Palliative Care to the People:
Partnering with a Patient Experience Department to Raise Awareness of Palliative Care in the Community
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www.med.stanford.edu/palliative-care

@Stanford_PC
Co-Presenters

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Stanford Health Care – Department of Patient Experience

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Disclosures

- The presenters have no financial disclosures.
Learning Objectives & Roadmap

1. Describe the **development and implementation** of a novel partnership between a clinical department of palliative care and a department of patient experience.

2. Describe a **systematic approach to developing, implementing, and evaluating** a multifaceted strategy to improve palliative care awareness in the community.

3. Identify **novel ways to increase awareness of palliative care** in the community.
Background
Most People Have Never Heard of Palliative Care

- 47-73% never heard of palliative care
  - Of those who have heard of PC, only 36% could describe it\(^1\)

- The US is among countries with the lowest level of knowledge about PC

![Pie chart showing:
- 47-73% Never Heard of PC
- ~27% Heard of PC
- 10% Could Explain PC to a Friend](chart.png)
Lack of Awareness is a Barrier to Palliative Care

- Both patients and providers report
  - Poor awareness and knowledge of palliative care
  - Misconceptions of palliative care

- These results in:
  - Not referring &
  - Late referrals
Late Referrals or Lack of Palliative Care is Bad

- Receiving Palliative Care is associated with improved:
  - Quality of life
  - Symptom control
  - Spiritual wellbeing
  - Psychological symptoms
  - Satisfaction with care

- Median Estimates of Survival:
  - 11.6 months early PC group
  - 8.9 months in standard group
Goal

Increase awareness about PC in the community
Patient Experience & Developing a Partnership
How Did We Get Started?

- Creating a Partnership:
  - Donor Support
  - Relationship with patient experience
  - Connected to palliative care

- Provided Program Director, Project Manager, and 0.1 FTE of Physician time
Your Experience with Patient Experience

- Has anyone heard of or worked with patient experience?

- Does your hospital have a department of patient experience or something similar?
What is Patient Experience?

- Of approximately 1000 institutions globally, ~30% have “established” patient experience departments

- Patient Satisfaction/surveys
- Patient and Family Advisory Councils
- Patient Relations/Patient Advocacy
- Quality Measurement/Analytics
- Volunteer Services
- Community Relations
- Marketing
- Health Education
Patient Experience @ Stanford

- Large, well-established
- Multiple branches
  - Health Education, Engagement, and Promotion (HEEP)
    - Caregiver Center
    - Health Libraries
    - Supportive Care Program
    - Tobacco Cessation
    - Palliative Care

- Resources
  - Style/Design assistance
  - “Messaging/Branding”
  - Photography
  - Videography
  - Health literacy review
Patient Experience @ Stanford

A Different Perspective
Maximizing Strengths & Bridging Departments

Division of Palliative Medicine

- Clinical expertise
- Content development
- Connections within the field
- Providers to participate

Patient Experience Department

- Marketing and messaging experience
- Connections to Community-Based Organizations (CBOs)
- Practical support for activities
- Linkage to other resources
Our Approach to Increase Awareness of Palliative Care in the Community
What Would You Do?

▪ Your goal is to increase awareness of palliative care in the community surrounding your medical center

▪ You have a MD a ½ day per week and you have a program director and project manager who are primarily dedicated to the project

▪ How would you approach this task?
Choosing a Focus

Community Outreach & Education

Non-Specialty PC at Stanford

Stanford Palliative Care
Vision & Mission Statement

Vision Statement:
A world where all people receive health care that relieves suffering and pursues the goals that matter most to them.

Mission Statement:
To raise community awareness and knowledge of palliative care’s role in improving quality of life and pursuing the goals that matter most to people and families living with a serious illness.
Guiding Principles

- Don’t reinvent the wheel
  - When possible, be a connector, not a creator

- Balance visibility, relationship building, and impact

- Leverage Stanford’s strengths

- When possible, utilize evidence-based interventions

- Measure impact as much as possible
Ideal State for Community

Knowledge:
- Palliative Care ≠ Hospice
  - PC can help throughout dz course
  - PC is for any pt with serious illness

Attitudes:
- Death is a part of life
  - PC is not giving up
  - Deserve goal-concordant care

Skills:
- Ask for PC Referral
  - Start ACP with family and/or MD
Getting Palliative Care to the People
Event Recordings

Video recordings and slides to download of past educational events about palliative care

11.19.20: Everything you want to know about palliative care
Download the slides to the 11.19.20 event HERE

10.22.20: An introduction to palliative care for the South Asian community
Download the slides to the 10.22.20 presentation HERE

5.22.20: Managing pain when living with cancer
Download the slides to the 5.22.20 presentation in English HERE
Descargar las diapositivas del seminario web en español AQUI

7.30.20: Palliative care was a game changer—an introduction to palliative care
Download the slides to the 7.30.20 presentation HERE
Welcome!

