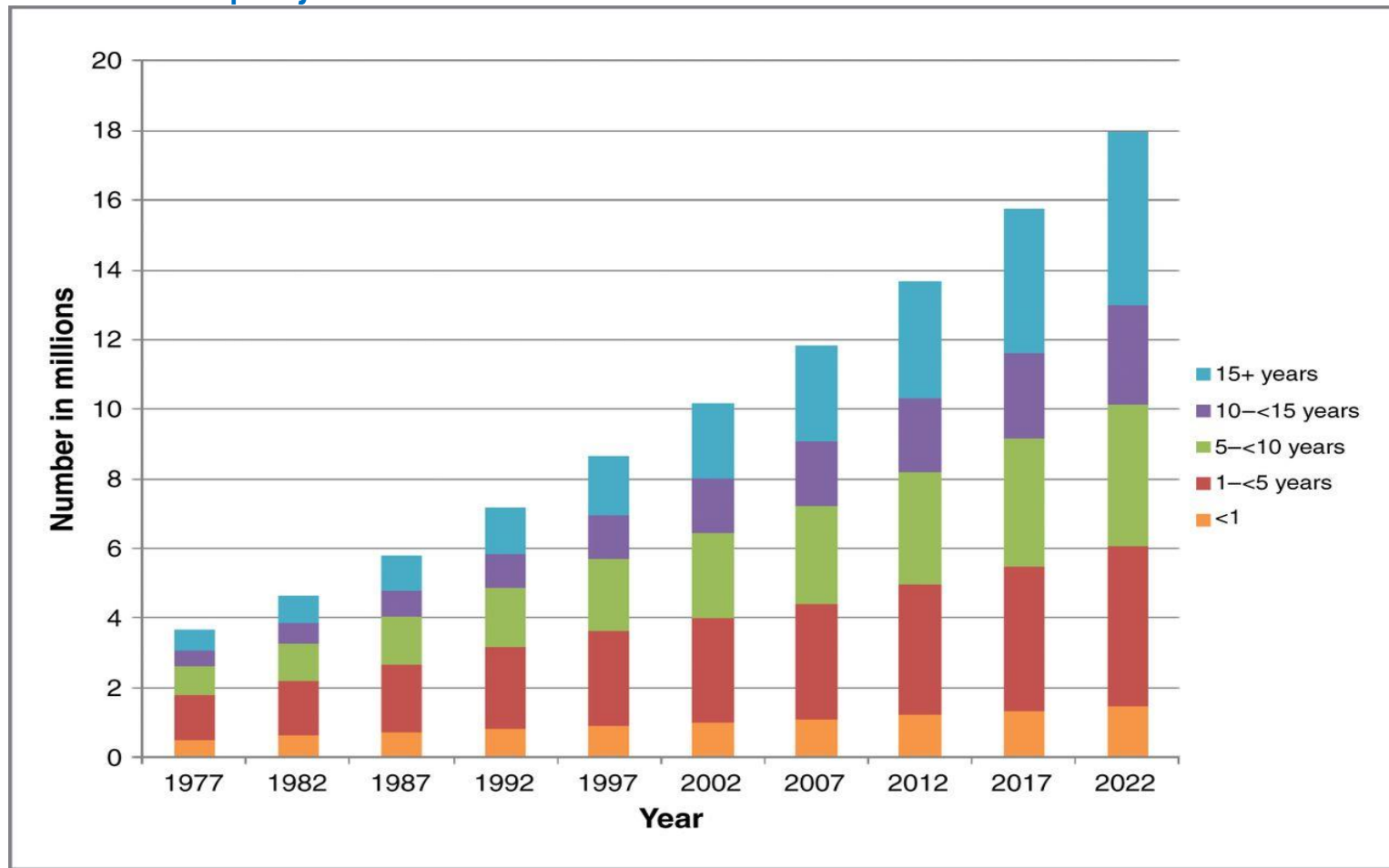
Treatment Summary & Care Plans for Survivors after HCT

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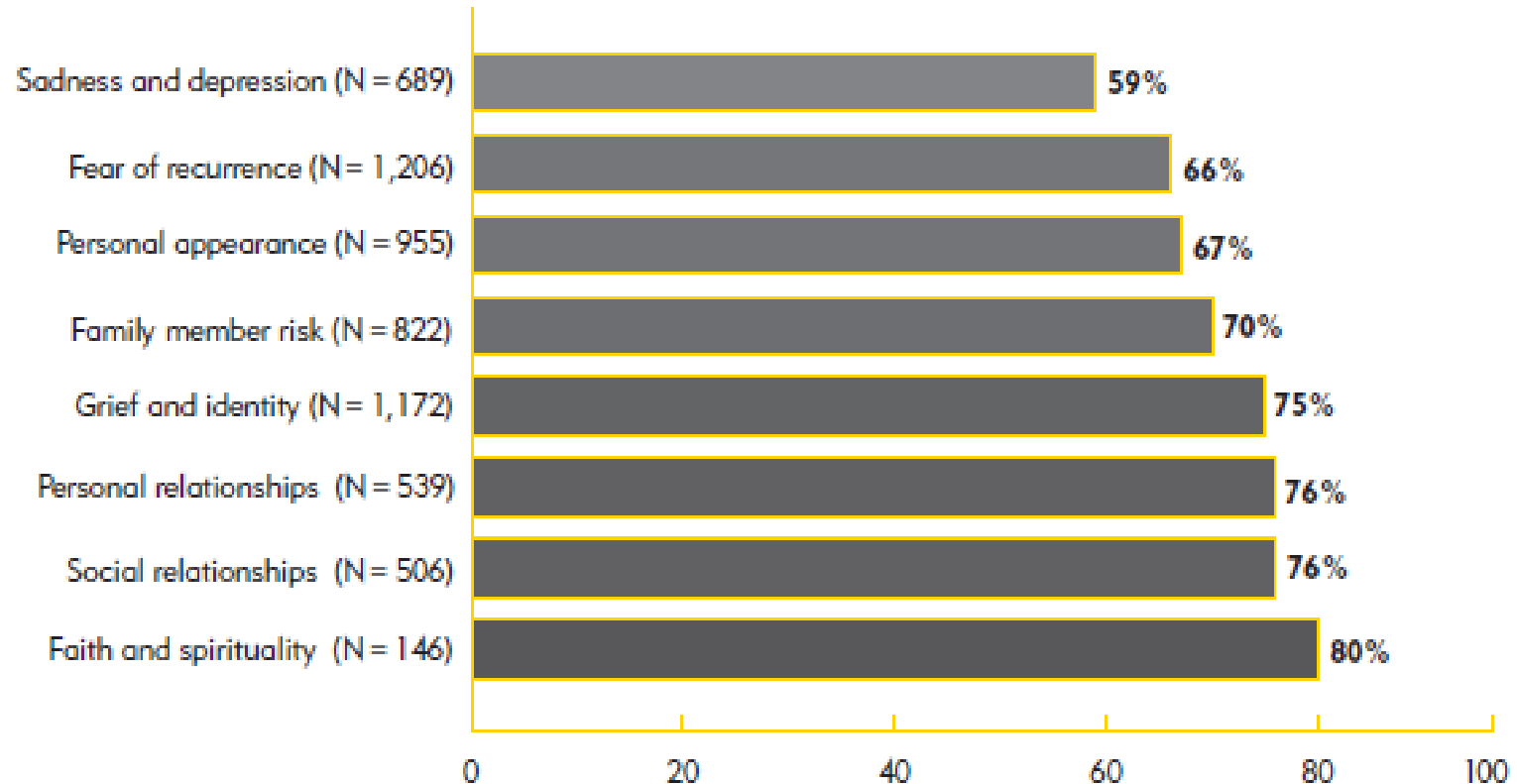
Estimated and projected number of cancer survivors in the U.S. 1977-2022



