

Towards developing a bilingual treatment summary and survivorship care plan responsive to Spanish language preferred breast cancer survivors

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Abstract

Background Treatment summary and survivorship care plan studies are at the forefront of research priorities with precedence for ethnic minority inclusion. This preliminary study joined the advocacy, scientific, and medical communities to inform the development and evaluation of the Treatment Summary and Survivorship Care Plan (TSSCP-S) template targeted for Latino breast cancer patients (LCA).

Methods The development of the TSSCP-S began as modifications to the American Society of Cancer Oncology (ASCO) (TSSCP-ASCO) template via a transcreation process informed by 12 LCA survivors/advocates, and evaluated by 10 survivor/advocates and health professionals. The TSSCP-S template development was guided by the Shared Care, Psychooncology Models, and Contextual Model of Health Related Quality of Life.

Results The bilingual TSSCP-S was independently evaluated by bilingual, survivor/advocates, and health professionals ($n=10$). Preliminary analyses indicate that the TSSCP-S template was rated more favorably than the TSSCP-ASCO on the following domains: content ($p=0.02$), clarity ($p=0.02$), utility ($p=0.04$), cultural and linguistic responsiveness ($p=0.03$), and socioecological responsiveness ($p=0.01$). Evaluators noted that the TSSCP-S template was more patient-centered, and endorsed the acceptability as well as the potential utility and applicability of the bilingual TSSCP-S template to appropriately guide surveillance and follow-up care.

Conclusions Our findings indicate that the TSSCP-S achieved clinical, cultural, and linguistic responsiveness relevant to Latinos. Patient-centered TSSCP that are presented in a bilingual format are necessary to achieve the intended goals of TSSCP including appropriate patient information, education, and resources pertaining to their treatment, potential side effects, and recommended surveillance and follow-up care for English language limited patients. Additionally, our culturally responsive TSSCP-S development framework offers a model for TSSCP template development for targeted and underserved populations, including ethnic and linguistic minority cancer survivors.

Implications for Cancer Survivors These data support the development and evaluation of a TSSCP targeted to an underserved, high-risk population, LCAs. Identifying methods to improve surveillance and follow-up guideline adherence may lead to improved clinical cancer outcomes and quality of life.

Keywords Treatment summary and survivorship care plan · Breast cancer · Latina · Health disparities · Community-based participatory research

Introduction

Treatment summary and survivorship care plan (TSSCP) studies are at the forefront of research priorities [1, 2] with a precedence for ethnic minority inclusion in these investigations. Ethnic minorities bear an unequal burden of cancer [3] warranting the National Institutes of Health (NIH) [4], National Cancer Institute (NCI) [5], Centers for Disease Control [6], Agency for Healthcare Research and Quality (AHRQ) [7], and American Cancer Society (ACS) [8] joining the Institute of Medicine's (IOM) urgent call for cancer research to address health disparities and bring cancer equity. Further, ethnic minority representation among the general

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population is rapidly growing and currently at 36.6 % [9], and importantly their numbers among cancer survivors are steadily increasing and approaching 25 % of the <5 year cancer survivor population [10].

With the aim of improving disease-free survival, surveillance, quality post acute treatment care, and health related quality of life (HRQOL), the IOM recommends providing patients with a TSSCP that documents treatment summary, potential medical side effects, surveillance and follow-up care guidelines, and health advisories and HRQOL issues [1]. Further, the American College of Surgeons' Commission on Cancer (CoC) mandates the implementation of TSSCP by 2015 [2]. The sparse literature on TSSCP with Latinos underscores inadequate medical, health advisories, and psychosocial information that are culturally and linguistically responsive [11]. Further, there is only one available TSSCP template provided by the LiveStrong foundation that targets Latinos [12]. However, no data has been published on the utilization of the LiveStrong Spanish template, and current limitations exist including implementation primarily within major university- or research-affiliated cancer centers; Online availability, only; and the generation of the TSSCP in Spanish or English. Thus, to date, the generation of a comprehensive bilingual TSSCP that facilitates enhanced survivorship care communication between Spanish language preferred patients and their providers is not possible.

The impact of cancer among US Latinos has increased in public awareness and is gaining significance in public health [13] and in genetic [14], clinical [15], and behavioral research [16–18] as cancer is the number one cause of death among Latinos [15]. Moreover 7 % of the total expected cancer cases will be Latinos [19]. Breast cancer is the most common cancer and most common cause of cancer death among Latinas [13, 15]. Moreover, emerging research suggest that Latinas are overrepresented among women who are diagnosed with premenopausal breast cancer [20]. California State data shows that 34 % of Latinas diagnosed with breast cancer are <45 years [21]. Further, Latinos represent 17 % of the US population and over 50 % speak Spanish in the home and prefer to communicate in Spanish [9].

Latinas are at greater risk for poor medical outcomes, psychological burden, and are confronted with elevated rates of distress, depression, anxiety, and psychosocial strain [16, 18]. Further, Latinas diagnosed with breast cancer face deleterious prognostic factors that may stem from diagnostic and therapeutic delays [13, 22], treatment nonadherence [13], treatment dissatisfaction [23], poor provider communication [23], uncoordinated care [24], and inadequate knowledge of surveillance and follow-up care guidelines [25]. Hence, providing Latina patients with TSSCP may improve quality post acute treatment and follow-up care, adherence to surveillance, and enhanced self-care.

This paper presents important procedures in the Spanish language transcreation of the ASCO breast cancer treatment summary template. In addition, the paper provides the findings of the preliminary diverse stakeholder evaluation of the transcreated TSSCP-S.

Method

Methodological framework

This project employed a two-component (development of TSSCP-S and evaluation of TSSCP-S) and mixed-methods approach. This study was grounded in a community-based participatory research (CBPR) approach that builds upon a series of research and projects conducted by the Center of Community Alliance for Research and Education (CCARE) with community partners. CBPR is a process and methodological framework that adheres to a collaborative approach between scientific and community partners/researchers sharing ownership and involvement in all aspects of the study [26, 27]. Additionally, the TSSCP-S template development was guided by the Shared Care [28] and Psychooncology Models [29, 30], and Contextual Model of Health Related Quality of Life [31]. The Contextual Model provides the cultural dimensions that are relevant to the health advisories and HRQOL domains of the TSSCP-S template, particularly as it relates to the lived experiences of LCA including cultural health practices (spirituality) and socioecological burden (language, immigration) that impact survivorship outcomes and follow-up care. The Shared Care Model [28] brings primary and oncology providers to coordinate follow-up care, and the psychooncology framework is particularly relevant to comprehensive patient-centered care, and defines the following three areas pertinent to health advisories and HRQOL: (1) overcoming health system and patient barriers to psychooncology care (e.g., providing resources for access and treatment); (2) addressing patient quality care (e.g., facilitating patient-provider communication); and (3) facilitating symptom management and relief (e.g., improving medical and self-care adherence by referring patients to cancer and community resources, social services, and supportive care) [29, 30].

Participants

Twelve (12) Latina breast cancer (LCA) survivor/advocates were recruited to form a consensus building group to inform the development of resources and TSSCP for Latinos. Participants were recruited from local Latina-focused cancer support and health advocacy groups focusing on breast health and survivorship issues such as Komen and The Cancer

Support Community. Participants' age ranged from 40–54 ($M=48.2$; $SD=4.97$). Participants were 2–11 years post-diagnosis, and reported being initially diagnosed at stages 1 (27 %), 2 (64 %), and 4 (9 %). Age at initial breast cancer diagnosis ranged from 33–45 ($M=40.9$; $SD=3.53$). These survivor/advocates represented Latina country of origin diversity in Los Angeles [9]. Seven were Mexican-American, three were Central American, and two were South American.

