Healthcare for Living and Dying: an Academic Patient Perspective
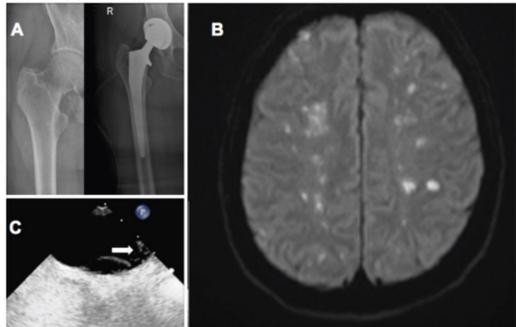
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BACKGROUND

foramen
malformation fracture danlos
syndrome embolic death
cancer dysplasia pneumonia
aspiration aging arteriovenous
stroke hip pulmonary
ovale ehlers loss
function patent

CORONAVIRUS ALERT
NO VISITORS ALLOWED

Not every disability is Visible.

APPROACH

PubMed.gov

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The Ehlers Danlos Society

#HELP FOR HIP DYSPLASIA
THE PODCAST

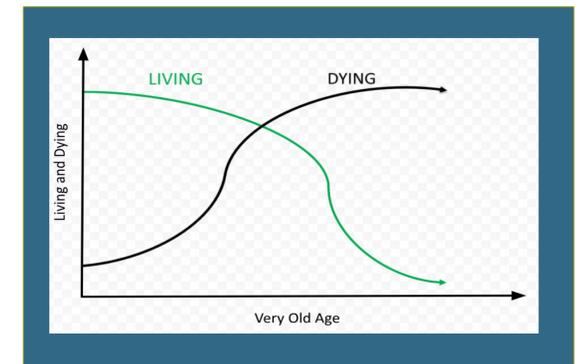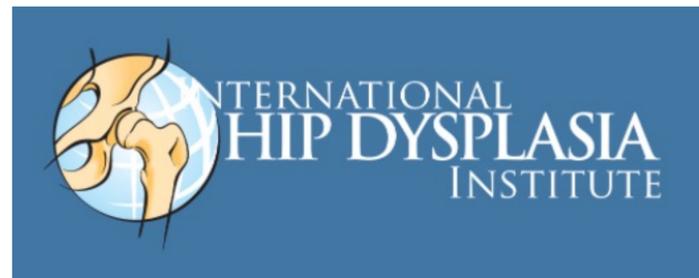INTERNATIONAL HIP DYSPLASIA INSTITUTE

RESULTS

- Physicians often do not have enough time for a complete history, extensive physical examination, or review of specialist notes.
- Patients now have access to physician notes, including those of specialists.
- Health advocacy groups and some health systems provide reliable health information online.
- Social media offers new avenues of information and support for rare health conditions.
- With this dispersion of information and limited access to healthcare providers, families may be left to coordinate care and make medical decisions without substantial guidance.

If you want to contribute, let me know.

GOOGLE.COM
EDS friendly medical professionals - Google My Maps
Doctors, Dentists, Chiropractors, Nutritionists, etc that are EDS knowledgable or willing to l...

- Care for geriatric patients is particularly limited in our fractured system.
- Healthcare tends to be focused on fixing problems, rather than caring for the whole person whose needs are changing with advanced age.
- The physical mobility and cognitive function needed to attend in-person appointments, manage prescriptions, and coordinate care are often not considered by medical providers.
- Healthcare tends to be focused on preserving organ system function; hospice offers comfort for the dying; palliative care can provide care in between.

CONCLUSIONS

- Our medical system continues to be **fractured and over-burdened**, worsened by the COVID-19 pandemic and workforce shortages.
- These limitations further exaggerate **healthcare inequities** because when the patient/family has to coordinate care, only those with resources, education, and support succeed.
- While **online resources** exist, few physicians or healthcare systems are vetting these or fully coordinating care using these resources.
- Physicians and other providers need time to learn and communicate about available resources.
- A **data science approach** to diagnostics and coordination of care could transform the healthcare landscape.
- **Elder care** should address mobility, cognitive reserves, and the tension between living and dying.

ABSTRACT: 2022 ELAM Institutional Action Project

Project Title: Healthcare for Living and Dying: an Academic Patient Perspective

Name and Institution: Audrey R. Tyrka, MD, PhD; Alpert Medical School of Brown University

Topic Category: Healthcare

Background: The original focus of my project was on approaches to support research faculty. However, over the course of the year, I encountered major health challenges personally and among close family members. Through consultations, literature review, and a search of online resources, I gained significant insight into our healthcare system and supports for living and dying.

Objectives: My objective is to increase awareness about strengths and challenges in our healthcare system from the dual lens of a physician scientist and a patient/family member. I share my experience because our humanity is borne of our responses to shared existential realities, and we can enrich our lives and those of our patients by discussing and learning from these experiences and insights.

Methods: Health conditions spanned several medical disciplines and included acute, chronic, rare, and life-threatening health problems: examples included adult hip dysplasia, Ehlers Danlos Syndrome, hip fracture, embolic stroke, patent foramen ovale, pulmonary arteriovenous malformation, breast cancer, aging and loss of function, aspiration pneumonia, and death. The following resources were consulted:
- Treating, consulting, and "curb-sided" physicians in primary care and neurological, surgical, cardiac, and genetic subspecialties at several healthcare/academic systems in the Northeast
- Review of primary literature and practice guidelines
- For rare conditions: Facebook support groups, nonprofit information clearinghouses, and podcasts

Results: <u>Access to physicians is limited, even within patient centered medical homes. Patients may obtain healthcare information from other sources, without much guidance from their physicians.</u>
- Physicians often do not have time to take a complete history, do an extensive physical examination, or review specialist notes.
- Patients now have access to physician notes, including those of specialists.
- Health advocacy groups and some health systems provide reliable health information and identify physicians with expertise in rare conditions.
- Social media offers new avenues of information and support for rare health conditions.
- With this dispersion of information and limited access to healthcare providers, families may be left to coordinate care and make medical decisions without substantial guidance.

<u>Care for geriatric patients is particularly limited in our fractured system.</u>
- Care tends to be focused on fixing problems, rather than care for the whole person whose needs are changing with advanced age.
- The physical mobility and cognitive function needed to attend in-person appointments, manage prescriptions, and coordinate care are often not considered by medical providers.
- Healthcare tends to be focused on preserving organ system function; palliative care centers comfort the dying; there is little in between.

Discussion and Impact:
- Our medical system continues to be fractured and over-burdened, worsened by the COVID-19 pandemic and workforce shortages.
- These limitations further exaggerate <u>healthcare inequities</u> because when the patient/family has to coordinate care, only those with resources, education, and support succeed.
- While online resources exist, <u>most physicians and healthcare systems are not vetting these or coordinating care using these resources.</u>
- Physicians and mid-level providers require time to learn and communicate with patients about available resources.
- A data science approach to diagnostics and coordination of care could transform the healthcare landscape.
- Elder care should address mobility, cognitive reserves, and the tension between living and dying.