Post-treatment Reality

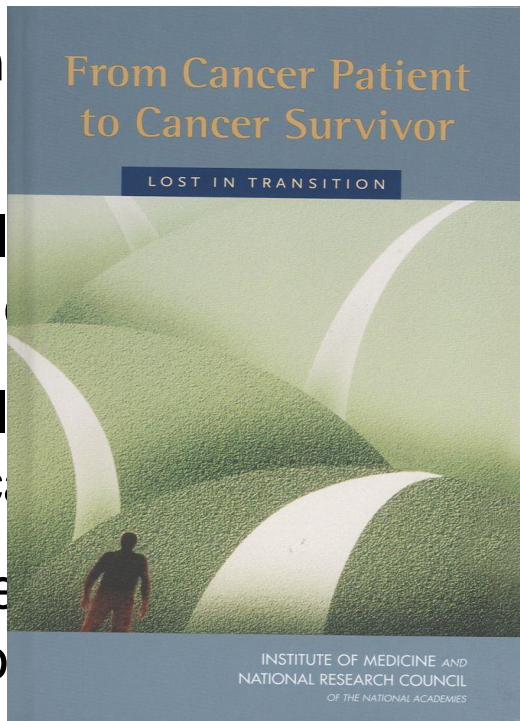
- Survivors more likely to have comorbidities
 - Multiple comorbidities common (most often Musculoskeletal, HTN, & pulmonary); Report poorer health outcomes and need for help with ADLs; Consistent across time, including long-term survivors
- More likely to die of non-cancer causes
 - Leading causes of death are cardiovascular and respiratory disease; Excess of deaths especially high ≤ 5 years from diagnosis
- Survivors more likely to develop a second primary cancer
 - Majority of new cancers arose in a separate organ system; Smoking and alcohol intake accounted for 35% of excess cancers; Lifestyle risk factors (e.g., weight, physical activity) also contribute

Lack of care: Percentage of respondents who did not receive help for their emotional concerns



From Cancer Patient to Cancer Survivor: Lost In Transition (IOM, 2006)

1. Every survivor should have a treatment summary and care plan at the end of treatment.
2. Prevention, surveillance, and management of new and recurrent cancer.
3. Prevention, surveillance, and management of consequences of cancer treatment.
4. Coordination between cancer and primary care providers to ensure that survivors are in the right place at the right time.



Inclusion of Survivorship in Accreditation Standards (2012)

1. A survivorship care plan is prepared by the principal provider(s) who coordinated the oncology treatment for the patient with input for the patients other care providers.
2. The survivorship care plan is given to the patient on completion of treatment
3. The written or electronic survivorship care plan contains a record of care received, important disease characteristics, and a follow-up care plan incorporating available and recognized evidence-based standards of care, when available.

COC Standards Implementation

- **SCP Requirement rolled out gradually over five years**
 - Jan. 1, 2016: Provide SCPs to 25% of eligible patients
 - Jan. 1, 2017: Provide SCPs to 50% of eligible patients
 - Jan. 1, 2018 and beyond: Provide SCPs to 75% of eligible patients
 - Eligible Patients: Patients who completed “active therapy (other than hormonal treatment).” Patients should receive a SCP, regardless of disease site, but patients with metastatic disease are not targeted by the standard.
 - HCT NOT ADDRESSED

Treatment Summary: Required Content

- Contact information of the treating institutions and providers
- Specific **diagnosis**, histologic subtype when relevant
- **Surgery?** If yes: Surgical procedure with body location, Date(s)
- **Chemotherapy?** If yes: Names of systemic therapy agents administered (individual names rather than regimens), End date(s) of chemotherapy treatment (year required)
- **Radiation?** If yes: Anatomical area treated by radiation, End date(s) of radiation treatment (year required)
- Ongoing **toxicity** or **side-effects** of all treatments received (including surgery, systemic therapy and/or radiation) at completion of treatment, information on the likely course of recovery

Follow-up care plan (1)

- Oncology team contacts w/ treatment facility location
- Need for ongoing adjuvant therapy for cancer: name, planned duration
- Schedule of follow up related clinical visits including who will provide the follow-up visit, how often and where this will take place:
 - Cancer surveillance tests for recurrence, in table format
 - Cancer screening for early detection of new primaries—to be included only if different from the general population, in table format

Follow-up care plan (2)

