Genetics in Palliative Care (PC)

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Thanks to my colleagues, patients, and the Sapporo community

I have no financial relationships to disclose, nor will I discuss off-label or investigational usage of drugs.

My 1° career goal is to help make genetics work to help people and improve health.

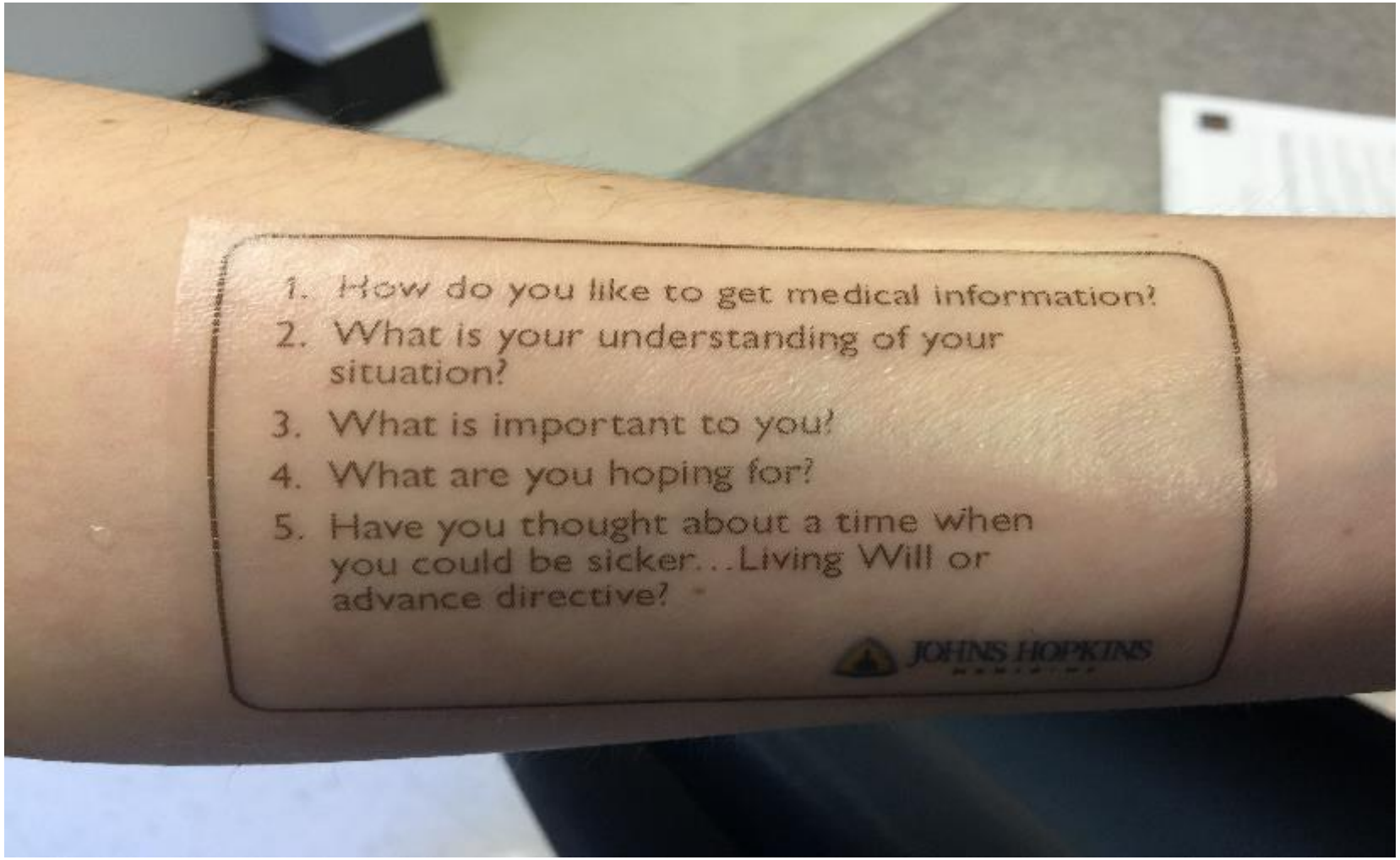
Terms

- **Family History (FH)**: A record of medical information and stories/ecological family information about an individual and their biological family
- **Genetic counseling (GC):** The process of helping people understand and adapt to the medical, psychological and familiar implications of genetic contributions to disease
- **Predictive genetic testing (GT)**: The use of a genetic test in an asymptomatic person to predict future risk of disease. This is best done after a relative with cancer has been diagnostically tested to identify the predisposing gene within the family
- **DNA Banking**: The collection and long term storage of genetic material
  - Genetic testing can involve complex and emotional decision making
  - Banking gives relatives time to seek counseling and carefully consider their options, without feeling pressured to pursue testing prior to a loved one dying
  - According to previous studies, many physicians (oncologists/palliative care providers) do not offer DNA banking and many are not aware of its availability

What do you think? What would you do?

The patient is a 32-year old woman dying with breast cancer in palliative care. Her mother died of some “female” cancer in her 30s when the patient was a young child. You overhear her ask her husband, “Do you think our 5-year old daughter will get cancer?”

How do you like to get **genetic** information?



Where in the cancer care continuum does the mother's question get addressed?

- Optimally upstream as part of active cancer care or preventive primary care with FH review

- But, if it comes up in palliative care, how do you handle it?

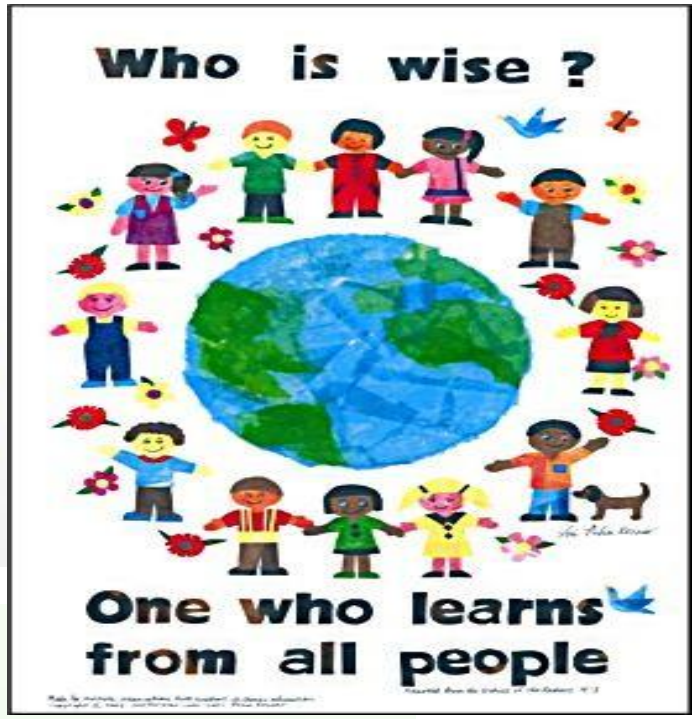
Alternatives

- Ignore?
- Encourage the patient to talk with her oncologist, primary care doctor, nurse, social worker, caregiver, child's pediatrician etc. about any genetic concerns?
- Ask?
  - What are your concerns for your daughter?
  - Are you worried about cancer risk in your family?
  - Have you ever talked with someone about your family history of cancer?
  - Do you want to talk with someone about your cancer and family history?
  - When would be a good time to talk about this? Learn about resources? Consider a referral to a genetics professional, genetic testing, and/or DNA banking?

Cultural humility is vital.