Thank you for visiting our website. We are so glad you are here.

We hope that this website gives you information that is empowering. Please feel free to take your time and explore these pages. On this site, you can learn more about what palliative care is, whether it is right for you, and how to access it. We also have information about advance care planning.

Also, please check out our community resources page to find many more resources both here at Stanford and outside of Stanford.

The palliative care team supports the medical, social, and emotional needs of people living with a serious illness, their families, and caregivers. Our team works with your health care team, and together we can help with:

- Symptoms that are hard to manage
- Advance care planning
- Decisions about transitions in care
- Learning about illness and treatment options
Wednesday, December 9th, 6pm-7pm

An Introduction to Palliative Care for Grief Support Volunteers with Kara Spanish Services

Presenter: Dr. Josh Fronk, Palliative Care Physician, Clinical Assistant Prof. of Medicine, Stanford School of Medicine, Clinical Director, Outpatient Palliative Care

Dr. Fronk will give an overview of palliative care to volunteers in local nonprofit, Kara Grief Support Spanish Services. Live interpreted into Spanish by Stanford Health Care’s interpreter Services team.

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Thursday, November 19th: 12pm-1pm PST

Everything You Want to Know About Palliative Care

This free webinar for the general public will clarify what palliative care is, with a panel of each member of the interdisciplinary team. They will discuss their role, and how they collaborate to provide people living with serious illness and their loved ones a better quality of life, by caring for the whole person—body, mind, spirit.

Co-hosted by:
UCSF Meri Center for Education in Palliative Care at Mt. Zion

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What Matters Most: Palliative Care Myths, Misconceptions, and Setting the Record Straight

Hosted by: SF Community Living Campaign

Presenter: Dr. Grant Smith, palliative care physician, Clinical Assistant Professor of Medicine, Stanford

Join this event to learn about palliative care, a medical specialty that focuses on caring for people and families living with a serious illness. Palliative care focuses on providing relief from the symptoms and stress of an illness and aims to improve quality of life. It can be appropriate for people at any age and at any stage of illness, and it can be delivered alongside curative treatment. Come learn about what palliative care can offer and why it might be a great addition to your health care team.
Stanford Doctor Discusses Palliative Medicine, Hospice, and...  
4.2K views • 1 year ago

Stanford Health Care

Grant Smith, MD, explains palliative medicine and how it helps patients with life threatening illnesses. He

Stanford Doctor on Palliative Care for Patients with Heart and Lung...  
925 views • 7 months ago

Stanford Health Care

Palliative care is specialized medical care for people facing a serious illness like congestive heart failure. The

Stanford Palliative Care Webinar: What if I Get Seriously Ill? Advance...  
1K views • 7 months ago

Stanford Health Care

Stanford Palliative Care physician and Clinical Assistant Professor Dr. Grant Smith discusses advance care
Great article out at @sciamic and @undarkmag about hospice and palliative care access for people living with kidney disease.

Few Kidney Patients Can Access Palliative Care Treatments that reduce suffering and common in kidney disease care. Tha

Happy Holidays from @Stanford_PC! And yes, that is a giant sloth head with a Santa hat on @GSmithHPM's shirt #holidayhpc

Order a copy of the Guide today by visiting eolcareguide.org

It's a good time to P.L.A.N. (©Prepare for Life After Now)
Stanford Palliative Care
Stanford’s interdisciplinary palliative care team and the Palliative Care Center of Excellence, including our Palliative Care Health Education team!
med.stanford.edu/palliative-care
Building Community Relationships
Tuesday, February 4th, 2020: 11am-12:30pm
What Matters Most, Part I: Advance Care Planning
A talk for people living with cancer

Presenters:
Dr. Grant Smith, Palliative Care, Clinical Assistant Professor of Medicine
Dr. Ramy Salah, Hospice and Palliative Medicine, Palo Alto Medical Foundation

In this workshop format, we'll be engaging in hearing what truly matters to a person living with a serious illness, a caregiver of a loved one, and some form of a care plan in the event you are unable to speak for yourself and your family with the comfort and confidence knowing that these plans are in place. Come learn about the questions you should by
Free, virtual event open to all:
Managing Pain When Living With Cancer
Tuesday, September 22nd: 12pm-1pm PST
*Live interpretation in Mandarin and Spanish available!*

Pain can worsen the quality of life for many people living with cancer. Fortunately, there are many treatments that can help manage and reduce pain.

