Exposing Quality of Life and Deadly Health Disparities: Using Research to Change Health Care Policy

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Associate Dean for Research and Professor,
Co-Director, UIC Center of Excellence for Eliminating Health Disparities
Part 1: Quality of Life Index

Part 2: Cultural Beliefs about Breast Cancer

Part 3: Using Research to Change Health Care Policy
Part 1: Quality of Life Index
Ferrans & Powers Quality of Life Index (QLI)

- One of the earliest measures of quality of life.

- One of the best-known quality of life instruments.
  - 250+ published studies used the QLI to measure quality of life.
  - 1,920+ citations of the original QLI publications in scientific journals.
Quality of Life: the Patient’s Perspective

- Provides understanding of impact of illness from patient’s viewpoint
  - Different from health status or physical functioning
  - Quality of life can be good even with physical disability.
  - Quality of life is more than health problems, loss of abilities, or functional deficits.

- Incorporation of the patient’s values makes QOL different from measures of health status.

**GOAL:** Capture the PATIENT’S evaluation of their quality of life as accurately as possible in a standardized questionnaire.
Composed of two parts, with paired questions:

Part 1: **SATISFACTION with the aspects of life**
Example: How satisfied are you with your health?

Part 2: **IMPORTANCE of those same aspects of life**
Example: How important is your health to you?
Ferrans & Powers Quality of Life Index

Part 1: **SATISFACTION** with the aspects of life
Part 2: **IMPORTANCE** of those same aspects of life

**SCORING:**

- Importance ratings are used to weight the satisfaction responses, so they reflect the values of the individual patient.

- Highest item scores = high importance + high satisfaction

- Lowest item scores = **high** importance + low satisfaction

*Unique scoring system*
Ferrans & Powers Quality of Life Index

Five Scores:

- Quality of Life
- Health and Functioning Domain
- Social and Economic Domain
- Psychological/Spiritual Domain
- Family Domain
Steps in Development of the QLI

- Extensive literature review
- Qualitative interviews with dialysis patients
- Development of ideological approach
- Item (question) writing
- Development of scoring system for items to capture ideological approach
- Development of Generic Version and Pilot testing with graduate students
- Development of the Dialysis Version and Pilot testing with dialysis patients
- Factor analysis with 349 dialysis patients
- Development of the Cancer Version and Pilot testing with 111 cancer survivors
- Cognitive interviews to refine items
  - improve understanding and reduce reading level required (low literacy)
  - Cross-cultural clarity (African Americans speaking English and Mexican Americans speaking Spanish/translation).
- Finalize “Version III” core set of items for cancer patients
- Psychometric testing with 115 cancer patients in active treatment and 180 cancer survivors
- Development of additional versions and translations.
Ferrans and Powers Quality of Life Index
Reliability and Validity

- **Internal consistency reliability**
  - Alphas = .84 to .98 (26 studies)

- **Stability reliability**
  - Test retest = .78 to .81 (4 studies)

- **Content validity**
  - Patient reports
  - Literature review
  - Content Validity Index

- **Concurrent validity**
  Correlations with other life satisfaction measures = .61 to .93 (5 studies)

- **Construct Validity**
  - Factor analysis (USA and Norway): four primary factors and one higher order factor
  - Contrasted groups: pain, depression, and coping with stress.
Predictive of length of survival in advanced cancer (baseline assessment prior to treatment):

- Breast
- Colon
- Prostate
- Pancreas
- Lung

**Independent of cancer stage (published data)**
Versions of the Quality of Life Index

- Cancer
- Cardiac
- Chronic Fatigue Syndrome
- Diabetes
- Dialysis
- Epilepsy
- General Population

- Liver Transplant
- Multiple Sclerosis
- Nursing Home
- Pulmonary
- Sickle Cell
- Spinal Cord Injury
- Stroke

www.uic.edu/orgs/qli

Free – no payment for use.
Ferrans & Powers Quality of Life Index

- USA
  - General population
  - African Americans
  - Mexican Americans
  - Korean Americans
  - Others