- Other periodic testing and examinations
- Symptoms of cancer recurrence
- List of late and/or long-term effects a survivor may experience based on his/her individual diagnosis and treatment, including symptoms of such conditions
- Local and national resources to assist the patient in obtaining proper services
- Information regarding the importance of healthy diet, exercise, smoking cessation and alcohol use reduction

HCT Survivors Cancer Treatment Summary

Date of preparation:

| | | | |
|---|-----------------------------|---------------------------|------------|
| Patient Name | John H. Smith | | |
| MR Number: | 123456-987654 | Date Birth: | 04/22/1961 |
| Cancer Diagnosis: | Precursor B-cell ALL | Date Diagnosis: 11/6/1997 | |
| Subtype: | t(1:19)(q22;q11) F3A/PRY4 | | |
| Significant Past Medical History | | | |
| | | | |
| Transplant Center: | Fred Hutchin | | |
| Date of HSC: | 09/24/1999 | | |
| Cell Source: | Double Umbilical Cord Blood | Number of HSCT: 1 | |
| | | HSCT: | |
| Donor Gender: | Male | HSCT: | |
| Ex-Vivo Graft Manipulation: | No | Method: | na |
| Graft vs. Host Disease Prophylaxis: Tacrolimus, mycophenolate | | | |

1. TREATMENT SUMMARY

| Preparative Regimen | | | |
|---|--|--|-------------------------|
| Chemotherapy | | Total Prescribed Dose | mg/m ² mg/kg |
| Cyclophosphamide | | 120 | |
| Fludarabine | | 150 | X |
| Antithymocyte Globulin | | 30 | X |
| Radiation Therapy | | | |
| Type of Radiation Given | | Total Dose | |
| Total Body Irradiation | | 1200 cGy | |
| Significant Pre-Transplant Treatment Exposures | | | |
| Chemotherapy: Anthracyclines | | | |
| Radiation: | | | |
| Other: | | | |
| Post Transplant Follow-up | | | |
| Last Follow-up Form: Annual Year: 4 | | | |
| Graft Versus Host Disease (Allogeneic Transplants only) | | | |
| Maximum Grade of Acute GVHD : III | | Maximum extent of Chronic GVHD: Limited | |
| | | Date of Diagnosis Chronic GHVD: 01/01/2000 | |
| Disease Status Post-Transplant | | | |
| Relapse or Progression after HSCT: No Method of Detection: Date of Detection: | | Donor Cellular Infusions (DCI) Date of first DCI: none reported Total number DCI: Type of cells: Indication: | |
| LONG TERM EFFECT (annual, male, adult, cGVHD, steroid exposure, TBI) | | RECOMMENDATION | |

| Long term effects and Follow-Up care | Recommendation |
|--------------------------------------|---|
| Cardiac Health | Heart problems can occur after certain chemotherapy drugs (anthracyclines) or after chest radiation based on the doses you have received... |
| Lung/Respiratory | Chemotherapy and radiation may impact lung function. If you are experiencing coughing, increased fatigue |
| Musculoskeletal | After cancer treatment. For exercise both |
| Cognitive/Memory concerns | Memory and these affects improve |
| Fertility | Chemotherapy and radiation can affect your fertility. It is important to know your fertility status. Women should keep track of menstrual cycles and report any changes ... |
| Hormonal Changes | Treatment of your cancer may cause hormone changes which can lead to hot flashes, vaginal dryness, mood fluctuations, fatigue, menstrual irregularities, bone density issues , and memory changes.... |
| Secondary cancers | There is a low risk for leukemia or other secondary cancers related to chemotherapy and/or radiation exposure. Notify your health care provider... |

2. CARE PLAN

| FOLLOW-UP CARE <i>(to be filled in relevant for each patient)</i> | | | | |
|---|-----------|------------------------|---------------------|----------|
| TEST | LAST DONE | FREQUENCY | PROVIDER TO CONTACT | NEXT DUE |
| Complete Physical Exam | | Yearly | | |
| Oncology Follow-up | | As per oncologist | | |
| Surveillance for Risk of Recurrence | | Set by your Oncologist | | |
| Bone Density Test (DEXA) | | Every 2-5 years | | |
| Colonoscopy | | Every 10 years | | |
| Screening Labs, Lipids, <u>etc</u> | | Every 1-2 years | | |
| Gynecological Exam | | Yearly | | |
| Pap Smear | | Every 3 years | | |
| Mammogram | | Every 2 years | | |
| Breast MRI | | | | |
| Skin Exam | | Yearly | | |
| Cardiac Screening | | TBD | | |
| Vision Exam | | Yearly | | |
| Dental Exam | | Twice a year | | |
| Immunizations | | Yearly | | |
| CONTACT/RESOURCES | | | | |

Significance

- Appropriate long-term follow-up of our HCT survivors is critical:
 - So that they can be followed appropriately for the development of late adverse complications
 - And be educated on what their specific long-term risks are based on the specific details of the transplant/therapy they received
- Implementation of appropriate monitoring, screening and preventative practices will be critical as we work towards reducing the early mortality risk in our survivors
- Effectiveness of TS/SCP at helping achieve the above goals for HCT survivors needs to be prospectively studied

Individualized Care Plans for HCT Survivors

A randomized controlled trial (RCT)

Acknowledgement. This study was partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Award #CD-12-11-4062



The CIBMTR® (Center for International Blood and Marrow Transplant Research®) is a research collaboration between the National Marrow Donor Program® (NMDP)/Be The Match® and the Medical College of Wisconsin (MCW).