Also, 10 diverse stakeholders were enlisted from hospitals and Latino focused advocacy organizations (i.e., Latinas Contra Cancer) and support groups to form a consensus team to evaluate the TSSCP-S. Evaluators consisted of health professionals (i.e., two oncologists, one breast cancer surgeon, one primary care physician, two nurses, one genetic counselor), and two survivors, and one community advocate. These evaluators also represented diverse Latino heritage; four were Mexican-Americans, two were Central Americans, three were South Americans, and one was Cuban American.

All evaluators had at least 4 years experience serving diverse populations of cancer survivors with a focus on underserved and ethnic minority patients including LCA.

Procedure

Development of TSSCP-S We conducted two consensus meetings with LCA survivors/advocates ($n=12$). Institutional Review Board approval from participating entities was obtained, and all participants signed an informed consent form to participate and to be audio-recorded and were informed that the information gathered would contribute towards culturally and socioecologically responsive modifications to the content and structure of a Spanish language TSSCP that attended to

the targeted population by being clinically, culturally, and linguistically responsive. We focused on LCA's need for their treatment-related information and surveillance guidelines particularly since Latinas are overrepresented among women diagnosed with premenopausal breast cancer. We also attended to Latinas' limited access to resources, and on cultural, clinical, and socioecological contexts that are relevant to the transcreation of the American Society of Clinical Oncology (ASCO) Breast Cancer Adjuvant Treatment Plan and Summary and Survivorship Care Plan [32] to create the TSSCP-S targeting Latinas. The ASCO TSSCP template includes the standard components recommended by the IOM, including cancer-related information (i.e., treatment history, side effects), and follow-up care/surveillance, health advisories, and HRQOL information. LCA completed a short questionnaire that included demographic and breast cancer-related medical information and were provided with information about the TSSCP general content and structure.

Evaluation of TSSCP-S This preliminary study joined the advocacy, scientific, and medical communities to comprise a 10-member diverse stakeholder review group to evaluate the TSSCP-S and the TSSCP-ASCO templates. The evaluation form and copies of the TSSCP-S and TSSCP-ASCO with a description of the evaluation project were e-mailed to the evaluators. The evaluators were asked to rate the templates using the 21-item evaluation form. Each item on the evaluation form (e.g., "How well does the TSSCP present information relevant to LCA?") was rated on a 4-point scale (1=Poor to 4=Excellent). The evaluation form provided space for written comments and critique of the

Table 1 LCA Recommended Modifications to the TSSCP-ASCO template by domain

Domain	TSSCP-S template modifications
Content	i. Additional spaces for patients to note medications used as well as dates of treatment dose modifications ii. Health advisories that were responsive to the overall health status and breast cancer experience of LCA iii. A Quality Of Life section was included for patients to track emotional, physical, and psychosocial issues
Clarity	iv. Providing definitions for the medical oncology terms (e.g., TNM staging, Oncotype DX Recurrence Score) v. Information on breast cancer genes is included with statistics on lifetime breast cancer risk
Utility	vi. A preamble describing the purpose, content, and use of the TSSCP added to the beginning of the form
Cultural and linguistic responsiveness	vii. Cultural and linguistic relevance can be achieved via appropriate content, imaging, and language (i.e., Spanish language) viii. It is important to incorporate information responsive to cultural values (familism, personalism, trust, respect) and social practices including spirituality (prayer and faith) and family support ix. LCA recommended that patient activation to participate as part of one's own care team is a must, despite cultural tradition of deference to authority
Socioecological responsiveness	x. Consideration of cultural, economic and living situation contexts are essential so that medical and supportive care teams can provide patient-centered, culturally appropriate community resources

templates. The completed evaluations were all returned via e-mail.

Data analyses

Development of TSSCP-S

The data derived from the consensus groups were thematically coded by two independent members of the research team. After the coding process, the research team met to review and discuss the group data and recommendations on the

relevant cultural and socioecological input for the TSSCP-S. Next following the consensus groups’ recommendations (Table 1), the research team generated the TSSCP-S template.

Evaluation of TSSCP-S

Quantitative analysis All quantitative evaluative data were entered into SPSS v.20 [33]. Evaluation items were summed to generate overall scores for each of the five evaluative domains: content, clarity, utility, cultural and linguistic responsiveness, and socioecological responsiveness. Wilcoxon



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.

Sabia Usted? La Comisión de Cáncer del Colegio Americano de Cirujanos ha ordenado la implementación de un plan de cuidado de sobrevivencia para el año 2015. Un plan de sobrevivencia puede mejorar la sobrevivencia y reducir la morbilidad mediante del cuidado clínico coordinado y la documentación de un plan de vigilancia y pruebas recomendadas así como el manejo de síntomas y la promoción de prácticas de una vida saludable.

Breast cancer is the most commonly diagnosed cancer and the second leading cause of cancer death among Latinas in the United States. Latinas are diagnosed at a younger age, at advanced stages, have larger tumors, lower 5-year survival rates*, and are at somewhat greater risk of BRCA mutations.** Latinas report delays in diagnostic and therapeutic care and greater distress due to breast cancer.***

El cáncer del seno es el cáncer más comúnmente diagnosticado y la segunda causa de muerte por cáncer entre las mujeres Latinas en los estados Unidos. Latinas son diagnosticadas a una edad más joven, en etapas avanzadas, tienen tumores más grandes, índices más bajos de sobrevivencia a los 5 años*, y tienen un riesgo más alto de mutaciones de BRCA.** Latinas han reportado retrasos en el diagnóstico y el cuidado terapéutico y mayor angustia a causa del cáncer del seno.***



*American Cancer Society
**Weitzel et al.
***Ashing-Giwa et al.

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?

Después de ser diagnosticada con cáncer de seno, muchas experimentan un poco de miedo y ansiedad, y se pueden preocupar sobre qué hacer para tener los mejores resultados a través de las fases del tratamiento, después de finalizar el tratamiento activo, y durante las próximas etapas de la vida. La mayoría de las sobrevivientes de cáncer de seno recuperan al bienestar y el funcionamiento normal dentro de 1 a 2 años. El plan de cuidado de sobrevivencia es un mapa para el cuidado de seguimiento y el bienestar.

El plan de cuidado de sobrevivencia responde a tres preguntas principales:

- ¿Que tratamientos son más efectivos para mí y cuáles son los efectos secundarios posibles?
- ¿Que cuidados de seguimiento necesito de mi oncólogo y equipo de cuidado médico primario?
- ¿Que acciones y comportamientos debo practicar para mejorar la salud y el bienestar?

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

¿Qué es un Plan de Cuidado de Sobrevivencia?

Un plan de cuidado de Sobrevivencia es un modelo para el cuidado de cáncer de calidad. El plan se completa por usted, su equipo de oncología y puede incluir so equipo de cuidado médico primario. Esta especialmente preparado para usted y sus necesidades con información sobre su:

- Historia de salud y de cáncer de seno, incluyendo tipó y etapa
- Tratamientos y efectos secundarios posibles
- Tratamiento de seguimiento, exámenes médicos y cuidado continuo
- Contactos y referencia para el cáncer y otros proveedores de salud
- Recomendaciones y recursos para un estilo de vida saludable

Fig. 1 TSSCP-S

signed rank tests were used to compare ratings on each domain for the TSSCP-S and TSSCP-ASCO templates.

Qualitative analysis Data from the written comments were independently coded and organized by two researchers by domain (e.g., utility, clarity, cultural, and linguistic issues). The researchers first coded the data and then met to compare their independent coding and resolve any discrepancies. After resolving discrepancies and agreeing on the coding of the data, one of the researchers revised the codes in order to incorporate

and reflect the agreed upon codes. The data was then organized into a matrix according to the evaluation domains.

Results

Development of TSSCP-S

The LCA noted that *cancer characteristics* are central to determining needs and related resources; therefore stage, age

Why do I Need an SCP?

