



Disability in Nursing Practice and Nursing Education



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Why Disability Matters



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VU CON Standardized Patients with Disabilities



Support

Association of Standardized Patient Educators

Bristol-Myers Squibb Foundation

Health Resources & Services Administration

Inglis Foundation of Inglis House

National Institute of Nursing Research

National Institute of Child Health and Human Development

National Multiple Sclerosis Society

Robert Wood Johnson Foundation

Why are disability and health important topics?

Why does disability matter?

Compared with individuals without disabilities, those with disabilities are more likely to:

- Experience difficulties or delays in getting the health care they need.**
- Not have had an annual dental visit.**
- Not have had a mammogram in past 2 years.**
- Not have had a Pap test within the past 3 years.**
- Not engage in fitness activities.**
- Use tobacco.**
- Be overweight or obese.**
- Have high blood pressure.**
- Experience symptoms of psychological distress.**
- Receive less social-emotional support.**
- Have lower employment rates.**

(CDC, 2010)



Key Terms

- ❑ **Definitions of disability**
- ❑ **Models of disability**
- ❑ **Disability vs. disabling condition**



Disability Defined

ADA's Definition of Disability:

A physical or mental impairment that substantially limits one or more major life activities,

a record or history of such an impairment, *or*

is regarded/perceived by others as having such an impairment.

The American with Disabilities Act of 1990 <http://www.ada.gov/pubs/ada.htm>

A Word about ADA: A Progress Report

Peacock, G., Iezzoni, L.I., & Harkin, T.R. (2015) Health care for Americans with disabilities--25 Years after the ADA. *N Engl J Med.* 2015 Sep 3;373(10):892-3.

Conclusion: Progress has been made in many parts of society to ensure access of people with disabilities. However, less progress has been made in areas of health and health care!!!



Disability Defined...

International Council of Nurses (ICN)

Disability: a physical, mental, sensory, or social impairment that, in the long term, adversely affects one's ability to carry out normal day-to-day activities

ICN supports programs designed to integrate PWD in all aspects of daily life --- in the family, school, workplace and community

ICN position statement: Prevention of disability and the care of people with disabilities (2000, revised 2010)

Disability Defined...

International Council of Nurses (ICN)...

ICN position statement:

- ...nurses are expected to have an understanding of the particular problems faced by people with disabilities (PWD) and their families and to have advocacy skills and knowledge of programs and resources in the community
- ...nurses are expected to assist, support and advocate for PWD and their families to access education, information and support services that allow them to lead fulfilling lives



Another view of disability:

“Disability is a universal experience that affects nearly everyone without exception at sometime in their lives.”

(Kirschner & Curry, 2009)

Kirschner K & Curry R. (2009). Educating health care professionals to care for patients with disabilities. *Journal of the American Medical Association*, 302(12), 1334-1335.

Models of Disability

Medical and Rehabilitation models

- View disability as a problem of the individual; goal is to cure (or “fix”) the individual or modify his/her behavior)
- Health care providers (HCPs) are the “experts”

Social model

- Disability viewed as socially constructed; caused by society’s failure to provide access and accommodations
- Fix is through social and/or political change
- Does not address health-related issues well

Models of Disability...

Biopsychological model

- Integrates medical and social models
- Addresses health from a biologic, individual, and social perspective

Functional model

- Based on WHO's *International Classification of Functioning, Disability & Health*
- Views disability as umbrella term for impairments, activity limitations, participation restrictions and their interaction with environmental factors
- Addresses health rather than disability as consequence of disease

Models of Disability...

Interface model

- Based on the life experience of the person with a disability
- Views disability at the intersection (i.e., interface) of health issue and environmental barriers
- Considers rather than ignores the health issue or medical problem

