

Neurologist faces the other side of brain cancer

Cancer Caregiver Survivorship: An Integrative Approach

“Poised at the Abyss”

Hedy S. Wald, PhD

Clinical Professor of Family Medicine
Alpert Medical School of Brown University
Director, Resident Resilience & Wellbeing
Residency Programs in Child Neurology &
Neurodevelopmental Disabilities

Boston Children's Hospital - Harvard Medical School
Writer, Mother, Grandmother, Cancer Caregiver



Wald, HS. Poised at the Abyss, 2016 <http://bit.ly/2aYen4e>

Wald, HS. Commentary on Big Bang. Acad Med., 2017



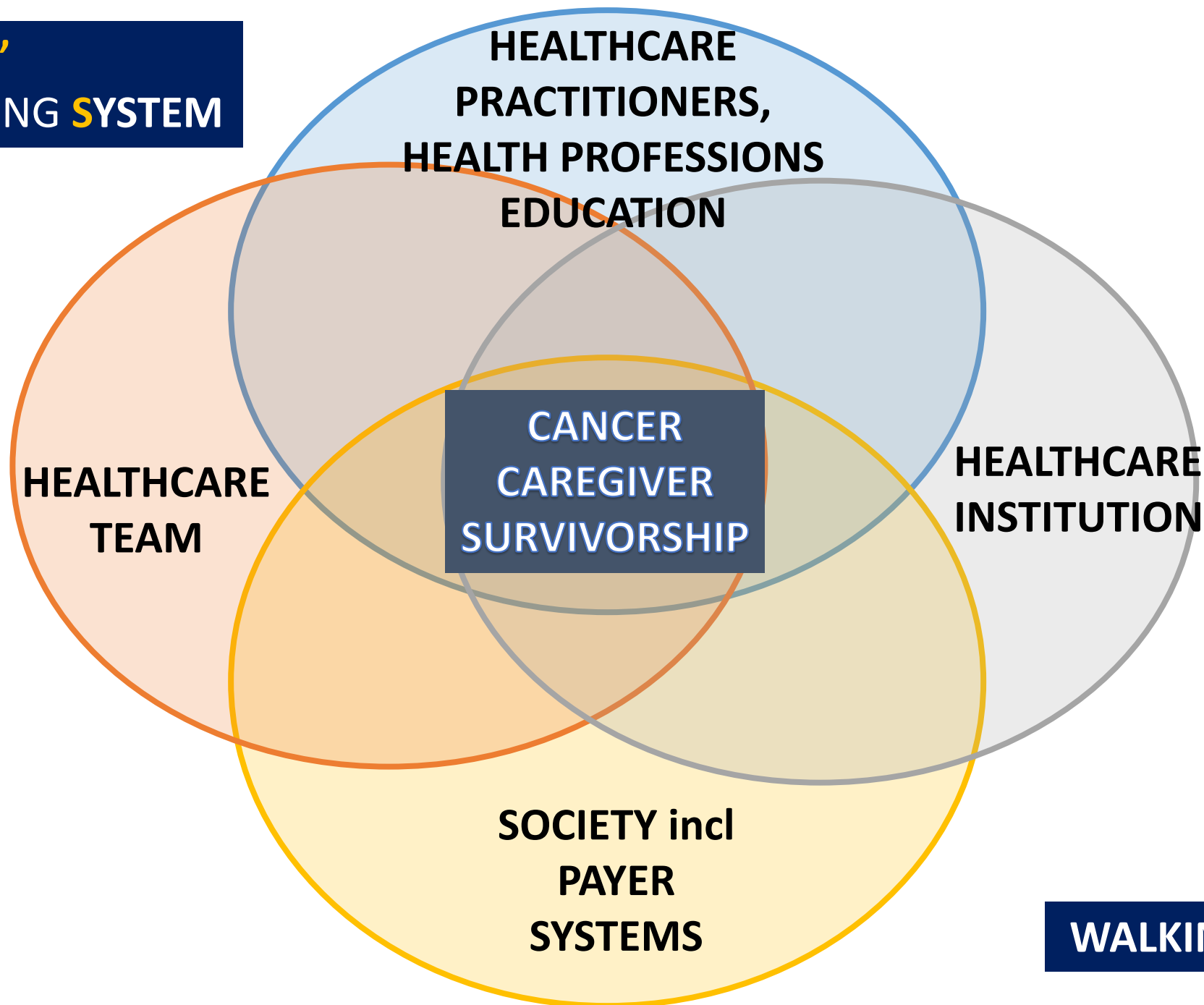
Family **C**ancer **C**aregiver **E**xperience

