Intervention to Increase Access and Benefit of Survivorship Care Planning with African Americans

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SBM, 2016



Breast Cancer Statistics

- Nearly 3 million breast cancer survivors (BCS) in the U.S.¹
- Estimated 234,190 new breast cancer diagnoses in 2015²
- Lifetime risk: 1 in 8 (12.3%)³
- Ethnic minorities comprise 14% of the newly diagnosed population (U.S. Cancer Statistics Working Group, CDC & NCI, 2011)

- 1. Howlader, N., et al. (eds). SEER Cancer Statistics Review, 1975-2011. Retrieved from http://seer.cancer.gov/csr/1975_2011/browse_csr.php?sectionSEL=4&pageSEL=sect_04_table.25.html
- 2. American Cancer Society. Cancer Facts & Figures 2015. Retrieved from http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-044552.pdf. 2015.
- 3. American Cancer Society. Breast Cancer Facts & Figures 2013-2014. Retrieved from http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-040951.pdf. 2013.



Breast Cancer Statistics & Disparities

- Lifetime prevalence in African Americans: 1 in 9 women⁴
- Overall incidence rate (for women of all ages) lower in African Americans than in Whites
 - Among women under age 45, incidence rate higher in African Americans⁴
- Number of new breast cancer cases among African Americans
 increasing
 - 19,540 new diagnoses in 2009⁵
 - 27,060 new diagnoses in 2013⁴
- Death rate 41% higher in African American than in White women⁴
- 5-year survival = 79% in African American women; 92% in White women⁶
 - 4. American Cancer Society. Cancer Facts & Figures for African Americans 2013-2014. American Cancer Society, Inc., Atlanta, GA, USA (2013). www.cancer.org
 - 5. American Cancer Society. Cancer Facts & Figures for African Americans 2009–2010. American Cancer Society, Inc., Atlanta, GA, USA (2009). www.cancer.org
 - 6. 6. U.S. Cancer Statistics Working Group. United States Cancer Statistics: 2003–2007 Incidence and Mortality Web-based Report. Centers for Disease Control and Prevention and National Cancer Institute; 2010. Available at: www.cdc.gov/uscs.



Community Inclusion: Symbiotic Partnership





Treatment Summary Survivorship Care Plan

- To facilitate best care practice for survivors, the Institute of Medicine (IOM), the Centers for Disease Control and Prevention (CDC), the American College of Surgeons' Commission on Cancer (COC), and the American Society of Clinical Oncology (ASCO) advise that cancer survivors be provided with personalized treatment summaries and Survivorship Care Plan (TSSCP) [6].
- Despite their increased burden, African American BCS remain understudied.

• TSSCP investigations and practice models are urgently needed to improve follow-up care and cancer outcomes in this vulnerable group.



Purpose of Sister Survivor Project

Scientific PI Motivation:

- Support the goals of African American peer-based support organizations
- Enhance the role of survivor-advocates
- Examine the benefits of peer-navigation
- Address the gaps in the literature regarding the role of peer-based support to improve outcomes for AABCS



COH/CCARE Survivorship Care Plan Guidelines

Methods of Guideline Development¹⁶⁻²²

- The development of the Treatment Summary and Survivorship Care Plan began as modifications to the American Society of Cancer Oncology (ASCO) template via a transcreation process informed by cancer survivors/advocates, and evaluated by survivors, advocates, and health professionals.
- The Treatment Summary and Survivorship Care Plan template development was guided by the Shared Care, Patient Centered Care and Psycho-oncology Models, and Contextual Model of Health Related Quality of Life

COH/CCARE Survivorship Care Plan

Guidelines structured to include:

- Emphasis on shared-care, patient-centered care
- Culturally- and linguistically-responsive Preamble to increase knowledge and usability
- Health history (e.g., chronic conditions, medications)
- An integrative care and co-disease management approach
- Health Advisories (nutrition, physical activity, stress mgmt.)
- Symptom management and self-care
- HRQOL (sources of distress, social support, spirituality, resilience)
- Resources (Community, National, Ethnic and Linguistic responsiveness)



Culturally Responsive TSSCP

CCARE - City of Hope 流 City₀f Hope.. Breast Cancer Treatment Summary and Survivorship Care Plan

Did You Know? The American College of Surgeons' Commission on Cancer mandated the implementation of the survivorship care plan by 2015. A survivorship care plan may improve survival and reduce morbidity via coordinated clinical care informed by documenting and following surveillance care and recommended tests, late effects and symptom management, and healthy lifestyle promotion.

African-American women have a five year survival rate of 78 percent after diagnosis as compared to 90 percent for white women. Early detection, appropriate treatment, post-treatment tests and follow-up care save lives.



Kimlin Tam Ashing-Giwa, Ph.D., director of City of Hope's Center of Community Alliance for Research & Education (CCARE), and the National African American Cancer Coalition are joining forces to educate and navigate survivors to get the best information and resources to improve follow-up care.

After being diagnosed with breast cancer, many experience some fear and anxiety and may worry about what to do to gain the best outcomes through the phases of treatments, after active treatment ends and during the next stages of life. Most breast cancer survivors recover to normal well-being and functioning within one to two years. The survivorship care plan is your roadmap to follow-up care and well-being.

A survivorship care plan answers three main questions:

- What treatments are most effective for me and what are the possible side effects?
- What follow-up care do I need from my oncology and primary care team?
- What actions and behaviors should I practice to improve my health and well-being?

What is a Survivorship Care Plan?