Goodall, 1995



Disability vs. Disabling Conditions

Knowing details about disabling conditions is

IS NOT

the same as knowing about disability



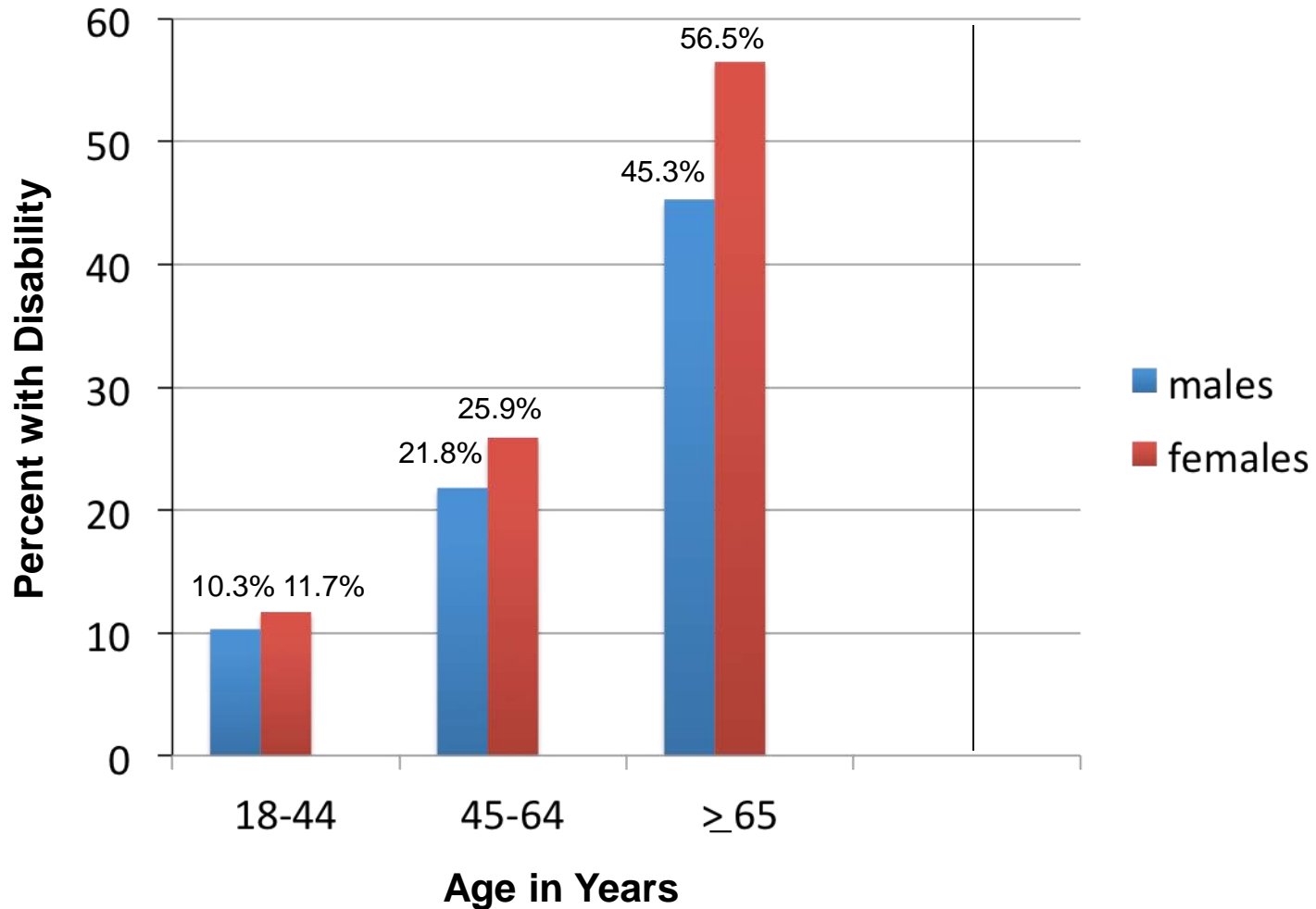
Significance of Definitions and Models of Disability

- ❖ Determine eligibility of persons with disabilities (PWDs) for services and what services are allowed and what is mandated by law
- ❖ Determine our views and perceptions of and attitudes toward PWDs and how we treat and interact with PWDs
- ❖ Serve as check on our attitudes and values about PWDs
- ❖ Influence how we teach others about disability-related issues