日本遺伝カウンセリング学会

Japanese Society for Genetic Counseling



Sapporo Conference for Palliative and Supportive Care in Cancer

2nd Sapporo Conference for Palliative and Supportive Care in Cancer

Dates	June16(Fri.)-17(Sat.),2017
Venues	Sapporo Park Hotel,Japan
Chair	Hideki Onishi (Saitama Medical University International Medical Center)

Key points

- Patients have
  - different languages
  - religious and scientific beliefs
  - ways of understanding their illness experience
- Culture fundamentally shapes how patients and families make meaning out of illness, diagnosis, suffering, and dying.

Key points

- Many dying individuals voice concern for the health of their surviving relatives.
- Genetic testing is frequently more useful when interpreted in the family context.
- Reality is under-recognition of family history implications prior to death.
- Genetic testing will continue to improve.

Key points

- Good communication practices can help in understanding patient & family preferences/needs.
- CA genetic counseling & testing are becoming important services in progressive cancer care – with diagnosis, in survivorship, at end of life, and with incorporation of family history throughout journey.
- Ethical frameworks influence what and how we communicate, e.g. what tests & treatments we offer.

Key points

- DNA banking (consideration of genetic testing) can be legacy act for the dying patient and costs ~150 US$.
- DNA banking may give relatives time to seek counseling and consider testing decisions.
- Performing testing earlier in life likely preferable, but it often has not happened.

We learn from each other across families, miles, and years.

40 years ago @ Kawatana Byoin

- 3 teen-age brothers dying with Duchenne muscular dystrophy
- What thoughts and feelings do you bring to the table?
  - Genetic counseling with mother at diagnosis in first son
  - Hoping for best without discussion

Mental model

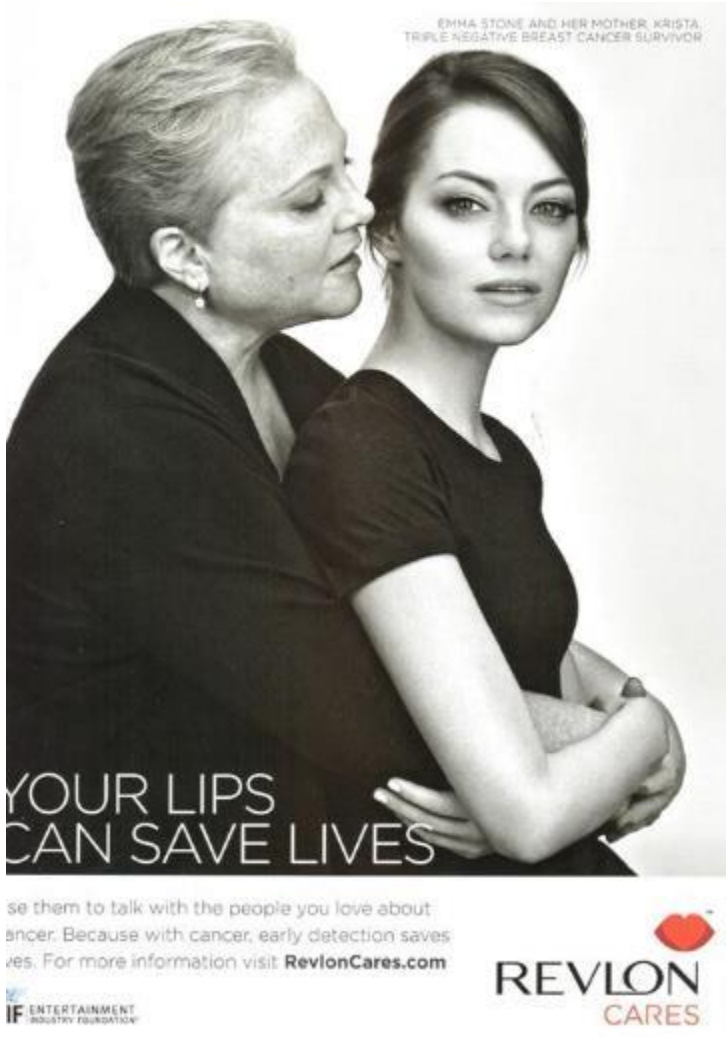
Family Health History

(FH) matters.

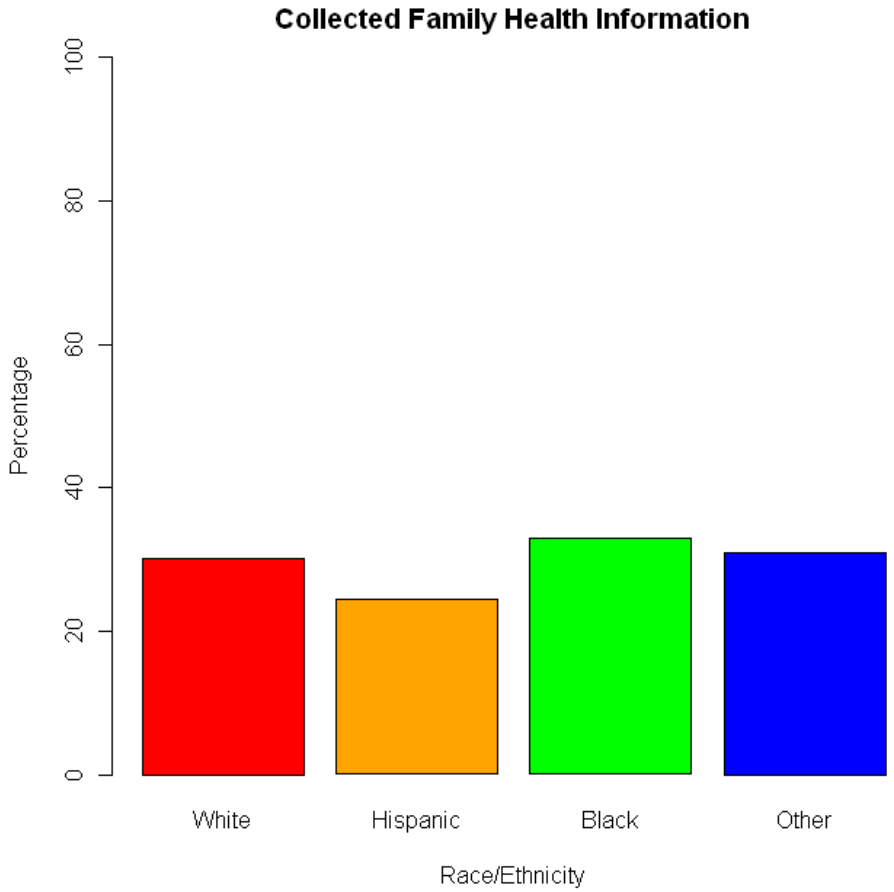
FH discussion is a central family communication tool to improve public health prevention, family health, and well-being, voila

More healthy

birthdays!