A survivorship care plan (SCP) is a blueprint for quality cancer care. The SCP is completed by you, your oncology team and may include your primary care team. It is uniquely suited to you and your needs with information on your:

- Health history and breast cancer, including type and stage
- Treatments and possible side effects
- Follow-up treatments, medical exams and ongoing care
- Contacts and referrals for cancer and other health-care providers
- Recommendations and resources for healthy lifestyle

SCPI



Cancer Treatment Summary and Survivorship Care Plan Resumen de Tratamiento de Cáncer y Plan de Cuidado Last name:

Nombre:_____ Apellida: _____

Cancer Treatment Summary and the Survivorship Care Plan Resumen de Tratamiento de Cáncer y Plan de Cuidado de Sobrevivencia

First name:

GENER AL INFORM ATION /INFORMACIÓN GENERAL								
Patient na me: Nombre del Paciente:		Patient ID: Número de Identificación del Paciente:						
Patient phone:	Patient DOB:/	Age:						
Número de Teláfano del Paciente:	Fecha de Nacimienta	Edad:						
Height	Weight (pre treatment)	Weight (post treatment)						
Estatura	Peso (antes de tratamiento)	Peso (despues de tratamiento)						
Support contact name:	Phone:	Relationship:						
Nombre del Contacto de Apoyo:	Número de Teléfono:	Relación:						

This Treatment Summary and Survivorship Care Plan (SCP) is a brief report of your treatment summary, recommendations for follow-up care and tests, cancer careteam contact information, a directory of support services and resources, and health promotion information. This is not a complete patient history or comprehensive record of intended theopies. This blank SCP may be capied for later updates or corrections.

Este Resumen de Tratamiento de Cáncer y Plan de Quidado de Sobreviven cia es un breve archivo de su tratamiento de cáncer y las recomendaciones de seguimiento. Incluye aspectos importantes, como información de contacto de su equi po médico, un resumen del tratamiento, recomendaciones para las pruebas de cuidado de seguimiento, un directorio de servicios de apoyo y recursos y promoción de salud. Esto no es una historia completa del paciente o archivo completo de las tempias destinadas. Este plan en blanco se puede capiar para actualizar después o para correcciones.

	CAN CER RELATED INFORMATION/INFORMACIÓN R	ELACIONADA CON EL CÁNCER	(completado por el equipo oncológico)
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CHIELE REDITED IN CHINETOLY INCOMPLEM REFERENCES EL CHIELE (UMplatedopur a appointanges)						
Cancer type/location: Tipo/Localización de Cáncer:		Age at diagnosis: Edad al Diagnostico:				
	LEFT BREAST/SENO IZQUIERDO	RIG HT BREAST/SENO DERECH				
	New Dx:// Recurrence:// Nuevo Diagnostico:// Recurrencia://	New Dx:// Recurrence:// Nuevo Diagnostico:// Recurrencia://				
Surgical procedure/location/findings: Procedimiento quirúngica/localización/conclusiones						
Definitive breast surgery Cinugia definitiva del seno	None/Ninguna Diagnosis only/Diagnostico solarrente, date/fecha:// Palliative resection/Resection palativa, date/fecha:// Curstive resection/Resection curativa, date/fecha://	date/fecha://				
Pathologic stage: Staging tells the extent of the original turnor and if it has spread in the body. Etapa pathlógica: La etapa describela extensión del turnor original ysi seha propagado en el cuerpo		0 I_ 0 II_ 0 III_ 0 IV_				
TNM staging: Description based on the turnor size (T), the extent of spread to lymph nodes (N), distai metastasis or spread of the can car (M) Etapa TNM: Descripción basado en el tamoño del turnor (T), el grado de propagación a los nódulos linfáticos (N), metástasis dista o propagación del cáncer (M)	TN M D_N/A	T N M D N/A				
Hormonal status: Description based on estrogen (ER), progesterone (PR) and HE R2 receptors to inform what treatment may work best Status Hormonal: Descripción basada en estrógeno (ER), de progesterono (PR) y receptores HER2 para informar que tratamiento puede funcionar	□ ER+ □ PR+ □ HER 2+ □ ER- □ PR- □ HER 2- □ Triple Negative/Triple Negativo	□ ER+ □ PR+ □ HER2+ □ ER- □ PR- □ HER2- □ Triple Nega®ve/ Triple Negativo				



Cancer Treatment Summary and Survivorship Care Plan Resumen de Tratamiento de Cáncer y Plan de Cuidado First name: _____ Last name: ____

Nombre:______ Apellida

GENER AL INFORM ATION /INFORMACIÓN GENERAL					
OLIVER AL INFOR					
	LEFT BREAST/SENO IZQUIERDO	RIGHT BREAST/SENO DERECH			
Tumor type/Histology/Grade: Description of cancer cells, growth rate Tipo de tumor/histologia/grado: Descripción de las cilulas cancerosas, la tasa de crecimiento					
Lymph nodes: Part of the immune system. Breast cancer can spread to lymph nodes under the arms. It is biopsied to check for cances. Los nódulos linfáticos: Parte del sistema immunológica. El cáncer de seno se puede propagar a los nódulos linfáticos bajo los brazos. Se realiza una biopsia para detectar el cáncer.					
Oncotype DX Recurrence Score (if applicable): Lab test of the likelihood of cancer coming back Oncotipo DX puntuoción de recurrencia (si es aplicable): Pueba de laboratorio de la probabilidad de que el cáncer regrese.					
Reconstruction: Reconstruction can be a good treatment to restore balance and body image. Consulting with a surgeon and dematologist who understand healing and keloids can reduce scaring and improve appearance. Reconstrucción: Lo reconstrucción puede ser un buen tratamiento para restaurar el equilibrio y la imagen del cuerpo. Consultar con un dematólogo y ciujano que entienden la curación y los quebides puede reducir clostrices y mejorar la opariencia.	 In progress./En progreso Planned/Planeado N/A 	□ In progress/En progreso □ Planned/Planeado □ N/A			
GENETIC TESTING/PRUEBAGENÉTICA					
BRCA1:	Positive Negative Ambiguous Resitive Negative Ambiguo	Positive Negative Ambiguous Positive Negative Ambiguo			
BRCA2	□ Positive □ Negative □ Ambiguous □ Positivo □ Negativo □ Ambiguo	Positive Negative Ambiguous Absitive Negative Ambiguo			
BRCA1/2 mutation is linked to 60% lifetime breast cancer risk and 15 to 40% lifetime ovarian cancer risk and more common in whites and Hispanics. La mutación BRCA1/2 esta relacionada con un riego de 60% de cáncer de seno por vida y un 15:40% de riego de cáncer de ovarios por vida y es más común en las mujeres caucáseas y las hépanas.					

