# END OF LIFE PLANNING

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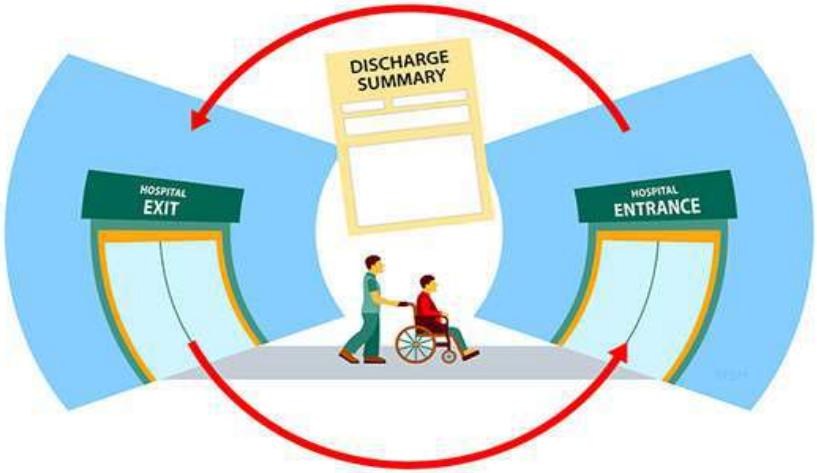
Advance Care Planning is a series of conversations between patients, family members and clinicians to discuss the patient’s values, goals and preferences for treatments.

# Reasons Clinicians or Families Avoid ACP

- Maintain hope
- Avoid patient distress
- Avoid stress on proxy decision makers
- Belief that talking about death will hasten it
- Belief that clinicians will “give up”

# Outcomes of Advanced Care Planning

- Avoid hospital readmissions
- Reduced cost / days of hospitalization
- Reduced outpatient / ED / urgent care use
- Avoid skilled nursing transfers



# Systematic Reviews of Advance Care Planning >80 systematic reviews with 1600 publications

- Many factors influence ACP(legislation, policies, culture).
- ACP benefits include improved EOL communication, documentation of preferences, dying in a preferred place and health care savings.
- Factors for success include repeated and interactive discussions, decision aids, interventions targeting multiple stakeholders.

Jimenez, Tan, Virk, Low, Car, Ho. JPSM 56(3) Sept. 2018

# Continued Challenges to Optimal Use of Advance Care Planning

- Literacy levels
- Misunderstanding legal aspects
- Who is the decision maker?
- Cultural beliefs
- Religious beliefs
- Family conflict

# A Critical Factor: Focus on “the form” vs “the conversation”

# Defining Advanced Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel

"Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."

Sudore, R., et al. (2017) Defining Advanced Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. Journal of Pain and Symptom Management, Volume 53(5):821-832.e1

# Communication

- What is your understanding of your illness now?
- What have you been told about the treatment planned for you?
- What are you hoping for? What do you think the treatment will do for you?
- What do you think will happen if you are no longer getting the treatment?
- How do you make decisions about your care? Who helps you make decisions?

Wiegand & Hinderer. “Advance Care Planning” in Advanced Practice Palliative Nursing. Oxford University Press (2016) Dahlin, Coyne, Ferrell

# Many Outstanding Models and Resources Exist

- “Respecting Choices”
- Aging with Dignity (5 Wishes)
- The Conversation Project
- NHPCO Caring Connections
- POLST

# What is “the conversation”?

- It involves listening
- It is an invitation to understand
- It is an opportunity to learn more about the patient as a person

# An Ongoing Conversation…

Initiated Early

- “We are very interested in knowing more about you and what is most important to you.  In one of our clinic visits ahead...”

Preparing for the Conversation

- “We are at a time when you will be needing to make some decisions about treatments.  Next Thursday when you return to the clinic…”

Having the Conversation…. First Step

- “I would like to talk to you today about some important things such as who could help you make decisions about your care…”

# An Ongoing Conversation

Making Decisions

- “I feel like we are at a fork in the road.  We need to help you to think about…”

Revisiting Decisions

- “Last month you said if the chemotherapy didn’t make the tumor shrink, you think you may be “done” with treatment…”

# Advance Care Planning is More Challenging in cases with high uncertainty and rapid changes in status (such as hematologic malignancies)