An SCP is key to being informed and prepared to attain your best life as a breast cancer survivor. Having a personal breast cancer treatment record and advisories can empower both you and your loved ones in:

- Preparing for life after a cancer diagnosis and treatment
- Participating in your cancer care
- Keeping your medical follow-up tests and schedule that your oncology care team recommends
- Actively monitoring your ongoing health-care needs
- Identifying your cancer or treatment related symptoms/side effects (they can occur years later)
- Facilitating better communication among all your health-care providers
- Creating and maintaining healthy lifestyle habits to improve your survival and well-being
- Understanding the quality of life and emotional side of cancer
- Knowing where to find national and community resources to enhance coping and well-being

¿Por qué necesito un Plan de Cuidado de Sobrevivencia?

Un plan es clave para mantenerse informada y preparada para lograr una mejor vida como sobreviviente de cáncer de seno. Tener un registro personal de su tratamiento de cáncer de seno y las advertencias puede empoderar tanto a usted como a sus seres queridos en:

- Prepararse para la vida después de un diagnóstico de cáncer y el tratamiento
- Participar en su cuidado de cáncer
- Mantener sus exámenes médicos de seguimiento y plan que su equipo de oncología le recomienda
- Monitorizar activamente sus necesidades continuas de salud
- Identificar los síntomas y efectos secundarios relacionados con el cáncer o tratamiento (pueden ocurrir años después)
- Facilitar mejor comunicación entre todos sus proveedores de salud
- Crear y mantener hábitos de vida saludables para mejorar su sobrevivencia y bienestar
- Entender el lado emocional del cáncer y la calidad de vida
- Saber dónde encontrar recursos nacionales y comunitarios para mejorar la sobrevivencia y el bienestar

Breast cancer is the most common cancer among all women. Most women return to good health after a breast cancer diagnosis and its treatment. However, breast cancer and its treatments can be accompanied by increased medical and quality-of-life issues, including new cancers, heart, bone, lymphedema, dental, emotional, cognitive, social and sexual concerns, and for younger women the added problems of menopause and fertility. These health concerns require proper preventive screening and follow-up care, as provided in an SCP, to reduce your risk and promote well-being.

El cáncer del seno es el cáncer más común entre las mujeres. La mayoría de las mujeres vuelven a la buena salud después de un diagnóstico de cáncer de seno y sus tratamientos. Sin embargo, el cáncer de seno y sus tratamientos pueden ser acompañados por un aumento de los problemas médicos y de calidad de vida, incluyendo nuevos cánceres, problemas con el corazón, los huesos, linfedema, dentales, emocionales, cognitivos, sociales, y sexuales, y para las mujeres más jóvenes los problemas añadidos de la menopausia y la fertilidad. Estos problemas de salud requieren exámenes de detección y cuidado de seguimiento adecuado, como está dispuesto en el plan, para reducir su riesgo y promover el bienestar.

How can I use this SCP Template?

The Treatment Summary section is a bit technical. At first, you may be intimidated by this level of detail. However, it is very important for your health-care providers to educate and inform you of your treatment and the potential side effects.

With a comprehensive treatment summary, your primary care provider and oncology team will be better informed to plan the appropriate follow-up care for you. Also, armed with this knowledge, you will be guided to obtain the follow-up care and resources that you need.

The Health Advisories section of the SCP tailors information for you on healthy lifestyle behaviors, health advisories and quality-of-life resources that you can use to manage side effects, and for symptom relief and better well-being.

¿Cómo puedo usar este plantilla del plan?

La sección de Resumen de Tratamiento es un poco técnica. Al principio, es posible que se sienta intimidada por este nivel de detalle. Sin embargo, es muy importante que sus proveedores de salud la eduquen y la informen sobre sus tratamientos y los efectos secundarios posibles.

Con un resumen integral de tratamiento, su proveedor de salud principal y su equipo de oncología estarán mejor informados para planear el cuidado de seguimiento adecuado para usted. Asimismo, armada con este conocimiento, usted será guiada para obtener el cuidado de seguimiento y los recursos que usted necesita.

La sección del plan de Advertencias de Salud adapta información para usted sobre los hábitos de vida saludables y avisos de salud y recursos de calidad de vida que usted puede utilizar para controlar los efectos secundarios, y para aliviar los síntomas y mejorar su bienestar.

PLEASE PRESENT THIS TEMPLATE TO YOUR ONCOLOGY CARE TEAM AND PRIMARY CARE TEAM SO THAT YOUR HEALTH-CARE TEAM CAN COMPLETE PAGES SCP III TO SCP V, PROVIDING YOU WITH YOUR INDIVIDUALIZED SCP.

POR FAVOR PRESENTE ESTA FORMULARIO A SU EQUIPO DE ONCOLOGÍA Y EQUIPO DE CUIDADO MÉDICO PRIMARIO PARA QUE SU EQUIPO DE CUIDADO DE SALUD PUEDA LLENAR LAS PAGINAS SCP III A SCP V PARA PROVEERLA CON SU PLAN INDIVIDUALIZADO.

Center of
Community
Alliance for
Research
& Education
(CCARE)



This template is a modified American Society of Clinical Oncology breast cancer survivorship care plan template v3 10/09 available at www.cancer.net/patient/survivorship. Funding provided by California Breast Cancer Research Program and City of Hope (principal investigator: Kimlin Tam Ashing-Giwa, Ph.D., professor of Beckman Research Institute of City of Hope and director of the Center of Community Alliance for Research & Education - CCARE). Developed in collaboration between CCARE, and other breast cancer advocates and survivors, including the National African American Breast Cancer Coalition, Hispanic Nurses Association and Herald Cancer Association.



SCP ii

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

Fig. 1 (continued)

at diagnosis, cancer type, genetic risk, and years since diagnosis should inform targeted resources. LCA recommended that the TSSCP should be responsive to patient cancer and health status to guide best care. In terms of *cultural relevance*, LCA recommended that cultural relevance in TSSCP templates can be achieved via appropriate content, imaging, and Spanish language translation. LCA also noted the importance of incorporating information responsive to cultural values (familism, trust, respect) and social practices including

spirituality (prayer and faith) and family support. For the *socioecological context*, LCA indicated that the phase of life and living contexts must be considered. They recommended that age, marital status, family constellation, career/work, and neighborhood are important factors impacting the cancer experience and influence resource needs, and must be addressed in the TSSCP. LCA reported that *health advisories, HRQOL and supportive care* information and resources are inadequately documented and discussed. LCA recommended that health