In this event, Stanford palliative care doctor Grant Smith, MD will highlight ways to treat pain by considering the physical, psychological, and spiritual contributors to pain.

We will discuss how to lessen pain using medicine, as well as other treatments. We will also discuss which medical teams can help treat your pain, and when to ask your doctor for a referral to these teams.
¿SON APROPIADOS EN SU CASO LOS CUIDADOS PALLIATIVOS?

Tiene dificultades para:

CONTROLO SINTOMAS
- Sistema que no funciona.
- El dolor en el que se complica con su vida.

TOMAR DECISIONES SOBRE LOS TRATAMIENTOS
- Ingiri tratamiento.
- Decidir si es mejor la atención y los tratamientos con base en lo que usted considera más importante.

SOBRELLEVAR LA SITUACIÓN
- Estar en la enfermedad grave que puede que es.
- Compartir con su familia y amigos sobre su enfermedad.
- Comprender lo que usted considera más importante en este momento.

LE BRINDAN APoyo A CUALQUIER EDAD Y EN CUALQUIER ETAPA DE SU ENFERMEDAD
- Puede recibir cuidados paliativos en cualquier momento de su enfermedad. Puede comenzar a recibir estos cuidados tan pronto como le diagnóstiquen una enfermedad grave.

PLANEAR LA ATENCIÓN MÉDICA
- Proporciona un diagnóstico.

APORTAN PARA CUIDAR UNA CALIDAD DE VIDA
- Mayor soporte, a su familia y a los que están a su alrededor.

OFRECEN ALIVIO PARA EL CUERPO, LA MENTE Y EL ESPÍRITU
- Los cuidados paliativos pueden aliviar el dolor, los enojos y el miedo que suelen experimentar al tiempo que se cuida de su enfermedad grave.

Pueden ayudar y colaborar con su equipo de atención médica.

SON VALIOSOS SOBRE LOS CUIDADOS PALLIATIVOS

¿CÓMO PUDIERAN AYUDAR? A USTED Y A SU FAMILIA

Podemos ayudar en:

- Cómo hablar sobre sus problemas
- Cómo ayudar a amigos y familia a través de la enfermedad
- Cómo ayudar a amigos y familia a través de la enfermedad
- Cómo ayudar a amigos y familia a través de la enfermedad
- Cómo ayudar a amigos y familia a través de la enfermedad

¿SON APROPIADOS EN SU CASO LOS CUIDADOS PALLIATIVOS?

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¿SON APROPIADOS EN SU CASO LOS CUIDADOS PALLIATIVOS?
What Would You Do?

- What would you measure to show your impact?
- How would you go about that?
Our Progress After 1 Year
Exposure

- **Exposure = 10,213**
  - 766 Twitter followers
  - 127 Instagram followers
  - 7472 YouTube views
    - across 7 recorded lectures/webinars
  - 1642 New Users to website (launched April 2020)
    - 6881 Website hits
  - 205 Signed-Up for list-serve
**Engagement**

- **Engagement = 26 Events**
  - 3 Tabling Events
  - 12 Talks/Lectures
  - 11 Advance Care Planning Workshops

- **Engagement = 1663**
  - Large numbers Mar-Apr
    - ACP During COVID
    - Coping with stress during COVID

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**Engagements**

- **Per Month**
- **Cumulative**

*Presented by: Grant Smith, MD (@GSmithHPM)*
Likelihood to Recommend (LTR)

- How likely are you to recommend this session to a friend, family member, or someone you know living with a similar condition?
  - 1 = Not likely
  - 5 = Very likely

- Qualitative
  - Best part of session...
  - Could be improved by...

![Graph showing LTR scores from Sep to Aug.

  - Sep: 4.61
  - Oct: 4.84
  - Nov: 4
  - Dec: 3.9
  - Jan: 4
  - Feb: 5
  - Mar: 4.7
  - Apr: 4.7
  - May: 4.7
  - Jun: 4.7
  - Jul: 4.7
  - Aug: 4.7

Presented by: Grant Smith, MD (@GSmithHPM)
Additional Lessons Learned

**Connect**
- Patient Experience
- Marketing
- Health Education
- Interpreter Services
- IT Service
- Other PC teams

**Leverage Technology**
- Free or cheap
- Website
- Twitter
- Instagram
- YouTube
- Webinars

**Use Your Team**
- Connect to community
- Leverage special interests
- Everything is better with the IDT
- Learn promotion ladders
Challenges and Next Steps

**Challenges**
- Reaching populations less likely to access palliative care
- Defining/Measuring impact
- Finding focus, balancing productivity with longevity

**Next Steps**
- Build/Strengthen relationships with community-based organizations
- Monitor demographics and respond accordingly
- Hone our messages and develop a “brand identity”
Wrap Up & Discussion
What Can You Do?