“FACE” this,
See our **FACE**
Cancer-specific
stress
Caregiver distress
impacts patients

(Kent et al, 2016, Cancer; Eppel et al, PNAS)

"SOS"

STRESS OFFSETTING SYSTEM



WALKING THE TALK

43.5 million US adults provided care to an adult or child (for any serious/chronic health condition) in preceding 12 months (2015)

Cancer – Fourth most prevalent reason for caregiving

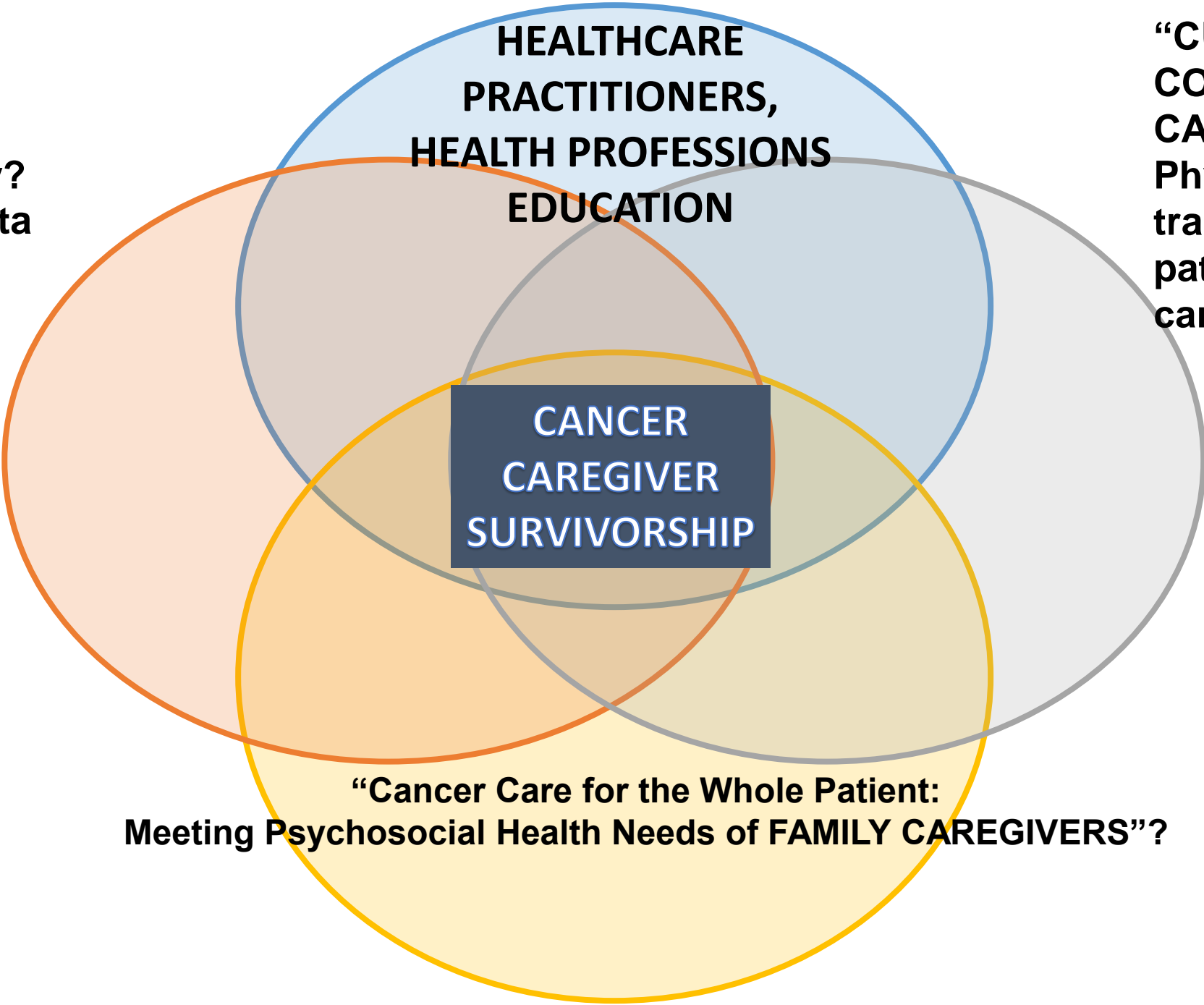
12 million cancer survivors in US (2011)

