

NHPCO Project ECHO 2023

Equity Where It Matters

Topic: Supporting Chinese Patients in Serious Illness at End of Life

“Don’t Tell Her: Navigating Truth Telling of Serious News Among Chinese Americans”

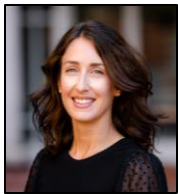
Date: 5/18/2023

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Disclosures

Disclosure

The planners and faculty disclose that they have no financial relationships with any commercial interest.

Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

Evaluation

You will be receiving an email with a link to complete a short survey about this session. Please complete the survey within 48 hours. We ask all participants to take the survey as it will help us to improve future sessions.

Ground Rules and Video Teleconferencing Etiquette

- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

Today's Agenda

- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

Session Faculty

Sandy Chen Stokes, RN, MSN

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Didactic Presentation

Not understanding different cultural values and not having appropriate access to information pose barriers to health equity and health justice.

Introduction

JOURNAL OF PALLIATIVE MEDICINE
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Palliative Care Specialists Series

Feature Editors: Christopher A. Jones and Arif H. Kamal

Open camera or QR reader and scan code to access this article and other resources online.



Top Ten Tips Palliative Care Clinicians Should Know About Caring for Chinese American Patients

Cynthia X. Pan, MD,¹ Esther J. Luo, MD,² Eric Wang, BS,³ Deborah A. Szeto, MSN, RN,⁴ Hillary Lum, MD, PhD,⁵ Jessica Ma, MD,^{6,7} Sandy Chen Stokes, RN, MSN,⁸ Sandy Chan, LCSW, APHSW-C,⁹ Christian Wong, DO,¹⁰ Jing Guo, MD,¹¹ Lifeng Wang, BCC,¹² Victor Chang, MD,^{13,14} and Robert S. Crupi, MD¹

Didactic Presentation:

- Tip 1: Because relationship, harmony, and reliance within the family may supersede autonomy, advance care planning needs to identify the family hierarchy and elicit the patient's desire to participate in decision making.
- Tip 2: Acknowledging that traditional filial piety can influence families to pursue intensive End of Life (EOL) treatments that conflict with the patient's desire for comfort-focused care can build respect and decrease the medical team's moral distress.

Didactic Presentation

- Tip 3: In contrast to a more direct American/Western approach, discuss advance care planning with Chinese patients using indirect approaches to avoid offending the patient and family.
- Tip 4: Use interpreters to discuss sensitive topics such as EOL care and to accurately describe palliative care and hospice care.

Didactic Presentation

- Tip 9: Engage chaplaincy to help support patients through using plain language and a practical approach when introducing the service.
- Tip 10: Chinese culture inherently respects physicians, so it is important for clinicians to build a trusting relationship, provide a safe space to discuss difficult topics or mediate conflicts, and feel comfortable making medical recommendations.

A Useful Tool in Palliative Care: Family Meetings

Why are family meetings important?



Open Communication



Time to think about who are the stakeholders and who should participate?



The Meeting before the Meeting is important!



Ensure everyone feels heard



Ensure family members feel included and are knowledgeable about the patient's condition

End of life Care Glossary: useful translations of key terms

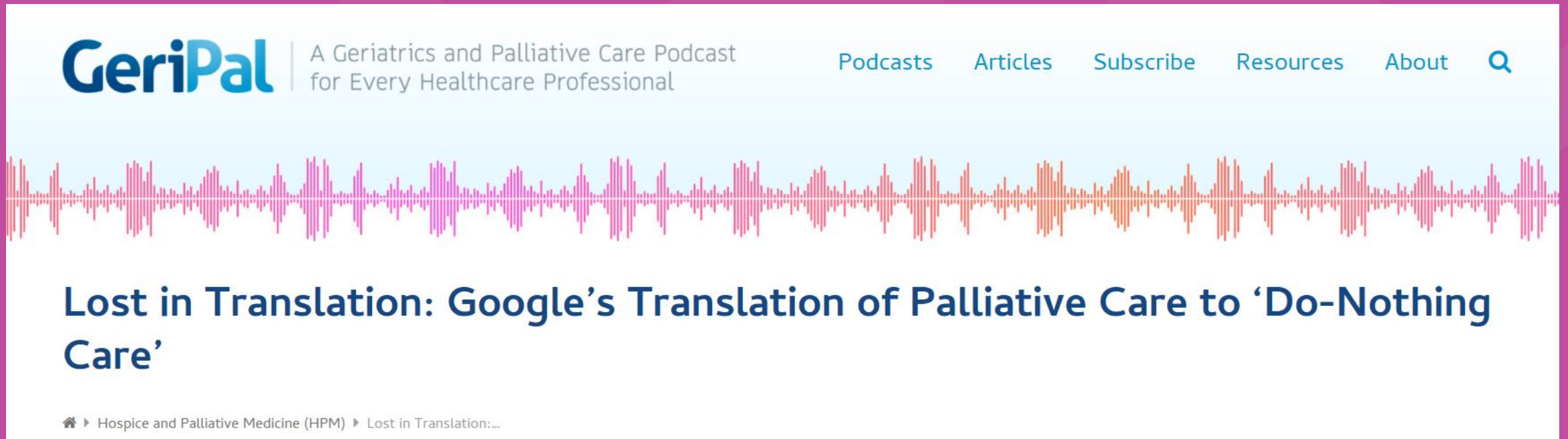
Heart to Heart Cafes promote Advance Care Planning in Chinese Communities