Notes:/Notas:



Eng/Span	Cancer Treatment Summar Resumen de Tratamiento de l				st name: . mbre:		Last name: Apellida			
	с ,	IE MOTHER								
TSSCP		Tratamiento en ensayo clínico: SI No Chemotherapy intent:								
	Curative, adjuvant or neoadju Curative, adjuvante o neoadjuvant									
	 Disease or symptom control Cantrol de enfermedad o síntomas 									
	Echocardio gram or MUGA re Ecocardiograma o resultado MU									
	Chemotherapy agents Agentes de Químioterapia	Start date Fecha deinicio	End date Fecha Find	Dose Dost	Route Ruta	#cycle #decidas	% dose reduction % reducción de dosis	Regimen completed Régimen completado		
							□Yes% □No Si% No	□Yes% □No Si% No		
							□Yes% □No Si% No	□Yes% □No .Si% No		
							□Yes% □No Si% №	□Yes% □No S% No		
							□Yes% □No Si% №	□Yes% □No .Sr% No		
	Nonchemotherapy agents Agentes no quimioterapéuticas (e.g. Tamaxijen, Herceptin, etc.)	Start date Fecha deinicio	End date Fecha Final	Dose Dost	Route Ruta	#cycle # de ciclos	Purpose/Goal Propázito/Meta	Regimen completed Régimen completado		
								□Yes% □No .Si% №		
								□Yes% □No % №		
								□Yes% □No .S% No		
	Major treatment side effects/E	fectos secundari	os principales del ti	ratamiento:						
	Perdida de cabello Co DNausea, Vomiting / DPa	w blood count/ nteo de sangre baj iin/Dabr tigue/Fatiga	o Sinto D Card D Infer	nopaus e sym mas demenoj diac/Condiaco rtility/Infertili rth sore/Llog	ausia dad	□ Sepsis/Sep □ Dental pro Problemose DSkin proble Problemose	blems/ Disfu dentales ⊡Cogr ems/ Data	uil dysfunction/ nción sexual nitive impairment/ rion cognitivo x/Otro		
Reason for stopping treatment: Completion loss Toxicity Progression Other										
		Complete 🗅 Completo		Response spuesta	Progres	ession ⊒U ön D	Inknown ⊒Other escanacido Otro			
Treatment related hospitalization required: □ Yes Seneces to hespitalización relacionada con el tratamiento: S/					No No					
	Ongoing toxicity at completion Taxicidad continuo al terminar el tratami			(type/grad xv/grado)	e)			No No		
	Seri ous taxi cities during treatm Taxicidades graves durante el tratamient									C'1
							ırvivorship Care Plan	SCP v	Ž	Hope

Cancer Treatment	nt Summary and S	iurvivorship Care Plan
Resumen de Trata	imiento de Cáncer	y Plan de Cuidado

First name: _____ Last name: _____ Nombre: _____ Apellida:

		ADIATION THERAP						
TERAPIA DE RADIACIÓN (completado por el equipo oncológico)								
Radiation therapy: Terapia de Radiacion:	□Not planned No planeada	Planned Ramada	Administe Administrada					
Start date: Fecha de Inicia:	End date: Fecha Final:	Region treated: Region tratada		Radiation dose: Desis de radiacion:				
	tamente elevado Recurrencia pos	urrence based on imagin ible basado en imágenes	S DEN	o evidence of disease o evidencio de enfermedad vidence of persistent/re idencio de enfermedad persis				
	CUIDADO DE SEGUIMIENTO	UP CARE AND SURV Y VIGILANCIA (compl						
Follow-up care Cuidado de seguimiento		Frequency Frequencia	Provider Proveedor	Contact info Info de Contacto	Updates Actualizaciones			
Physical exam: Years 1 Examen Físico: Años 1 a		Every 3 months Cada 3 meses						
Physical exam: Years 4 Examen Físico: Años 4 a		Every 6 months Cada 6 meses						
Mamografía después de	ded for premenopausal women)	Every 6-12 months Cada 6 a 12 meses						
Pelvic examination Exanimación pélvica		Every year Cada año						
Oncologist reevaluation Reevaluación del Oncólo		After 1 year Después de 1 año						
Cardiology examination Examen cardiológico	1	Every 3 years Cada 3 años						
fracture risk	ecks for oste oporosis and prueba la densidad ósea para la e fracturos.	Every 3 years Cada 3 años						
family history of breast cancer at any age Consejo Genético: En los	rremenopausal cases, and a cancer before 50 or ovarian casos premenopóusicos, y una r de seno antes de los 50 años de ec quier edad.	Recommended Recomendado lad						
Reproductive Health Vi Cita Para la Salud Repro		Recommended Recomendado						
	suit prior to cancer treatment. L'Consulte antes del tratamiento	By patient need Por necesidad del paciente						
	nd other cancer screenings e los Ovarios y otros exámenes de	By patient need Por necesidad del paciente						
Dental exam Examen dental		Every 6 months Cada 6 meses						



Cancer Treatment Summary and Survivorship Care Plan Resumen de Tratamiento de Cáncer y Plan de Cuidado

Eng/Span

TSSCP

First name: _____ Last name: _____

Apellida:

CARE TEAM/EQUIPODE CUIDADO

Nombre:

Coordination of Care: About a year after diagnosis, you may continue to visit your oncologist or transfer your care to a primary care doctor. Women receiving hormone therapy should talk with their oncologist about how often to schedule follow-up visits for re-evaluation of their treatment.

