

# Health Care Disparities for People with Disability and Potential Role of Physician Bias

**Lisa I. Iezzoni, MD, MSc**

**Professor of Medicine, Harvard Medical School**

**Health Policy Research Center, Massachusetts General Hospital**

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# CONTEXT

- **61 million Americans with disability and these numbers are growing**
- **“Disability in America is not a minority issue ... Disability affects today or will affect tomorrow the lives of most Americans.” (National Academy of Medicine, 2007)**
- **30+ years since passage of the Americans with Disabilities Act**
- **43+ years since regulations implemented under Section 504 of 1973 Rehabilitation Act**

Why is it so hard to make health care fully equitable and accessible to people with disability?

Why in 2021 do people with disability still confront barriers and experience disparities in their health care?

# ORGANIZATION OF TALK

- **Disparities: social determinants of health**
- **Disparities: screening and preventive services**
- **Physicians' attitudes and perceptions: survey findings**
- **Michael's story**

# Social determinants of health

Social determinants of health – social factors that can affect physical and emotional wellbeing and ability to receive health care services. Increasing recognition of their role in population health.



# SOCIAL DETERMINANTS OF HEALTH

- Low incomes
- Low education
- High unemployment rates
- Poor housing, inaccessible housing, and/or housing insecurity
- Significant transportation problems
- Food insecurity
- Domestic violence, intimate partners, or caregiver abuse (men and women)

# RACE/ETHNICITY INTERSECTIONALITY

## Disability rates

- 24% for Whites
- 30% for Black Americans
- 31% for Hispanics
- 16% for Asians
- 25% for Native Hawaiians or Other Pacific Islanders
- 40% for Native Americans or Alaskan Natives

Coronavirus pandemic has underscored how minority populations are at risk of worse health outcomes.

We know that racial and ethnic minority populations experience significant health care disparities.

Health care disparities

## *HEALTHY PEOPLE*

- Every 10 years, federal officials put together a road map for improving public health over the next 10 years – *Healthy People*
- *Healthy People 2010*, published in November 2000, was first time people with disability were identified as experiencing disparities
- *Healthy People* attributed these disparities partially to erroneous assumptions about the daily lives, values, and expectations of people with disability

Common misconceptions about people with disabilities contribute to troubling disparities in the services they receive, especially an “underemphasis on health promotion and disease prevention activities.”

*Healthy People 2020*, published in November 2010, also identified disparities for people with disability. Recommendations involved addressing social determinants of health.

# PAP TEST RATES

- **No disability: 85%**
- **Mobility difficulty: 78%**
- **Sensory difficulty: 80%**
- **Mental health difficulties: 74%**
- **Cognitive difficulties: 76%**
- **Self-care limitations: 68%**



# PAP TEST RATES BY MOBILITY DISABILITY LEVEL

- **No difficulties: 85%**
- **Least severe difficulties: 82%**
- **Level two: 80%**
- **Level three: 78%**
- **Level four: 72%**
- **Most severe difficulties: 65%**

Women with major mobility difficulties are 70% less likely to be asked by their physicians about their need for contraception.

# STAGE 1 BREAST CANCER TREATMENT

- **SEER data merged with Medicare data**
- **All women < age 65 with Stage 1 breast cancer**
- **62% of women without disability got breast conserving surgery compared with 54% of women with disability**
- **After accounting for age at diagnosis, race, ethnicity, tumor characteristics, and other factors, women with disability 24% less likely than other women to get breast conserving surgery**

# AFTER BREAST CONSERVING SURGERY

- Equivalent outcomes as mastectomy if women with early stage breast cancer follow up with radiation therapy
- Looking only at women < age 65 with breast conserving surgery, women with disability 17% less likely to get radiation therapy
- Women with Stage 1 breast cancer and disability 45% more likely to die of their breast cancer than other women