Half of cancer patients will be cared for by immediate family (est)

75% US families will care for a cancer patient (relative or friend) at some point (est)

“Valuing the Invaluable” Caregiving services: value \$350 billion (est)

**APPROACH TO
CANCER
CAREGIVER**
Presence? Story?
Quality of life data



**“CULTURALLY
COMPETENT
CARE”?**
Physician/nurse
training - cancer
patients &
caregivers’ needs?

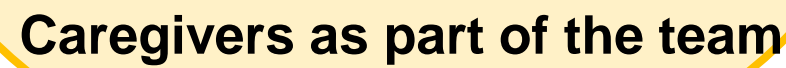
**“Cancer Care for the Whole Patient:
Meeting Psychosocial Health Needs of FAMILY CAREGIVERS”?**





Information: work, child care, financial, online resources, tapping into strengths, resilience strategies (beyond “crisis”)

Ascertaining treatment details understood?



**Adequate resources for
caregivers' psychosocial
support? Funding?**

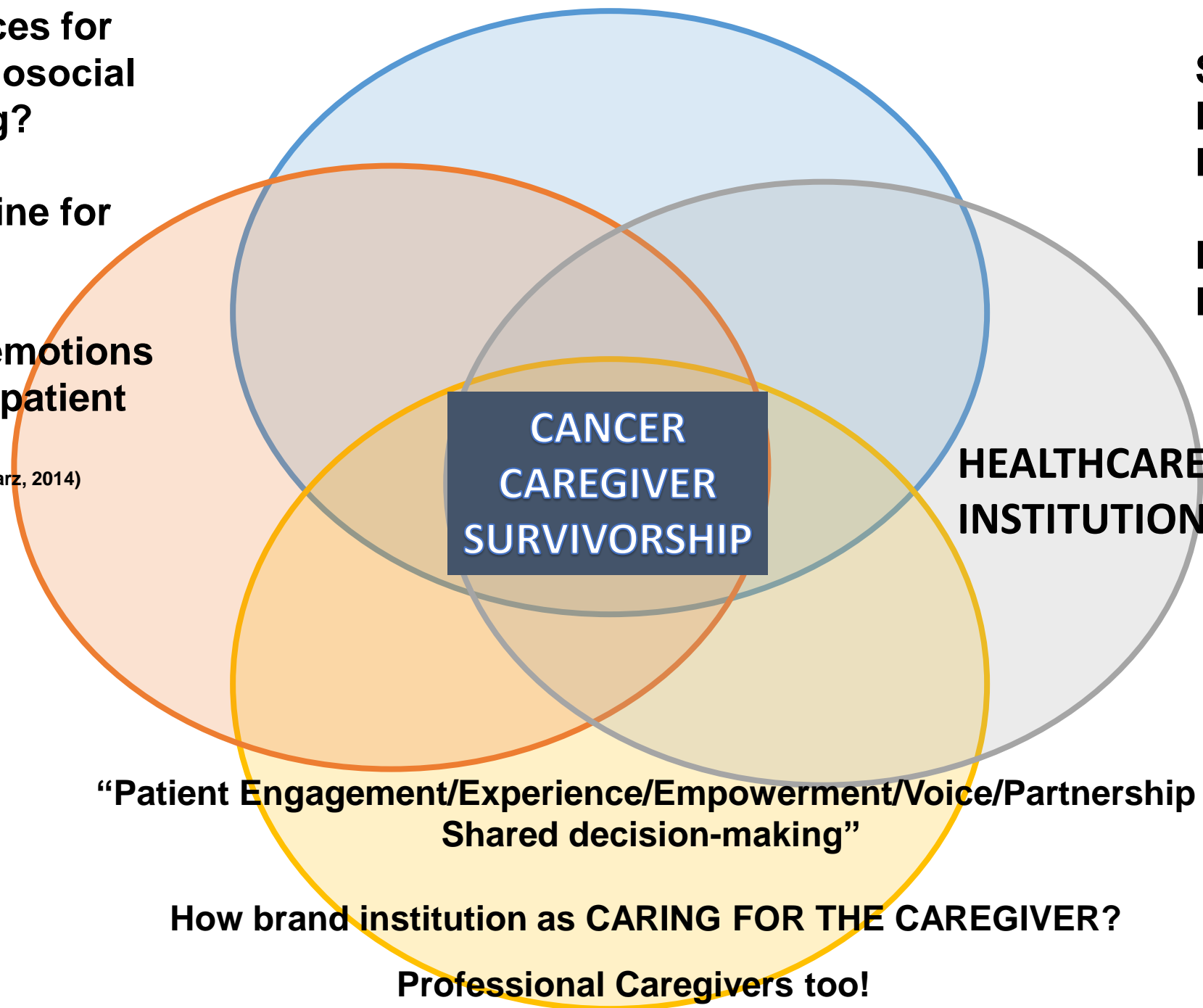
**Integrative Medicine for
caregiver?**

**Communication/emotions
skills training for patient
AND caregiver?**

(Tulsky et al, 2017, Hauser & Schwarz, 2014)

**Stress
Reduction?
Billing**

**Physical
Environment?**



**HEALTHCARE
INSTITUTION**

**“Patient Engagement/Experience/Empowerment/Voice/Partnership
Shared decision-making”**

How brand institution as CARING FOR THE CAREGIVER?

Professional Caregivers too!

