Reducing Barriers to Better Self Care: Changing Stereotypes

22nd Annual Colloquium on Aging

Susan Heidrich, PhD, RN
Helen Denne Schulte Professor
September 21, 2010
Acknowledgements

- Grant Number RO1AG022914 from the National Institute on Aging and the National Cancer Institute
  - Co-investigators: Dr. Sandra Ward, Dr. Sanjay Asthana, Dr. Roger Brown
- NIH R55 NR0774 from the National Institute of Nursing Research
- P20 CA103697 from the National Cancer Institute
- P20NR008987 from the National Institute of Nursing Research
- University of Wisconsin-Madison School of Nursing Research Committee Award.
- Judith Egan, RN, MS; Hyun-E Yeom, RN, PhD; Carol Cowgill, RN, MS; Heather Royer, RN, PhD, Cyndi Phelan, RN, PhD; Feng Lin, RN, MS; Rachel Roiland, RN, MS
Goals for today

- Relationship of symptoms to physical and psychological well-being
- What beliefs, attitudes, and strategies about symptoms and symptom management influence better self care and well-being?
“I enjoy talking with very old people. They have gone before us on a road by which we, too, may have to travel, and I think we do well to learn from them what it is like.”

Socrates, in Plato’s The Republic
360 B.C.E.
Number of people age 65 and over, by age group, selected years 1900-2000 and projected 2010-2050

Note: Data for 2010-2050 are projections of the population.
Reference population: These data refer to the resident population.
Source: U.S. Census Bureau, Decennial Census and Projections.
Life expectancy

At birth

White female
Black female
White male
Black male

At 65 years

White female
Black female
White male
Black male

Year
1970
1980
1990
2000
2004

Life expectancy in years
100
90
80
70
60
50
40
30
20
10
0

SOURCES: Centers for Disease Control and Prevention, National Center for Health Statistics, *Health, United States, 2007*, Figure 18. Data from the National Vital Statistics System.
Activity limitation among older adults due to chronic conditions, 2004–05

Number of persons with limitation of activity per 1,000 population

SOURCES: Centers for Disease Control and Prevention, National Center for Health Statistics, *Health, United States, 2007*, Figure 16. Data from the National Health Interview Survey.
Percentage of people age 65 and over who reported having good to excellent health, by age group and race and Hispanic origin, 2002-2004

Note: Data are based on a 3-year average from 2002-2004. People of Hispanic origin may be of any race.
Reference population: These data refer to the civilian noninstitutionalized population.
Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Health Interview Survey.
What are common or frequent symptoms reported by older persons?

<table>
<thead>
<tr>
<th><strong>Musculoskeletal</strong></th>
<th><strong>“Hormonal”</strong></th>
<th><strong>Neurocognitive</strong></th>
<th><strong>Sleep</strong></th>
<th><strong>“Dryness”</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Aching</td>
<td>Depression</td>
<td>Dizziness</td>
<td>Waking too often</td>
<td>Dry skin</td>
</tr>
<tr>
<td>Joint pain</td>
<td>Mood swings</td>
<td>Balance problems</td>
<td>Waking too early</td>
<td>Itching</td>
</tr>
<tr>
<td>Stiffness</td>
<td>Feeling anxious</td>
<td>Trouble concentrating</td>
<td>Difficulty falling asleep</td>
<td>Hair thinning</td>
</tr>
<tr>
<td>Pain</td>
<td>Nightmares</td>
<td>Memory problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weakness</td>
<td>Weight gain</td>
<td>Numbness/tingling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>Headache</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Decreased sex drive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swelling in arms/legs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased urination</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incontinence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Women
  - Vaginal discharge
  - Vaginal dryness
  - Hot flashes

- “Dryness”
  - Dry skin
  - Itching
  - Hair thinning
  - Dry mouth
Are symptom clusters related to quality of life?