Coordinación del Cuidado: Alrededor de un año después de su diagnóstico, usted puede seguir haciendo citas directamente con su oncólogo, o puede transferir su cuidado a un doctor de cuidado primario. Mujeres que reciben terapia hormonal deberían de hablar con su oncólogo sobre la frecuencia de las visitas de seguimiento para una revaloración del tratamiento

Team Equipo	Provider Provee dor	Institution Institución	Contact Information Info de Contacto
Medical oncologist Oncólogo medico			
General/Breast surgeon Cirujano general/de seno			
Radiation therapist Terapista de Radiación			
Plastic surgeon Cirujano plástico			
Primary care physician Medico de cuidado primario			
OB-GYN Ginecólogo			
Nurse/Nurse practitioner Enfermera Practicante			
Mental health/Social worker Salud Mental/Trabajador social			
Reproductive Health/ Fertility Specialist Especialista de Fertilidad/ Salud Reproductiva			
Geneticist/Genetic Counselor Genetecista/Consejero Genético			
Other specialists Otros especialistas			
Other specialists Otros especialistas			



Cancer Treatment Summary and Survivorship Care Plan Resumen de Tratamiento de Cáncer y Plan de Cuidado

First name: Last name: Nombre: _____ Apellida:

MEDICAL INFORMATION / INFORMACIÓN MEDICA						
FAMILY HISTORY/HISTORIAL FAMILIAR						
Family history/Predisposing conditions for cancer: Historial familia/condiciones que predisponen al cáncer:	None Ningung	Ist degree relative Pariente de 1º grado				
	2nd degree relative Pariente de 2º grado	 Multiple relatives Parientes múltiples 				

List of 1st degree relatives with cancer/Lista de parientes de 1º grado con cáncer:

OTHER CHRONIC CONDITIONS/ OTRAS ENFERMEDADES CRÓNICAS (completado por su médico de auidado primario)

Please check the appropriate box for the condition(s) that apply to you. If you do not have a particular condition please leave that line blank. Parfavar marque la caja apropiada para la condición (es) que se aplica a usted. Si no tiene una condición particular, por favor deje en blanco la línea.

	Before Cancer Antes de Cáncer	Now Actual				Un controlled Des controlado	Medication(s) Medicamento(s)
Allergies/Alergias							
Arthritis/Artritis							
Asthma/Asma							
Cancer (other)/ Cáncer (Otro)							
Diabetes/Diabetes							
Overweight/Obesity Sobrepeso/Obesidad							
Reproductive Concerns/ Preocupaciones Reproductivos							
Sexual Dysfunction/ Trastomos Sexuales							
Vision/Eye Concerns/ Problemas con la Visión/los Ojos							
Digestive Disorder(s)/ Desordenes digest ivos	ū		۵	ū.		ū	
Headaches, migraines/ Dolores de cabeza, migrañas	ū		ū	u.	۵	ū	
Heart disease/ Enfermedad cardiaca	ū						
High blood pressure/ Alta presión	ū.						
Lymphedema/Linfedema							
Osteoporosis/Osteopenia							
Thyroid (over or underactive)/ Tiroides (hiper- o hipo-activos)							
Psychological diagnoses / Diagnósticos Psicológicos							
Cigarette/Tobaccouse/ Uso de cigarrillos, Tabaco	ū.						
Problems with alcohol / Problemas con el alcohol							
Other (specify):/ Otro (Especifique):	ū.	٦	٦				



Survivorship Care Plan/Plan de Cuidado de Sobrevivencia

HEALTH ADVISORIES/ADVERTENCIAS DE SALUD

		THE RET THE THE THE THE THE THE THE THE THE T
	health needs. Please consu Estas son advertencias gener	dvisories and may not represent the complete list of advisories recommended for your individual It with your health provider(s) concerning additional or other health advisories. rales de salud y puede no representar la lista completa de los avisos recomendados para sus necesidades ror consulte con su proveedor de salud sobre estas advertencias de salud u otras advertencias.
	Risks of recurrence Riesgo de recurrencia	Follow-up with your physician because the risk of breast cancer returning continues for more than 15 years after remission. If you are a younger woman, or if you have not had bilateral mastectomies, you are at higher risk to develop a new, unrelated breast cancer at some time in the future. El seguimiento con su médico es importante porque el riesgo de que regrese el cáncer de seno sigue por más de 15 años después de la remisión. Si usted es una mujer joven, o si usted no ha tenido mastectomías bilaterales, usted corre un mayor riesgo de desarrollar en el futuro un nuevo cáncer del seno, no relacionado con cáncer inicial.
- 1	Symptoms of recurrence Síntomas de recurrencia	Report these symptoms to your doctor: new lumps, bone pain, chest pain, shortness of breath or difficulty breathing, abdominal pain or persistent headaches. Reporte estos síntomas a su médico: nuevos bultos, dolor en los huesos, dolor en el pecho, falta de aire o dificultad para respirar, dolor abdominal o dolores de cabeza persistentes.
- 1	Lymphedema Linfedema	Damage or removal of lymph nodes may cause lymphatic fluid blockage and swelling in the arm of the breast surgery called lymphedema. Lymphedema can occur within a few days of surgery or years later and can be mild or severe. It is important to attend to any changes in the arm to seek timely medical attention to reduce the physical symptoms and pain associated with lymphedema. Lymphedema can be treated via physical therapy, compression devices, exercise and surgery. El daño o extirpación de los nódulos linfáticos puede causar obstrucción del líquido linfático e hinchazón en el brazo de la cirugía del seno lo cual se llama linfedema. El linfedema puede ocurrir a los pocos días de la cirugía o años mas tarde y puede ser leve o severa. Es importante prestar atención a cualquier cambio en el brazo para buscar atención médica oportuna para reducir los síntomas físicos y dolores asociados con el linfedema. El linfedema a targia física, dispositivos de compresión, el ejercicio y la cirugía.
	Preventive care recommendations Recomendaciones para el cuidado preventivo	Obtain appropriate medical care for bone health, cholesterol monitoring/management, nutrition, exercise, mental/cognitive health, weight management, physical therapy, immune function, sexual health, fertility, skin care, pain and fatigue, and dental and eye care. Obtenga atención médica adecuada para su salud ósea, la vigilancia y manejo del colesterol, la nutrición, el ejercicio, salud mental/cognitiva, control de peso, terapia física, la función inmune, la salud sexual, la fertilidad, cuidado de la piel, dolor y fatiga, y el cuidado dental y ocular.
	Vaccinations Vacunas	The following vaccinations are recommended by the CDC for adults age 20-60: flu (annually), chicken pox (2 doses), HPV (3 doses), Measles, Mumps & Rubella (1 or 2 doses), Meningitis (1 or more doses), Tdap: Tetanus Diphtheria & Whooping Cough (once, then a booster every 10 years), Hepatitis A (2 doses) and Hepatitis B (3 doses). Please consult with your doctor regarding your vaccination needs or if you plan to travel abroad. Lassiguientes vacunas son recomendadas por el CDC (el Centro para el Control y la Prevención de Enfermedades) para adultos de 20 a 60: influenza (anual), varicela (2 dosis), VPH (3 dosis), sarampión, paperas & rubéola (1 o más dosis), Tdap: Tétanos, Difteria, y Tas Ferina (una vez, luego un dosis de refuerzo cada 10 años), la hepatitis A (2 dosis), y la hepatitis B (3 dosis). Por favor consulte con su doctor tocante a las vacunas que usted necesita, o si tiene planes de viajar internacionalmente.