- International research (30+ countries)
  - North & South America: Canada, Mexico, Brazil, Chile
  - Europe: Denmark, France, Great Britain, Hungarian, Italy, Lithuania, Norway, Poland, Portugal, Romania, Russia, Spain, Sweden
  - Middle East: Israel, Jordan, Turkey
  - Africa: South Africa
  - Asia: India, China, Korea, Japan, Thailand, Taiwan
  - Australia and New Zealand
21 Languages

- Arabic
- Chinese
- Danish
- English
- French
- Hebrew
- Hungarian
- Italian
- Japanese
- Korean
- Lithuanian
- Norwegian
- Polish
- Portuguese
- Romanian
- Russian
- Spanish
- Swedish
- Tamil
- Thai
- Turkish
Part 1: Conclusions

Quality of Life Index:

- Measures quality of life from the patient’s perspective.
- Unique scoring algorithm for combining satisfaction and importance.
- 14 illness versions.
- Robust evidence for reliability and validity across numerous illness populations, cultural groups, and languages.
- 25 years of use in research and clinical practice.
Part 2: Cultural Beliefs about Breast Cancer
Question 1.

*Cultural Beliefs about Breast Cancer: Can they be deadly?*
We developed a 15-item instrument to measure beliefs that would be barriers to:

- Participation in Screening
- Diagnosis of Suspicious Breast Symptoms
- Follow through with Treatment
Newly diagnosed breast cancer patients (n = 954)

Cultural beliefs were associated with:

- Breast cancer *detected with symptoms*, rather than mammogram.
- *Longer delay* (3+ months) before seeking diagnosis of suspicious symptoms.
- *Later stage of cancer* at diagnosis (Stage 2,3,4 vs 0,1).
- *Longer delay* (3+ months) in starting cancer treatment.
Misconceptions predict timing of care and later stage

Symptomatic detection: $P = 0.0185$

$>90$ days to medical presentation: $P = 0.0038$

$>90$ days to treatment: $P = 0.0003$

$>90$ days total delay: $P < 0.0001$

Later stage: $P = 0.0099$

Later stage (invasive): $P = 0.0942$
Participants

- General Population
  \[ n = 117 \]

- Suspicious Breast Symptoms from two medical centers serving low SES
  \[ n = 266 \]

- Breast Cancer (newly diagnosed 3-4 months) from throughout Chicago
  \[ n = 954 \]
Characteristics of Breast Lumps

If a breast lump is not painful, it is not cancer.

<table>
<thead>
<tr>
<th>Population</th>
<th>AA 5%</th>
<th>Latina 11%</th>
<th>White 0%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gen Pop</td>
<td>AA 14%</td>
<td>Latina 18%</td>
<td>White 5%</td>
</tr>
<tr>
<td>Symptoms</td>
<td>AA 6%</td>
<td>Latina 18%</td>
<td>White 1%  (p&lt;.0001)</td>
</tr>
</tbody>
</table>
# Characteristics of Breast Lumps

If a breast lump is not painful, it is not cancer.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Gen Pop</th>
<th>Symptoms</th>
<th>Breast Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>AA 5%</td>
<td>Latina 11%</td>
<td>White 0%</td>
</tr>
<tr>
<td>AA</td>
<td>AA 14%</td>
<td>Latina 18%</td>
<td>White 5%</td>
</tr>
<tr>
<td>Latina</td>
<td>AA 6%</td>
<td>Latina 18%</td>
<td>White 1% (p&lt;.0001)</td>
</tr>
</tbody>
</table>

If a breast lump does not get bigger, it is not cancer.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Gen Pop</th>
<th>Symptoms</th>
<th>Breast Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bigger</td>
<td>AA 13%</td>
<td>Latina 14%</td>
<td>White 0% (p=.05)</td>
</tr>
<tr>
<td>AA</td>
<td>AA 11%</td>
<td>Latina 4%</td>
<td>White 5%</td>
</tr>
<tr>
<td>Latina</td>
<td>AA 13%</td>
<td>Latina 24%</td>
<td>White 3% (p&lt;.0001)</td>
</tr>
</tbody>
</table>