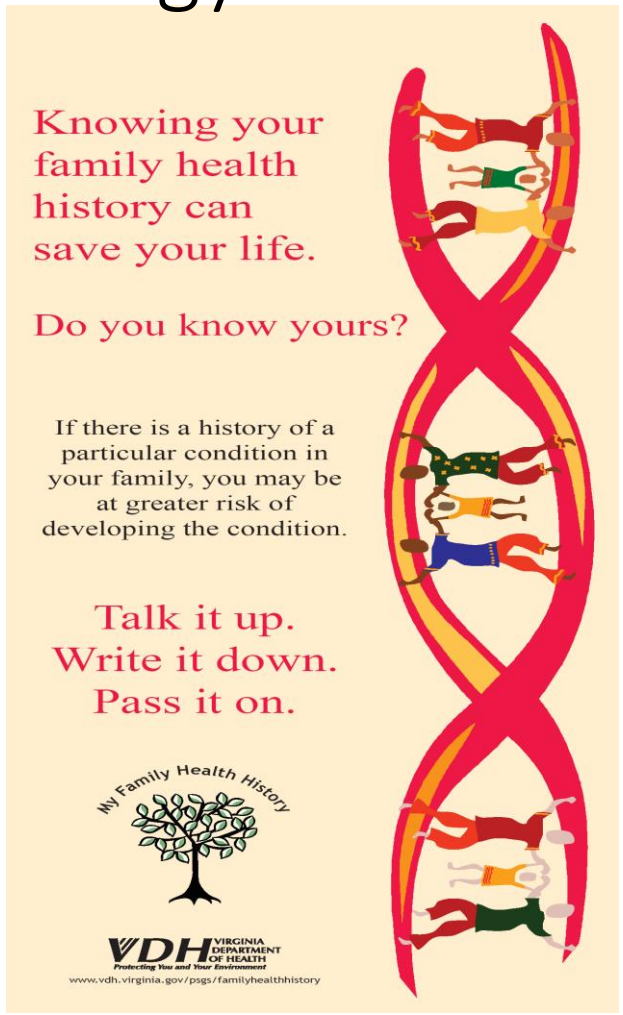


96% of Americans believe that family history is important to health. Yet, only about 30% have tried to collect and organize their family history information.



http://www.cdc.gov/genomics/resources/diseases/family.htm

What have you done lately about FH in your own family and oncology work?



- Talking it up?
- Writing it down?
- Passing it on?

What We Know about Family Health History

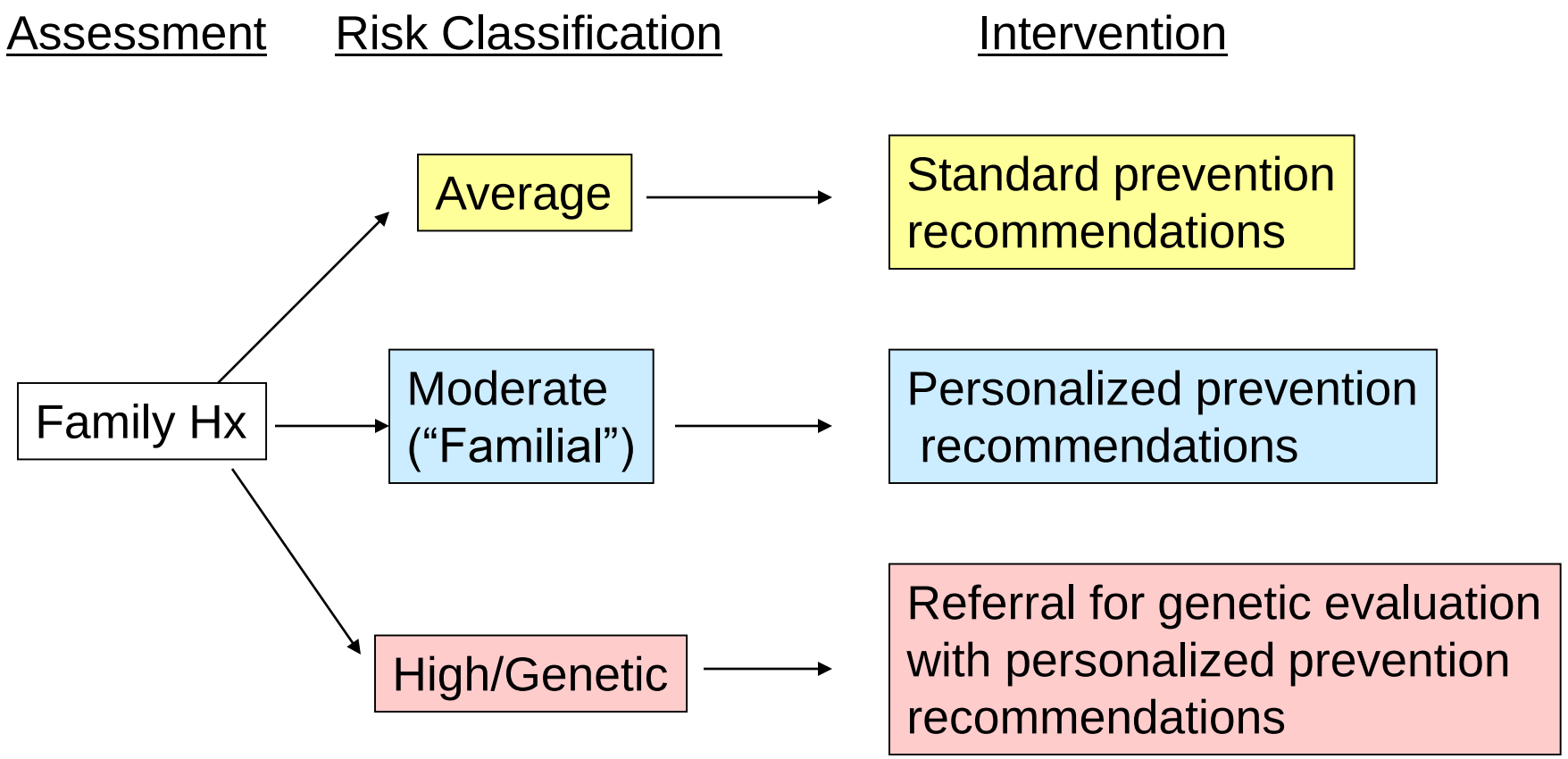
- Accuracy is OK for close relatives (95% for breast CA, 90% for colon CA) (Ziogas et al., 2003)
- Has potential to motivate positive behaviors
- Generally does not increase anxiety
- Clinicians vary with respect to FH collection:
  - Residency training and length in practice
  - Time with patient
  - Available FH collection tools
- More likely to report FH to your doctor if you are:
  - Female
  - Have insurance
  - Moderate to high SES

NIH Consensus Conference, 2009

Challenges with FH

- Small family size
- Small number of people of the susceptible sex in sex-specific CAs.
- Inaccurate/incomplete/missing information about the FH (e.g. adoption, non-paternity).
- Parents and other 1st or 2nd degree relatives of pediatric patients are often young, and CA may not have developed yet.
- Family communication issues
- Emotional/social/cultural (shame, guilt) issues

Goal: Tier risk
Who needs what?



SIDE questions

- Mother's side Father's side

Any **S**imilar problems?