<table>
<thead>
<tr>
<th></th>
<th>Musculoskeletal</th>
<th>Hormonal</th>
<th>Neurocognitive</th>
<th>Dryness</th>
<th>Sleep</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life – Physical</td>
<td>-.73**</td>
<td>-.18*</td>
<td>-.37**</td>
<td>-.36**</td>
<td>-.32**</td>
</tr>
<tr>
<td>Quality of Life – Mental</td>
<td>-.33**</td>
<td>-.57**</td>
<td>-.37**</td>
<td>-.31**</td>
<td>-.23**</td>
</tr>
<tr>
<td>Depression</td>
<td>.47**</td>
<td>.34**</td>
<td>.35**</td>
<td>.41**</td>
<td>.43**</td>
</tr>
<tr>
<td>Purpose in Life</td>
<td>-.24**</td>
<td>-.44**</td>
<td>-.32**</td>
<td>-.28**</td>
<td>-.22**</td>
</tr>
<tr>
<td>Positive Relationships</td>
<td>-.07</td>
<td>-.37**</td>
<td>-.22*</td>
<td>-.22*</td>
<td>.08</td>
</tr>
</tbody>
</table>

* p < .05 ** p < .01
Common symptoms in old age are related to:

- Worse social function
- Worse physical function
- More psychological distress
- Worse overall quality of life
An intervention to improve symptom management in older women

IRIS*

Beliefs about symptoms and symptom management

Self Care Behaviors & Strategies

Symptom Distress

Quality of Life
Primary Outcome: Severity Inventory

\[ F_{\text{group} \times \text{time}} = 5.68 (1,505), \ p = .0175 \]
Primary Outcome: Symptom Interference

$F_{(\text{group x time})} = 6.11\ (1,507), \ p = .0138$
Primary Outcome: Mood Disturbance from symptoms

\[ F \text{ (group x time)} = 14.33 \ (1,507), \ p = .0002 \]
All would live long but none would be old. - Ben Franklin
What factors influence how older adults manage symptoms successfully?

- Stereotypes about Aging
- Beliefs about symptoms
- Communication
  - Health care providers’ attitudes
Ageist stereotypes and Ageism

- Stereotypes about ageing can be both positive and negative, but negative are more prevalent.
- Ageism = Prejudice, stereotyping and scapegoating of people based solely on age.
  - Ageist self-stereotypes
  - Ageist stereotypes held by others
When is someone old?

“I’m 65 and I guess that puts me in with the geriatric set. But, if there were 15 months in every year, I’d only be 48.”

James Thurber
Stereotypes have real effects on older people

- Negative stereotypes
  - Memory
  - Handwriting
  - Will to live
  - Cardiovascular reactivity/blood pressure

- Positive stereotypes
  - Walking speed
  - Functional status
  - Survival (7.5 years)

Examples of stereotypical cultural beliefs about aging

“You can’t teach an old dog new tricks”
“The horse is out of the barn”
“The secret to successful aging is to choose your parents wisely”
“The lights may be on but the voltage is low”
Stereotypes about teaching older adults

- Older adults are resistant to change.
- Older adults are unable to retain new material.
- Older adults defer to younger family members, and therefore the family should be the main focus in the teaching interaction.
What factors influence how older adults manage symptoms successfully?

Stereotypes about Aging

Beliefs about symptoms

Health care providers’ attitudes

Communication
Ageist Beliefs about symptoms

- Symptoms are just a normal part of getting older
- Nothing can be done about age-related symptoms
- In old age, it is better just to learn to live with symptoms
These beliefs are related to:

- Less engagement in health behaviors (Greene et al., 2002)
- Decreased health care seeking (Grunfeld et al., 2002)

Poorer symptom management and lower quality of life
Results related to beliefs about symptoms

Many symptoms are a normal part of growing older

It’s important not to complain about symptoms when you are old

It’s important for HCPs to focus on curing the illness, not wasting time managing symptoms

The “cure” for symptoms is often worse than the disease

HCPs might find it annoying to be told about symptoms
More results about symptom beliefs

If I talk about symptoms, my HCP will think I’m a complainer

At my age, it is better just to learn to live with symptoms

At my age, this is the best I can expect to feel

*At my age, it is not worth it to learn new ways of managing symptoms
What factors influence how older adults manage symptoms successfully?