Survivorship Care Plan/Plan de Cuidado de Sobrevivencia

	HEALTH ADVISORIES/ADVERTENCIAS DE SALUD
Medications Medicamentos	Take doses as recommended by your health-care provider. Discuss all your medications including vitamins with each health-care provider including doctors, pharmacists and dentists. Tome la dosis según la recomendación de su médico. Discuta todos sus medicamentos, incluyendo vitaminas con cada proveedor de salud, incluyendo médicos, farmacéuticos y dentistas.
Nutrition (healthy eating) Nutrición (comer saludable)	Healthy diets include nine servings of fruits and vegetables, and three to five servings of plant proteins (peas, beans, nuts) and whole grains each day. During treatment, you may need extra protein and calories to cope with the effects of treatments, and eating more fish is helpful. Red meats should be limited to less than three times/week and cured meats should be avoided. Consulting a dietician who is knowledgeable about culture and ethnic foods may be useful. Una dieta saludable incluye nueve porciones por dia de frutas y vegetales, y tres a cinco porciones de proteinas de plantas (guisantes, frijoles, nueces) y cereales integrales. Durante el tratamiento, usted puede necesitar mas proteínas y calorías para enfrentar los efectos del tratamiento, y comer mas pescado es útil. Debe limitar las cames rojas a menos de tres veces por semana y debe evitar cames curadas. Consulte con un dietista que conozca comidas culturales y étnicas que tal vez sean útiles.
Maintain healthy weight Mantener un peso saludable	Being overweight and weight gain are associated with increased risk for cancer recurrence and increased comorbidity and poor health. Exercise three times a week for at least 30 to 45 minutes for improved health and to maintain a healthy weight. If weight loss is desired, exercise for at least 30 to 45 minutes four to five times a week. Discuss your exercise plans with your doctor before beginning. New research shows that exercise can improve survival and provide relief from the symptoms associated with treatments, as well as depression, anxiety and stress. <i>El sobrepeso y el subir de peso se asocian con un mayor riesgo de recurrencia del cáncer, la comorbilidad aumentada y la mala salud. Ejercicio tres veces a la semana durante al menos 30 a 45 minutos para mejorar la salud y mantener un peso saludable. Si desea perder peso, haga ejercicio por lo menos 30 a 45 minutos cuatro o cinco veces a la semana. Discuta sus planes de ejercicio con su médico antes de comenzar. Una nueva investigación muestra que el ejercicio puede mejorar la sobrevivencia y proporciona alivio de los síntomas asociados con los tratamientos, así como la depresión, la ansiedad y el estrés.</i>
Stress management and well-being Manejar el estrés y el bienestar	Learning to manage the increased stress that the experience of cancer and its treatments may bring is quite important in the recovery process. Among other problems, too much stress can lead to fatigue, sleep problems and feelings of anxiety and depression. Exercise, meditation and guided relaxation are known stress relievers. For optimal well-being, a minimum of six hours of sleep per night is needed. Many cancer survivors reveal they are comforted and strengthen and find increased meaning and purpose in their lives through their spiritual faith and through their advocacy or volunteer work in cancer-related, health or community programs. Aprender a manejar el estrés relacionado con la experiencia del cáncer y sus tratamientos es muy importante en el proceso de recuperación. Entre otros problemas, el exceso de estrés puede conducir a la fatiga, problemas de sueño y sentimientos de ansiedad y depresión. El ejercicia, la meditación y la relajación guiada son conocidos para aliviar el estrés. Para el bienestar optimo, es necesario un minimo de seis horas de sueño por noche. Muchos sobrevivientes de cáncer revelan que se consuelan y fortalecen y encuentran un sentido mayor y propósito en sus vidas a través de su fe espiritual y a través de sus actividades de abogacía o trabajo voluntario en los programas relacionados con el cáncer, la salud o la comunidad.