Objectives

- **Primary Objective**

- To evaluate the impact of an individualized SCP on survivor knowledge about confidence in knowledge of recommended survivorship care treatment summary

- **Secondary Objectives**

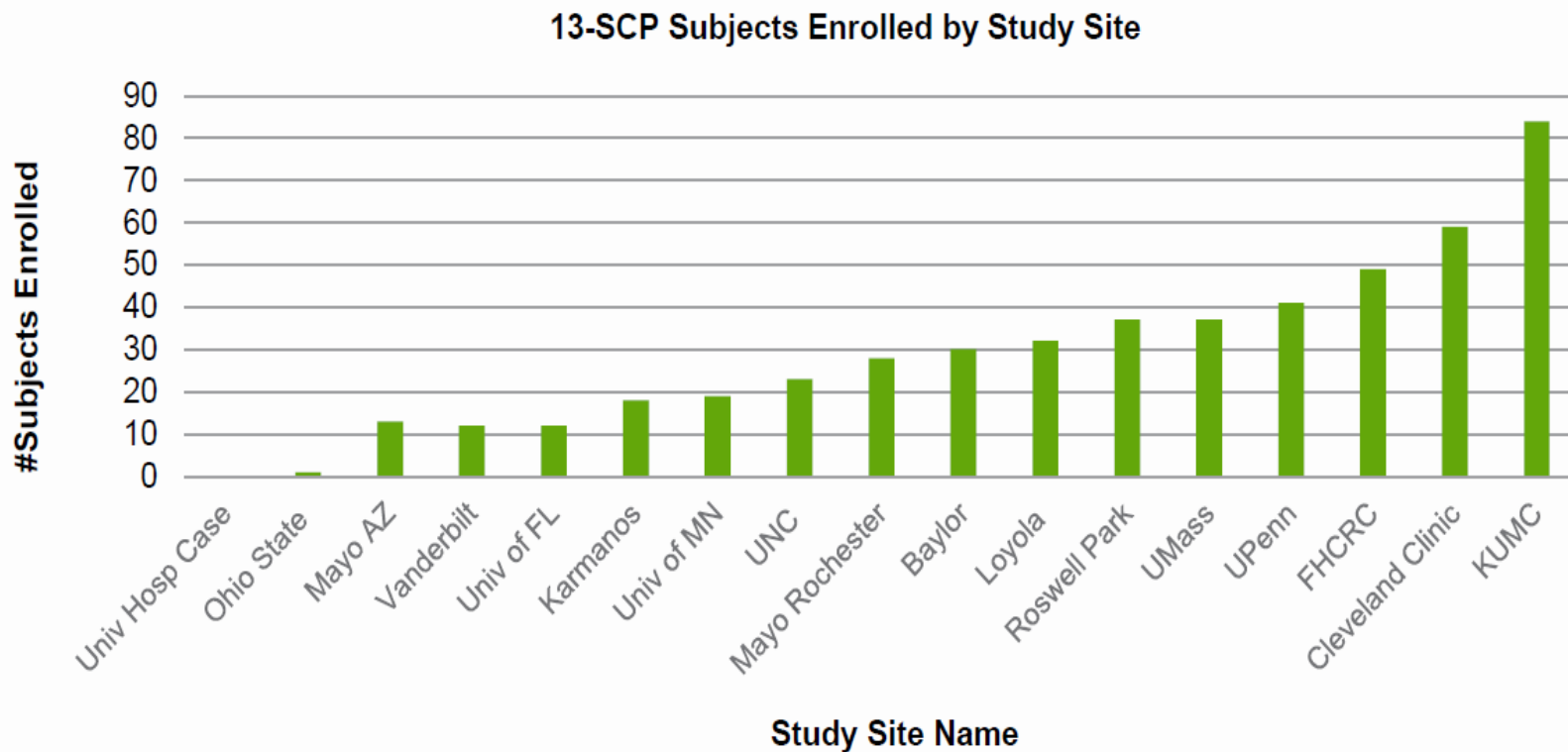
- Evaluate impact of SCP on HCT-related distress, health behaviors and health care utilization

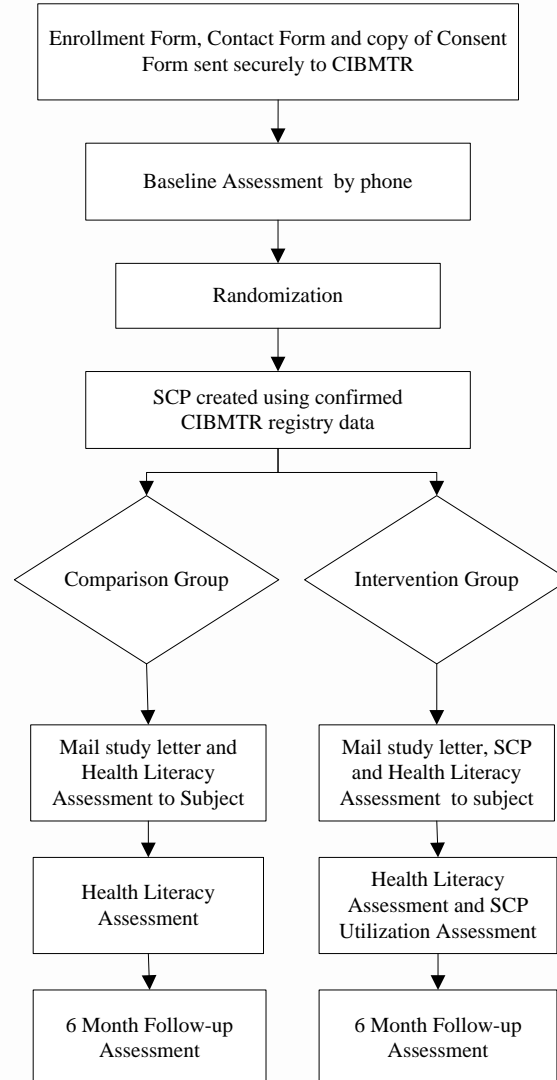
RCT Participant Criteria

- >18 years of age at time of transplant
- 1-5 years after most recent post-autologous or allogeneic transplant
- All diagnoses
- Disease in remission
- All types of transplant and graft sources
- Could have more than 1 transplant
- Randomly assigned to intervention or control group