Prevalence of Disabilities

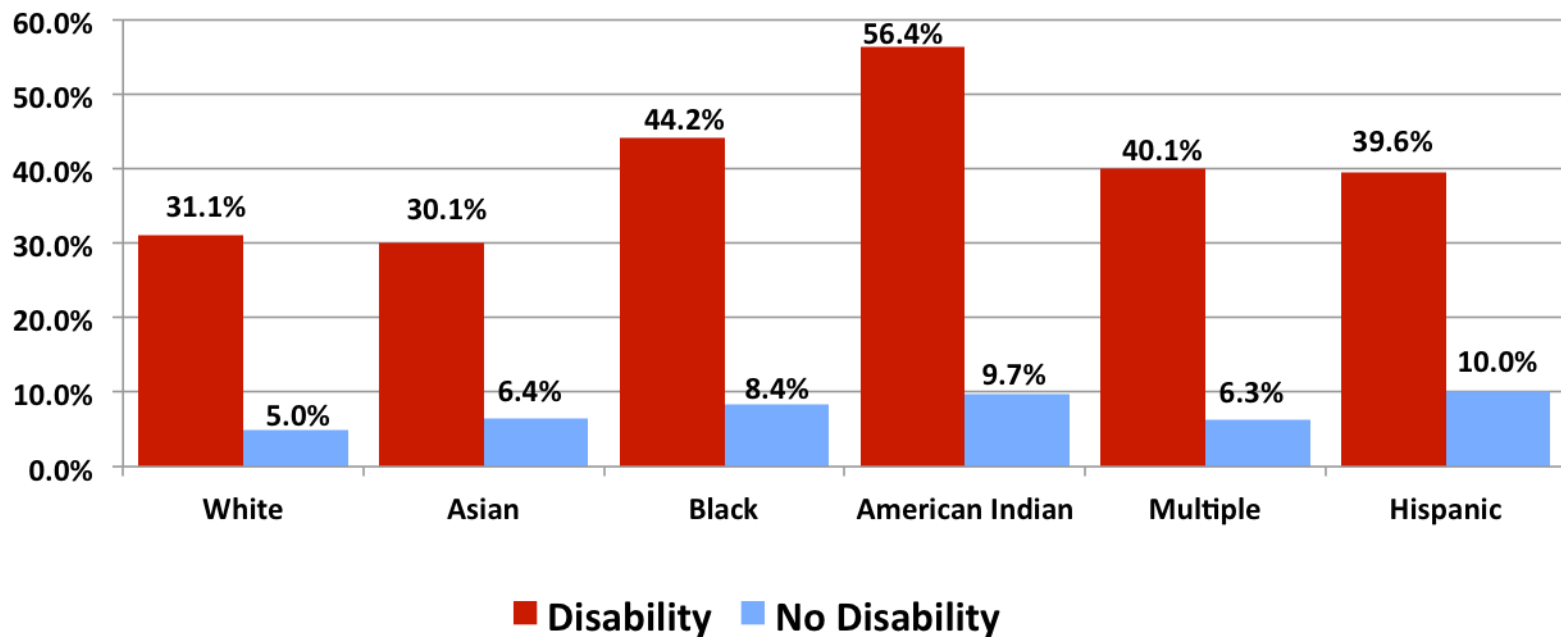
- ~ 60 million people in the U.S. and 1 billion worldwide live with one or more disabilities
- One in every 4 or 5 people (20% - 25%) lives with one or more disabilities
- Disability occurs across the life span
 - 13.9% of children
 - 11.0% of 18 - 44 year olds
 - 23.9% of 45 - 64 year olds
 - 51.8% of those \geq 65 years
 - 44.8% of 65-74 year olds
 - 63.7% of 75-84 year olds
 - 84.2% for frail elderly

Percent of People with a Disability by Age and Gender (CDC,2011)



Differences among Racial/Ethnic Groups

- More people with disabilities from minority racial/ethnic groups report having **fair or poor health** than those without disabilities
- More people with disabilities from minority racial/ethnic groups report having **fair or poor health** than Caucasians with disabilities



(2002-2008 MEPS-Household, adults 18-64 years)

Characteristics of Disabilities

- **Disabilities vary in severity**
 - Very mild (inconvenience)
 - Moderate (interfere with some activities)
 - Severe (assistance needed for IADLs, ADLs)
 - Very severe (technology needed for survival)
- **Disabilities vary in type**
 - Physical disabilities
 - Sensory (vision and hearing) disabilities
 - Psychiatric mental health disabilities
 - Cognitive/intellectual or developmental disabilities
 - Communication disabilities

Characteristics of Disabilities...

- **Disabilities vary in visibility**
 - Not at all visible to others
 - Visible to informed others
 - Visible to all
- **Population of PWDs is increasing in size**
 - Advances in health care and survival of people with disabilities across the lifespan (VLBW babies, adults who are chronically critically ill, etc.)
 - Increased numbers of elderly, frail elderly and people with chronic disease
 - Increased survival of those with trauma (for all those killed in mass shootings, bombings and natural events, many more are disabled as a result)