- Stereotypes about Aging
- Beliefs about symptoms
- Communication
- Health care providers’ attitudes
Examples

✔ He/she is too old to try a new treatment
✔ He/she will be unwilling to try new treatments
✔ Medical therapies are less effective in older adults

Almost 50% of older adults reported experiencing ageist stereotypes on the part of their health care providers (Ory et al, 2003)
Ageist attitudes from health care providers

- You're worrying too much
- Compared to other women with your health condition, your problems are minor
- It's not necessary for you to know the details about your condition
- You should be thankful you've lived as long as you have
- Felt a symptom you reported was not dealt with to your satisfaction.
What factors influence how older adults manage symptoms successfully?

- Stereotypes about Aging
- Beliefs about symptoms
- Health care providers’ attitudes
- Communication

Stereotypes about Aging

Beliefs about symptoms

Health care providers’ attitudes

Communication
Problems older people report about communicating with health care providers

- What symptoms to report?
- Which doctor to talk to?
- Is this too minor to talk about?
- Will I be seen as a ‘problem’ patient’?
  - Will I distract my doctor from more important issues?
Difficulty communicating with health care providers

- Not knowing which doctor to talk to: 41.6%
- Not sure which symptoms to tell about: 37.9%
- Not sure if doctors are communicating about my health: 34.7%
- Symptoms seem minor, and don’t want to be a “complainer”: 27.4%
- Worry I am ignoring serious symptoms: 26.3%
- Worry about being “labeled”: 10%
Perceived Ageist Attitudes from HCPs

Negative Beliefs about Symptom Management

Difficulty Communicating about Symptoms

Quality of Life

Standardized, *p < .05  **p < .01
Strategies to improve symptom management

• Self Monitoring (diaries, logs, journals) – take to appointments
• Using language that gets someone to listen to you
• Utilize the nurse
• Even if one symptom is your priority, tell your HCP about all of the symptoms you are experiencing
• Prioritize
• If your symptom is a long-term problem.....
Strategies to improve symptom management

• Self Monitoring (diaries, logs, journals) – take to appointments
  • When did it start
  • How often? How severe?
  • Is it getting better or worse?
  • What makes it worse? Better?
Strategies to improve symptom management

• Using language that gets someone to listen to you
  • State how is this problem affecting you
    • I need help with this because I am no longer able to……
    • pick up my grandchild
    • go to a movie because I can’t climb the stairs
    • Enjoy anything I used to love
  • State what your major concern or worry is
    • Is it potentially a major problem?
    • Is it potentially a recurrence of a major problem?
    • How will I know?
• State what your goal is
  • To be symptom free?
  • To be able to do X, even with the symptom?
Strategies to improve symptom management

• Utilize the nurse (not the person who answers the phone—the gatekeeper)
  • To sort out if this is an issue that needs immediate attention or can wait
  • To get information to your primary care provider or physician if you need more urgent attention
• Give the nurse all of the information previously mentioned
Strategies to improve symptom management

- Even if one symptom is your priority, tell your HCP about all of the symptoms you are experiencing.
- May be critical to accurately diagnosing the problem or finding the right treatment.
  - Shortness of breath versus
  - Shortness of breath, swollen ankles, fatigue
Strategies to improve symptom management

- Prioritize
  - Write down all of your questions about your symptoms
  - Prioritize
  - Ask the #1 question first!

- If you can’t get to all of your questions?
  - Ask for a follow up appointment
  - Ask if you can email your other questions
Strategies to improve symptom management

• If your symptom is a long-term problem:
  • Ask for another look at the problem
  • Ask for consultations and referrals

<table>
<thead>
<tr>
<th>Physical or occupational therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balance clinic</td>
</tr>
<tr>
<td>Rheumatologist</td>
</tr>
<tr>
<td>Pain clinic</td>
</tr>
<tr>
<td>Diabetes classes</td>
</tr>
<tr>
<td>Nutritionist</td>
</tr>
<tr>
<td>Psychologist or Social worker</td>
</tr>
</tbody>
</table>

• Monitor your symptom to see if any changes are helping and **report back** if not
You and your health care provider should be a team

**Your job**
Communicate as much information as you can as clearly as possible
Be clear about what your concerns and worries are
Be clear about your goals
Be ready to work hard at different treatments and therapies

**Your health care providers’ job**
Listen to you
Answer your questions
Do an examination and assessment of your symptoms
Communicate the options to you
Help you consider your options
This old dog learned a new trick!

Thank you