| RECOMMENDATIONS FOR YOUR ANNUAL PREVENTIVE CARE | |
|--|---|
| MOUTH | QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES |
| <p>It's important that you brush and floss every day to prevent infections. Also, your doctor needs to check your mouth to make sure your teeth, tongue and throat are healthy and there are no signs of oral cancer.</p> <ul style="list-style-type: none"> <input type="checkbox"/> General mouth, teeth, tongue, and throat exam at least 1 time every year <input type="checkbox"/> Because you have a history of GVHD, you need to have mouth, teeth, tongue, and throat exams at least 2 times every year. Talk to your doctor and dentist about when you should have these check-ups. <input type="checkbox"/> Dental exam and teeth cleaning by a dentist at least 1 time every year <input type="checkbox"/> Tell your doctor and dentist if you have dry mouth. This could be a side effect of a medication you are taking or a sign of GVHD. | <ul style="list-style-type: none"> • Other than not smoking, and brushing and flossing every day, are there other things I can do to keep my mouth healthy? |
| LUNGS | QUESTIONS TO ASK YOUR DOCTOR AND YOUR NOTES |
| <ul style="list-style-type: none"> <input type="checkbox"/> Lung exam at least 1 time every year <p>If you have problems breathing or have had breathing problems in the past, you may need more tests such as:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Pulmonary function tests <input type="checkbox"/> Chest x-ray | <ul style="list-style-type: none"> • What can I do to minimize my risk of getting infections? • What tests should I have and how often? • What can I do to help me quit smoking? |

Number of Subjects Enrolled by Transplant Center





Baseline Patient Characteristics

| | Intervention (n=231) | Control (n=227) |
|----------------------------------|-------------------------|--------------------|
| Variable | N(%) | N (%) |
| Number of centers | 16 | 15 |
| Mean Age at HCT, in years | 56.3 (12.1) | 55.7 (12.2) |
| Median age at HCT, years (range) | 59.0 (19.4-81.1) | 58.5 (20.2-77.2) |
| Sex | | |
| Male | 112 (48.5) | 136 (59.9) |
| Female | 119 (51.5) | 91 (40.1) |
| Race | | |
| Caucasian | 222 (96.1) | 208 (91.6) |
| African-American | 5 (2.2) | 15 (6.6) |
| Asian | 2 (0.9) | 3 (1.3) |
| Native American | - | - |
| Pacific Islander | 1 (0.4) | - |
| Missing | 1 (0.4) | 1 (0.4) |
| Ethnicity | | |
| Hispanic or Latino | 8 (3.5) | 7 (3.1) |
| Not Hispanic or Latino | 216 (93.5) | 216 (95.2) |
| Missing | 7 (3.0) | 4 (1.8) |

| Baseline Patient Characteristics (continued) | Intervention (n=231) | Control (n=227) |
|--|-------------------------|--------------------|
| Variable | N(%) | N (%) |
| Disease | | |
| Acute lymphoblastic leukemia | 10 (4.3) | 8 (3.5) |
| Acute myelogenous leukemia or ANLL | 52 (22.5) | 46 (20.3) |
| Hodgkin lymphoma | 13 (5.6) | 10 (4.4) |
| Myelodysplastic/myeloproliferative disorders | 19 (8.2) | 23 (10.1) |
| Non-Hodgkin lymphoma | 49 (21.2) | 47 (20.7) |
| Plasma cell disorder/Multiple Myeloma | 78 (33.8) | 80 (35.2) |
| Other* | 10 (4.4) | 13 (5.7) |
| Transplant Type | | |
| Allogeneic Related | 47 (20.4) | 36 (15.9) |
| Allogeneic Unrelated | 64 (27.7) | 64 (28.2) |
| Autologous | 120 (52.0) | 127 (56.0) |
| TBI | | |
| Yes | 49 (21.2) | 46 (20.3) |
| No | 182 (78.8) | 181 (79.7) |
| Myeloablative conditioning | | |
| Myeloablative | 168 (72.7) | 176 (77.5) |
| Non-myeloablative | 62 (26.8) | 50 (22.0) |
| Missing | 1 (0.4) | 1 (0.4) |

*Other: intervention group: Chronic myelogenous leukemia (CML) (n=2), Other acute leukemia (n=1), Other leukemia (n=5), Severe aplastic anemia (n=2); Control: Chronic myelogenous leukemia (CML) (n=3), Inherited abnormalities erythrocyte differentiation or function (n=1), Other leukemia (n=3), Severe aplastic anemia (n=4), solid tumors (n=2);

Baseline Patient Characteristics

| Baseline Patient Characteristics (continued) | Intervention (n=231) | Control (n=227) |
|--|-------------------------|--------------------|
| Variable | N(%) | N (%) |
| Chronic GvHD (Allo HCT only) | | |
| Yes | 67 (60.4) | 66 (66.0) |
| No | 44 (39.6) | 34 (34.0) |
| Time from diagnosis to transplant, months | | |
| Median (range) | 20.8 (0.7-266.0) | 22.9 (1.25- 327.3) |
| Median follow-up of survivors (range), months | 47.0 (22.1-74.4) | 48.7 (21.5-72.9) |
| Health Literacy Assessment results | N=208 | N=208 |
| Adequate literacy | 154 (74.0) | 172 (82.7) |
| Possibility of limited literacy | 36 (17.3) | 27 (13.0) |
| High likelihood of limited literacy | 18 (8.7) | 9 (4.3) |

Patient-Reported Measures

| Instrument | Items | Time point | Estimated Time to complete |
|---|-------|-------------------|----------------------------|
| Confidence in Survivorship Information | 13 | Baseline 6 mos | 2 min |
| Cancer and Treatment Distress | 27 | Baseline 6 mos | 3 min |
| Knowledge of Transplant Exposures | 5 | Baseline 6 mos | 2 min |
| Health Behaviors | 31 | Baseline 6 mos | 8 min |
| Health Care Utilization | 26 | Baseline 6 mos | 4 min |
| Short Form (SF)-12 | 12 | Baseline 6 mos | 3 min |
| Generalized Self-Efficacy Scale | 10 | Baseline 6 mos | 2 min |
| Newest Vital Sign | 6 | 2-4 wks | 2 min |
| Survivorship Care Plan Utilization Assessment | 5 | 2-4 wks 6 mos | 3 min |

Confidence in Survivorship

- 13-item patient self-reported tool
- Assessed confidence in knowledge of:

Past cancer
diagnostic and
treatment details

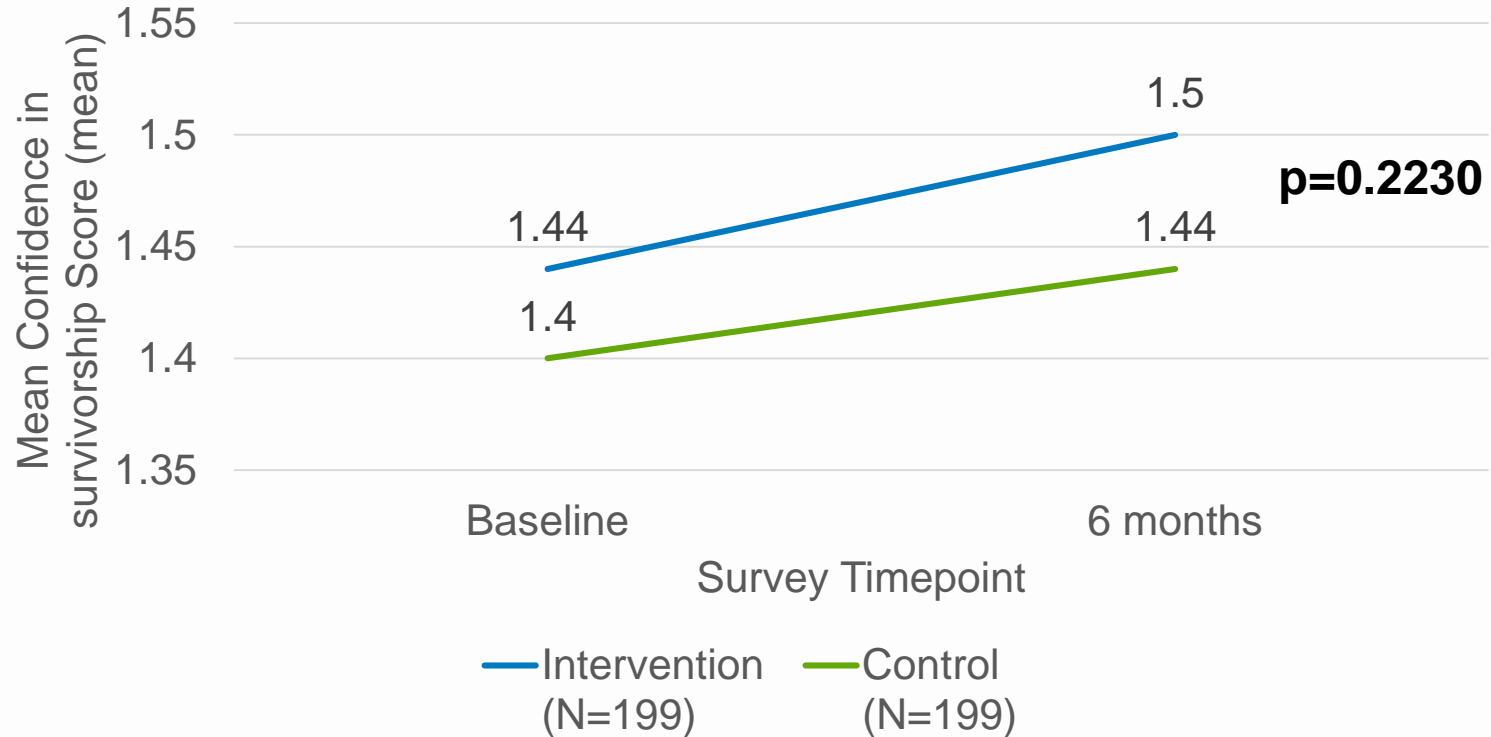
Treatment and
prevention of long-
term and late-
effects of disease
and treatment

Prevention of future
disease

Access to
resources

Familial risk of
cancer

Confidence in Survivorship Results



- No statistically significant difference between intervention and control groups

Cancer and Treatment Distress

- 27-item questionnaire
- Assessed distress or worry specific to HCT and associated complications; includes:

Uncertainty

Family strain

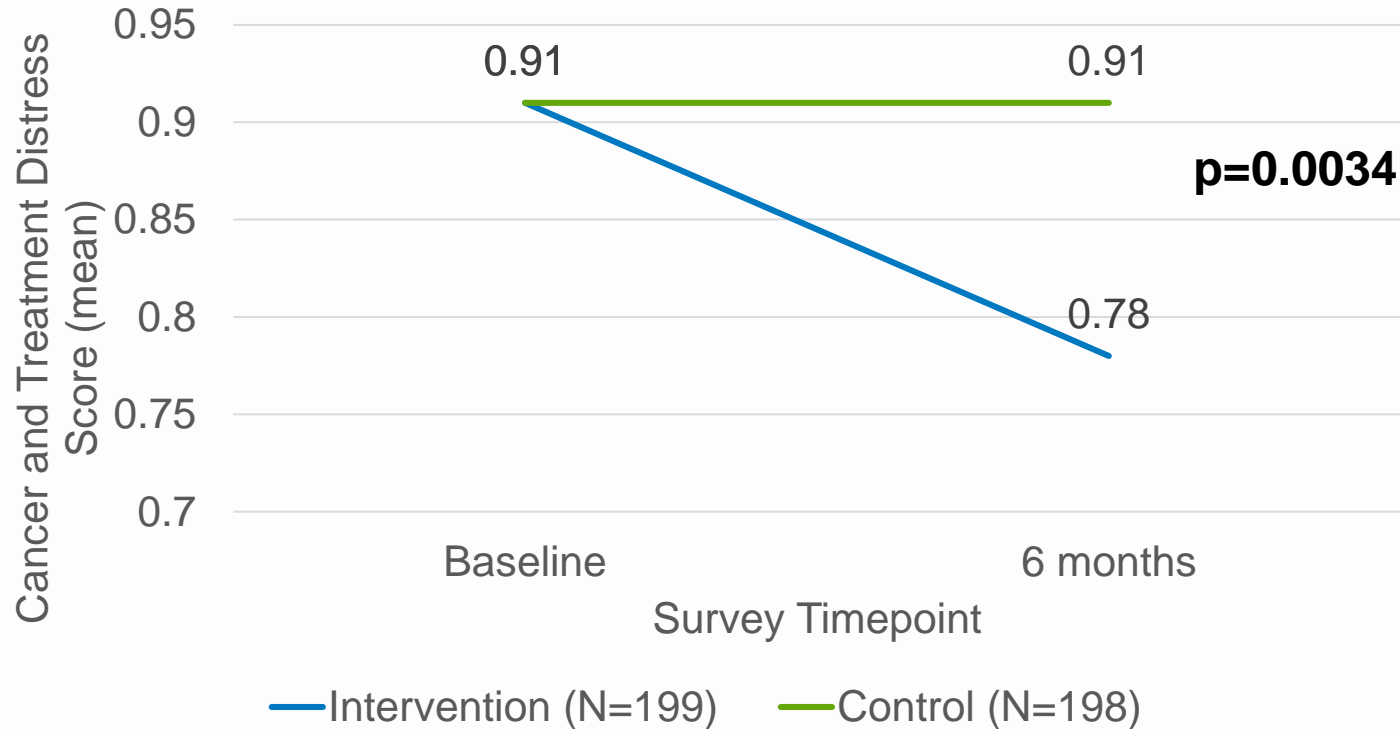
Medical
system
demands

Health
burden

Finances

Impact on
function

Cancer and Treatment Distress Results



- Statistically significant difference between intervention and control groups

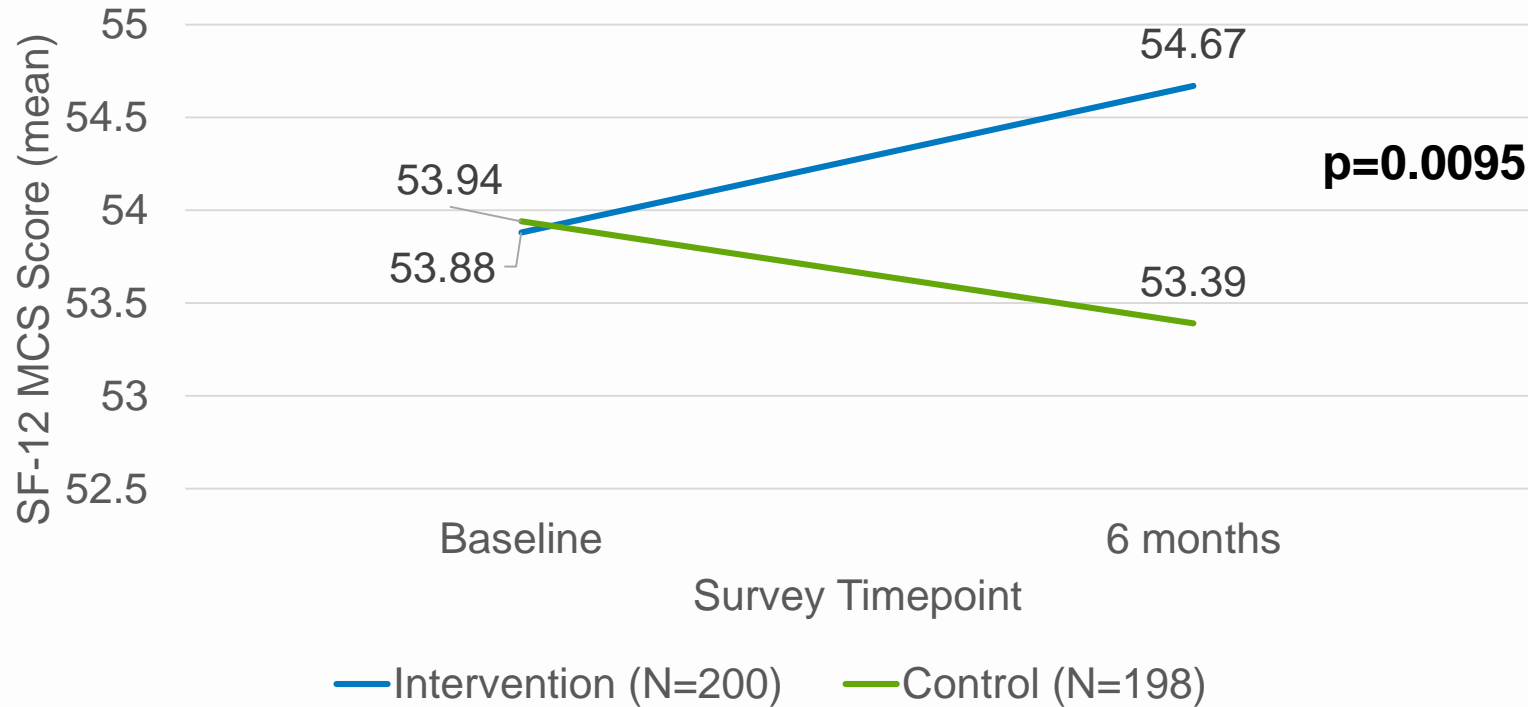
SF-12

- 12-item questionnaire

Mental Health
Component
Summary Score

Physical Health
Component
Score

SF-12: Intervention Improved Mental Component Score



- Statistically significant difference between those who received intervention vs. control

Other Secondary Endpoint Results

- No statistically significant effect was observed for any of the other secondary outcomes:
 - Knowledge of Transplant Exposures
 - Health Behaviors
 - Health Care Utilization
 - Generalized Self-Efficacy Scale
 - SF-12: Physical Component Summary Score

“How useful have the Treatment Summary and Care Plan been in helping you to...”