Survivorship Care Plan/Plan de Cuidado de Sobrevivencia

HEALTH ADVISORIES/ADVERTENCIAS DE SALUD	
Hydration (water consumption) Hidratación (consumo de agua)	Drink at least eight glasses of water a day for optimal health. Water helps the body rid itself of waste that comes from cellular or bodily function, medications, environmental and food sources. Lack of water contributes to headaches, constipation, digestive, skin and sleep problems and mood imbalance. Additional sources of water include fruits and vegetables. Beba por lo menos ocho vasos de agua al día para una salud óptima. El agua ayuda al cuerpo a deshacerse de los residuos que provienen de la función celular o del cuerpo, los medicamentos, y de las fuentes ambientales o de alimentos. La falta de agua contribuye a dolores de cabeza, problemas de estreñimiento, digestivos, de la piel y el sueño y el desequilibrio del estado de ánimo. Otros
Alcohol, Tobacco and Controlled Substances Alcohol, Tabaco y las Sustancias Controladas	fuentes de agua son las frutas y los vegetales. It is recommended that you do not smoke or use tobacco products and avoid second hand smoke. Also, women diagnosed with breast cancer should avoid alcohol, or limit to a drink a day. In time of stress, like a cancer diagnosis, people may consider using these substances to cope. However, the dangers are serious and increase your health problems. Please reach out to your health care team or counselor for help and support. Se recomienda que usted no fumeni use productos de tabaco y evite el humo de segunda mano. Además, mujeres diagnosticadas con cáncer del seno deberían de evitar el alcohol, o limitarse a una bebida al día. En tiempos de estrés, personas pueden considerar el uso de estas sustancias para enfrentar la situación. Sin embargo, los peligros son graves y aumentan sus problemas de salud. Por favor, hable con su equipo de cuidado médico o su consejero para ayuda y apoyo.
Reproductive Health Salud Reproductiva	Young survivors are faced with reproductive health concerns. These issues include pregnancy, fertility, menopause, and body image. Request a referral to a fertility or reproductive health specialist in order to address your concerns Las sobrevivientes jóvenes enfrentan preocupaciones con la salud reproductiva. Estos temas incluyen el embarazo, fertilidad, menopausia, y el imagen corporal. Pida una referencia para un especialista en la fertilidad o la salud reproductiva para tratar con sus preocupaciones.
Health provider communication Comunicación de proveedor de salud	Many women may feel it is not their place to talk with their doctors. Writing your questions and sharing your concerns are necessary for receiving appropriate care. Tell your doctors about all your medications and use of complimentary and herbal supplements. Share your physical and emotional concerns to get the best care. At times you may need the services of a health-care advocate or navigator to help you obtain the best care. Many health-care settings have navigators or social workers to assist you. Taking a family member or support person to medical appointments can facilitate better communication and quality care from providers. <i>Muchas mujeres pueden sentir que no pueden hablar con sus médicos. Escribir sus preguntas</i> <i>y compartir sus precupaciones son necesarios para recibir la atención adecuada. Digale a sus</i> <i>médicos sobre todos sus medicamentos y el uso de suplementas a base de hierbas. Comparta sus</i> <i>preocupaciones físicas y emocionales para conseguir la mejor atención. A veces es posible que</i> <i>necesite los servicios de un defensor de cuidados de la salud o un navegador que le ayudaran a</i> <i>obtener la mejor atención. Muchos de los centros de salud tienen navegadores o trabaj adores</i> <i>sociales para ayudarle. Llevar un familiar o persona de apoyo a las citas médicas puede facilitar una mejor comunicación y una atención de calidad de sus proveedores.</i>



Survivorship Care Plan/Plan de Cuidado de Sobrevivencia

HEALTH ADVISORIES/ADVERTENCIAS DE SALUD		
Bone Health Salud Ósea	Breast cancer treatment and menopause can decrease bone strength and bone density. Your doctor can measure your bone density with a DXA scan to determine if you have suffered any bone loss. You can also keep your bones strong through healthy living. Eating a healthy diet rich in calcium and vitamin D and exercising regularly, in particular weight bearing exercise, can help reduce bone loss. Women should consume about 1200mg of calcium daily, or 1500 mg if they are post menopausal. La menopausia y el tratamiento para el cáncer del seno pueden disminuir la fuerza y densidad ósea. Su doctor puede medir su densidad ósea con una escánea de DXA (absorciometría de rayos-x de energía dual) para determinar si usted ha padecido de pérdida ósea. También puede mantener sus	
	huesos saludables a través de un estilo de vida saludable. Comer una dieta rica en calcio y vitamina D y hacer ejercicio regularmente, especialmente ejercicios de carga natural, pueden ayudar a reducir la pérdida ósea. Las mujeres deberían de consumir alrededor de 1200mg de calcio al día, o 1500mg si son posmenopáusicas.	
Dental Health Salud Dental	Cancer treatment can cause oral problems including painful mouth and gums, dry mouth, cavities, tooth decay, and changes in taste. Taking care of your mouth and teeth is crucial to your overall well-being. Discuss any dental concerns with your oncologist and dentist. Also, please make sure to visit a dentist twice a year. Los tratamientos para el cáncer pueden causar problemas orales, que incluyen dolores en la boca y las encillas, boca seca, caries, decadencia, y cambios en gustación. Cuidar de su boca y dientas es esencial para su bienestar total. Hable con su oncólogo o dentista sobre cualquier preocupación dental que tiene. Además, por favor visite su dentista dos veces por año.	
Heart Health Salud del Corazón	Heart health is an important concern for cancer survivors, especially among young survivors, patients who received radiation to the chest area, or who received certain anti-cancer drugs (i.e., taxanes, anthracyclines, Herceptin). A heart-healthy lifestyle includes a diet low in sodium, saturated fat, meat and animal products, and high in fruits, vegetables and fiber; at least 40 minutes of physical activity per day; and six to eight hours of sleep per night. Your care team should inform you about all your treatments and the possible side effects. Symptoms of heart problems may include: shortness of breath (especially when lying flat), leg swelling, palpitations/heart fluttering, intolerance to exercise. Make sure to ask your doctor about what specific heart tests are needed before, during and after treatment. La salud del corazón es algo muy important e para los sobrevivientes del cáncer, especialmente los sobrevivientes jóvenes, pacientes que recibieron radiación al pecho, o que recibieron ciertas drogas anti-cancerosas (p. ej., taxanes, anthracyclines, Herceptin). Un estilo de vida saludable para el corazón incluye una dieta baja en sodio, grasa saturada, carne, y productos de animal; y seis a ocho horas de sueño cada noche. Su equipo de cuidado médico le debería de informar sobre sus tratamientas y los posibles efectos secundarios. Sintomas de problemas cardiacos podrán incluir: falta de aire (especialmente cuando está acostada en su espalda), hinchazón en sus piernas, palpitaciones, intolerancia al ejercicio. Pregúntele a su doctor sobre las pruebas cardiacas específicas que se necesitan hacer antes, durante, y después del tratamiento.	
Other Medical Tests Otras Pruebas Médicas	These tests may be considered during routine breast cancer follow-up: breast MRI, FDG-PET scans, complete blood cell counts, automated chemistry studies, chest x-rays, bone scans, liver ultrasound and tumor markers (CA 15-3, 27, 29, CEA). Talk to your doctor about testing. Estas pruebas se pueden considerar durante el cuidado de seguimiento rutina para el cáncer. IRM del seno, escáneas de tomografía (FDG-PET), conteos completas del sangre, estudias químicos aumatizados, rayos-x del pecho, escáneas del hueso, ultrasonido del hígado, y marcadores de tumor (CA 15-3, 27, 29, CEA). Hable con su doctor sobre las pruebas.	



