

THE EHR & WHAT IT DOESN'T TELL US



MISPERCEPTIONS AND MISSED OPPORTUNITIES

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DISCLOSURES

 The speaker has no conflicts of interest to disclose

OVERVIEW

- Interactions with the EHR
 - Care Team Members
 - Individuals
- Case Study: Fragrance Sensitivity
- 4 Key Takeaways

INTERACTIONS WITH THE EHR



WHAT THE CARE TEAM SEES IN THE EHR

- Personal/family history
- Test results
- Diagnoses (a.k.a. "The Problem List")
- Treatment history
- Health outcomes & patient-reported outcomes measures (PROMs)
- Social Determinants of Health (SDOH) information
- *Person-generated health data (PGHD) not standard

WHAT THE CARE TEAM DOES WITH THE EHR

- Update personal and family histories
- Review diagnoses and previous care
- Check test results and PROMs
- Order things (tests, Rx medications, durable medical goods, referrals)
- Schedule appointments and consultations
 - Internal (social services, pastoral care, Child Life)
 - Skilled nursing care
 - Evaluation for hospice

WHAT THE INDIVIDUAL EXPERIENCES

- Changes in personal health (positive/negative)
- Changes in effectiveness of, tolerance for treatment
- Changes in function (recognized and unrecognized)
- Inaccuracy/incompleteness of the EHR
- Changes in access to care
 - Insurance
 - Provider network changes
 - Transportation
 - Ability to pay

WHAT GETS MISSED

- Impact of illness or disability on daily life
- Impact of changes in personal circumstances
 - Change/loss of family, caregivers
 - Change/loss of employment/income
 - Change/loss of housing
- Impact of these changes on the individual's health and ability to function in all their roles and environments



CASE STUDY

FRAGRANCE SENSITIVITY

- Fragrance: a concentration of chemical substances that have an odor
 - 2,000+ used in consumer products, with preservatives, fixatives, etc.
 - A fragrance may contain 10s to 100s of compounds
 - Some ingredients used to make fragrance linger in the air
 - Some ingredients used to mask unpleasant odors
 - Fragrance composition typically proprietary
- Symptoms: Variable, may include respiratory, dermatologic, GI, others
- Diagnosis: Patch testing can identify some sensitivities
- Prevalence: up to 4.5% in testing for specific compounds; 20%-25% among people tested for contact dermatitis

WHAT THE CARE TEAM SEES IN THE EHR

- Symptoms reported by the individual
 - Possibly attributed to fragrance or something else
- Allergy or other test results (e.g., pulmonary tests)
- Prescription drugs ordered (if any) and order dates
- Notes about patient education offered

WHAT THE CARE TEAM DOES WITH THE EHR

- Document discussion about fragrance-related issues
- Order tests
- Annotate recommendations for over-the counter medication(s)
- Prescribe Rx medication(s)
- Create a referral to dermatologist, allergist, other specialists

WHAT THE INDIVIDUAL EXPERIENCES

- Symptoms
 - Sinus discharge
 - Headaches / migraines
 - Light sensitivity
 - Nausea
 - Others
- Challenges of self-managing variable symptoms
- Life limitations when their environments and roles can't be adapted

WHAT GETS MISSED

- Reduced social interaction due to need to avoid public places with assigned seating (restaurants, theaters, public transportation)
- Reduced career options and opportunities leading to other life limitations (access to health insurance, lifetime earning potential, housing options)
- Reduced income for supportive services (e.g., home food delivery), products for self-management
- Symptom-specific risks
 - Antihistamines \rightarrow increased hazard while driving due to sleepiness
 - Light sensitivity → higher risk of falls due to sunglasses use indoors
 - Nausea -> greater risk of falls due to dizziness from meal skipping



KEY TAKEAWAYS

4 KEY TAKEAWAYS

- EHRs document health information but not the effects of impairments on individuals' lives, thereby limiting care teams' ability to recognize needs
- People have varying degrees of health literacy and digital skills, and they
 may be unable to fully document health/disability issues and their impact
 on function in the terminology of medical professionals and agencies
- Health conditions and disabilities are dynamic, with variable and changing effects on function that aren't captured in the EHR
- Determination of function and disability is NOT a function of technology but a <u>PROCESS</u> between an individual and their care team
 - Technology may be a facilitator, NOT a solution

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QUESTIONS & ANSWERS