If a breast lump is touched/pressed often, the lump will turn out to be breast cancer.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Gen Pop</th>
<th>Symptoms</th>
<th>Breast Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Touched</td>
<td>AA 13%</td>
<td>Latina 3%</td>
<td>White 8%</td>
</tr>
<tr>
<td>AA</td>
<td>AA 7%</td>
<td>Latina 16%</td>
<td>White 5%</td>
</tr>
<tr>
<td>Latina</td>
<td>AA 11%</td>
<td>Latina 30%</td>
<td>White 2% (p&lt;.0001)</td>
</tr>
</tbody>
</table>
Self-Help Techniques

The more you worry about breast cancer, the more likely you will get it.

<table>
<thead>
<tr>
<th>Category</th>
<th>AA</th>
<th>Latina</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gen Pop</td>
<td>8%</td>
<td>17%</td>
<td>8%</td>
</tr>
<tr>
<td>Symptoms</td>
<td>8%</td>
<td>16%</td>
<td>11%</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>7%</td>
<td>26%</td>
<td>4%</td>
</tr>
</tbody>
</table>

If you take good care of yourself, you won’t get breast cancer.

<table>
<thead>
<tr>
<th>Category</th>
<th>AA</th>
<th>Latina</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gen Pop</td>
<td>13%</td>
<td>24%</td>
<td>5%</td>
</tr>
<tr>
<td>Symptoms</td>
<td>18%</td>
<td>27%</td>
<td>11%</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>8%</td>
<td>21%</td>
<td>2%</td>
</tr>
</tbody>
</table>

If you have a breast lump, a “natural” remedy can help to get rid of it.

<table>
<thead>
<tr>
<th>Category</th>
<th>AA</th>
<th>Latina</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gen Pop</td>
<td>11%</td>
<td>17%</td>
<td>20%</td>
</tr>
<tr>
<td>Symptoms</td>
<td>8%</td>
<td>10%</td>
<td>11%</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>12%</td>
<td>10%</td>
<td>6%</td>
</tr>
</tbody>
</table>
Faith-Based Beliefs

If a woman has enough faith in God, she won’t need treatment for breast cancer.

- **Gen Pop**
  - AA 24%  Latina 11%  White 0%  \((p = .004)\)
- **Symptoms**
  - AA 17%  Latina 6%  White 0%  \((p=.04)\)
- **Breast Cancer**
  - AA 18%  Latina 16%  White 1%  \((p<.0001)\)

Faith in God can protect you from breast cancer.

- **Gen Pop**
  - AA 39%  Latina 38%  White 5%  \((p < .001)\)
- **Symptoms**
  - AA 38%  Latina 35%  White 5%  \((p = .02)\)
- **Breast Cancer**
  - AA 29%  Latina 49%  White 3%  \((p<.0001)\)

If you pray enough, sometimes breast lumps will disappear.

- **Gen Pop**
  - AA 39%  Latina 33%  White 25%
- **Symptoms**
  - AA 43%  Latina 18%  White 11%  \((p<.001)\)
- **Breast Cancer**
  - AA 35%  Latina 27%  White 7%  \((p<.0001)\)
Futility of Treatment

If breast cancer is cut open in surgery, it will grow faster.
Gen Pop  AA 32%  Latina 14%  White 8%  (p=.019)
Symptoms  AA 31%  Latina 33%  White 26%
Breast Cancer  AA 19%  Latina 30%  White 10%  (p<.0001)

If a woman is poor, she won’t get cured from cancer, because she won’t get the best treatment.
Gen Pop  AA 29%  Latina 25%  White 42%
Symptoms  AA 22%  Latina 12%  White 4%  (p=.07)
Breast Cancer  AA 24%  Latina 29%  White 35%  (p=.002)