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

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

GENERAL INFORMATION/INFORMACIÓN GENERAL		
Patient name: <i>Nombre del Paciente:</i>		Patient ID: <i>Número de Identificación del Paciente:</i>
Patient phone: <i>Número de Teléfono del Paciente:</i>	Patient DOB: ___/___/___ <i>Fecha de Nacimiento:</i>	Age: <i>Edad:</i>
Height <i>Estatura</i>	Weight (pre treatment) <i>Peso (antes de tratamiento)</i>	Weight (post treatment) <i>Peso (después de tratamiento)</i>
Support contact name: <i>Nombre del Contacto de Apoyo:</i>	Phone: <i>Número de Teléfono:</i>	Relationship: <i>Relación:</i>
<p>This Treatment Summary and Survivorship Care Plan (SCP) is a brief report of your treatment summary, recommendations for follow-up care and tests, cancer care team 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 therapies. This blank SCP may be copied for later updates or corrections.</p> <p><i>Este Resumen de Tratamiento de Cáncer y Plan de Cuidado de Supervivencia es un breve archivo de su tratamiento de cáncer y las recomendaciones de seguimiento. Incluye aspectos importantes, como información de contacto de su equipo 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 terapias destinadas. Este plan en blanco se puede copiar para actualizar después o para correcciones.</i></p>		
CANCER RELATED INFORMATION/INFORMACIÓN RELACIONADA CON EL CÁNCER (completado por el equipo oncológico)		
Cancer type/location: <i>Tipo/Localización de Cáncer:</i>		Age at diagnosis: <i>Edad al Diagnóstico:</i>
	LEFT BREAST/SENO IZQUIERDO	RIGHT BREAST/SENO DERECH
	<input type="checkbox"/> New Dx: ___/___/___ <input type="checkbox"/> Recurrence: ___/___/___ <input type="checkbox"/> Nuevo Diagnóstico: ___/___/___ <input type="checkbox"/> Recurrencia: ___/___/___	<input type="checkbox"/> New Dx: ___/___/___ <input type="checkbox"/> Recurrence: ___/___/___ <input type="checkbox"/> Nuevo Diagnóstico: ___/___/___ <input type="checkbox"/> Recurrencia: ___/___/___
Surgical procedure/location/findings: <i>Procedimiento quirúrgico/localización/conclusiones</i>		
Definitive breast surgery <i>Cirugía definitiva del seno</i>	<input type="checkbox"/> None/Ninguna <input type="checkbox"/> Diagnosis only/Diagnostico solamente, date/fecha: ___/___/___ <input type="checkbox"/> Palliative resection/Reseccion paliativa, date/fecha: ___/___/___ <input type="checkbox"/> Curative resection/Reseccion curativa, date/fecha: ___/___/___	<input type="checkbox"/> None/Ninguna <input type="checkbox"/> Diagnosis only/Diagnostico solamente, date/fecha: ___/___/___ <input type="checkbox"/> Palliative resection/Reseccion paliativa, date/fecha: ___/___/___ <input type="checkbox"/> Curative resection/Reseccion curativa, date/fecha: ___/___/___
Pathologic stage: Staging tells the extent of the original tumor and if it has spread in the body. <i>Etapa patológica: La etapa describe la extensión del tumor original y si se ha propagado en el cuerpo</i>	<input type="checkbox"/> I_ <input type="checkbox"/> II_ <input type="checkbox"/> III_ <input type="checkbox"/> IV_	<input type="checkbox"/> I_ <input type="checkbox"/> II_ <input type="checkbox"/> III_ <input type="checkbox"/> IV_
TNM staging: Description based on the tumor size (T), the extent of spread to lymph nodes (N), distal metastasis or spread of the cancer (M) <i>Etapa TNM: Descripción basada en el tamaño del tumor (T), el grado de propagación a los nódulos linfáticos (N), metástasis distal o propagación del cáncer (M)</i>	T__ N__ M__ <input type="checkbox"/> N/A	T__ N__ M__ <input type="checkbox"/> N/A
Hormonal status: Description based on estrogen (ER), progesterone (PR) and HER2 receptors to inform what treatment may work best <i>Status Hormonal: Descripción basada en estrógeno (ER), de progesterona (PR) y receptores HER2 para informar que tratamiento puede funcionar</i>	<input type="checkbox"/> ER+ <input type="checkbox"/> PR+ <input type="checkbox"/> HER 2+ <input type="checkbox"/> ER- <input type="checkbox"/> PR- <input type="checkbox"/> HER 2- <input type="checkbox"/> Triple Negative/Triple Negativo	<input type="checkbox"/> ER+ <input type="checkbox"/> PR+ <input type="checkbox"/> HER 2+ <input type="checkbox"/> ER- <input type="checkbox"/> PR- <input type="checkbox"/> HER 2- <input type="checkbox"/> Triple Negative/Triple Negativo

Fig. 1 (continued)

advisories including physical activity and nutrition guidelines and HRQOL resources should be included in the TSSCP. LCA encouraged *patient activation* as part of the process of TSSCP implementation, “To participate as part of one’s own care team is a must, despite cultural traditions such as “respeto.” One advocate stated, “An involved patient is an advocate for herself, and this is often passed to others.” LCA indicated that patient activation can be achieved via peer support, navigation, and advocacy training. These

findings informed the development of the TSSCP-S targeting Latinas.

Overall, the development of the TSSCP-S template was informed by the cultural data derived from the consensus group and the literature [13, 16, 17, 34] and (1) contains clarifications and definitions; (2) specifies the purpose, use, and benefits of the TSSCP; and (3) presents treatment summary and surveillance guidelines; health status and comorbidities; provider contacts and referrals; and health advisories,

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

GENERAL INFORMATION/INFORMACIÓN GENERAL		
Patient name: <i>Nombre del Paciente:</i>	Patient ID: <i>Número de Identificación del Paciente:</i>	
Patient phone: <i>Número de Teléfono del Paciente:</i>	Patient DOB: ___/___/___ <i>Fecha de Nacimiento:</i>	Age: <i>Edad:</i>
Height <i>Estatura</i>	Weight (pre treatment) <i>Peso (antes de tratamiento)</i>	Weight (post treatment) <i>Peso (después de tratamiento)</i>
Support contact name: <i>Nombre del Contacto de Apoyo:</i>	Phone: <i>Número de Teléfono:</i>	Relationship: <i>Relación:</i>
<p>This Treatment Summary and Survivorship Care Plan (SCP) is a brief report of your treatment summary, recommendations for follow-up care and tests, cancer care team 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 therapies. This blank SCP may be copied for later updates or corrections.</p> <p><i>Este Resumen de Tratamiento de Cáncer y Plan de Cuidado de Supervivencia es un breve archivo de su tratamiento de cáncer y las recomendaciones de seguimiento. Incluye aspectos importantes, como información de contacto de su equipo 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 terapias destinadas. Este plan en blanco se puede copiar para actualizar después o para correcciones.</i></p>		
CANCER RELATED INFORMATION/INFORMACIÓN RELACIONADA CON EL CÁNCER (completado por el equipo oncológico)		
Cancer type/location: <i>Tipo/Localización de Cáncer:</i>		Age at diagnosis: <i>Edad al Diagnóstico:</i>
	LEFT BREAST/SENO IZQUIERDO	RIGHT BREAST/SENO DERECH
Tumor type/Histology/Grade: Description of cancer cells, growth rate <i>Tipo de tumor/histología/grado:</i> Descripción de las células 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 cancer. <i>Los nódulos linfáticos:</i> Parte del sistema inmunológico. 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 <i>Oncotipo DX puntuación de recurrencia (si es aplicable):</i> Prueba 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 dermatologist who understand healing and keloids can reduce scarring and improve appearance. <i>Reconstrucción:</i> La reconstrucción puede ser un buen tratamiento para restaurar el equilibrio y la imagen del cuerpo. Consultar con un dermatólogo y cirujano que entienden la curación y los queloides puede reducir cicatrices y mejorar la apariencia.	<input type="checkbox"/> In progress/En progreso <input type="checkbox"/> Planned/Planeado <input type="checkbox"/> N/A	<input type="checkbox"/> In progress/En progreso <input type="checkbox"/> Planned/Planeado <input type="checkbox"/> N/A
GENETIC TESTING/PRUEBA GENÉTICA		
BRCA1:	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Ambiguous <input type="checkbox"/> Positivo <input type="checkbox"/> Negativo <input type="checkbox"/> Ambiguo	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Ambiguous <input type="checkbox"/> Positivo <input type="checkbox"/> Negativo <input type="checkbox"/> Ambiguo
BRCA2:	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Ambiguous <input type="checkbox"/> Positivo <input type="checkbox"/> Negativo <input type="checkbox"/> Ambiguo	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Ambiguous <input type="checkbox"/> Positivo <input type="checkbox"/> Negativo <input type="checkbox"/> Ambiguo
<p>BRCA1/2 mutation is linked to 60 percent lifetime breast cancer risk and 15 to 40 percent lifetime ovarian cancer risk and more common in whites and Hispanics. <i>La mutación BRCA1/2 esta relacionada con un riesgo de 60% de cáncer de seno por vida y un 15-40% de riesgo de cáncer de ovarios por vida y es más común en las mujeres caucásicas y las hispanas.</i></p> <p>Notes:/Notas:</p>		

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Fig. 1 (continued)

quality of life, and community and national resources focusing on the health risk and needs of LCA. The TSSCP-S template is designed as a road map with information and guidelines for optimal patient follow-up care, surveillance, and survivor-directed self-care. The reading level of the TSSCP-S was 10.4 according to the Flesch-Kincaid reading level due to the medical terminology used in the treatment summary section; however, it was lower than the ASCO TSSCP template reading level of 13.7. The TSSCP-S template was translated

into a bilingual (English-Spanish) format (Fig. 1) through the application of a rigorous forward translation, reconciliation, back translation, and multiple reviews [35, 36].