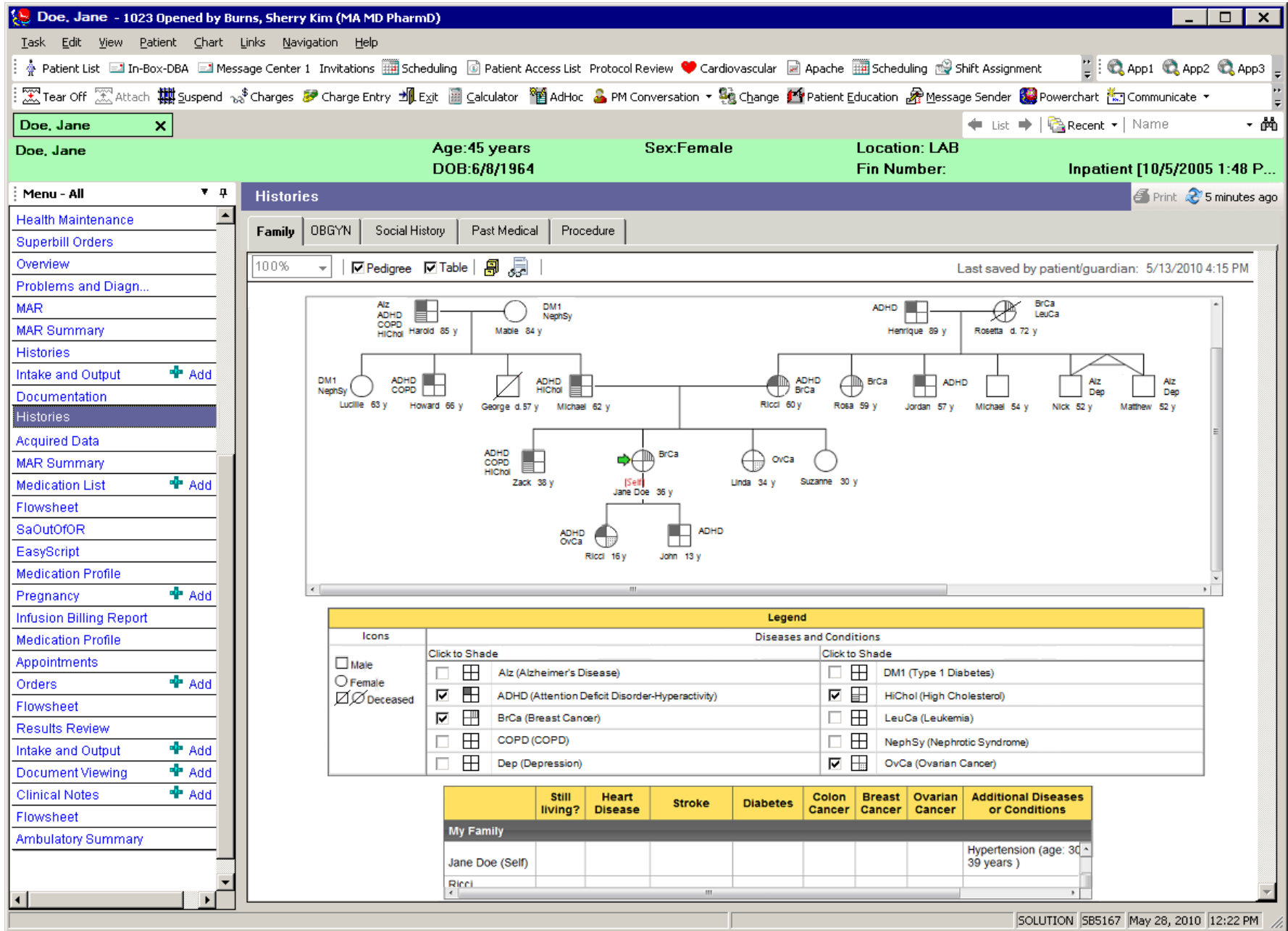
Any **I**nherited conditions in family?

Any unexplained **D**eaths < 50 yoa?

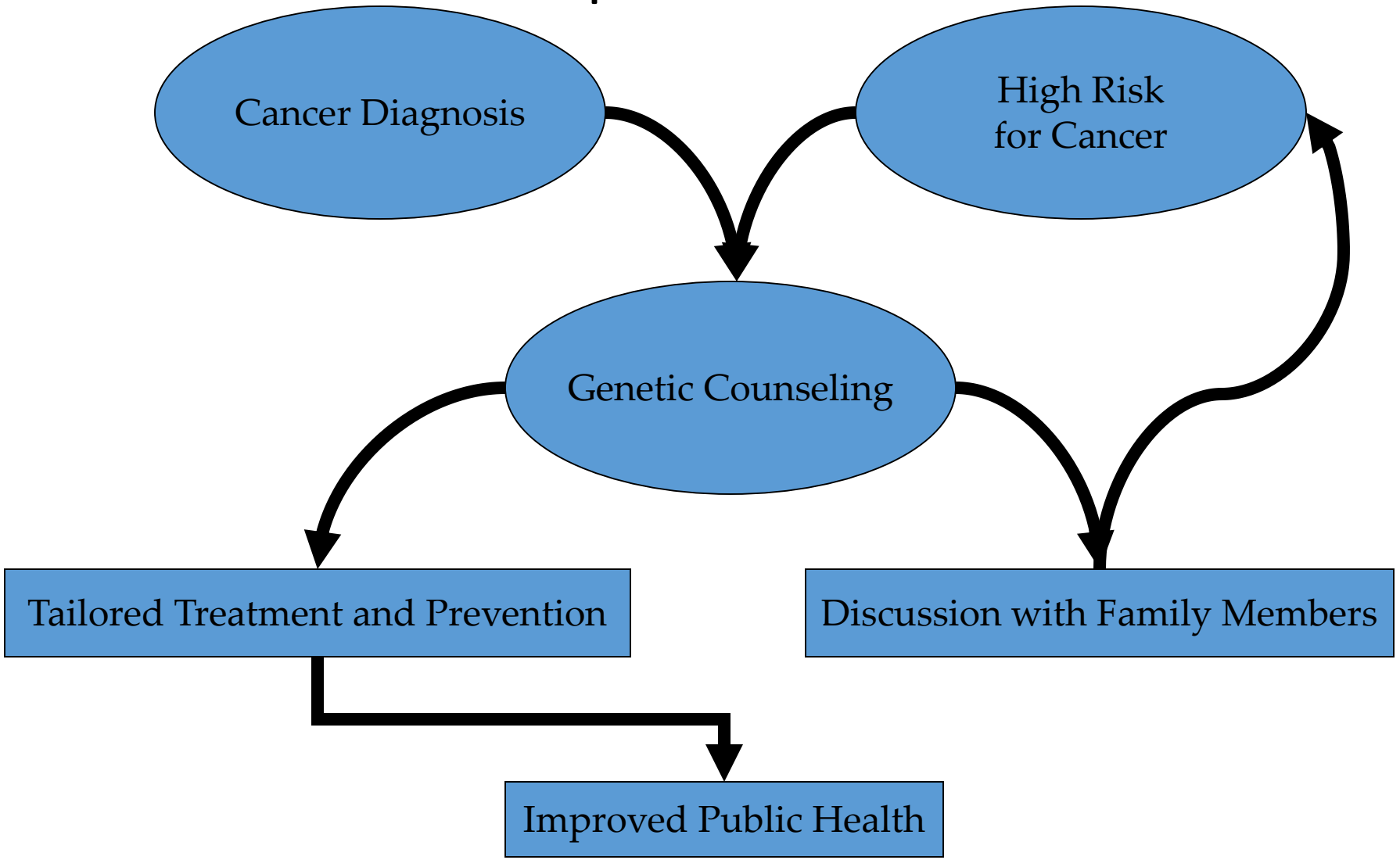
Any **E**xtraordinary lab results, health events, genetic testing?