Better understand:

transplant and related treatment



side effects of transplant



how to manage your health



Communicate:

transplant and related treatment



side effects of transplant



Schedule appointments with medical providers



0% 20% 40% 60% 80% 100%

■ Very useful ■ Useful ■ Not at all useful ■ I have not done this ■ Did not respond

Theme: SCP Helped Survivors Focus on Overall Health

“The care plan was useful because it gave [me] a list of questions to ask medical providers in one document. Before seeing this treatment summary and care plan, did not know that [I] was at a higher risk for certain cancers and health problems. **The documents were a source to know what to learn more about [my] health.**”

“It really got me to go for my mammogram, blood work and I just scheduled a colonoscopy. **It made me look at the bigger picture of my health.**”

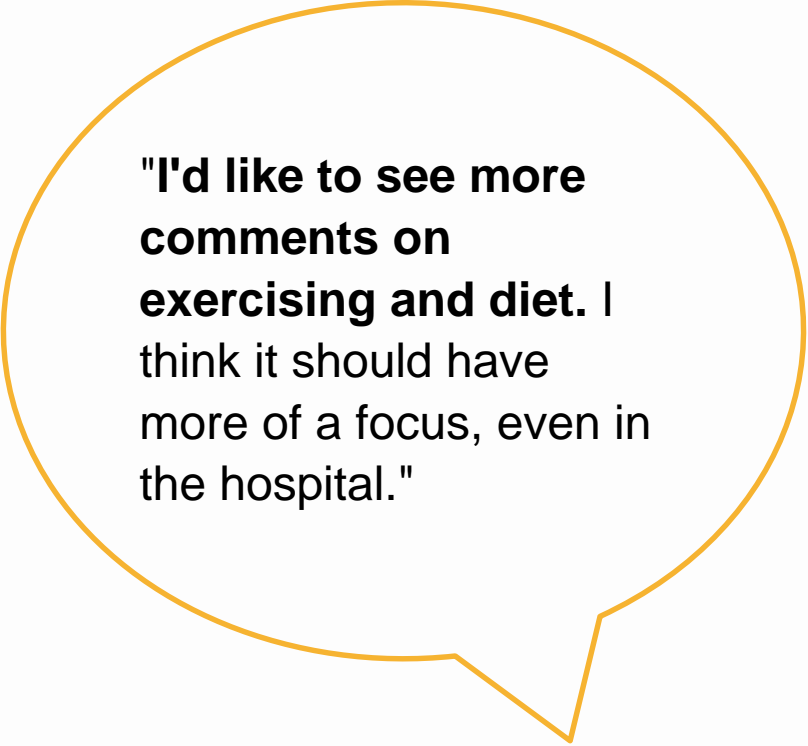
“**They have made me aware of what I've been through and what is important for my well-being.** I am also now a mentor for other cancer patients - people needing BMT. I am able to encourage patients to stay in touch with their providers. **The care plan and summary have given me a lot of confidence; reminding me to be compliant.**”

Theme: Supported Patients in Making Care Decisions With Providers

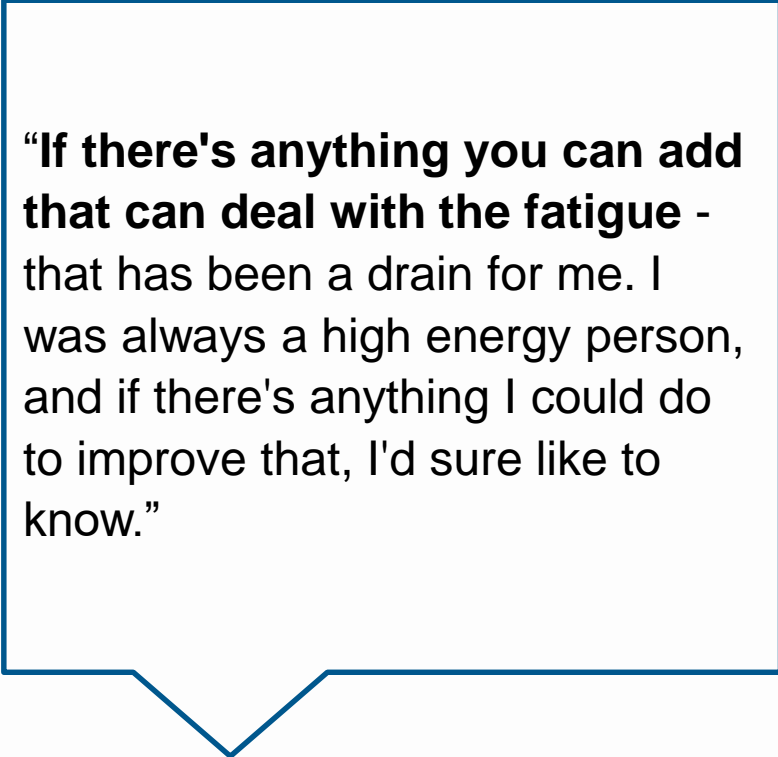
“It enabled me, or gave me the knowledge, to let local health providers know what they need to know- to challenge them if they didn't think I needed certain follow-up.”

“They gave me an opportunity to dialogue with my PC and other providers- like my orthopedist- and to be able to talk in some detail about my cancer. It is a very useful tool- specifically as a springboard for conversation. It has been very helpful for my wife as well.”

Theme: Lifestyle, Nutrition and Exercise



"I'd like to see more comments on exercising and diet. I think it should have more of a focus, even in the hospital."



"If there's anything you can add that can deal with the fatigue - that has been a drain for me. I was always a high energy person, and if there's anything I could do to improve that, I'd sure like to know."

Theme: Emotional Health and Coping

"Care plan has been helpful to me and my husband both- to read and understand what's going on- to know that certain things are not unusual- to 'not get bent out of shape'. My husband uses it a lot."

"I was blindsided by the emotional aspect of getting cancer- ravaged by going through some of these things. I sought help through faith and friends and even though it wasn't counseling I was looking for, having it acknowledged - knowing that the researchers are aware of the emotional components is very important and validating."

"Allowed me to be more accepting of the side effects. Giving me permission to ask for help. That was one of my biggest things of not asking to help. I wanted to keep doing the same things despite the pain."

Conclusions

- Individualized SCPs generated using the CIBMTR clinical registry was feasible
- SCPs were associated with lower cancer treatment and distress scores, and improved mental health component scores at 6 months
- Our study supports further development and implementation of individualized SCPs in this population

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| William Wood Jr. | University of North Carolina Hospitals |

Panel Discussion

- Moderator: Linda J Burns, MD
- Physician: K. Scott Baker, MD
- Transplant recipient: Ed Plass
- Caregiver: Kate Plass

Evaluation Reminder

Please complete the Council Meeting 2017 evaluation in order to receive continuing education credits and to provide suggestions for future topics.

We appreciate your feedback!