Evaluation of TSSCP-S

Quantitative findings The Wilcoxon signed rank test analyses comparing the ratings of the TSSCP-S and TSSCP-ASCO templates indicate that the TSSCP-S template was rated more

Cancer Treatment Summary and Survivorship Care Plan First name: _____ Last name: _____
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CHEMOTHERAPY/QUIMIOTERAPIA (completado por el equipo oncológico)							
Treatment on clinic trial: <input type="checkbox"/> Yes <input type="checkbox"/> No Tratamiento en ensayo clínico: <input type="checkbox"/> Sí <input type="checkbox"/> No Chemotherapy intent: Intención de Quimioterapia: <input type="checkbox"/> Curative, adjuvant or neoadjuvant Curativa, adyuvante o neoadyuvante <input type="checkbox"/> Disease or symptom control Control de enfermedad o síntomas				Treatment regimen:/Régimen de tratamiento:			
Echocardiogram or MUGA result prior to chemotherapy (if obtained): EF = _____ % Ecocardiograma o resultado MUGA antes de la quimioterapia (si se obtiene): EF = _____ %							
Chemotherapy agents Agentes de Quimioterapia	Start date Fecha de inicio	End date Fecha Final	Dose Dosis	Route Ruta	#cycle # de ciclos	% dose reduction % reducción de dosis	Regimen completed Régimen completado
						<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ % <input type="checkbox"/> Sí _____ % <input type="checkbox"/> No _____ %	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ % <input type="checkbox"/> Sí _____ % <input type="checkbox"/> No _____ %
						<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ % <input type="checkbox"/> Sí _____ % <input type="checkbox"/> No _____ %	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ % <input type="checkbox"/> Sí _____ % <input type="checkbox"/> No _____ %
						<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ % <input type="checkbox"/> Sí _____ % <input type="checkbox"/> No _____ %	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ % <input type="checkbox"/> Sí _____ % <input type="checkbox"/> No _____ %
						<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ % <input type="checkbox"/> Sí _____ % <input type="checkbox"/> No _____ %	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ % <input type="checkbox"/> Sí _____ % <input type="checkbox"/> No _____ %
Nonchemotherapy agents Agentes no quimioterapéuticos (e.g. Tamoxifen, Herceptin, etc.)	Start date Fecha de inicio	End date Fecha Final	Dose Dosis	Route Ruta	#cycle # de ciclos	Purpose/Goal Propósito/Meta	Regimen completed Régimen completado
							<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ % <input type="checkbox"/> Sí _____ % <input type="checkbox"/> No _____ %
							<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ % <input type="checkbox"/> Sí _____ % <input type="checkbox"/> No _____ %
							<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ % <input type="checkbox"/> Sí _____ % <input type="checkbox"/> No _____ %
Major treatment side effects/Efectos secundarios principales del tratamiento:							
<input type="checkbox"/> Hair loss/ Pérdida de cabello		<input type="checkbox"/> Low blood count/ Cuento de sangre bajo		<input type="checkbox"/> Menopause symptoms/ Síntomas de menopausia		<input type="checkbox"/> Sepsis/Septicemia <input type="checkbox"/> Dental problems/ Problemas dentales	
<input type="checkbox"/> Nausea, Vomiting/ Nausea, Vómito		<input type="checkbox"/> Pain/Dolor <input type="checkbox"/> Fatigue/Fatiga		<input type="checkbox"/> Cardiac/Cardiaco <input type="checkbox"/> Infertility/Infertilidad		<input type="checkbox"/> Sexual dysfunction/ Disfunción sexual <input type="checkbox"/> Cognitive impairment/ Deterioro cognitivo	
<input type="checkbox"/> Neuropathy/Neuropatía				<input type="checkbox"/> Mouth sore/Llagas en la boca		<input type="checkbox"/> Skin problems/de la piel <input type="checkbox"/> Other/Otro _____	
Reason for stopping treatment: Razon por interrupción del tratamiento:				<input type="checkbox"/> Completion loss Terminado perdido <input type="checkbox"/> Toxicity Toxicidad <input type="checkbox"/> Progression Progreso <input type="checkbox"/> Other _____ Otro _____			
Response to treatment: Respuesta al tratamiento:				<input type="checkbox"/> Complete Completo <input type="checkbox"/> Partial Parcial <input type="checkbox"/> No Response No Respuesta <input type="checkbox"/> Progression Progresión <input type="checkbox"/> Unknown Desconocido <input type="checkbox"/> Other _____ Otro _____			
Treatment related hospitalization required: Se necesita hospitalización relacionada con el tratamiento:				<input type="checkbox"/> Yes Sí <input type="checkbox"/> No No			
Ongoing toxicity at completion of treatment: Toxicidad continuó al terminar el tratamiento:				<input type="checkbox"/> Yes (type/grade) _____ Sí (tipo/grado) _____ <input type="checkbox"/> No No			
Serious toxicities during treatment (list all): Toxicidades graves durante el tratamiento (lista de todas):							
RADIATION THERAPY/TERAPIA DE RADIACIÓN (completado por el equipo oncológico)							
Radiation therapy: Terapia de Radiación:				<input type="checkbox"/> Not planned No planeada <input type="checkbox"/> Planned Planeada <input type="checkbox"/> Administered Administrada			
Start date: Fecha de Inicio:	End date: Fecha Final:	Region treated: Region tratada:		Radiation dose: Dosis de radiación:			
Disease status at end of treatment (check all that apply) Status de enfermedad al terminar el tratamiento (marque todos los que aplican):				<input type="checkbox"/> No evidence of disease No evidencia de enfermedad <input type="checkbox"/> Evidence of persistent/recurrent disease Evidencia de enfermedad persistente/recurrente			
<input type="checkbox"/> Persistently elevated tumor marker Marcador de tumor persistentemente elevado		<input type="checkbox"/> Possible recurrence based on imaging Recurrencia posible basado en imágenes					

Fig. 1 (continued)

favorably on several domains. Specifically, the TSSCP-S had higher ratings on content ($Z=-2.31, p=0.02$), clarity ($Z=-2.25, p=0.02$), utility ($Z=-2.03, p=0.04$), cultural and linguistic responsiveness ($Z=-2.18, p=0.03$), and socioecological responsiveness ($Z=-2.52, p=0.01$). These results suggest that the TSSCP-S achieved clinical, cultural, and socioecological responsiveness relevant to the LCA population.