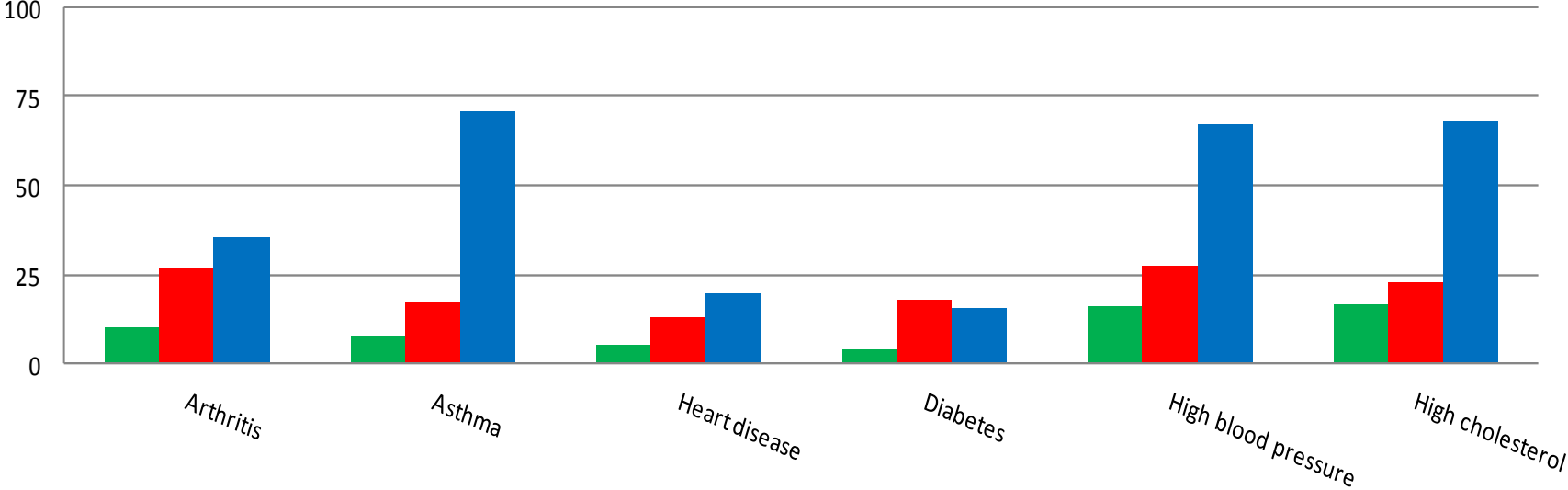
Common Experiences Reported by People with Disabilities (PWDs)

- ❖ Communication between HCPs and PWDs is often ineffective; HCPs fail to communicate directly with PWDs**
- ❖ HCPs often assume that quality of life of PWDs is poor and believe that PWDs cannot be healthy**
- ❖ HCPs often fail to recognize experience, knowledge and expertise of PWDs about their own health and disability**
- ❖ PWDs have a higher incidence of health disparities than non-disabled peers**
- ❖ Higher incidence of health disparities than those without disabilities**

Health Disparities Due to Disability: National Statistics

2006 Medical Expenditures Panel Survey
(Reichard, Stolze, & Fox, 2011)

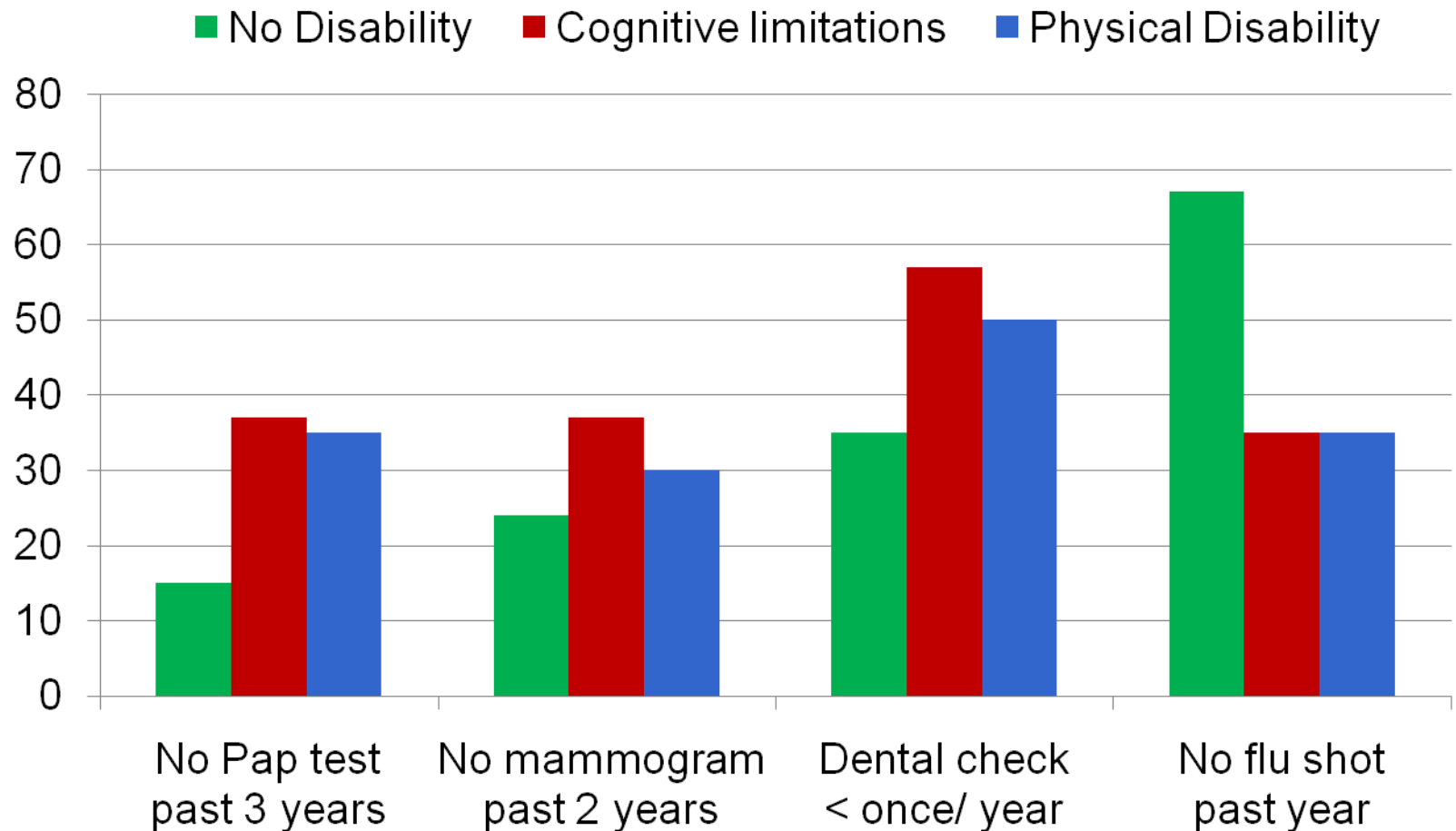
■ No Disability ■ Cognitive Limitation ■ Physical Disability