English 英文	Traditional Chinese 繁體中文	Simplified Chinese 簡體中文
active dying	瀕死	濒死
advance care planning	事前療護計劃	预立医疗照护计划
advance health care directive/ AD	醫療照護事前指示	医疗照护事前指示
apnea	呼吸暫停	呼吸暂停
aromatherapy	芳香療法	芳香疗法
art therapy	藝術療法	艺术疗法
artificial nutrition and hydration	人工營養及水份補充	人工营养及水分补充
autopsy	驗屍	尸检
bedsore/pressure sore	褥瘡/壓瘡	褥疮/压疮
benefit versus burden	利益vs負擔	利益与负担对比
bereavement	傷慟/喪慟	伤恸/丧恸
bioethics	生命倫理	生命伦理
brain death	腦死	脑死亡
cardiopulmonary resuscitation (CPR)	心肺復甦術	心肺复苏术
chaplain	靈性輔導師	灵性辅导员

Heart to Heart® Café is a communication activity designed to make it easier for a family member, a caregiver, or a health provider to understand what a loved one wants done when life is ending. However, it is also used with perfectly healthy people who want family members to know what they would like when their lives are threatened by injury or disease.



Accurate translations are critical to accessing palliative and hospice services!



The screenshot shows the GeriPal website header with the logo and tagline "A Geriatrics and Palliative Care Podcast for Every Healthcare Professional". Navigation links include "Podcasts", "Articles", "Subscribe", "Resources", "About", and a search icon. Below the header is a red audio waveform. The main content area features the title "Lost in Translation: Google's Translation of Palliative Care to 'Do-Nothing Care'" in a large, bold, dark blue font. At the bottom left of the content area, there is a breadcrumb trail: "Home > Hospice and Palliative Medicine (HPM) > Lost in Translation:..."

[Lost in Translation: Google's Translation of Palliative Care to 'Do-Nothing Care' \(geripal.org\)](https://geripal.org)

Didactic Presentation Q&A

Case Study Presentation:

“Don’t Tell Her: Navigating Truth Telling of Serious News Among Chinese Americans and Mediating Family Conflicts”

Situation

- Mrs. C. is an 85 year old Chinese woman with decreased appetite, weight loss and functional decline who was brought to her primary care physician (PCP). The doctor recommends further workup to rule out cancer, and would like to speak with Mrs. C about medical procedures to diagnose what's going on.
- Mrs. C's family requests the PCP to not tell the patient anything about cancer but to proceed with medical workup.
- Before the workup could take place, the patient becomes acutely ill, short of breath, fell at home, and family calls 911 to bring the patient to the hospital.
- In the hospital, Mrs. C gets a CT scan that is concerning for metastatic cancer. The family continues to tell the doctors "Don't tell her because she won't be able to handle the news."
- Mrs. C speaks Mandarin Chinese and needs Chinese interpretation for medical discussions
- The doctors feel the patient has capacity and the social worker reports that Mrs C is asking "What's wrong with me? Am I ok?" in Chinese.
- The older son spoke with the doctors and ask them to "do everything for my mother!"

Background

- Mrs. C was born in China and immigrated to the US 10 years ago, after her husband passed away (from cancer).
- She has 3 children and 4 grandchildren, who support her and visit her frequently.
 - Son is oldest, with 2 younger daughters.
- Mrs. C lives with her youngest daughter who is her caregiver. The youngest daughter usually takes the patient to doctors' visits.
- The oldest son lives and works out of state. He opposes telling the patient about the diagnosis.
- The 2 daughters live near Mrs. C and told the social worker that Mrs C. has been asking about her condition and how much time she has left.
- Mrs. C is Buddhist and is spiritual, and has told the daughters "I don't want to suffer."