Qualitative findings Health professional evaluators provided written comments based on their assessment of both templates (Table 2). Several evaluators noted that the TSSCP-S template was more patient-user-friendly, “The [TSSCP-S] template has vocabulary that is simple; especially the care plan components are understandable to patients.” Other evaluators noted that they liked that the template was bilingual with Spanish translations adjacent to the English text, “I like it because the

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FOLLOW-UP CARE AND SURVEILLANCE/ CUIDADO DE SEGUIMIENTO Y VIGILANCIA (completado por el equipo oncológico)				
Follow-up care Cuidado de seguimiento	Frequency Frecuencia	Provider Proveedor	Contact info Info de Contacto	Updates Actualizaciones
Physical exam: Years 1 to 3 Examen Físico: Años 1 a 3	Every 3 months Cada 3 meses			
Physical exam: Years 4 to 5 Examen Físico: Años 4 a 5	Every 6 months Cada 6 meses			
Post-treatment mammography Mamografía después de tratamiento	Every year Cada año			
MRI: Magnetic resonance imaging is a test used to detect abnormality or cancer using multiple, clear pictures. MRI: Magnetic resonance imaging is a test used to detect abnormality or cancer using multiple, clear pictures. La resonancia magnética es un examen utilizado para detectar anomalías o cáncer utilizando varias imágenes claras.	Every 3 years Cada 3 años			
Bone densitometry: Checks for osteoporosis and fracture risk Densitometría ósea: comprueba la densidad ósea para la osteoporosis, y el riesgo de fracturas.	Every 3 years Cada 3 años			
Pelvic examination Examinación pélvica	Every year Cada año			
Oncologist reevaluation Reevaluación del Oncólogo	After 1 year Después de 1 año			
Genetic counseling: In premenopausal cases, and a family history of breast cancer before 50 or ovarian cancer at any age Consejo Genético: En los casos premenopáusicos, y una historia familiar de cáncer de seno antes de los 50 años de edad o cáncer del ovario a cualquier edad.	Recommended Recomendado			
Fertility specialist: Consult prior to cancer treatment. Especialista de fertilidad: Consulte antes del tratamiento de cáncer.	By patient need Por necesidad del paciente			
Colonoscopy and other cancer screenings Colonoscopia y otros exámenes de detección para el cáncer	By patient need Por necesidad del paciente			
CARE TEAM/EQUIPO DE CUIDADO				
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.				
Team Equipo	Provider Proveedor	Institution Institución	Contact Information Info de Contacto	
Medical oncologist Oncólogo médico				
General/Breast surgeon Cirujano general/de seno				
Radiation therapist Terapeuta de Radiación				
Plastic surgeon Cirujano plástico				
Primary care physician Médico de cuidado primario				
OB-GYN Ginecólogo				
Nurse/Nurse practitioner Enfermera Practicante				
Mental health/Social worker Salud Mental/Trabajador social				
Other specialists Otros especialistas				
Other specialists Otros especialistas				

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Fig. 1 (continued)

translations in Spanish are next to English” and “I appreciate the bilingual format so that patients and their clinician can be on the same page.” Other evaluators noted that the quality, amount of detail, and information provided in the form was good. For instance, one respondent noted that the “[TSSCP-S] template has an introduction and narrative which is good for primary care providers and patients, especially nondominant cultures.”

Written comments coded as “constructive critiques” were made by four evaluators about the medical terminology. Evaluators noted that perhaps some more commonly-used Spanish words might be used to replace some of the ones selected by the template translators. Others noted that there was plenty of medical terminology that makes the form appear as though it is geared towards the medical providers as well. Perhaps, some of the reviewers did not comprehend that while

Cancer Treatment Summary and Survivorship Care Plan
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First name: _____ Last name: _____
 Nombre: _____ Apellido: _____

MEDICAL INFORMATION/INFORMACIÓN MÉDICA							
FAMILY HISTORY/HISTORIA FAMILIAR							
Family history/Predisposing conditions for cancer: Historia familiar/condiciones predisponentes para el cáncer: _____				<input type="checkbox"/> None Ninguna		<input type="checkbox"/> 1st degree relative Familiar de 1º grado	
				<input type="checkbox"/> 2nd degree relative Familiar de 2º grado		<input type="checkbox"/> Multiple relatives Familiares múltiples	
List of 1st degree relatives with cancer/Lista de familiares de 1º grado con cáncer: _____							
MAJOR CO-MORBIDITIES/COMORBILIDADES PRINCIPALES (completado por medico de cuidado 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. Por favor 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	Severe Severo	Moderate Moderado	Controlled Controlado	Uncontrolled Descontrolado	Medication(s) Medicamento(s)
Allergies/Alergias	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Arthritis/Artritis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Asthma/Asma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Cancer (other)/ Cáncer (Otro)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Diabetes/Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Glaucoma/Glaucoma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Digestive Disorder(s)/ Desordenes digestivos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Headaches, migraines/ Dolores de cabeza, migrañas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Heart disease/ Enfermedad cardiaca	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
High blood pressure/ Alta presión	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Lymphedema/Linfedema	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Osteoporosis/Osteoporosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Thyroid (over or underactive)/ Tiroides	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Psychological diagnoses / Diagnostico Psicológico	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Cigarette/Tobacco use/ Uso de cigarrillos, Tabaco	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Problems with alcohol/ Problemas con el alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Other (specify):/ Otro (Especifique):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____

Fig. 1 (continued)

the TSSCP-S template was modified to be more accessible to patients, it is still a medical form that should be completed by the patient's medical providers.

Discussion

This paper describes important initial procedural components in the Spanish language transcreation of the ASCO breast cancer treatment summary template. The paper also provides

the findings of the preliminary diverse stakeholder evaluation of the transcreated TSSCP-S. The work and findings presented are necessary preliminary tasks required for the development of a clinically and linguistically responsive TSSCP that is intended to educate, increase treatment and surveillance compliance, and ultimately improve survivorship outcomes and survival.

As hospitals gear up for the implementation of the CoC TSSCP provision in 2015, the need for linguistically appropriate templates is evident. Therefore, this study is responsive to the CoC requirement, as this study may inform the

Survivorship Care Plan

HEALTH ADVISORIES/ADVERTENCIAS DE SALUD	
<p>These are general health advisories and may not represent the complete list of advisories recommended for your individual health needs. Please consult with your health provider(s) concerning additional or other health advisories. <i>Estas son advertencias generales de salud y puede no representar la lista completa de los avisos recomendados para sus necesidades individuales de salud. Por favor consulte con su proveedor de salud sobre estas advertencias de salud u otras advertencias.</i></p>	
<p>Risks of recurrence <i>Riesgo de recurrencia</i></p>	<p>Follow-up with your physician because the risk of breast cancer returning continues for more than 15 years after remission and because 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. <i>El seguimiento con su médico por el riesgo de que regrese el cáncer de seno sigue por más de 15 años después de la remisión y debido a que no ha tenido mastectomías bilaterales, usted tiene un mayor riesgo de desarrollar un nuevo cáncer no relacionado con el seno en el futuro.</i></p>
<p>Symptoms of recurrence <i>Síntomas de recurrencia</i></p>	<p>Report these symptoms to your doctor: new lumps, bone pain, chest pain, shortness of breath or difficulty breathing, abdominal pain or persistent headaches. <i>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.</i></p>
<p>Lymphedema <i>Linfedema</i></p>	<p>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. <i>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 más 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 puede ser tratado a través de la terapia física, dispositivos de compresión, el ejercicio y la cirugía.</i></p>
<p>Preventive care recommendations <i>Recomendaciones para el cuidado preventivo</i></p>	<p>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. <i>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.</i></p>
<p>Nonrecommended tests <i>Exámenes no recomendados</i></p>	<p>These tests are not recommended for routine breast cancer follow-up: 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. <i>Estas pruebas no se recomienda para el seguimiento del cáncer de seno: MRI del seno, tomografía FDG-PET, conteo de sangre completo, estudios automatizados de química, radiografías del pecho, gammagrafía ósea, ecografía hepática y de los marcadores tumorales (CA 15-3, 27, 29, CEA). Hable con su médico acerca de estas pruebas.</i></p>
<p>Medications <i>Medicamentos</i></p>	<p>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. <i>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.</i></p>
<p>Nutrition (healthy eating) <i>Nutrición (comer saludable)</i></p>	<p>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. <i>Una dieta saludable incluye nueve porciones por día de frutas y vegetales, y tres a cinco porciones de proteínas de plantas (guisantes, frijoles, nueces) y cereales integrales. Durante el tratamiento, usted puede necesitar más proteínas y calorías para enfrentar los efectos del tratamiento, y comer más pescado es útil. Debe limitar las carnes rojas a menos de tres veces por semana y debe evitar carnes curadas. Consulte con un dietista que conozca comidas culturales y étnicas que tal vez sean útiles.</i></p>

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Fig. 1 (continued)

development of TSSCP templates responsive to underserved cancer patients. Further, this study attempts to address a critically important issue in TSSCP development and implementation, namely compliance with culturally and linguistically appropriate services in health care (CLAS) [37].