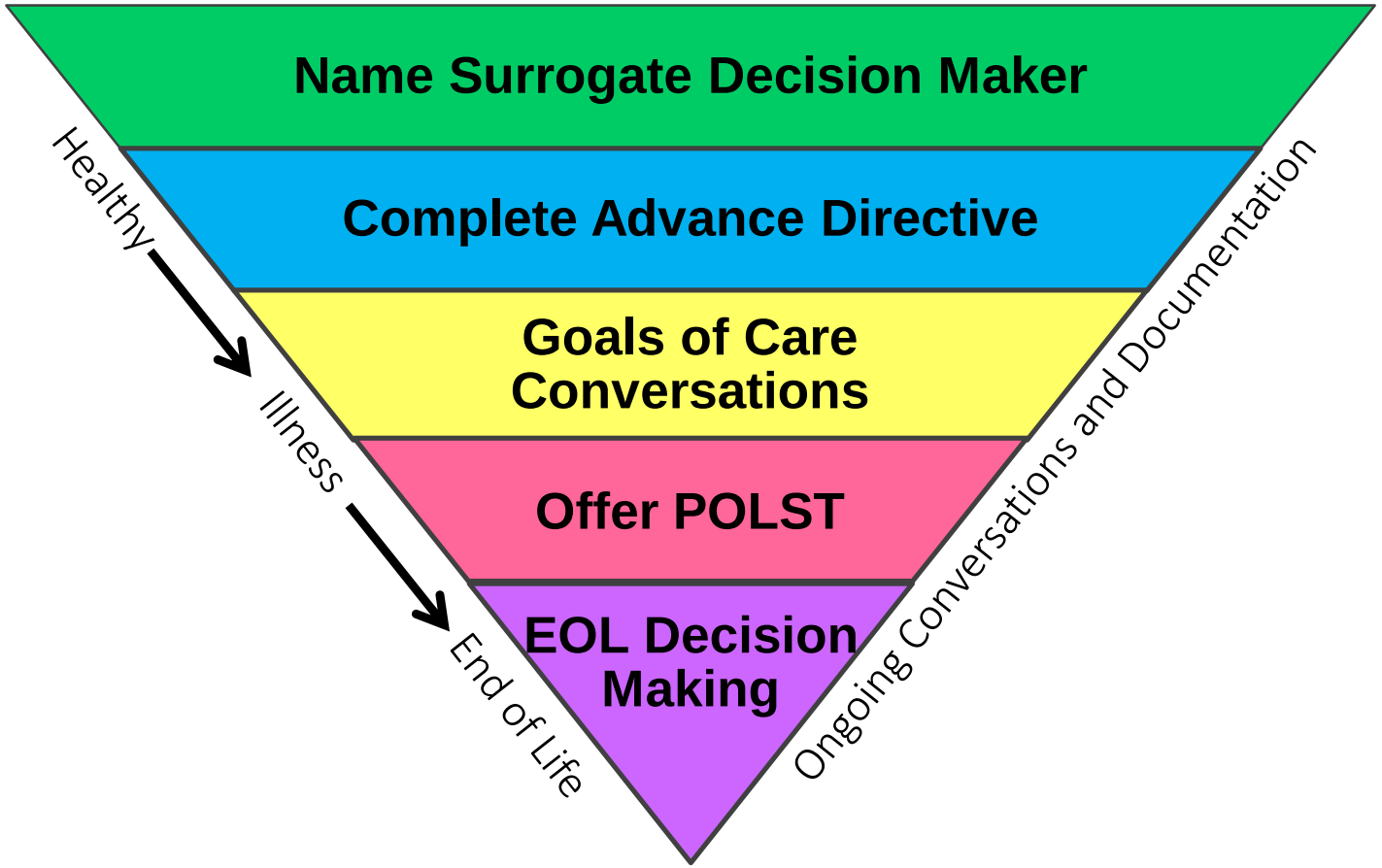
End of Life Planning versus

Beginning of Illness Planning

# Enhancing Advanced Care Planning Conversations by Nurses in a Bone Marrow Transplantation Unit.

Izumi, Shigeko (Seiko), PhD,R.N., F.P.C.N., Burt, Malinda,M.N.E., R.N., Smith, Jennifer,M.S.W., L.C.S.W., McCord, Keren,L.C.S.W., O.S.W.-C., & Fromme, Erik K,M.D., M.C.R. (2019). Enhancing advance care planning conversations by nurses in a bone marrow transplantation unit. *Oncology Nursing Forum, 46*(3), 288-297. doi:http://dx.doi.org/10.1188/19.ONF.288-297