Preventive Screenings: National Statistics

2006 Medical Expenditures Panel Survey

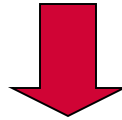
(Reichard, Stolzle, & Fox, 2011)



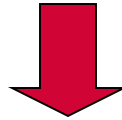
Common Research Findings Across Disciplines:

- **PWDs receive less health care and lower quality of care;**
- **PWDs have reported being refused health care**
- **Health care sites (imaging centers, offices, etc.) continue to be inaccessible despite the ADA**
- **PWDs have a thinner margin of safety/health than those without disability**
- **HCPs often have negative attitudes toward PWDs (and more negative toward PWDs with some types of disabilities)**
- **PWDs' encounters with health care providers are often negative resulting in failure to seek further care**

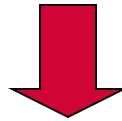
Consequences of Discrimination and Negative Encounters with Health Care Professionals



People with disabilities often avoid health care unless and until *absolutely necessary*



- Inadequate health care, including preventive screening
 - Delay in treatment or lack of treatment
- Low level of participation in health promotion activities



Poor health status, increased risk of poor QOL and secondary conditions, isolation, psychological issues

Health Issues of People with Disabilities

- **Although many issues are the same for people with disabilities as those without disability there are some differences:**
 - **Some common health issues more likely to be ignored in women with disabilities: sexual health, sexual practices, sexual abuse, STDs, contraception, pregnancy, childbearing**
 - **Higher risk of violence for women with disabilities (those with developmental or mental disabilities, or who are blind or deaf at greatest risk)**
 - **Some health issues have earlier onset of age-related conditions in people with disabilities**