Electronic Tools

Image courtesy of https://familyhistory.hhs.gov/fhh-web/home.action

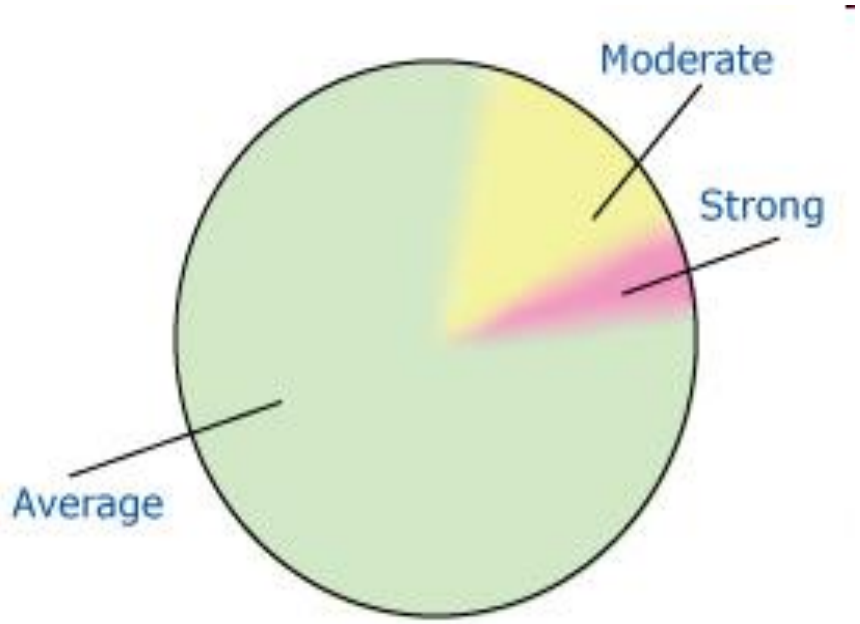

Doe, Jane - 1023 Opened by Burns, Sherry Kim (MA MD PharmD)
Task Edit View Patient Chart Links Navigation Help
Patient List In-Box-DBA Message Center 1 Invitations Scheduling Patient Access List Protocol Review Cardiovascular Apache Scheduling Shift Assignment App1 App2 App3
Tear Off Attach Suspend Charges Charge Entry Exit Calculator AdHoc PM Conversation Change Patient Education Message Sender Powerchart Communicate
Doe, Jane
List Recent Name
Doe, Jane Age:45 years Sex:Female Location: LAB
DOB:6/8/1964 Fin Number: Inpatient [10/5/2005 1:48 P...
Menu - All
Health Maintenance
Superbill Orders
Overview
Problems and Diagn...
MAR
MAR Summary
Histories
Intake and Output Add
Documentation
Histories
Acquired Data
MAR Summary
Medication List Add
Flowsheet
SaOutOfOR
EasyScript
Medication Profile
Pregnancy Add
Infusion Billing Report
Medication Profile
Appointments
Orders Add
Flowsheet
Results Review
Intake and Output Add
Document Viewing Add
Clinical Notes Add
Flowsheet
Ambulatory Summary
Histories
Print 5 minutes ago
Family OBGYN Social History Past Medical Procedure
100% Pedigree Table
Last saved by patient/guardian: 5/13/2010 4:15 PM
Alz ADHD COPD HiChol Harold 85 y
DM1 NephSy Mable 84 y
ADHD Henrique 89 y
BrCa LeuCa Rosetta d. 72 y
DM1 NephSy Lucille 63 y
ADHD COPD Howard 66 y
George d. 57 y
ADHD HiChol Michael 62 y
ADHD BrCa Ricci 60 y
BrCa Rosa 59 y
ADHD Jordan 57 y
Michael 54 y
Alz Dep Nick 52 y
Alz Dep Matthew 52 y
ADHD COPD HiChol Zack 38 y
BrCa [Self] Jane Doe 36 y
OvCa Linda 34 y
Suzanne 30 y
ADHD OvCa Ricci 16 y
ADHD John 13 y
Legend
Icons
Male
Female
Deceased
Diseases and Conditions
Click to Shade
Alz (Alzheimer's Disease)
ADHD (Attention Deficit Disorder-Hyperactivity)
BrCa (Breast Cancer)
COPD (COPD)
Dep (Depression)
DM1 (Type 1 Diabetes)
HiChol (High Cholesterol)
LeuCa (Leukemia)
NephSy (Nephrotic Syndrome)
OvCa (Ovarian Cancer)
Still living?
Heart Disease
Stroke
Diabetes
Colon Cancer
Breast Cancer
Ovarian Cancer
Additional Diseases or Conditions
My Family
Jane Doe (Self)
Hypertension (age: 30 39 years)
Ricci
SOLUTION SB5167 May 28, 2010 12:22 PM

Where does it fit in palliative care?



Familial Disease

- ~5-10% of cancers & heart disease have a major genetic component
- ~8% of children with CA have a germline mutation
- National guidelines re high-risk families
- In Japan
  - HBOC
  - Lynch syndrome



Some Japanese reports (in English!)

- In 2012 Asian ARCA survey, Japan reported not offering chemoprevention, contralateral mastectomy, prophylactic mastectomy and did offer annual MRI, RRSO with self-pay for genetic testing offered at 80 centers offering full services Nakamura et al 2015
- 2010 survey of breast cancer specialists – ¼ of facilities providing CA genetic services, 36% aware of potential risk of HBOC, 14% recommended young BC patients to visit genetic specialists Bando 2014

Some Japanese reports (in English)

- Patient-completed questionnaires for assessment of hereditary gynecologic CAs have clinical utility Masuda et al 2017
- In 2015 survey, 8% of CA departments conducted universal screening for Lynch syndrome Yamano et al 2017
- 40 individuals from 33 families with Lynch syndrome – 75% advised their relatives to seek medical assessment, tended to speak with spouses 1st, "to avoid feeling the same sorrow" was most common reason for encouraging relatives Ishii et al 2011

PTEN hamartoma syndrome

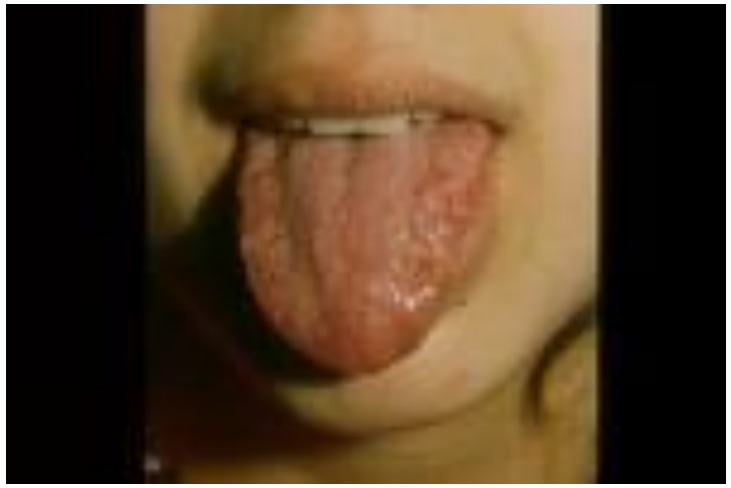
Cowden and Bannayan-Riley Ruvalcaba syndrome

PTEN, *SDHB*, *SDHD*, and *KLLN* mutations

Autosomal dominant with increased breast, endometrial, thyroid and other CAs

Some patients with large heads, intellectual disability, penile freckling

trichilemmomma



oral mucosal papillomatous growth

Example of a common CA & criteria that warrant assessment for cancer risk

Cancer	When to refer to genetic counselling	Syndromes to consider
Breast cancer	• Dx at age ≤50 •Triple-negative dx at age ≤60 • ≥2 primary breast cancers in the same person • Ashkenazi Jewish ancestry and breast cancer at any age • ≥3 cases of breast, ovarian, pancreatic, and/or aggressive prostate cancer in close relatives, including the patient • Breast cancer and one additional LFS tumor in the same person or in two relatives, one dx at age ≤45 • Breast cancer and ≥1 PJ polyp in the same person • Lobular breast cancer and diffuse gastric cancer in the same person • Lobular breast cancer in 1 relative and diffuse gastric cancer in another, one dx at age <50 • Breast cancer & 2 additional Cowden syndrome criteria in the same person	•HBOC, OMIM: 604370, 612555; LFS, OMIM 151623 • PJS, OMIM 175200 • HDGC, OMIM 137215 • Cowden, OMIM 158350

Who decides in family-centered care?

Cancer patient's top 3 questions*

1. Am I going to die?
2. What will my treatment be and how long will it take? (because I can't afford to miss time from work)
3. What will happen to my children? Will they get cancer?