Enhancing Advance Care Planning Conversations by Nurses in a Bone Marrow Transplantation Unit




Continuum of Advance Care Planning

Izumi S, Fromme EK. A Model to Promote Clinicians' Understanding of the Continuum of Advance Care Planning. *Journal of palliative medicine. 2017;20(3):220-221.*

# Integration of Palliative Care for Cancer Patients on Phase 1 Clinical Trails


## City of Hope

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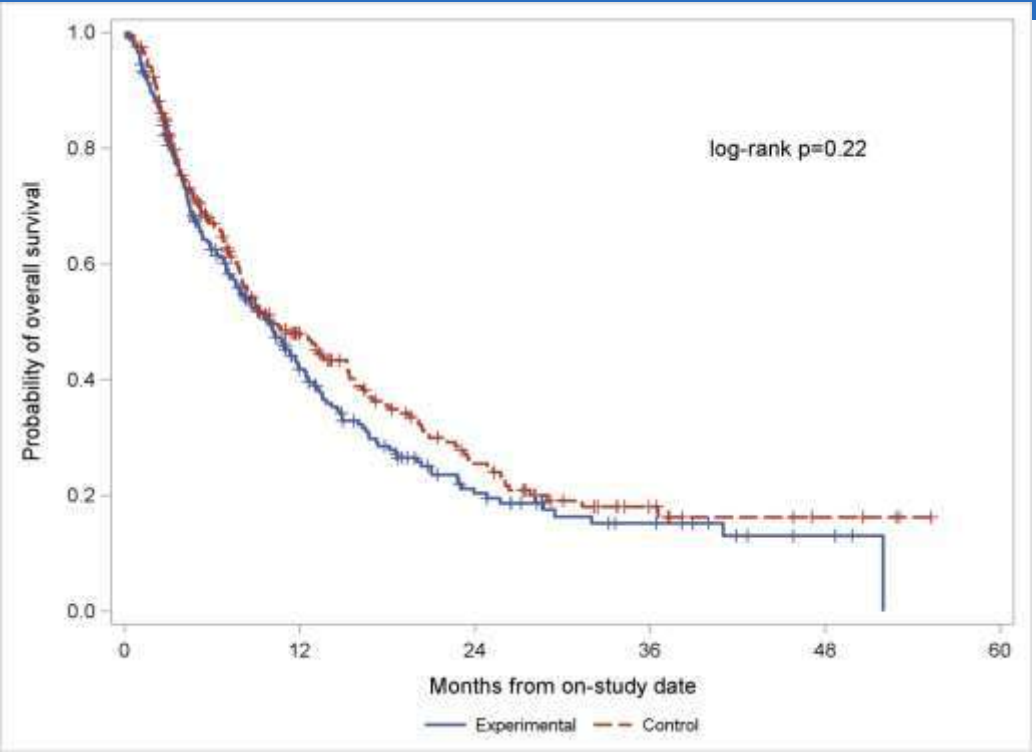
the MIRACLE of SCIENCE with SOUL City of Hope

# Probability of overall survival from on-study date, Experimental vs Control arm




No difference between groups in survival. Both groups had Median survival of 10 months post entry on Phase I trial.

**Palliative Care Resource Utilization and Treatments**

| Chart Audit Data Elements | (n=479) |
|---|---|
| Advanced Care Directive (completed) | 187 (39.0%) |
| Proxy decision maker, N (%) | 168 (35.1%) |
| Code Status, N (%) | |
| DNR | 168 (35.1%) |
| Full Code | 311 (64.9%) |
| **Hospice Use** | |
| Hospice referral, N (%) | 187 (39.0%) |
| Hospice enrollment, N (%) | 147 (30.7%) |
| Months from hospice referral to death, mean (SD) | 1.6 (2.3) |
| Months from hospice enrollment to death, mean (SD) | 1.2 (2.3) |
| Median Survival months (95%CI)* | 10.1 (8.4, 11.9) |
| **Supportive Care Referrals** | |
| Palliative care referral, N (%) | 79 (16.5%) |
| Social Work referral, N (%) | 222 (46.3%) |

† calculation includes only patients who were deceased at last follow-up
* Kaplan-Meier estimate for overall survival from time of initiating Phase 1 Trial to last contact date/death all subjects.