**Earlier onset of age-related health conditions
in women with disabilities**



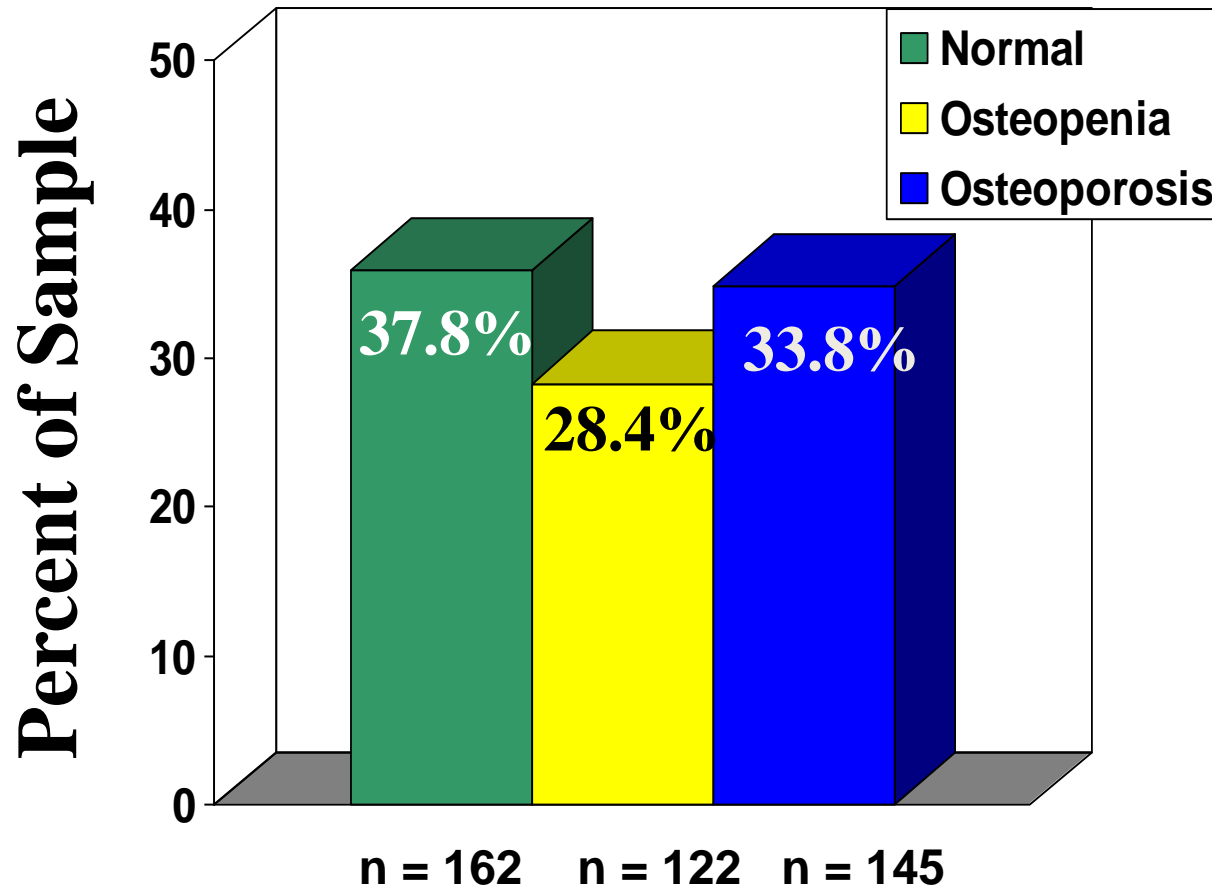
Low bone density/osteoporosis

Purposes

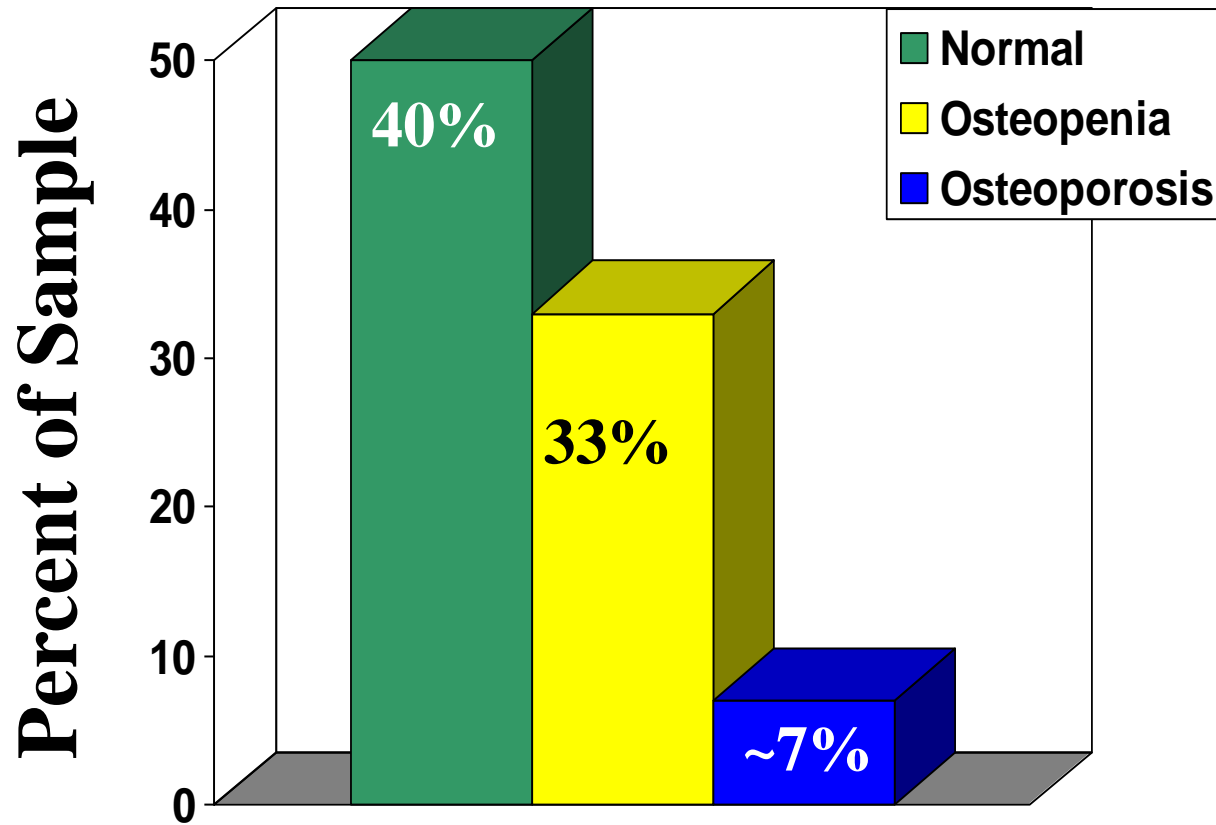
- ❖ **To examine bone density and osteoporosis risk factors in women with disabilities**
- ❖ **To examine their use of osteoporosis prevention strategies and previous bone density screening**