*Lillie Shockney, JH CA survivorship leader

The PC setting dynamics

- Many people with advanced CA will have contact with PC health professionals for holistic care at the end of their lives.
- Discussions and assessment of cancer FH do not always take place in this phase of the patient's illness and the reasons include:

- Low levels of confidence of staff in dealing with genetic issues
- Perceived inappropriateness of the topic at this time
- Potential distress for patient and family
- Decisions regarding genetic testing/DNA banking are complex and can have profound emotional, familial and financial implications on those affected (like cancer itself)

Why Should We Pursue It?

- Many dying patients voice concern for the health & well-being of surviving relatives
- It may serve as a “teachable moment” about familial risk and motivate healthy behaviors for family members
- It may be the last opportunity for an:
  - elderly relative to document the family history of CA for future generations
  - affected family member to give blood to enable other family members to undergo predictive genetic testing
- It has also been suggested that disease progression, especially being told that CA is incurable, can provoke fears about genetic disease that are not given a voice.

Listening and providing the evidence

- What are genetic realities in PC setting?
- What do patients want?
- What do PC providers know?
- How do we enhance family history communication, risk perception, and prevention behaviors with individuals and families?

Our own work in PC inpt. settings

Structured interviews with chart reviews

VCU – 43 patients in 2008

- 74% enrollment, ½ African-American, mean age – 55y
- Of the 15 most frequent PC admission diagnoses ~1/3 had a significant genetic component
- 9/43 (21%) dying patients had a strong genetic risk. None of the patients had prior GC, testing or DNA banking

Johns Hopkins – 75 patients in 2016-17

- 75% enrollment; 27% black, mean age – 64y , 55% male
- At least 27/75 (36%) with high CA risk for 1st, 2nd degree relatives (Hampel et al criteria)
- 14/75 (19%) had no FH chart documentation

Key findings – 75 participants with cancer, PC consultation, interview and chart review

- Minimal referrals/visits for genetic counseling (2/75; one in distant past and one related to pregnancy) from chart review
- Minimal germline genetic testing (1 for BRCA, 1 for hemochromatosis); 2/75 (3%)from chart review
- Patients did not make clear distinction between germline vs. somatic testing when answering that they had had genetic testing – 11/75 (15%); per chart review, 27/75 (36%) with somatic testing, 2/75(3%) with germline testing

Patient preferences re resources

For genetic testing

- Conversation with MD/nurse (83%)
- Written materials (71%)
- Appointment with genetic specialist (69%)
- Not interested (3%)

For sharing test results with family

- My health professional talk with them (51%)
- A letter from my health professional (39%)
- Written material (29%)
- Would not share (1%)

Genetic testing – awareness and attitudes about Angelina Jolie's HBOC

- 54% men and 76% women aware of story
- 72% thought she did the right thing in sharing her story

Palliative care physician perspectives

- 2008 US survey of palliative care oncologists (n=133) in AAHPM
- 37% response, 1/3 female and mean age – 53.8 yrs
- ~80% assessed genetic risk for at least one patient
- None had banked DNA in preceding 12 mos.
- ~2/5 said they were “not qualified at all” to recommend DNA banking
- ~1/5 responded correctly to all the content questions
- ~3/5 wanted Web-based risk assessment tool & genetic counselor on staff

Keeping Information about Family Cancer Tune-Up "Kin FACT"

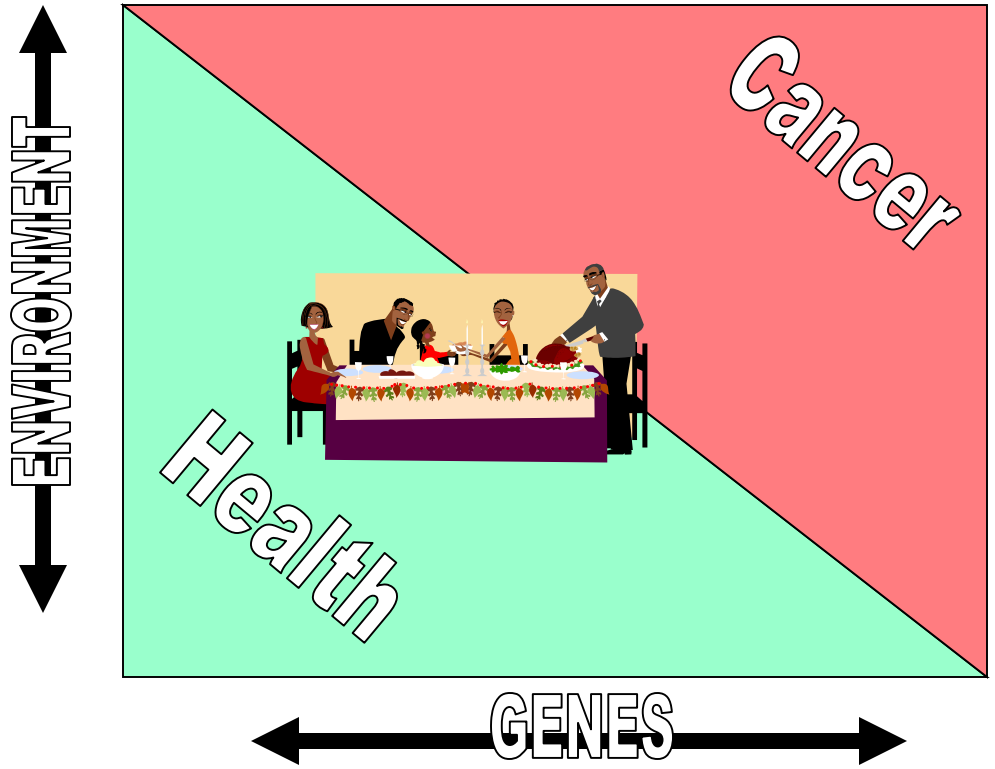
- Assess risk for breast and colon cancer
- Randomization
  - Provide tailored recommendations, including genetic counseling referral
  - Train effective family history communicators
- Baseline, follow up at 1, 6, and 14 months
- Outcomes
  - Process
  - Family history communication
  - Prevention
  - Genetic counseling

Talking about Cancer in the Family Could Save Your Life

Do I know my Kin Facts?

A guide for Jada Doe and my family

Why do you need to talk with your family?



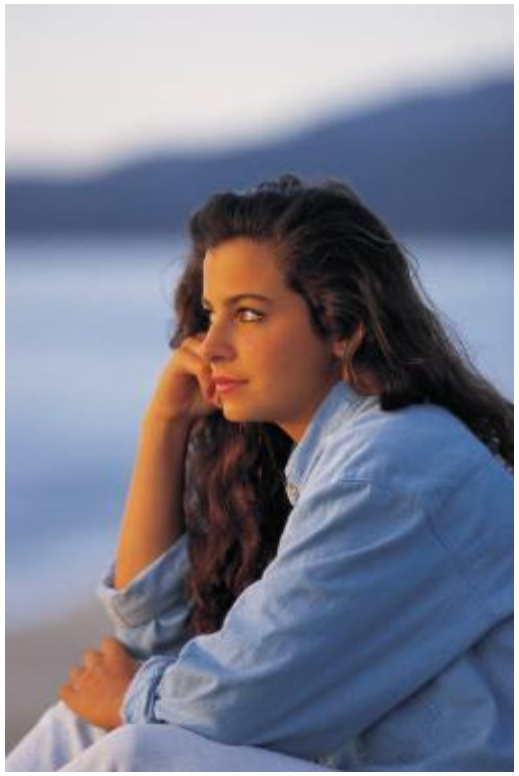
Basic Principles of Communication

- You cannot not communicate
- Communication is a two-way activity
- Words & actions are interpreted by the receiver
- Much communication is nonverbal
- Listening is the most important part of communication

What is the health and cancer story in your family?