- Is there something you heard about today that you can bring back to your group?
Take it Home

1. Learn your resources
2. Think of one (1) thing you can do at your institution
3. Consider piloting a public-facing webinar
Non-Specialty Palliative Care

Knowledge
- Palliative Care ≠ Hospice
- PC can help throughout dz course
- Any pt with serious/life-limiting illness

Attitudes
- Death is a part of life
- PC is a good collaborative partner
- PC is not giving up

Skills
- Communication
  - ACP, EOL Conversations**
  - Introduce PC Service
- Symptom Management
  - Basic Sx Mgmt*
  - Know when/how to refer

Ideal State for Clinicians
Ideal State for Stanford Palliative Care

Stanford Palliative Care

- Inpatient
- Outpatient
- TeleHealth
- Home-Based
- EOL/Hospice Care
- Bereavement
Serious Illness Care at Stanford

- Specialty Palliative Care
  - Specialty Care for Serious Illness
    - Oncology
    - Cardiology
    - Pulmonology
  - Primary Care
    - Internal Medicine
    - Family Medicine
    - Senior Care
- Non-Specialty Palliative Care
  - Other Consulting Services
    - Radiation Oncology
    - Pain Medicine
    - Interventional Radiology
  - Allied Health Services
    - Spiritual Support
    - CM/SW
    - PT/OT, Nutrition
    - Integrative Medicine
How Do I Get Palliative Care at Stanford?

- You can refer yourself
  - Call our clinic at (650) 724-0385
  - Website: https://stanfordhealthcare.org/medical-clinics/palliative-care.html

- You can ask your doctor to place a referral

- Locations in Palo Alto and South Bay
  - TeleHealth also available!

- Please take a brochure and a business card
Getting Started

Core Values  Vision  Mission
Core Values & Vision Statement

Core Values:
- Community
- Empowerment
- Equity
- Integrity
- Dignity
- Sustainability

Vision Statement:
A world where all people receive health care that relieves suffering and pursues the goals that matter most to them.
Cannot Do it All at Once

Community Outreach & Education

Non-Palliative Care Serious Illness Care (Champions/Friendlies)

Non-Palliative Care Serious Illness Care (Less Friendly)

Stanford Palliative Care?
Opportunities, Opportunities, Opportunities

- Opportunities we create
- Opportunities we didn’t create
- Requests

Palliative Care
Health Education

A Better, More Palliative Care Friendly World
Biopsychosocial Spiritual Model

- **Biomedical**
  - Bacteria, Viruses
  - Cancer
  - Heart Failure, COPD

- **Psychological**
  - Stress
  - Coping strategies
  - Health beliefs

- **Social**
  - Socioeconomic Status
  - Race/Ethnicity
  - Family/Social Supports

- **Spiritual**
  - Faith/Spirituality
  - Meaning making
  - Relationship to transcendent

Engel (1977) *Psychodynamic psychiatry*
Engel (1980) *Am J Psychiatry*
Sulmasy (2002) *The Gerontologist*
What is Success? What Should We Measure?

- Twitter as a model:
  - Impressions/Exposure
    - How many people “scrolled through your tweet”
  - Engagement
    - How many people clicked on it, liked it, retweeted, commented on it

PRESENTED BY: Grant Smith, MD (@GSmithHPM)
Palliative Care Program FY20

**Exposure**
- July 2020: 2562
- FYTD: 8110
- Target: Establish baseline in FY20

**Engagement**
- July 2020: 96
- FYTD: 1659
- Target: Establish baseline in FY20

**Likelihood to Recommend**
- July 2020: 4.6
- FYTD: 4.2
- Target: Establish baseline in FY20

**Drivers**
- Continued, consistent increase in YouTube video hits & website users
- Delivered interdisciplinary palliative care panel webinar

**Drivers** (extracted from survey responses)
- "Tim had a great story and it was brave of him to share it with such honesty."
- "I enjoyed listening to the patient to his incredible story—and what palliative care meant to him."
- The subject matter was organized and delivered in a well-ordered way. The speakers were excellent. I learned a lot."
- iDT Panel webinar participants
Conclusions and Implications

This work takes time and effort
- Administrative support is extremely helpful
- May not need too much provider time

A little bit can go a long way
- Well-placed marketing can drive a lot of traffic
- Timely topics

Make your efforts count double, triple, or more
- Record your talk, post on YouTube, tweet about it
- Do a quick survey after your talk to get feedback and for promotion