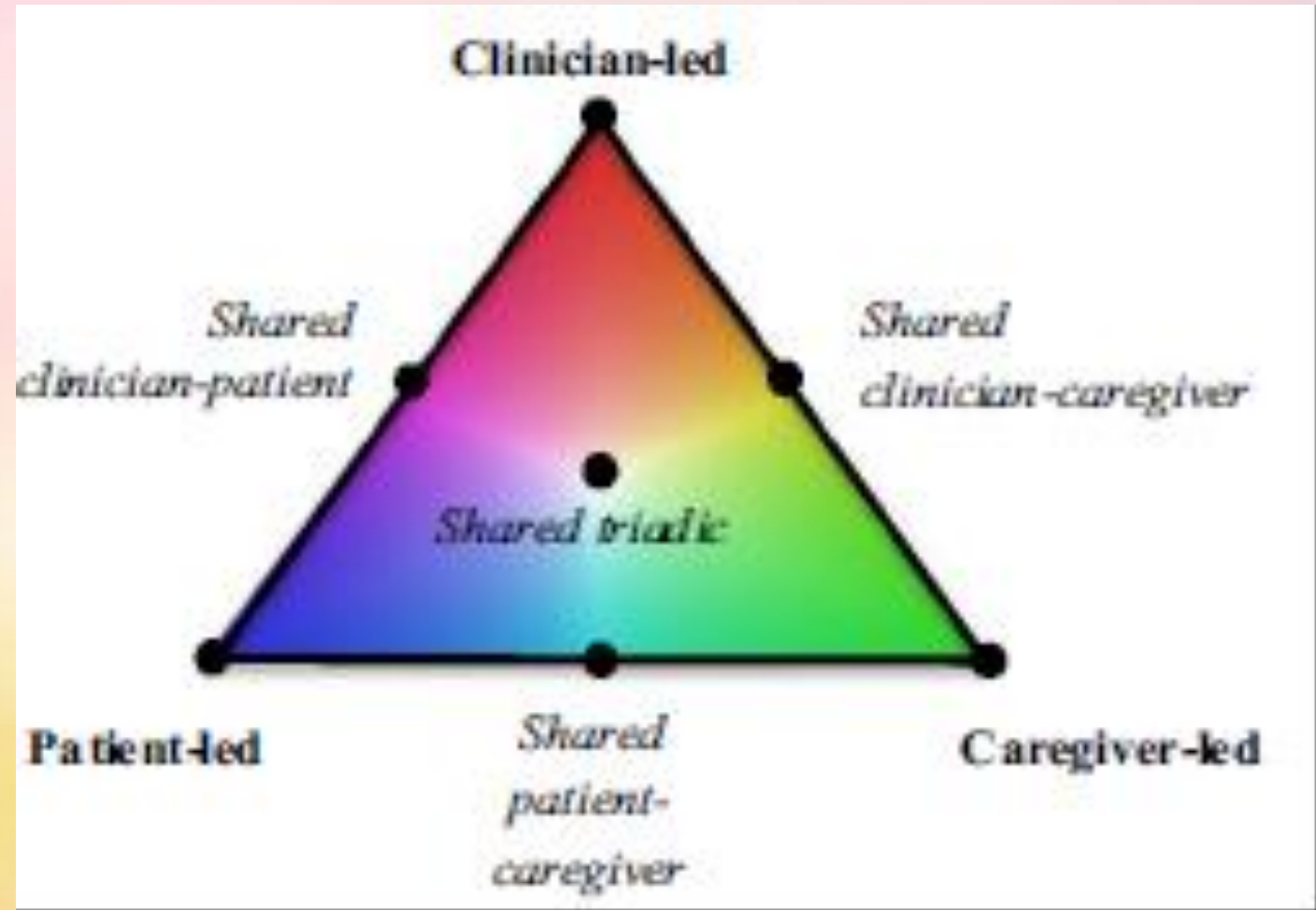
Shared Triad for Cancer Treatment Decision-Making ("TRIO" Framework, Powell et al, 2017)

CLINICAL TRIALS

Optimizing caregiver role for enrollment & success?

How convey story?

