

UCSF Center for Vulnerable Populations
Zuckerberg San Francisco General Hospital

Strategies and Policies for Health Care Organizations to Address the Needs of Patients and Families with Low Health Literacy

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Some highlights from yesterday

Session 1

Current health literacy demand of cancer communication across the continuum is suboptimal

Session 2

Literacy- appropriate cancer communication approaches exist and training should be widely disseminated

Session 3

- **Sylvia Chou:** Cancer misinformation is prevalent- need to build the evidence base
- **Lisa Fitzpatrick:** Communication chasm between public and scientists re: cancer
- **Ivan Oransky and James Hamblin:** scientists have a role to play in improving science journalism and lay understanding.

Session 4

April Oh: NCI Priorities: Reduce communication inequalities, multi-level interventions, participatory methods, dissemination and implementation science including iteration and context sensitivity

Galen Joseph: Lessons from health literacy research broadly can be applied to cancer communication

Health Literacy and Healthcare Organizations

A Health Literate Organization:

- 1) Leadership makes health literacy integral to its mission, structure, and operations
- 2) Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement
- 3) Prepares the workforce to be health literate and monitors progress
- 4) Includes populations served in the design, implementation, and evaluation of health information and services
- 5) Meets needs of populations with a range of health literacy skills while avoiding stigmatization
- 6) Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact
- 7) Provides easy access to health information and services and navigation assistance
- 8) Designs and distributes print, audiovisual, and social media content that is easy to understand and act on
- 9) Addresses health literacy in high-risk situations, including care transitions and communications about medicines
- 10) Communicates clearly what health plans cover and what individuals will have to pay for services