# POTENTIAL CAUSES OF DISPARITIES

- **Patients' complex underlying health conditions and competing priorities**
- **Disadvantages in social determinants of health**
- **Patients' preferences for care**
- **Inadequate training of health care professionals**
- **Ineffective communication accommodations**
- **Inaccessible medical diagnostic equipment, including weight scales and exam tables**
- **Inadequate knowledge about ADA mandates for equitable care**
- **Erroneous assumptions about people with disability**
- **Ableism attitudes among clinicians**

Physicians' attitudes and perceptions

# NATIONAL SURVEY OF PRACTICING PHYSICIANS

- First national U.S. survey of practicing physicians and their experiences with and perceptions of caring for people with disability
- Funded by *Eunice Kennedy Shriver* National Institute of Child Health and Human Development
- Because it was first national survey, we tried to cover wide-ranging topics: went shallow, not deep
- Results here about physicians' perceptions
- Published in *Health Affairs*, February 1, 2021

# THANKS TO RESEARCH TEAM

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# PHYSICIAN SPECIALITIES

- 1. Internal medicine/general internal medicine**
- 2. Family practice**
- 3. Rheumatology**
- 4. Neurology**
- 5. Ophthalmology**
- 6. Orthopedic surgery**
- 7. Obstetrics/gynecology**

# SURVEY DEVELOPMENT

- **Conducted in-depth individual interviews with 20 practicing physicians in Massachusetts**
- **Conducted 3 focus groups with 22 practicing physicians total across 3 states**
- **Identified key topic areas for survey**
- **Designed survey iteratively**
- **Conducted 8 cognitive interviews and 50 pilot tests of draft survey**
- **Final survey: 8 modules, 75 questions – again, broad but not deep**

# CONDUCTING SURVEY

- Randomly sampled practicing physicians from national list
- Eliminated trainees, VA physicians, locum tenens physicians, physicians no longer practicing, etc.
- Sampled 350 physicians in each primary care specialty + 140 physicians in each of the 5 specialties = 1,400 total in sample
- CSR mailed paper survey in October 2019, with \$50 bill inside
- Also offered option to answer survey on line
- Final follow up complicated by pandemic in Spring 2020
- Response rate: 61%

Many findings on various topics. Focus here on physicians' perceptions of caring for people with disability.

# MAIN FINDINGS

- **82% of physicians report that people with significant disability have overall worse quality of life than other people**
- **41% of physicians are very confident in their ability to provide equal quality care to people with disability**
- **56% strongly welcome people with disability into their practices**

## OTHER FINDINGS

- **18% of physicians strongly agree that people with disability are often treated unfairly in the health care system**
- **80% strongly agree that understanding their patients with disability is very valuable**

## MULTIVARIABLE ANALYSIS: QOL

- **Women physicians much LESS likely than men to report worse quality of life for people with disability**
- **Safety-net physicians much less likely than non-safety net physicians to report worse quality of life for people with disability**

# MULTIVARIABLE ANALYSIS: WELCOMING PWD

- **Women physicians much more welcoming than men**
- **Some racial/ethnic differences, but samples for under-represented minorities too small to evaluate fully**
- **Older physicians much less welcoming than younger physicians**
- **Physicians in private practice much less welcoming than physicians at teaching hospitals**
- **Physicians who value understanding patients with disability much more welcoming**
- **Physicians who feel very confident about ability to provide equal quality of care much more welcoming than other physicians**



# DISCUSSION #1

- **Social desirability bias not evident (survey gave physicians option to say people with disability have same – or better – QOL)**
- **Response about worse quality of life suggests strong confidence in their answer (i.e., that no one would argue with their response)**
- **Raises question about care for people with disability in times of scarce resources: COVID-19 pandemic**
- **Given potential bias of physicians, how do we ensure that people with disability get equal quality care**

## DISCUSSION #2

- **Only 41% of physicians feel confident in ability to provide equal quality care to people with disability**
- **Those who do not feel confident are less welcoming of people with disability in their practices**
- **30+ years after enactment of Americans with Disabilities Act, troubling that less than half of physicians feel confident about providing equal quality care**
- **Clearly, this must be addressed – but how quickly can that happen?**

Why should patients with disability need to prove to their doctor that they value the quality of their life to get equal quality care?

