Neurologist faces the other side of brain cancer

Cancer Caregiver Survivorship: An Integrative Approach

“Poised at the Abyss”
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Wald, HS. Commentary on Big Bang. Acad Med., 2017
FAmily Cancer Caregiver Experience

“FACE” this,
See our FACE Cancer-specific stress
Caregiver distress impacts patients
(Kent et al, 2016, Cancer; Eppel et al, PNAS)
HEALTHCARE TEAM

HEALTHCARE PRACTITIONERS, HEALTH PROFESSIONS EDUCATION

HEALTHCARE INSTITUTION

SOCIETY incl PAYER SYSTEMS

CANCER CAREGIVER SURVIVORSHIP

“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)

Caregiving in the US, Natl Alliance for Caregiving, 2015
www.thefamilycaregiver.org; CDC WMMR March 11, 2001
HEALTHCARE PRACTITIONERS, HEALTH PROFESSIONS EDUCATION

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

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

CANCER CAREGIVER SURVIVORSHIP

APPROACH TO CANCER CAREGIVER Presence? Story? Quality of life data
Quality of Care Coordination?

Support services/programs for caregivers’ psychosocial wellbeing integrated into care? Flow?

HEALTHCARE TEAM

Caregivers as part of the team

CANCER CAREGIVER SURVIVORSHIP

Ascertaining treatment details understood?

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

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

How brand institution as CARING FOR THE CAREGIVER?

Professional Caregivers too!

Stress Reduction? Billing

Physical Environment?
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?
THANK YOU

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

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