Methods

- ❖ **Bone density screening**
- ❖ **Administration of a questionnaire on risks, risk-reduction actions, medications, previous screening**



**WHO Classification of Bone Density
In Women with Disability (n = 429)
Smeltzer et al., 2005**



**WHO Classification of Bone Density
In Non-disabled Postmenopausal Women
(n = >200,000) Siris et al, 2001**

Summary of Findings on Osteoporosis in Women with Disabilities:

- **Women with disabilities have a higher incidence of low bone mineral density (BMD) and osteoporosis than expected and higher than women without disabilities**
- **And it is largely being ignored and women are not being screened or treated despite increased risk for falls and fractures**

Facts about Health Issues and Health Care in People with Disabilities

Fact: People with disabilities are at same (and sometimes increased) risk for health problems that others experience

Fact: People with disabilities may develop health issues at younger ages than people without disabilities so need greater--not less---attention to primary health care and screening.

Fact: Most people with disabilities have a normal or near-normal life span.

Fact: People with disabilities do not differ in desire for preventive health care and screening from other people; it is, however, often more difficult and frequently an ordeal.

Important Facts...

Fact: People with disabilities are no more and no less responsible for their disabilities than those without disabilities.

Fact: Disabilities is *not* illness; people with disabilities can be very healthy. Many of them are healthier than non-disabled populations.

Fact: People with disabilities go to school, get married, work, have families, do laundry, grocery shop, laugh, cry, pay taxes, get angry, have prejudices, vote, plan and dream like everyone else.

Fact: They have aspirations and want to participate just like everyone else!

Realities in Today's Health Care System

People with disabilities receive lower quality of care, less aggressive treatment and are offered few choices.

Health care providers are often unable (perhaps unwilling) to address sexuality, pregnancy, childbearing and common health problems in people with disabilities

People with disabilities encounter serious barriers to receiving quality health care including preventive care and screening and reproductive care.

Examples of Barriers to Health Care

- Lack of equipment and facilities to permit those with physical limitations to have complete physical exams
- Lack of understanding of interaction of disability and other aspects of health by some health care providers
- Belief on part of many health care providers that *ALL* health problems are due to the disability
- Lack of attention to disability issues in health care professions' education/training programs resulting in negative attitudes and stereotyping of PWD by health care professionals:
 - PWD don't need (or want) preventive screening
 - Preventive care would be waste of resources
 - PWD are (or should be) asexual, uninterested in childbearing and not at risk for pregnancy and STDs

Research Findings about Attitudes about PWDs of Health Care Professionals:

- **HCPs' have negative attitudes toward PWDs.**
- **HCP students have negative attitudes toward PWDs.**
 - **Nursing students' attitudes reported to be more negative than other HCP students!**
 - **Nursing faculty have more negative attitudes than HCPs students and than other HCPs!!**

**Concern about the Quality of Health
Care of Women with Disabilities
(with Focus on Nursing Care)**



**Qualitative Study of Nursing Care Experiences
Of People with Disabilities
During Hospitalization**

(Smeltzer, Avery & Haynor, 2012)

Four Themes From Study:

Poor Communication

- Nursing staff ignore people with disability and talk/listen instead to others (family, friends, others)...anyone but them
- PWD needed to explain and re-explain to nursing staff what works and what does not work for them; treated as if they knew nothing about their own disabilities
- They recommended that communication skills be part of the nursing curriculum, especially communication with people with disabilities

Compromised Care

- Disabilities are not taken into account during care due to inadequate knowledge; care not individualized
- Lack of caring, compassion, understanding, patience and respect toward PWD

Four themes...