Michael's story



# MICHAEL

- **61 years old, 21 year history of primary progressive multiple sclerosis (PPMS)**
- **Born Birmingham, England; DPhil physics Oxford University**
- **Excellent physical health: high altitude, long distance cyclist; became avid speed skater and cross country skier after moving to North America in 1981 for post-doc at Cornell**
- **PPMS diagnosed at age 42; needed wheelchair in 7 years**
- **Complete quadriplegia; cannot move his body volitionally below his neck**

**4,125 km ( $\approx$  2,563 miles) on  
wheelchair odometer after 3.5  
years of use**

# MICHAEL'S CARE PROVIDERS

- **To obtain required PCA services and other reasons, Michael enrolled in PACE (Program for All-Inclusive Care of the Elderly)**
  - **Nursing home-certifiable, Medicare,  $\geq$  age 55**
  - **Most members transported from home to adult day care, returning to family at night**
  - **Must exclusively use PACE physicians**
- **Some PACE leaders did not want him because he lives alone; they thought he should be in nursing home**
- **Worked well: PCA coverage 10 hours/day, home nursing daily**
- **Michael did not attend PACE adult day care, preferring to be active in his community**



# MICHAEL'S CANCER #1

- **March 2015, started complaining of:**
  - **Loss of appetite**
  - **Early satiety**
  - **Occasional vomiting and nausea**
  - **Reduced food intake**
  - **Change in bowel patterns**
- **Lower abdomen grew distended**
- **He asked PACE repeatedly for gastroenterology evaluation, but NP failed to schedule**

## **MICHAEL'S CANCER #2**

- **May 2015: blood pressure rose to 160/100-110, despite previously normal values; not controlled by medication**
- **June 2015: started having trouble saying more than several words before needing to take a breath**
- **Early July 2015: PACE primary care MD visited him at home for 6-month check up, but did not examine him saying he could not get Michael out of his wheelchair**
  - **Didn't even lift up his shirt**





## **MICHAEL'S CANCER #3**

- **My mid-July Michael's birthday visit**
- **Haggard, unable to eat, vomited even small meals, difficulty talking, hugely distended lower abdomen, edematous legs**
- **I got Michael's permission to actively advocate for him with PACE**
- **Following Friday, Michael had CT scan**

## **MICHAEL'S CANCER #4**

- **Over weekend after CT scan, had fever of 102°, could not eat**
- **Visiting nurse prescribed Tylenol**
- **Early Monday: I telephoned PCP to find out results of Friday's CT scan**
- **Lower abdominal mass**
- **I insisted he be treated at a major academic medical center in nearby city rather than their affiliated community hospital**

# MICHAEL'S CANCER #5

- **When admitted, found to have bilateral femoral vein clots**
- **July 30, 2015: Michael had a 15-pound gastrointestinal stromal tumor (GIST) removed and IVC filter placed (to prevent clots from reaching his lungs)**
- **His blood pressure fell to normal**
- **His breathing returned to baseline pattern**
- **Takes daily imatinib – fortunately, no side effects**
- **56 months later, tumor free**

# MICHAEL'S CANCER #6

- **Clearly, he got substandard care.**
- **But was there more going on?**
- **Home care nurse thought he was getting fat because he does not exercise.**
- **Diagnostic overshadowing**
  - **MS does cause constipation. Was abdominal distension caused by stool?**
  - **Severe MS can cause breathing problems.**
  - **No relationship between MS and hypertension.**



**Social worker admitted that palliation is PACE's goal: he is so "very disabled" that, for Michael, their primary goal was "palliation" rather than active exploration and intervention as needed. Hopefully, this attitude is rare, but maybe not ...**

Why should patients with disability need to prove to their doctor that they value the quality of their life to get equal quality care?