Did men and women both talk openly about health problems?

Did your grandparents talk about their health problems?



Does your family take on healthy habits together?

Were they afraid to say the word “cancer”?

Did anyone in your family have cancer? What was that experience like?

Be a good communicator

- **Show them you are listening & focus on the moment**
  - Affirm
    - Say, *“Uh, huh”*
    - Say, *“I see”*
  - Probe
    - Say, *“Tell me more”*
  - Rephrase what you hear
    - Say, *“What I hear you saying is…”*
    - Say, *“It sounds like…”*
    - Be a mirror

Ask

- What do they already know?
  - *“What do you know about our family history of cancer”*
  - *“What do you know about cancer risk in our family?”*
  - *“What do you know about how to prevent cancer in our family?”*

Can we talk about what I learned from the Kin Fact program about family cancer risk?

How can I be a good communicator?

- **Listen**
  - Affirm
    - “Uh, huh”
    - “I see”
  - Probe
    - “Tell me more”
  - Rephrase what your hear
    - “What I hear you saying is…”
    - “It sounds like…”
    - Be a mirror

Make a Plan with your Family Member

- *“Who else do we need to talk to?”*
- *“What else do we need to know?”*
- *“When should we talk about this again?”*
- *“What are we going to do to lower cancer risk?”*

Remember Your Kin Facts

- Families share genes, behaviors and environments that can lead to breast and colon cancers
- Your family can reduce their risks
- Talk with your relatives about the family cancer story and how to stay healthy

Results and Next Steps

- Results
  - intervention effect +
  - OR =2.73 (95% CI 2.01,3.71) for gather
  - OR =1.85 (95% CI 1.37,2.48) for share
  - Communication frequency increased (1.67 vs. 1.54)
  - Differences not modified by age, race, education, family history
  - Women with low genetic literacy did not show differences for gathering information

- Learn about the process and refine the intervention

Findings from the literature

- Some groups may trust health information from family +/or internet more than MD
- Family communication may be more understandable (accurate?) because not medical jargon
- Stories may have stronger effects on patient decision-making
- “Communicomics” occurs within micro (clinical) and macro (media) environments as individuals bond and bridge within and across families and networks

The legacy of cancer: why a health promoting approach is so important in PC – Baker et al 2015

- 27 interviews in UK with advanced CA patients

  -patients had more + attitude to CA than relatives

  -legacy work that their situation would positively impact others in the future

  -supported a health promotion approach in which PC extends to people that matter to the patient

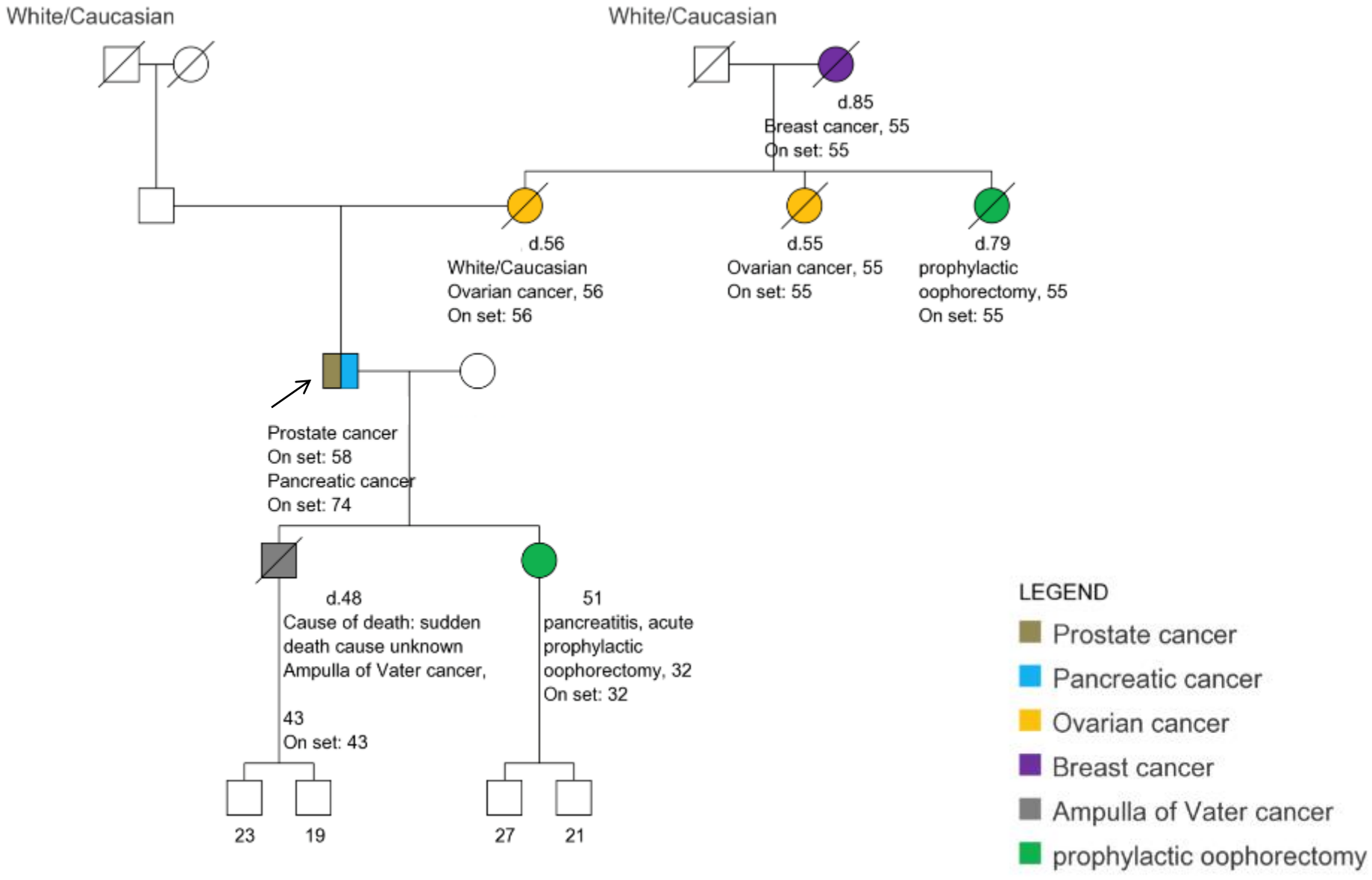
  -extend concept of making every contact count

Moving Forward

- Genetic counselors, medical geneticists, and genetic nurses facilitate comprehensive genetics evaluations, assist in test selection, provide informed consent, and education patients & family members about indications for and costs of testing and banking.
- No consensus on who should be approached or any specific communication strategies
  - “I’d like to talk with you about your family health history. Some health conditions tend to run in families and knowing your health history and seeing if it is connected to your illness could help others in your family to stay healthy. Most diseases are not strongly genetic, but sometimes it is helpful to have a genetic test or store a blood sample for testing later.”

Story 1: hereditary cancer

- The patient was a 75-year-old man diagnosed at age 58 with prostate cancer who presented with pancreatic cancer at age 74.
- His family history included a son diagnosed with an ampullary carcinoma at the age of 43, a mother and maternal aunt who died of ovarian cancer in their 50s, and a maternal grandmother with breast cancer at age 55.