The results of the evaluation served to improve the cultural and linguistic responsiveness of our TSSCP-S. While most evaluators' comments were positive, a few evaluators provided written critiques to further improve the TSSCP-S template, such as suggestions to address socioecological specific issues, and to

include information on survivorship resources that do not require Internet access. Results from our LCA consensus groups found that most LCA preferred print materials because not everyone has online access and some even felt that print materials were more credible than online sources. Even those that currently had online access and used the Internet were more comfortable with print materials. Our findings support existing research indicating that print-based and non-Internet based resources are more readily usable and accessible to persons 50 and over with limited Internet access and experience [38]. Thus,

Survivorship Care Plan

HEALTH ADVISORIES/ADVERTENCIAS DE SALUD	
<p>Maintain healthy weight <i>Mantener un peso saludable</i></p>	<p>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.</p> <p><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></p>
<p>Stress management and well-being <i>Manejar el estrés y el bienestar</i></p>	<p>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 strengthened 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.</p> <p><i>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 ejercicio, la meditación y la relajación guiada son conocidos para aliviar el estrés. Para el bienestar óptimo, es necesario un mínimo 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.</i></p>
<p>Hydration (water consumption) <i>Hidratación (consumo de agua)</i></p>	<p>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.</p> <p><i>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. Otras fuentes de agua son las frutas y los vegetales.</i></p>
<p>Alcohol and Tobacco <i>Alcohol y Tabaco</i></p>	<p>OIt is recommended that you do not smoke or use tobacco products and avoid secondhand smoke. Also, women diagnosed with breast cancer should avoid alcohol, or limit to a drink a day.</p> <p><i>Se recomienda que usted no fume ni use productos de tabaco y evite el humo de segunda mano. Además, las mujeres diagnosticadas con cáncer de seno deben evitar el alcohol, o limitarse a una bebida al día.</i></p>
<p>Health provider communication <i>Comunicación de proveedor de salud</i></p>	<p>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.</p> <p><i>Muchas mujeres pueden sentir que no pueden hablar con sus médicos. Escribir sus preguntas y compartir sus preocupaciones son necesarios para recibir la atención adecuada. Dígale a sus médicos sobre todos sus medicamentos y el uso de suplementos a base de hierbas. Comparta sus preocupaciones físicas y emocionales para conseguir la mejor atención. A veces es posible que necesite los servicios de un defensor de cuidados de la salud o un navegador que le ayudaran a obtener la mejor atención. Muchos de los centros de salud tienen navegadores o trabajadores 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></p>

Fig. 1 (continued)

phone numbers for advocacy organizations and resources were added to increase utility for all populations. The comment regarding access to TSSCP among very low-income LCA is very important. Lower socioeconomic status and related issues are major concerns among a significant proportion of our LCA as well as in underserved populations. The quality and access to care for LCA and other ethnic minority cancer patients remain critical challenges that result in disparate cancer outcomes

requiring greater public health, health policy and practice, and research attention [39].

Finally, the evaluators made the comment that physicians might not have the time to fill out this template. A similar concern was expressed by health professionals in a qualitative study [40] that examined perspectives on the prospect of providing TSSCP for cancer survivors. However, reluctance to complete TSSCP for patients may be best addressed at the

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

QUALITY OF LIFE/CALIDAD DE VIDA		
Aspect Aspecto	Issue Tema	Resource/Referral contact info Información de contacto de recurso
Emotional Emocional		
Physical symptoms Síntomas físicos		
Health coverage Cubertura de salud		
Financial Financieras		
Transportation Transportación		
Job/Career Trabajo/Profesión		
Daily living issues Temas de vida diaria		
Family, caregiver Familia, cuidador		
Relationship Relación		
Social support Apoyo social		
Sexual health Salud sexual		
Spiritual/Religious Espiritual/Religioso		
Legal issues Temas Legales		
Informational resources Recursos informativos		
Language Idioma		
Advocacy Abogacía		
Research involvement Involucramiento en estudios		
Other Otro		

Other sources of information on survivorship care plans and other resources for survivors:
Otras fuentes de información sobre planes de sobrevivencia y otros recursos para sobrevivientes (Solo disponible en inglés):

- American Society of Clinical Oncology: www.cancer.net/patient/survivorship 888-651-3038
- American Cancer Society: www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment 888-227-2345
- Journey Forward: www.journeyforward.org 707-636-5900
- 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: www.canceradvocacy.org 301-650-9127
- National Comprehensive Cancer Network: www.nccn.org/patients 215-690-0300
- Susan G. Komen for the Cure: www.komen.org 877-465-6636
- LIVESTRONG Care Plan: www.livestrong.org 855-220-7777
- Centers for Disease Control: www.cdc.gov/cancer/survivorship 800-232-4636

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 Duarte, CA 91010-3000
 Phone: 626-256-4673

Fig. 1 (continued)

Table 2 Key themes from evaluators organized by domain

Domain	Comments	Critiques
Content	-Information contained is thorough and detailed -The introduction with explanations of the documents is very useful	-Include more information on impact of cancer
Clarity	-Inclusion of definitions improved clarity -Includes information and an introduction that clarifies TSSCP purpose for patient	-Include more basic information to make sure patient understands the role of the TSSCP
Utility	-User-friendly with information to guide the user -Useful for medical staff	-Physicians may not have time to fill this out -There is an abundance of medical terminology
Cultural and linguistic responsiveness	-Template is bilingual Spanish/English -Culturally based domains included in the Health Advisories and Quality of Life section for Latinas	-Should include more commonly-used Spanish vocabulary for some items
Socioecological responsiveness	-Information specific to breast cancer and survivorship in Latinas (e.g., survivorship rates) -Includes Quality of Life section for documenting resources important to survivorship for Latinas and others	-More community-based programs -Needs non-Internet based resources listed

organizational level, especially since implementation of TSSCP for cancer survivors are mandated by 2015 by the CoC. To encourage TSSCP implementation, providers should have easy access to electronic medical records and insurance reimbursement for TSSCP template completion [40].

In summary, this is one of the first studies reporting on cultural and linguistic, clinical, and socioecological content modifications of TSSCP to increase its responsiveness and relevance for Latinas. Evaluators noted that the TSSCP-S template was more patient-centered and affirmed the utility, applicability, and acceptability of the TSSCP-S template. Moreover, the evaluators expressed that the TSSCP-S template was clear, informative, aesthetically appealing, and culturally relevant and competent. As suggested in previous studies [38, 41], modifications to documents, such as including culturally appropriate content and images, are generally considered ways in which to increase the acceptability and utility of health related materials for ethnic minority populations. Overall, our findings suggests that the TSSCP-S template significantly contributes towards filling scientific and clinical gaps with respect to improving posttreatment oncology care for underrepresented and underserved populations. Our multi-method process lends validity to study findings concerning the applicability and utility of the TSSCP-S with Latinas. Our study offers a practical and clinically relevant model for a TSSCP development and evaluative process that can be repeated to adapt the TSSCP template for various, targeted populations including ethnic and linguistic minority cancer survivors. This study is limited due to the small number of LCA who assisted in the development phase and the small number of stakeholder evaluators of the TSSCP-S template. However, although the LCA and evaluator consensus groups were small, they were heterogeneous in important aspects. Hence, the LCA informative group and the evaluators included diverse country of origin, and the evaluator included

diverse stakeholder groups (i.e., providers and survivors) to increase representativeness and credibility. As well, further implementation investigation of the TSSCP-S with LCA will provide valuable information and results on the efficacy and effectiveness of our bilingual TSSCP template.