If breast cancer is treated correctly, it can be cured.  (FALSE)
Gen Pop  AA 13%  Latina 19%  White 10%
Symptoms  AA 10%  Latina 0%  White 11%  (p=.07)
Breast Cancer  AA 8%  Latina 6%  White 13%  (p=.007)

It doesn’t really matter if you get treated for breast cancer, because if you get cancer, it will kill you sooner or later.
Gen Pop  AA 13%  Latina 11%  White 13%
Symptoms  AA 3%  Latina 14%  White 0%
Breast Cancer  AA 7%  Latina 25%  White 1%  (p<.0001)
Part 2: Cultural Beliefs

Question 2.

*Can cultural beliefs about breast cancer be changed?*
Beating Breast Cancer DVD

• Five African American women, all breast cancer survivors, are featured in the film.

• Unscripted; each woman tells her story in her own words.

• Addresses cultural beliefs and fear, which were identified as significant barriers in our earlier research.

• One of the featured survivors is a physician, and so provides the credibility of a medical expert.

Professional production company
"What about your male friends? How are they going to look at you? And I looked at him and I said, 'It's not about them. It's about me. I'm still a woman...and I'm focusing on living.'"

Tasha, age 37
Beating Breast Cancer DVD

- Endorsed by the American Cancer Society.
- Endorsed by Chicago Department of Public Health.
- National Telly Award, Health and Wellness Category for short film, 2011.

- YouTube 2,015 views to date.
Evaluation of DVD

- 262 African American women participants
- Questionnaires completed (all within one continuous session):
  1. Before watching DVD
  2. Immediately following DVD
  3. After Q & A with African American nurse
Lump is not painful, it's not cancer
Lump doesn't get bigger, it's not cancer
Lump is pressed often, turn out to be BC
Women with large breasts more likely to get BC
More you worry about BC, more likely to get it
Mammograms can cause BC
If BC is treated correctly, it can be cured
Faith in God can protect you from BC
Pray enough, breast lumps will disappear
A "natural" remedy can get rid of breast lumps
A poor woman won't get cured from cancer, because she won't get treated
It doesn't matter if you get treated, because BC will kill you
Enough faith in God will protect you from BC
No BC in your family, don't need a mam
If BC is treated correctly, it can be cured
A poor woman won't get cured from cancer, because she won't get treated
If BC is treated correctly, it can be cured
Faith in God can protect you from BC
Pray enough, breast lumps will disappear
A "natural" remedy can get rid of breast lumps
Responses to Beating Breast Cancer DVD:

• 99% thought the DVD was worth watching

• 89% stated they learned something new from the DVD

• 86% reported that the DVD helped them to decide to get a mammogram.
Dissemination: Beating Breast Cancer DVD

- 440 educational events have been held in the four target communities.
- 8,503 women have attended events and completed questionnaires.
- 461 women were given one-on-one help to find a mammogram they could afford (free).
- Almost all women were African American (94%), so we reached the intended audience.
Part 2: Conclusions

- **Cultural beliefs can be deadly:**
  - Breast cancer detected with symptoms, rather than mammogram.
  - Longer delay (3+ months) before seeking diagnosis of suspicious symptoms.
  - Later stage of cancer at diagnosis
  - Longer delay before starting cancer treatment.
Part 2: Conclusions

- Cultural beliefs can be changed:
  - First study (we know of) demonstrating that cultural beliefs about breast cancer can be changed by viewing a short film on DVD.
  - DVD provides a simple, cost-effective technique that can be easily used for wide dissemination.
Part 3: Using Research to Change Health Care Policy
Outcomes
Metropolitan Chicago Breast Cancer Task Force

- Illinois Reducing Breast Cancer Disparities Act (Public Law 95-1045)
  - Written directly from our Task Force Report.
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  - Improve quality of mammography.
  - Recently expanded to all of Illinois.