White/Caucasian
White/Caucasian
d.85
Breast cancer, 55
On set: 55
d.56
White/Caucasian
Ovarian cancer, 56
On set: 56
d.55
Ovarian cancer, 55
On set: 55
d.79
prophylactic
oophorectomy, 55
On set: 55
Prostate cancer
On set: 58
Pancreatic cancer
On set: 74
d.48
Cause of death: sudden
death cause unknown
Ampulla of Vater cancer,
43
On set: 43
51
pancreatitis, acute
prophylactic
oophorectomy, 32
On set: 32
23
19
27
21
LEGEND
Prostate cancer
Pancreatic cancer
Ovarian cancer
Breast cancer
Ampulla of Vater cancer
prophylactic oophorectomy

Better ending?

- The patient underwent a 29-gene hereditary cancer panel that included the APC, ATM, BMPR1A, BRCA1, BRCA2, BRIP1, CDH1, CDK4, CDKN2A, CHEK2, EPCAM, MEN1, MET, MLH1, MSH2, MSH6, MUTYH, NBN, PALB2, PALLD, PMS2, PTCH1, PTEN, RAD51C, RET, SMAD4, STK11, TP53, VHL genes.
- Within days of the genetic testing being ordered, the patient rapidly declined and expired before the results were available. The patient was found to have a pathogenic PALB2 c.1671_1676delinsGC (Phe557Leufs*3) mutation.
- This result was disclosed to the patient's wife and daughter.

More Challenges in End-of-Life Genomic Testing

- Improved genetics training for all health-care professionals
- Avoiding “one-size-fits-all” policies
- Promotion of individual and family choices

Reasons for DNA Banking

- Simple and inexpensive step to preserve genetic legacy to benefit the patient's family and future generations by providing access to information in the future that can help them better understand their own risk for disease.
- Patient may have a specific health condition and is concerned that other family members might be at risk for the same problem.
- Current technology has failed to find a genetic cause for what appears to be an inherited disease in the patient's family.
- Correct interpretation of DNA test results in a family member may only be possible through testing of one's DNA.
- Patient has a terminal illness and there is no time for standard genetic evaluation or testing.
- Genetic testing is not feasible, affordable, and/or not available to one as an affected individual right now, but may be available in the future.

Our JH PC study and DNA banking

~40% could give some definition

~85% had heard almost nothing, very little about it

~5% had banked their own DNA

~5% believed a relative had

~72% would consider banking their DNA

~45% willing to pay something to bank their DNA

Voluntariness of Consent

- Dying patients vulnerable
- Consent should be voluntary
- Some degree of guilt, feeling of obligation probably unavoidable
- Careful discussion can help prevent coercion

Your Cancer Genetics Plan

- **Know your Family History – talk it up, write it down, pass it on**
- **If Ashkenazi Jewish, young age, 2 or more relatives with BC/OC (esp. premenopausal) multiple CAs, talk with your PCP**
- **If multiple CCs, polyps in FH – talk with your PCP**
- **If you have CA, discuss with your oncologist/surgeon**
- **It is getting more complex – additional tests, need informed consent and understanding of test limitations**
- **High risk screening recommendations - different and evolving**
- **1-800-4CANCER, FORCE *www.facingourrisk.org*, *AACR***
- **Take care of yourself**
- **Consider genetic counseling (NSGC.org)**

Key points

- Family history involves social and genetic determinants
- Precision medicine needs matching with precision communication
- Technologies will advance &need trusted systems so disparities do not increase
- Communication is central to well-being, healthcare, and health behaviors
- Knowing your risk can provide prevention opportunities, focus screening, and tier strategies

When to refer to genetics?

- Positive **3, 2, 1** criteria:

- **Three** affected relatives with the same/associated CAs
- Across **two** generations
- With at least **one** person affected age <50 years.

The Present/Future

- Screening tailored to risk (e.g. MRIs with mammograms)
- Prevention tailored to risk (e.g. Tamoxifen/Raloxifene/aromatase inhibitors, preventive surgery)
- Therapies tailored to gene tests (e.g. choice of chemotherapy drugs, dosing of radiation)
- Just like we have moved forward with open discussions of cancer, smoking harms, palliative care and death, we may one day better integrate family history and genetic concerns in palliative care

Continuing support, survivorship, and lifelong issues

- Ask-tell-ask
- Listen
- Negotiate
- Give hope
- Consider developing systems that give options so families have choices

Thanks for listening and being patient- and family-centered.

- Thanks to my patients, colleagues, and Japanese friends.

Resources

- 1. Fast Facts: Genetic Screening and DNA Banking at the End of Life #206. Quillin J, Bodurtha J, Smith T
- 2. Genetics Assessment at the End of Life: Suggestions for Implementation in Clinic and future research. Quillin J, Bodurtha J, Smith T
- 3. Exploring Hereditary Cancer Among Dying Cancer Patients – A Cross-Sectional Study of Hereditary Risk and Perceived Awareness of DNA testing and banking. Quillin J, Bodurtha J, Siminoff LA
- 4. A practice guideline from the American College of Medical Genetics and Genomics and the National Society of Genetic Counselors: referral indications for cancer predisposition assessment. Hampel H, Bennett R
- 5. Hereditary Cancer, March 2015: A presentation by J Quillin, H Creswick
- 6. Prevention Genetics https://www.preventiongenetics.com/DNABanking/reasons.php
- 7. Germline Mutations in Predisposition Genes in Pediatric Cancer. Zhang J et al. NEJ Med 2015; 373:2336-2346 December 10,2015. http://www.nejm.org/doi/full/10.1056/NEJMoa1508054#t=articleDiscussion

Resources

- Genetests.org; Genetic Testing Registry; ASCO; ACMG; NSGC
- Lakhani NS1, Weir J, Allford A, Kai J, Barwell JG. Co triaging family history of cancer during palliative care enable earlier genetic counseling intervention? J Palliat Med. 2013 Nov;16(11):1350-5.
- Qullin J et al. Genetics assessment at the end of life: Suggestions for implementation in clinic and future research. Jnl Pall Med 2008; 11:451-458
- Quillin J et al. Exploring hereditary cancer among dying cancer patients – A cross-sectional study of hereditary risk and perceived awareness of DNA testing and banking. J Gen Counsel 2010; 19:497-525
- Quillin J, Bodurtha J, Siminoff LA, Smith TJ. Physicians' current practices and opportunities for DNA banking of dying patients with cancer. Jnl Onc Pract 2011; 7:183-187
- Quillin J, Bodurtha J, Smith T. Genetic screening and DNA banking at the end of life #206. Fast Facts and Concepts
- Skirton H et al. A legacy for the children – attitudes of older adults in the United Kingdom to genetic testing. J Clin Nurs 2006; 15:565-573
- Stephen H et al. End-of-life care discussions with nonmalignant respiratory disease patients: a systematic review. Palliat Med 2013; 16:555-65.

Genetics Resources

- Genetics Home Reference http://www.ghr.nlm.nih.gov
- GeneReviews, GeneTests
- The Alliance (1-800-336-GENE)
- OMIM®(On-line Mendelian Inheritance in Man)
- Smith's Recognizable Patterns of Human Malformation (Jones K, Saunders pub)
- U.S. Surgeon General's Family History Initiative www.hhs.gov/familyhistory/
- CDC www.cdc.gov/genomics/public/fam-hist.htm
- Massey Cancer Center http://www.massey.vcu.edu/pdf/FamilyHealthHistory.pdf
- CancerNET
- HuGE NET – www.cdc.gov/genetics/hugenet/default.htm
- National Guidelines Clearinghouse – www.guideline.gov
- National Society of Genetic Counselors – www.nsgc.org
- Genetic counselor directory National Society of Genetic Counselors http://www.nsgc.org
- Laboratories offering DNA banking http://www.genetests.org