Care Delivery Chasm

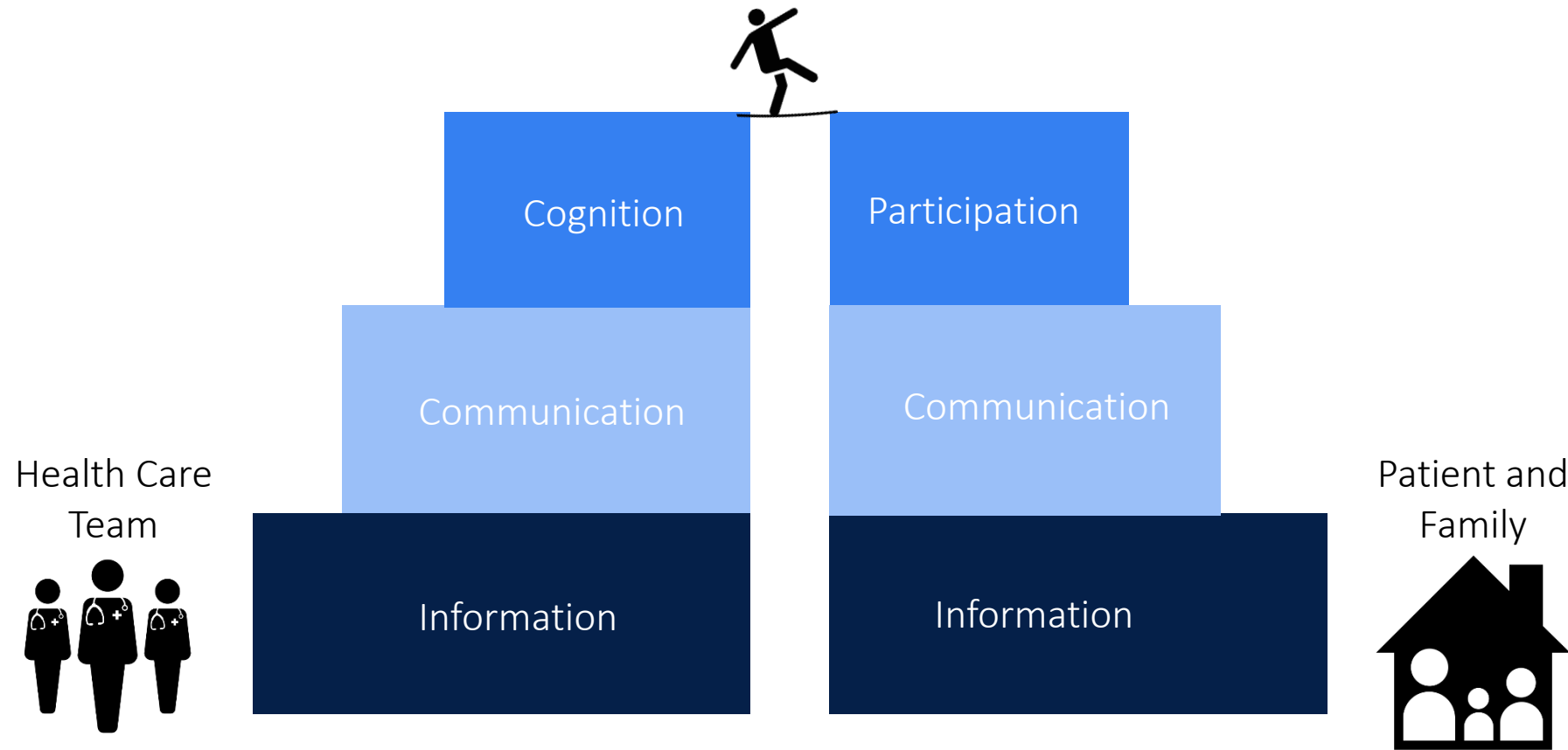


Image credit: Noun Project