- Illinois Breast and Cervical Cancer Program (IBCCP)
  - Expanded to cover all uninsured women in Illinois, for screening, diagnosis, and treatment.
Disparity in Breast Cancer Mortality

Three hypotheses to explain breast cancer disparities

- Access to Mammography
- Quality of Mammography
- Access and Quality of Treatment

Age-Adjusted Female Breast Cancer Mortality for Chicago, Per 100,000 Population
## Breast Cancer Mortality Rates, by Race, Chicago, 1996 - 2003

<table>
<thead>
<tr>
<th>Year</th>
<th>Black</th>
<th>White</th>
<th>How Much Higher is Black Rate?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996</td>
<td>36.5</td>
<td>36.5</td>
<td>0%</td>
</tr>
<tr>
<td>1999</td>
<td>42.0</td>
<td>32.5</td>
<td>29%</td>
</tr>
<tr>
<td>2000</td>
<td>41.1</td>
<td>29.5</td>
<td>39%</td>
</tr>
<tr>
<td>2001</td>
<td>37.3</td>
<td>24.4</td>
<td>53%</td>
</tr>
<tr>
<td>2002</td>
<td>41.0</td>
<td>24.7</td>
<td>66%</td>
</tr>
<tr>
<td>2003</td>
<td>40.4</td>
<td>24.0</td>
<td>68%</td>
</tr>
<tr>
<td>2005</td>
<td>41.3</td>
<td>19.2</td>
<td>116%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Year</th>
<th>New York City</th>
<th>US</th>
<th>Chicago</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>1.01</td>
<td>1.31</td>
<td>1.39</td>
</tr>
<tr>
<td>2001</td>
<td>1.13</td>
<td>1.36</td>
<td>1.66</td>
</tr>
<tr>
<td>2002</td>
<td>1.53</td>
<td>1.36</td>
<td>1.68</td>
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<tr>
<td>2003</td>
<td>1.66</td>
<td>1.39</td>
<td>1.62</td>
</tr>
<tr>
<td>2004</td>
<td>1.68</td>
<td>1.36</td>
<td>2.16</td>
</tr>
<tr>
<td>2005</td>
<td>2.16</td>
<td>1.47</td>
<td></td>
</tr>
</tbody>
</table>
Explaining Breast Cancer Disparities: Hypothesis 1

- **Access to Mammography:** Black women receive fewer mammograms.
Explaining Breast Cancer Disparities: Hypothesis 2

- **Quality of Mammography:**
  Black women receive mammograms of inferior quality.

(Data from 71 Mammography Providers in Chicago and suburbs – 82% response rate)
Characteristics of Mammography Services Offered, by Race, to Women Living in Chicago (2007)

Digital mammography available
- Black: 21%
- White: 56%

All mammograms read by breast specialists
- Black: 23%
- White: 57%

Face-to-face on same day as exam
- Black: 50%
- White: 67%
# Quality of Mammography at 3 Chicago Institutions

<table>
<thead>
<tr>
<th>Chicago Breast Centers</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td># cancers/1000 screens (Standard = 6-7/1000)</td>
<td>3.1</td>
<td>2.4</td>
<td>7.5</td>
</tr>
<tr>
<td>% minimal cancers (&gt;33%)</td>
<td>NA</td>
<td>17</td>
<td>63</td>
</tr>
<tr>
<td>% Stage 0 or 1 (&gt;50%)</td>
<td>NA</td>
<td>44</td>
<td>91</td>
</tr>
</tbody>
</table>
Explaining Breast Cancer Disparities: Hypothesis 3

- **Access and Quality of Treatment:**
  Black women have inadequate access to quality treatment once a cancer is diagnosed.

Predominately African American Community Areas.

Non- African American Community Areas.