Cancer Treatment Summary and Survivorship Care Plan Resumen de Tratamiento de Cáncer y Plan de Cuidado First name: _____ Last name: _____ Nombre: _____ Apellida:

QUALITY OF LIFE/CALIDAD DE VIDA Aspect Issue Resource/Referral contact info Aspecto Tema Información de contacto de recurso Emotional Emocional Physical symptoms Sintomas físicos Health cover age Cubertura de salud Financial Financieras Transportation Transporta ci ón Education/Job Training Educación/Entrenamiento en el Trabajo Job/Career Trabajo/Profesión Daily living issues Temas de vida diaria Family, caregiver Familia, avidador Parenting/Family Parentesco/Familia Relationship/Intimacy Relaciónes/Intimidad Social support Apoyo social Sexual health Salud sexual Reproductive Health/Fertility Salud Reproductiva/Fertilidad Identity Development/ Sense of Self Desarrollo de Identidad/ Senso de Si Mismo Spiritual/Religious Espiritual/Religioso Legal issues Temas Legales Informational resources Reaursos informativos Language Idioma Advocacy Abogacia Research involvement Involucramiento en estudios Other Otro



Survivorship Care Plan/Plan de Cuidado de Sobrevivencia

Other sources of information on survivorship care plans and other resources for survivors: Otras fuentes de información sobre planes de sobreviviencia y otros recursos para sobrevivientes (Solo disponible en ingles): American Society of Clinical Oncology: www.cancer.net/patient/survivorship 888-651-3038 American Cancer Society: www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment 888-227-2345 Bright Pink: www.bebrightpink.org 312-787-4412 CancerCare: www.cancercare.org 800-813-HOPE (4673) Cancer Legal Resource Center: www.disabilityrightslegalcenter.org/cancer-legal-resource-center 866-999-DRLC (3752) Centers for Disease Control: www.cdc.gov/cancer/survivorship 800-232-4636 · Fertile Action: www.fertileaction.org info@fertileaction.org Fertile Hope www.fertilehope.org 855-220-7777 FORCE Facing Our Risk of Cancer Empowered: www.facingourrisk.org 866-288-RISK (7475) Hope for Two: The Pregnant with Cancer Network: pregnantwithcancer.org 800-743-4471 Journey Forward: www.journeyforward.org 707-636-5900 · Know:BRCA: www.knowbrca.org LIVESTRONG Care Plan (disponible en español): www.livestrong.org 855-220-7777 Living Beyond Breast Cancer: www.lbbc.org 855-807-6386 My Oncofertility: www.myoncofertility.org 866-708-FERT(3378) National Cancer Institute: http://ncccp.cancer.gov/NCCCP-ASCO-Breast-Cancer-Survivorship-Care-Plan.pdf 800-422-6237 National Cancer Institute, Office of Cancer Survivorship: http://dccps.nci.nih.gov/ocs 301-402-2964 National Coalition for Cancer Survivorship: <u>www.canceradvocacy.org</u> 301-650-9127 National Comprehensive Cancer Network: www.nccn.org/patients 215-690-0300 Simms/Mann-UCLA Center for Integrative Oncology: www.simmsmanncenter.ucla.edu 310-794-6644 Sisters Network Inc. Young Survivors Initiative: www.sistersnetworkinc.org 866-781-1808 Susan G. Komen for the Cure: www.komen.org 877-465-6636 Young Survival Coalition: www.youngsurvival.org 877-972-1011



City of Hope 1500 East Duarte Road Duarte, CA 91010-3000 Phone: 626-256-4673



SCP xiv CCARE - City of Hope Resumen de Tratamiento y Plan de Cuidado de Sobrevivencia para el Cáncer del Seno

How do we anticipate that the guidelines will make a difference for survivors?

Educate and activate ethnically diverse patients into their medical care and self care, as well as help navigate through the cancer survivorship experience. <u>Patients will be informed</u> regarding their treatment and potential side effects, **surveillance**, referrals for followup care, other **chronic illnesses**, symptom management, self care, health advisories, quality of life and resources.