Assessment

- The medical team assesses that Mrs. C has advanced cancer with likely poor prognosis and limited life expectancy. The team feels that Mrs. C likely wants to know her diagnosis and prognosis, but there is family disagreement about disclosure of serious news.
- The medical team feels that the older son is being unreasonable in requesting the team not to inform the patient about her medical condition.
- The team also feels that ethically, its duty is to involve the patient since she has capacity.
- The team requests a Palliative care consultation to address goals of care and perhaps a family meeting to come to a consensus about next steps.

Discussion and Recommendations

Discussion and Recommendations

- Who is the decision maker in this case?
- Do you feel that Mrs. C has capacity to make her own medical decisions?
- What could be some reasons that the son is requesting the medical team to not tell the patient about her medical condition?
- What is the Chinese concept of “Filial Piety”?
- Does Mrs. C have advance directives?
- During her hospital stay, what resources can be used to clarify Mrs C’s wishes?
 - PCP?
 - Pastoral Care?
 - Ethics?
- Should there be a family meeting and who should organize it?
- Who should discuss code status and with whom?
- Is Mrs. C eligible for hospice care?

Key Takeaways

- With an expected exponential population rise, Chinese American patients who experience serious illness or approach end-of-life (EOL) may find their cultural values influencing the medical care they receive.
- **Relationship, harmony, and reliance** within the family may supersede autonomy, advance care planning needs to identify the family hierarchy and elicit the patient's desire to participate in decision making.
- Acknowledging that traditional **filial piety** can influence families to pursue intensive End of Life (EOL) treatments that conflict with the patient's desire for comfort-focused care can build respect and decrease the medical team's moral distress.
- Accurate translations are critical to accessing palliative and hospice services!

References

1. Pan CX, Luo EJ, Wang E, Szeto DA, Lum H, Ma J, Chen Stokes S, Chan S, Wong C, Guo J, Wang L, Chang V, Crupi RS. Top Ten Tips Palliative Care Clinicians Should Know About Caring for Chinese American Patients. *J Palliat Med*. 2023 Mar;26(3):423-430. doi: 10.1089/jpm.2022.0470. Epub 2022 Oct 18. PMID: 36260416.
2. CACCC website. <https://www.caccc-usa.org/>
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5. Chinese American Resource Guide https://www.nhpc.org/wp-content/uploads/Chinese_American_Outreach_Guide.pdf
6. Pan CX. GeriPal Blog: Lost in Translation: Google’s Translation of Palliative Care to ‘Do-Nothing Care’. [Lost in Translation: Google’s Translation of Palliative Care to ‘Do-Nothing Care’ \(geripal.org\)](https://www.geripal.org/lost-in-translation)
7. Stanford Medicine, Ethnogeriatrics website. [Geriatrics – Ethnogeriatrics \(stanford.edu\)](https://www.stanford.edu/ethnogeriatrics)

Session Evaluation and Certificate of Completion

- Your feedback is valuable as we plan upcoming sessions!
 - Please complete the [Project ECHO Session Evaluation](#)
- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for each session. To receive confirmation of completion, please complete the following within 10 days of each session using the links found on the Project ECHO webpage.
 - *Project ECHO Session Evaluation*
 - *Project ECHO Post-Session Knowledge Check*

NHPCO Health Equity Certificate

- Would you like to demonstrate your commitment to delivering culturally competent care across the continuum of serious illness in an equitable, inclusive, and person-centered manner?
 - NHPCO is pleased to offer a Health Equity Certificate for individuals who participate in at least 17 sessions in the *Equity Where It Matters* series
- To receive participate in the Health Equity Certificate, please complete the following within 10 days of each session using the links found on the Project ECHO webpage.
 - *Project ECHO Session Evaluation*
 - *Project ECHO Post-Session Knowledge Check*

Upcoming Sessions

Date: June 1

Topic: Supporting LGBTQ Patients at the End-of-life

Date: June 15

Topic: Breaking Down Language Barriers to Build Connection with Our Patients

Additional Information

NHPCO Project ECHO webpage:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/>

NHPCO Project ECHO session recordings and Key Takeaways:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/2023-project-echo-session-recordings/>

NHPCO Project ECHO Registration Link:

<https://nhpc.zoom.us/meeting/register/tZEsfu-trz4oGtQeKFw41UEIYNwjSli8QCBF>

For more information:

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