- Predominately African American Community Areas.
- Non-African American Community Areas.
- General hospitals that provide medical and Radiation oncology services and are certified by the American College of Surgeons Commission on Cancer
- General hospitals that provide medical and Radiation oncology services and are NOT certified by the American College of Surgeons Commission on Cancer

Map showing locations of community areas and hospitals.
Mobilization of Political and Community Support

- **Chicago Tribune Article (Oct 2006)**
  - Mortality data showing Black/White disparity
  - Backlog of 12,000 mammograms at Stroger Cook County Hospital
  - Plans for Task Force

- **Breast Cancer Summit (Mar 2007)**
  - Kickoff attended by 200+ people
Mobilization of Political and Community Support

- **Generation and Vetting of Report Recommendations (Mar – Sept 2007)**
  - Open Meetings and Town Halls (fostering shared ownership)
  - 74 organizations represented
  - 100+ people actively participated in the three action groups (monthly meetings)

- **Press Conference releasing Report (Oct 2007)**
5. Strategic Release of Information to Media and Political Leaders
Strategic Release of Information to Media and Political Leaders

Press Conference

- Report completely EMBARGOED until press conference

- Advance copies provided to directors only:
  - Illinois Department of Public Health
  - Cook County Department of Public Health
  - Chicago Department of Public Health

- Professional public relations team (Scofield Group)
  - Developed Press Pack and Press Release
  - Strategy for media coverage: TV, newspapers, radio (press conference and interviews)
Breast cancer deadlier for blacks

Why? Report blames racism, says mammograms, care may be inferior

BY JIM RITTER
Health Writer

African-American women in Chicago are much more likely than white women to die of breast cancer, and the racial gap is widening, according to a new study that calls the disparity "morally wrong, medically unacceptable and reversible."

Just 10 years ago, black and white women in Chicago died at the same rate from breast cancer. But the most recent figures available, for 2003, show the mortality rate among black women was 73 percent higher; researchers at Mount Sinai Hospital's Urban Health Institute report in a study being released today. Nationwide, the gap was about half that — 37 percent.

The disparity in death rates appears to be the result of racism, "and it appears to be institutionalized," said Alan Channing, chief executive of Sinai Health System.

In Chicago, white women are diagnosed with breast cancer at a rate 15 percent higher than the rate in black women. So why are more blacks dying from the disease?

One site spotted few cancers

One explanation that's often offered is that African-American women might be seeing fewer breast cancers because they have fewer mammograms. This was not the case in a study of mammograms taken at five medical centers. They found that African Americans were more likely to have mammograms than whites in some areas, but less likely in others.

The study was published in the Journal of the National Cancer Institute.

Lillie Bell of Chicago, photographed Monday at her West Side home, was diagnosed with breast cancer in 1999. The cancer was relatively advanced, even though Bell had been getting mammograms for years, she said.
After the Press Conference


 Creation of the Breast Cancer Quality Consortium (Public Law 97-1045)
  – Improve quality of mammography.
  – Recently expanded to all of Illinois.

 Continued political advocacy with Illinois legislators for Illinois Breast and Cervical Cancer Program funding.
Part 3: Conclusions

Research can be a powerful tool for changing healthcare policy:

- Compelling data (credible, current, and local) to identify the problems and causes.
- Evidence-based solutions proposed.
- Data packaged with clarity for the public.
- Mobilization of political and community support.
- Strategic release of Information to media and political leaders.
With gratitude to our funders:

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• Center of Excellence in Eliminating Health Disparities, University of Illinois at Chicago (NIH Institute on Minority Health and Health Disparities P60 MD003424)

• Roybal Center for Health Promotion and Translation, University of Illinois at Chicago (NIH National Institute on Aging P30 AG022849)
With gratitude to my colleagues

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- Richard Warnecke
With gratitude to my colleagues

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- Pamela Ganschow, MD, Stroger Hospital and Medical Center.
- Paula Grabler, MD, Northwestern University.
- Eileen Knightly, BSN, RN, Mercy Hospital and Medical Center.
- Elizabeth Marcus, MD, Stroger Hospital of Cook County.
- Ruta Rao, MD, Rush University.
Dedicated with gratitude to my mentor

Marjorie J. Powers, PhD, RN
Thank you!