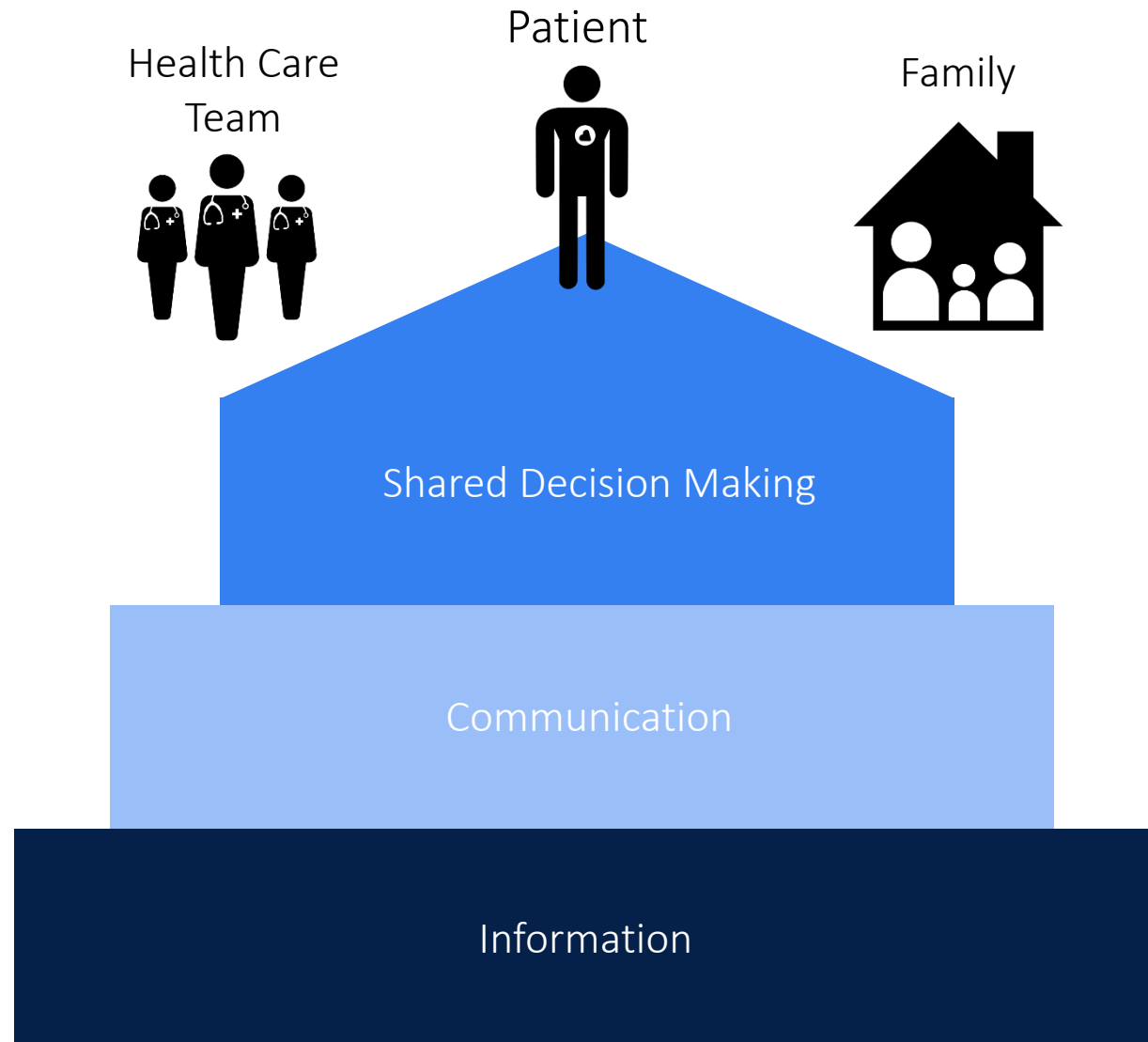
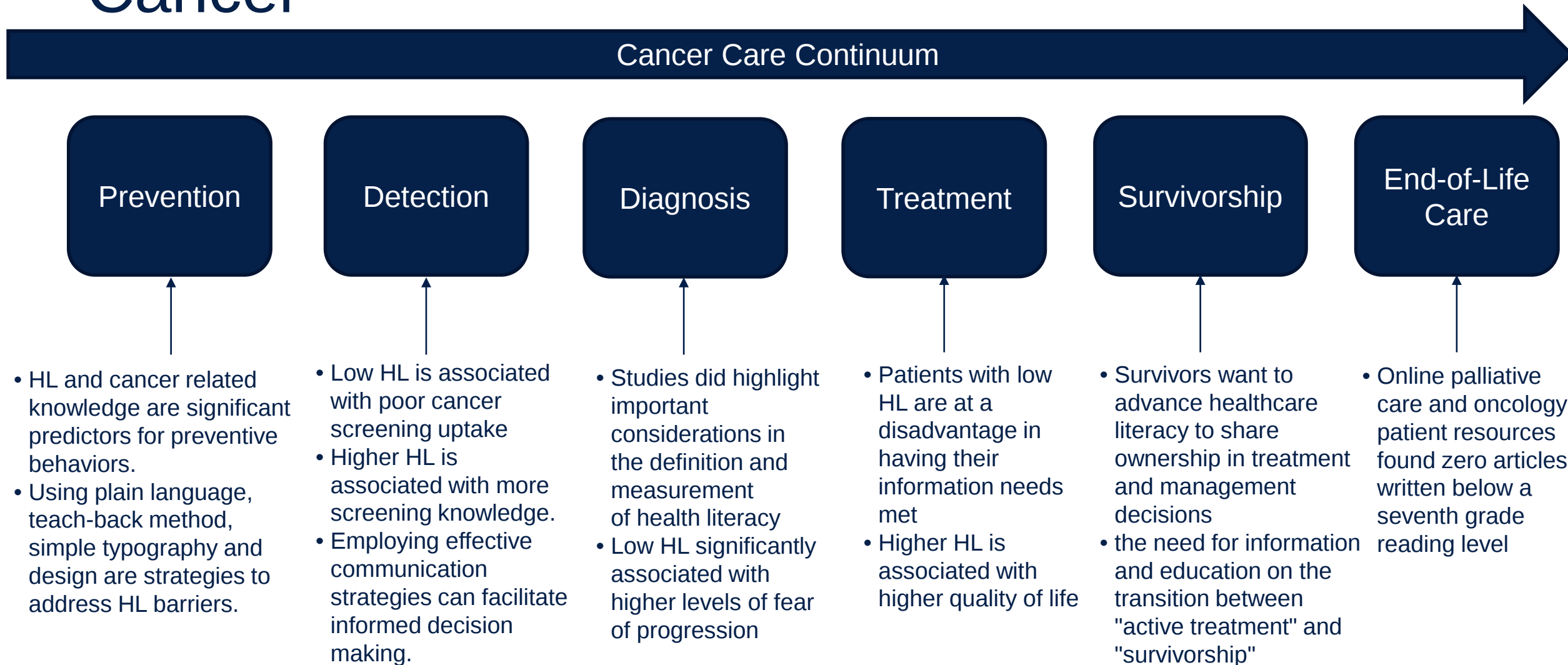