Health care delivery systems and providers' support for the TSSCP implementation and evaluation is critical to its long-term success and effectiveness. Indeed, the barriers to obtaining a TSSCP, and the impact of adherence to the TSSCP recommendations on survival and survivorship outcomes warrants more research. Therefore, longitudinal research that examines the long-term benefits and costs of TSSCP implementation, including *in vivo* testing of the TSSCP-S template, must be conducted to advance the science and practice of TSSCP utilization.

This investigation is timely and contributes to the emerging science and practice of TSSCP provision. Latina's high cancer-related morbidity and mortality evokes a critical need and urgency to improve surveillance and follow-up care documentation and implementation on the part of the medical team, and adherence on the part of the patient.

TSSCP that are responsive to the language needs of underserved patients and survivors are essential in providing culturally and linguistically competent care to improve patient education about their treatment and potential side effects, surveillance guideline, and hopefully enhance survival and survivorship. Our TSSCP-S was developed for the Spanish language patient to facilitate better communication with providers, understanding of clinically relevant information and resources, engagement in their cancer care, and improve adherence to the follow-up care recommendation. In addition, our approach and program of TSSCP development research may provide important details to inform the development of targeted TSSCP especially for at risk populations.

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References

- Institute of Medicine. Implementing cancer survivorship care planning: workshop summary. Washington, DC: National Academies Press; 2007.
- American College of Surgeons Commission on Cancer, Cancer program standards 2012: Ensuring patient-centered care. Retrieved on April 11, 2012 from <http://www.facs.org/cancer/coc/programstandards2012.html>, 2011
- Institute of Medicine., The unequal burden of cancer: an assessment of NIH research and programs for ethnic minorities and the medically underserved. 1999: National Academies Press
- National Institute on Minority Health & Health Disparities. in Science of Eliminating Health Disparities Summit. 2012.
- National Cancer Institute. NIH Comprehensive Strategic Plan To Reduce and Ultimately Eliminate Health Disparities. 2003; Available from: <http://www3.cancer.gov/announcements/healthdisrpt.pdf>
- Centers for Disease Control and Prevention (CDC). CDC health disparities and inequalities report—United States, 2011, 2011.
- Agency for Healthcare Research and Quality (AHRQ). National Healthcare Disparities Report. 2011; Available from: <http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf>
- American Cancer Society, cancer disparities—a chartbook. 2009
- U.S. Census Bureau., USA State and County QuickFacts, 2012
- Pulte D et al. Changes in survival by ethnicity of patients with cancer between 1992–1996 and 2002–2006: is the discrepancy decreasing? *Ann Oncol.* 2012;23(9):2428–34.
- Sabatino, S., et al., Receipt of cancer treatment summaries and follow-up instructions among adult cancer survivors: results from a national survey. *Journal of Cancer Survivorship*, 2012; p. 1–12.
- Campbell M et al. Adult cancer survivorship care: experiences from the LIVESTRONG centers of excellence network. *J Cancer Survivorship.* 2011;5(3):271–82.
- Siegel, R., D. Naishadham, and A. Jemal, Cancer statistics for Hispanics/Latinos, 2012. *CA: A Cancer Journal for Clinicians*, 2012. 62(5): p. n/a-n/a
- Weitzel, J.N., et al., Prevalence and type of BRCA mutations in Hispanics undergoing genetic cancer risk assessment in the Southwestern United States: a report from the Clinical Cancer Genetics Community Research Network. *Journal of Clinical Oncology*, 2012
- American Cancer Society, Cancer Facts & Figures for Hispanics/Latinos 2012–2014, 2012: Atlanta, GA.
- Gonzalez SJ, Davis C. Understanding the unique experiences of undocumented, Hispanic women who are living in poverty and coping with breast cancer. *J Immigr Refug Stud.* 2012;10(1):116–23.
- Ashing-Giwa K et al. Understanding the breast cancer experience of women: a qualitative study of African American, Asian American, Latina and European American cancer survivors. *Psycho-Oncology.* 2004;13:408–28.
- Ashing-Giwa, K., et al., Depressive symptomatology among Latina breast cancer survivors. *Psychooncology*, 2012. Published online first in Wiley Online Library
- Siegel R et al. Cancer treatment and survivorship statistics, 2012. *CA: A Cancer Journal for Clinicians.* 2012;62(4):220–41.
- Weitzel JN et al. Prevalence and type of BRCA mutations in Hispanics undergoing genetic cancer risk assessment in the southwestern United States: a report from the Clinical Cancer Genetics Community Research Network. *J Clin Oncol.* 2013;31(2): 210–6.
- CINA+, Cancer Incidence Rates in North America Vol.2., 2013
- Ashing-Giwa K et al. Diagnostic and therapeutic delays among multiethnic sample of breast and cervical cancer survivors. *Cancer.* 2010;116(13):3195–204.
- Fernandes-Taylor S, Bloom JR. Post-treatment regret among young breast cancer survivors. *Psycho-Oncology.* 2011;20(5): 506–16.
- Hoffman HJ et al. Having health insurance does not eliminate race/ethnicity-associated delays in breast cancer diagnosis in the District of Columbia. *Cancer.* 2011;117(16):3824–32.
- Hudson MM, Landier W, Ganz PA. Impact of survivorship-based research on defining clinical care guidelines. *Cancer Epidemiol Biomark Prev.* 2011;20(10):2085–92.
- Foster J, Stanek K. Cross-cultural considerations in the conduct of community-based participatory research. *Family Commun Health.* 2007;30(1):42.
- Israel BA et al. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health.* 1998;19(1):173–202.
- Shad A, Myers S, Hennessy K. Late effects in cancer survivors: “The Shared Care Model”. *Curr Oncol Rep.* 2012;14(2):182–90.
- McCabe, M.S., et al., American Society of Clinical Oncology Statement: Achieving High-Quality Cancer Survivorship Care. *Journal of Clinical Oncology*, 2013
- Chaturvedi SK, Venkateswaran C. New research in psychooncology. *Curr Opin Psychiatr.* 2008;21(2):206–10. doi:10.1097/YCO.0b013e3282f49289.
- Ashing-Giwa K. The contextual model of HRQOL: a paradigm for expanding the HRQOL framework. *Qual Life Res.* 2005;14:297–307.
- American Society of Clinical Oncology. Breast Cancer Adjuvant Treatment Plan and Summary. 2009
- IBM Corp., IBM SPSS Statistics for Windows, Released 2010., IBM Corp.: Armonk, NY
- Ramirez AG et al. A national agenda for Latino cancer prevention and control. *Cancer.* 2005;103(11):2209–15.
- Brislin R. Back-translation for cross-cultural research. *J Cross-Cult Psychol.* 1970;1:185–216.
- Eremenco SL, Cella D, Arnold BJ. A comprehensive method for the translation and cross-cultural validation of health status questionnaires. *Eval Health Prof.* 2005;28(2):212–32.
- Narayan MC. The national standards for culturally and linguistically appropriate services in health care. *Care Manag J.* 2001;3(2):77–83.
- Taha J, Sharit J, Czaja S. Use of and satisfaction with sources of health information among older Internet users and nonusers. *The Gerontologist.* 2009;49(5):663–73.
- Freeman HP. Poverty, culture, and social injustice: determinants of cancer disparities. *CA: Cancer J Clin.* 2008;54(2):72–7.
- Hewitt ME et al. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. *JCO.* 2007;25(16):2270–3.
- Finnie RKC et al. Beyond reading level: a systematic review of the suitability of cancer education print and Web-based materials. *J Cancer Educ.* 2010;25(4):497–505.