Negative Attitudes

- ❖ **Seen as low priority, marginalized and as burden by nursing staff**
- ❖ **Feared, ignored and on occasion abused**
- ❖ **Treated as children, as asexual and as uninterested in childbearing**

Fears about Hospitalization

- ❖ **Sense of vulnerability; lack of control over well-being and fear of being hurt while hospitalized**
- ❖ **Fear of being left without assistive devices based on previous experiences**
- ❖ **Fear of leaving the hospital in worse shape than when admitted**

Summary and Conclusions of Qualitative Study

- **Improvement in nursing care of PWDs with disabilities during hospitalization is needed.**
- **Education of nursing students and nurses in practice about care of PWDs is needed.**
- **Ancillary nursing staff are also in need of training about care of PWDs.**

Concerns re Quality of Nursing Care of PWD



What is being taught in nursing education about topic?



Study #1: Integration of disability-related content in UG nursing curricula
(*Nursing Education Perspectives*, 2005)

Study #2: Inclusion of disability-related content in textbooks used in UG nursing curricula
(*Nursing Education Perspectives*, 2005)

Study #3: Integration of disability content in NP programs
(*Journal American Academy of NP*, 2014)

Summary of Findings Related to Nursing Education on Topic of Disability:

- **Disability content largely invisible at both undergraduate and NP levels and in textbooks widely used in nursing education.**
- **Some faculty say they are teaching about it; responses suggest not.**
- **Faculty report that more important content would have to be deleted AND disability is not a very important issue.**
- **Students are not tested on it; therefore, it is not taught.**
- **Some faculty admitted that they never thought about the topic before participating in the study.**

Strategies for Nurses, Nursing Faculty, and Nursing Students to Address Disparities related to Disability:

- **Identify own attitudes, bias, and prejudices**
- **Increase own awareness, sensitivity and knowledge about disability, health issues of this population, and disparities related to disability**
 - **Read, search Internet, read life stories of people with disabilities**
 - **Attend programs on disability in practice and education**
- **Adopt “person-first language” and use disability etiquette in interactions with people with disabilities**
- **Assume that PWDs are the experts on their own disabilities**
- **Invite PWDs to participate in education of undergraduate nursing students and NP students (and faculty!)**
- **Welcome and accommodate nursing students with disabilities**

Strategies to Address the Health-Related Disparities...

- **Put ourselves in the shoes of people with disabilities, but verify that we have it accurate**
 - **Example: obtain material on diabetes self-care for person with vision impairment**
 - **Example: consider having a mammogram or gyn exam from the perspective of a woman who is a wheelchair user (try even finding an accessible office and scheduling an appointment!)**
- **Ask people with disabilities about their experiences and about how they learn best**
- **Become familiar with accommodations (large print, Braille, pictures, interpreters, tapes, etc.) needed to address PWDs' learning needs**
- **Learn from people with disabilities**

Recommendations to Improve Health of People with Disabilities

U.S. Surgeon General and others recommendations:

1. **Improve public recognition that people with disabilities can live long, healthy and productive lives and reduce stigma and discrimination;**
2. **Improve knowledge, skills and attitudes of health care providers to improve care;**
3. **Improve accessibility of health care, including insurance, facilities, equipment, transportation;**
4. **Improve opportunities for health promotion, safety and wellbeing;**
5. **Improve data on disability populations, and research on disability-related health disparities and interventions.**

(Fox & Courtney-Long, 2012)

Reports and agencies calling for improved knowledge, skills and attitudes of health care providers about care of PWDs and to improve their health care:

- ✧ **U.S. Surgeon General Reports (2002, 2005)**
- ✧ **Institute of Medicine Report on Disability (2007)**
- ✧ **National Council on Disability Report (2009)**
- ✧ **World Health Organization World Report on Disability (2011)**
- ✧ **International Council of Nursing Position Paper (2000, 2010)**
- ✧ **Patient Protection and Affordable Care Act (2010)**

Despite these multiple calls, nursing as a discipline has been largely silent on the issue of addressing disparities in care for PWD.

Another Call to Action

(3-22-16)

Nurses...

Nursing as a discipline...

Nursing education...

Nursing organizations and agencies...

Accrediting organizations

Certification organizations

Licensing boards

have the potential to take the lead to ensure that next generations of HCPs, including nurses, are prepared to care for PWDs.



Considering Disability...

“Disability is a universal experience that affects nearly everyone without exception at sometime in their lives.”

(Kirschner & Curry, 2009)

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Questions, thoughts or comments?



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