Health Inequity

Disparate health and disease outcomes, and access and quality of care

Source: Institute of Medicine (2002)

Health inequities are reflected in differences in length of life; quality of life; rates of disease, disability, and death; severity of disease; and access to treatment

Source: http://www.cdc.gov/chronicdisease/healthequity/



Intervention Study Addressing Inequities in Survivorship Care in African Americans BCS

- AABCS recruited from State Cancer Registry and support groups
- Randomization
 - Peer navigation + clinically- and culturally-informed breast cancer materials, or
 - Clinically- and culturally-informed BC materials only
- To increase cultural grounding and community relevance and acceptability:
 - AABCS (N=29) from advocacy groups trained as peer navigators
 - ASCO (American Society of Clinical Oncology) SCP template adapted to increase clinical relevance and patient-centeredness for AABCS
 - Personalized guide for appropriate follow-up care based on diagnosis and treatments received
 - Rooted in community based-participatory research (CBPR)

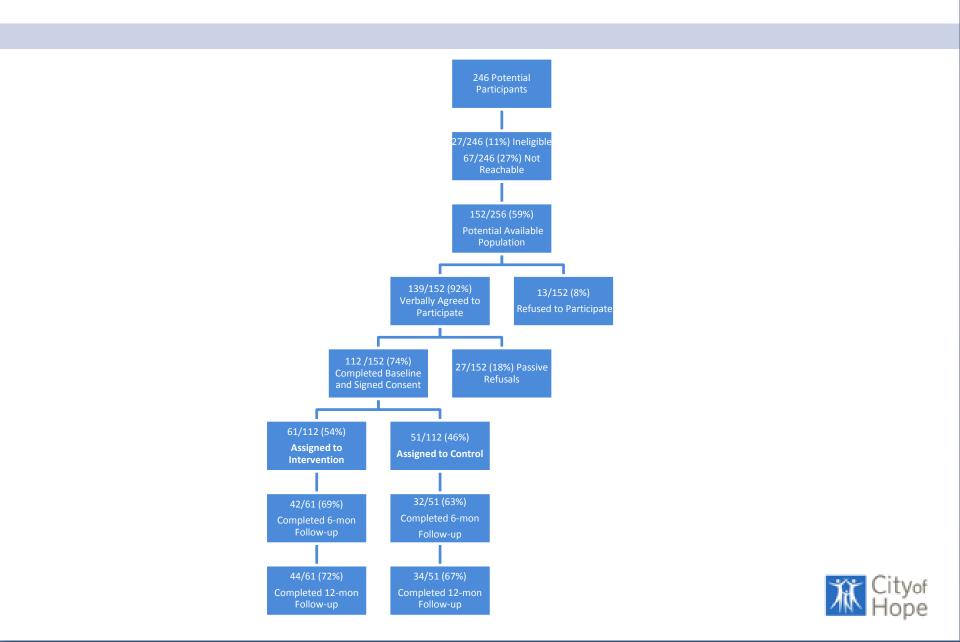


Intervention Study Addressing Inequities in Survivorship Care in African Americans BCS

- All participants received the resource booklet "Embracing Hope"
 - Included a blank form of the Treatment Summary and Survivorship Care Plan (TSSCP)
 - The peer navigation consisted of:
 - Four weekly, 40-minute navigation sessions delivered in-person or via telephone by a peer navigator
 - A 5th booster session 6 months after beginning the study
- Mailed, self-report assessments (baseline, 6- and 12-mo follow-up)
- All the information pooled and entered into the computer for analyses
 - Specific personal information not identifiable



Recruitment Outcomes



Demographic & Clinical Characteristics

- Nearly half (48.2%) were between 50 and 64 years of age.
- 44.4% were college educated
- 35.5% had annual family incomes of less than \$25,000
- 61.6% were unemployed or retired
- 45.9% were in a committed relationship
- 55.4% were diagnosed with stage I/II breast cancer
- 23.2% at stage 0, and 21.4 % at stage III breast cancer



Peer Navigation Outcomes

- Navigators showed that they can increase AABCS' confidence in their knowledge of cancer, treatment, and survivorship information as early as 6 months after starting the study.
 - This is clinically meaningful, as women who are 6-18 months post diagnosis are often very worried and want to understand how cancer and treatment will affect their life, and how they can live the best life possible



Study Outcomes

- At beginning of study, no one had a comprehensive TSSCP
- At 6 months, 45% of study participants received a personalized TSSCP from their oncology team; 64% received one at 12 months



Study Outcomes

- Statistically significant improvements in adherence to NCCN recommendations from baseline to 6- and 12-month follow-up (respectively)
 - Physical exam: 42.0%, 59.8%**, 70.5%***
 - Pelvic exam: 36.6%, 47.3%*, 44.6%
 - Breast self-exam: 56.1%, 67.3%, 79.6%***
 - Breast imaging: 56.1%, 72.4%***, 72.4%**



*p<0.05; **p<0.01; ***p<0.001

Study Outcomes

- After participating in the study:
 - 67% of AABCS were aware of the importance of participating in clinical studies
 - 73% would recommend the study to other survivors



Conclusions/Lessons Learned

- Currently, there is a lack of community inclusion in implementation of research interventions.
- We successfully trained peer navigators to educate and implement a SCP intervention with AABCS, a population that is historically medically underserved → enhanced community capacity
- Importantly, peer support helped to improve survivors' confidence in their knowledge of cancer, treatment, and survivorship information → better prepared for life after cancer



Conclusions/Lessons Learned

- To optimize the effectiveness of peers to provide resources and services, we can devote more time to peer training
 - Full day dedicated to each domain in the TSSCP template
- In the **future**, the scientific and community partners plan to independently continue **community-focused projects** to **improve the well-being of cancer survivors**.



Acknowledgements

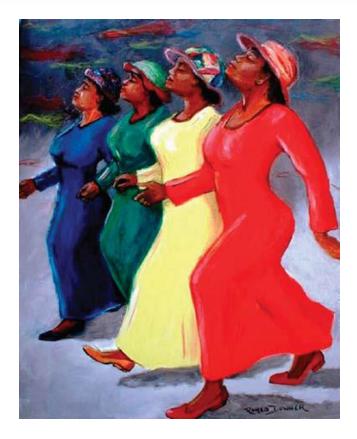
Women of Color

- Florence Britton Community PI
- Isis Pickens

• City of Hope/CCARE

- Dr. Kimlin Tam Ashing Scientific PI
- Mayra Serrano
- Alejandro Fernandez





THANK YOU!