Image credit: Noun Project

Background in Health Literacy/Language and Cancer



Example End-of-Treatment Consultation Note for Breast Cancer

EXAMPLES OF END-OF-TREATMENT CONSULTATION NOTES

Example of an End-of-Treatment Consultation Note: Breast Cancer

Date of note: April 12, 2005

Name: Jane Doe Age: 39

Date of tissue diagnosis of cancer: August 4, 2004

Diagnosis: Breast cancer

Stage of cancer: T1N1M0 Stage II

Pathologic findings: 1.5 cm. infiltrating ductal cancer in the left breast, moderately differentiated, ER positive, PR negative, Her2Neu negative; 3 of 10 nodes positive for metastatic cancer

Initial treatment plan:

- Surgery: Lumpectomy and axillary dissection
- Radiation therapy: 6 weeks of radiation therapy to the left breast
- Chemotherapy: 4 cycles of AC followed by Taxol; dose-dense regimen

Treatment received (specify dates, location, and providers):

Surgery performed as planned by Dr. David Smith at Happy Valley Hospital on 8/23/04.

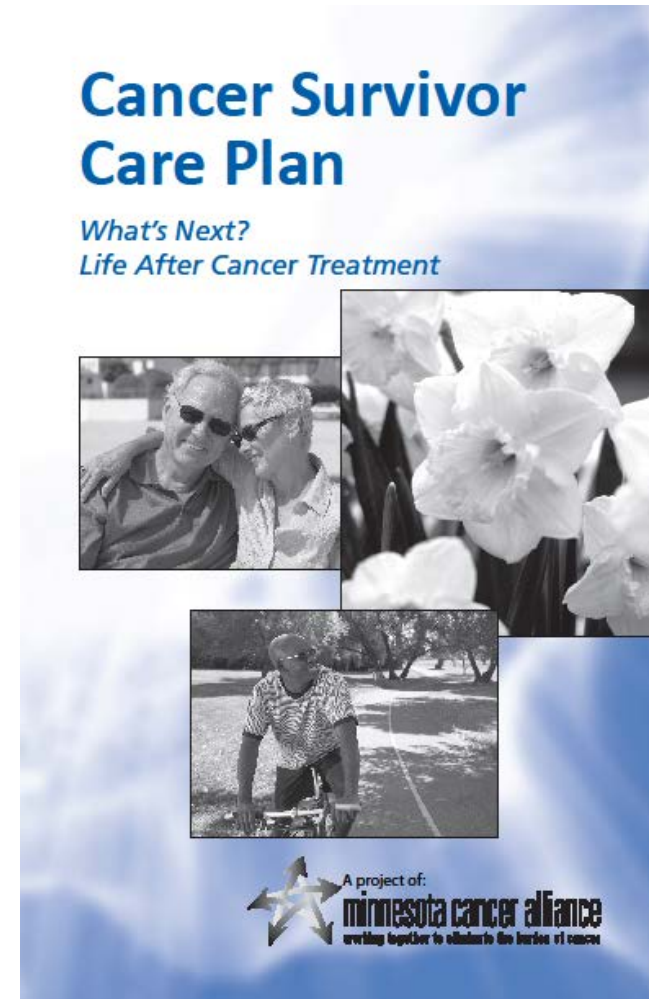
Chemotherapy administered by Dr. Mary Scott at Westside Oncology Center from 9/15/04 to 2/1/05. Patient received full dose as specified in published protocol Citron et al., JCO, 2003,

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

Case Study: Survivorship Care Plans

Problem

- Survivorship care plans (SCPs) communicate critical information needed for cancer survivors' long-term follow-up care.
- Required for accreditation
- Unclear efficacy in practice
- Unclear usability/ tailoring for diverse populations



Example SCP from Minnesota Cancer Alliance

Methods: Survivorship Care Plans

IOM Concordance

- We analyzed collected SCPs (n=16) from diverse care settings for concordance with Institute of Medicine (IOM) recommendations for SCP content, which include:
 - 1) a record of all care received (treatment summary)
 - 2) a follow-up care plan incorporating available evidence-based standards of care
- We adapted standardized methods from a study that created an evaluation tool for breast and colorectal cancer-specific SCPs by operationalizing the 18 sections of the IOM framework of recommended SCP content into a checklist of identifiable items
- We analyzed collected SCPs by coding whether they contained each component on the checklist, and then generating an overall percentage of included elements.