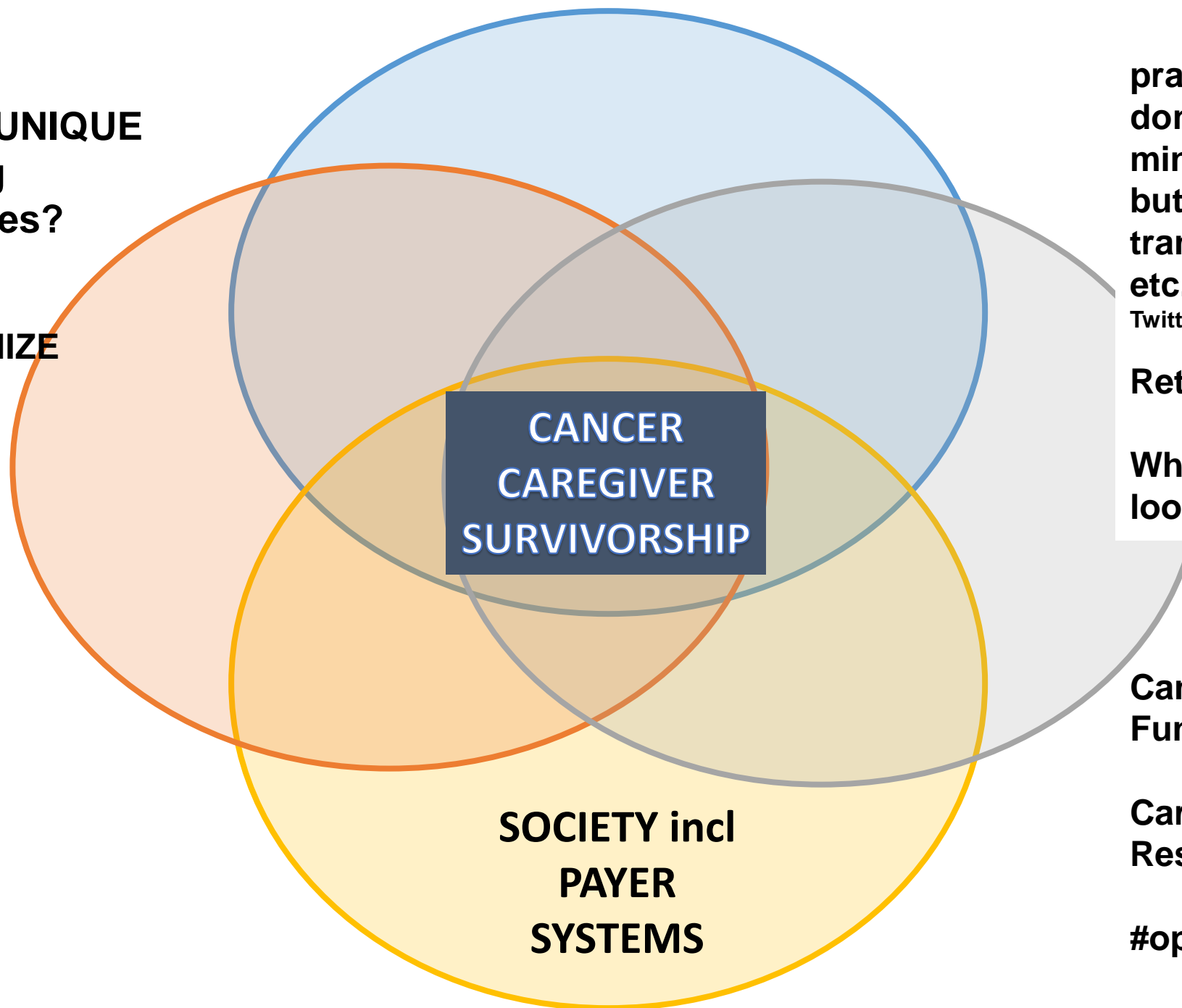
With > care provision at outpatient & community-based centers or home, how ease burden of > day-to-day demands on family caregivers? (Kent et al, 2016)



“The caregiver is critical to the success of a patient’s participation in a clinical trial” (Schnall)

**How create/fund
interventions for UNIQUE
cancer caregiving
experience features?**
(Kent et al, 2016)

DO NOT HOMOGENIZE



**practical help-
don't need crystals,
mindfulness or angels,
but respite, services,
transport, education
etc. #irishmed family carers,
Twitterchat @johpau**

Retraining?

**What could respite
look like?**

**Cancer Research
Funding!**

**Caregiver voice:
Research**

#openaccess

“We have been deported from the country of the well across the stark frontier that marks off the land of malady”

C Hitchens

**Can Society Bring Cancer Caregivers
Back From Exile?**

“REFUAH SHLEMA”



THANK YOU

**NASEM Health & Medicine
National Cancer Policy Forum**
Julia Rowland, PhD, Presenters, Attendees

hedy_wald@brown.edu

@hedy_wald