Methods: Survivorship Care Plans

Communication appropriateness

- We used the Suitability Assessment of Materials (SAM) instrument to assess whether patients from diverse backgrounds are likely to understand, accept, and use the plans.
- Validated with 172 health care providers from diverse cultures, the SAM instrument assesses patient suitability across 22 key factors, including content, literacy demand, graphics, layout and typography, learning stimulation, motivation, and cultural appropriateness
- The SAM framework provides a numerical score that may fall into one of three categories: superior (2), adequate (1), or not suitable (0).
- Overall suitability of a document is assessed by adding the ratings of each factor and dividing by the total possible score to generate a percent score, which is then grouped into ratings as follows: superior (70-100%); adequate (40-69%); and not suitable (0-39%).

Example SCPs

Summary of Cancer Treatment and Follow-Up Plan

Diagnosis
Date of Diagnosis
Additional Information

Pathology
Stage

TREATMENT SUMMARY

Surgery
Surgeon

Phone

Date	Procedure

Chemotherapy/Biotherapy
Medical Oncologist

Phone

Regimen

Drug	Drug

Regimen

Drug	Drug

Regimen

Drug	Drug

Print Date: Jul/8/2019



SAN FRANCISCO GENERAL HOSPITAL
AND TRAUMA CENTER

NAME
DOB
MRN
PCP

Patient ID / Addressograph

T-PO0021

ZSFG Breast Cancer Survivorship care plan

Diagnosis/Diagnosis/診斷

Health Care Providers/Profesionales de la Salud/醫療服務提供者

Primary Care Provider:
doctor de cabecera
主治醫師

Surgeon:
Cirujano
外科醫師

SFGH

Principal Oncologist Provider:
Oncólogo principal
主要腫瘤醫師提供者

SFGH

Radiation Oncologist:
oncólogo de radiación
放射腫瘤醫師

UCSF

Navigator:
Navegador(a)
引導員

Diagnosis/Diagnosis/診斷

Cancer Type/Location/Histology Subtype:
tipo de cáncer / localización del cáncer
癌症類型/位置/組織學亞型

Year of diagnosis:
año de diagnosis
診斷年份

STAGE/etapa/分期

☐ 一期 ☐ 二期 ☐ 三期
☐ Not applicable/no aplica/不適用

Treatment Summary/Resumen del Tratamiento/治療總結

SURGERY/cirugía

☐ Yes/sí/手術 ☐ No/否

Surgical procedure/location/findings:
tipo de cirugía/localización/conclusiones
手術程序/位置/發現

RADIATION/radiación/放射治療

☐ Yes/sí/手術 ☐ No/否

Body area treated:
área del cuerpo
接受治療的身體部位

Case Study: Survivorship Care Plans

Overall communication appropriateness of SCPs based on the Suitability Assessment of Materials (SAM) evaluation tool by hospital type

Results

- majority of plans (n=11) incorporated less than 60% of recommended content
- The average reading grade level 14
- 1 plan received a superior rating for cultural appropriateness

Hospital type	SCP	Reading grade level	Cultural appropriateness	Overall SAM score* (%)
Safety net	Plan 1	13	Superior	44
	Plan 2	14	Adequate	41
	Plan 3	9	Adequate	41
	Plan 4	10	Adequate	26
		Mean: 12		Mean: 38
Community	Plan 5	17	Adequate	38
	Plan 6	11	Adequate	59
	Plan 7	12	Adequate	29
	Plan 8	14	Adequate	29
		Mean: 14		Mean: 39
Academic	Plan 9	10	Adequate	62
	Plan 10	17	Adequate	21
	Plan 11	12	Adequate	53
	Plan 12	17	Adequate	50
		Mean: 14		Mean: 47
IDS	Plan 13	10	Adequate	35
	Plan 14	18	Adequate	32
	Plan 15	17	Adequate	24
	Plan 16	17	Adequate	24
		Mean: 16		Mean: 29

*Overall suitability using SAM: 70-100% superior; 40-69% adequate, 0-39% not suitable

Case Study: Survivorship Care Plans

Conclusions and Implications

- Suboptimal language access
- Suboptimal literacy level
- Co-design of SCPs may promote usability/ usefulness
- Intent of communication with primary care and with patient in one static document may not meet survivors' needs

Recommendations

- Re-examination of the intent of survivorship care plans
 - Consider separate vehicles for patient and primary-care-provider communication following treatment
 - Interoperability of electronic health records
 - Survivorship resources in interactive formats
- Literacy appropriate patient-facing communication in clinical oncology practice
 - Incentives for patient-provider optimal communication practices: asynchronous, literacy-appropriate, team-based
- Peer-to-peer communication across the cancer continuum

Thank you!

