Studies on Communicating with African American prostate cancer survivors

MOREHOUSE
SCHOOL OF MEDICINE

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Advisory

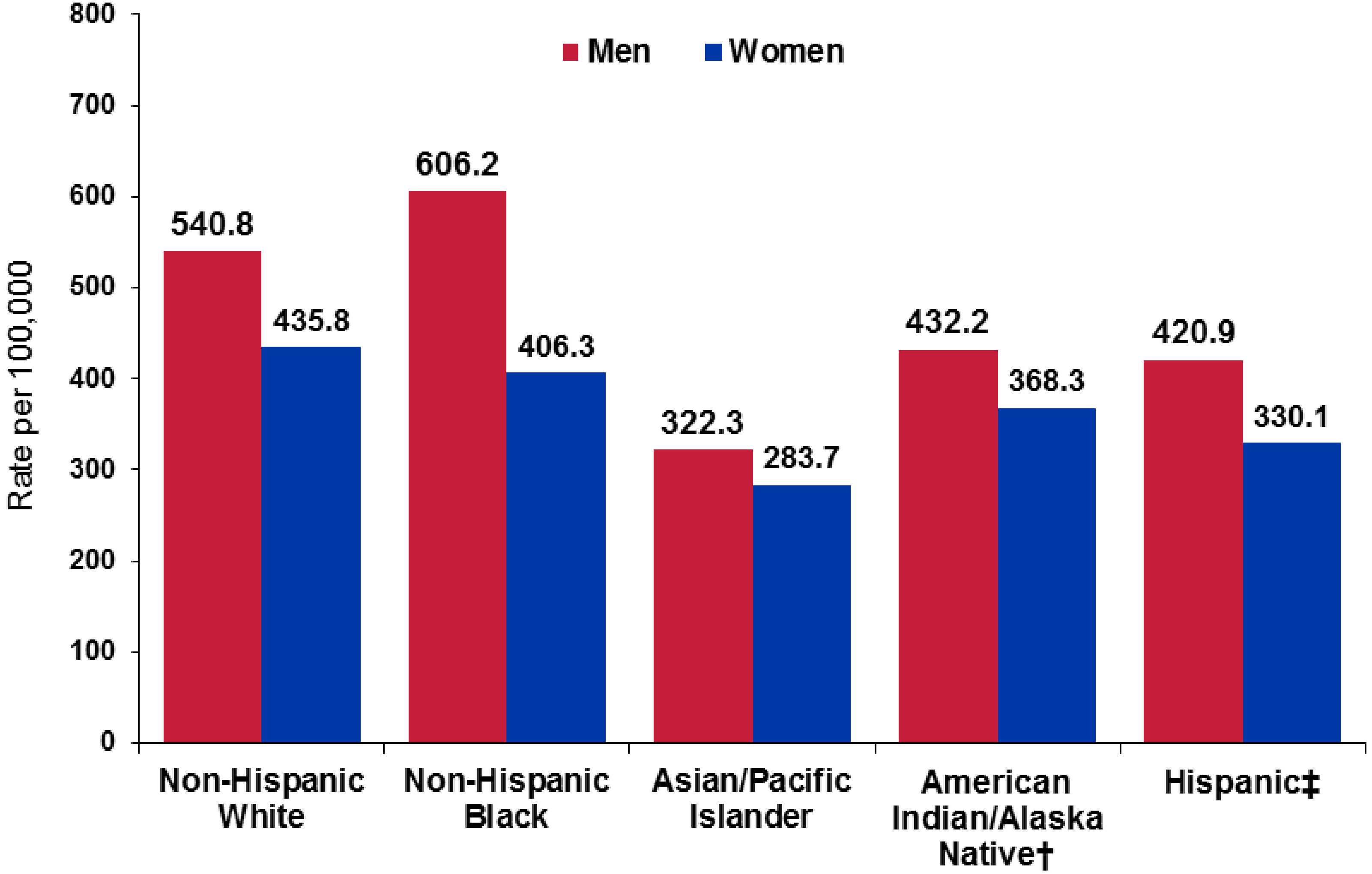
- NIH National Institute on Minority Health and Health Disparities
    - **National Advisory Council on Minority Health and Health Disparities (NACMHD)**
        - Establishes the scientific agenda for this nation to address minority health and health disparities.

- American Association for Cancer Research
    - **Minorities in Cancer Research Council**
        - Acts as an advisory body to the AACR leadership on issues of concern to minority investigators and is also responsible for organizing the activities of MICR through its committees.

Prostate Cancer Treatment and Survival

- 2.8 million men prostate cancer survivors;
- 241,740 new cases (2012);
- 90% of cancers discovered in the local or regional stages
  - 5-year relative survival rate approaches 100%;
  - 10-year survival rate, 97.8%
  - 15-year survival rate, 91.4%

Cancer Incidence Rates* by Race and Ethnicity, 2007-2011



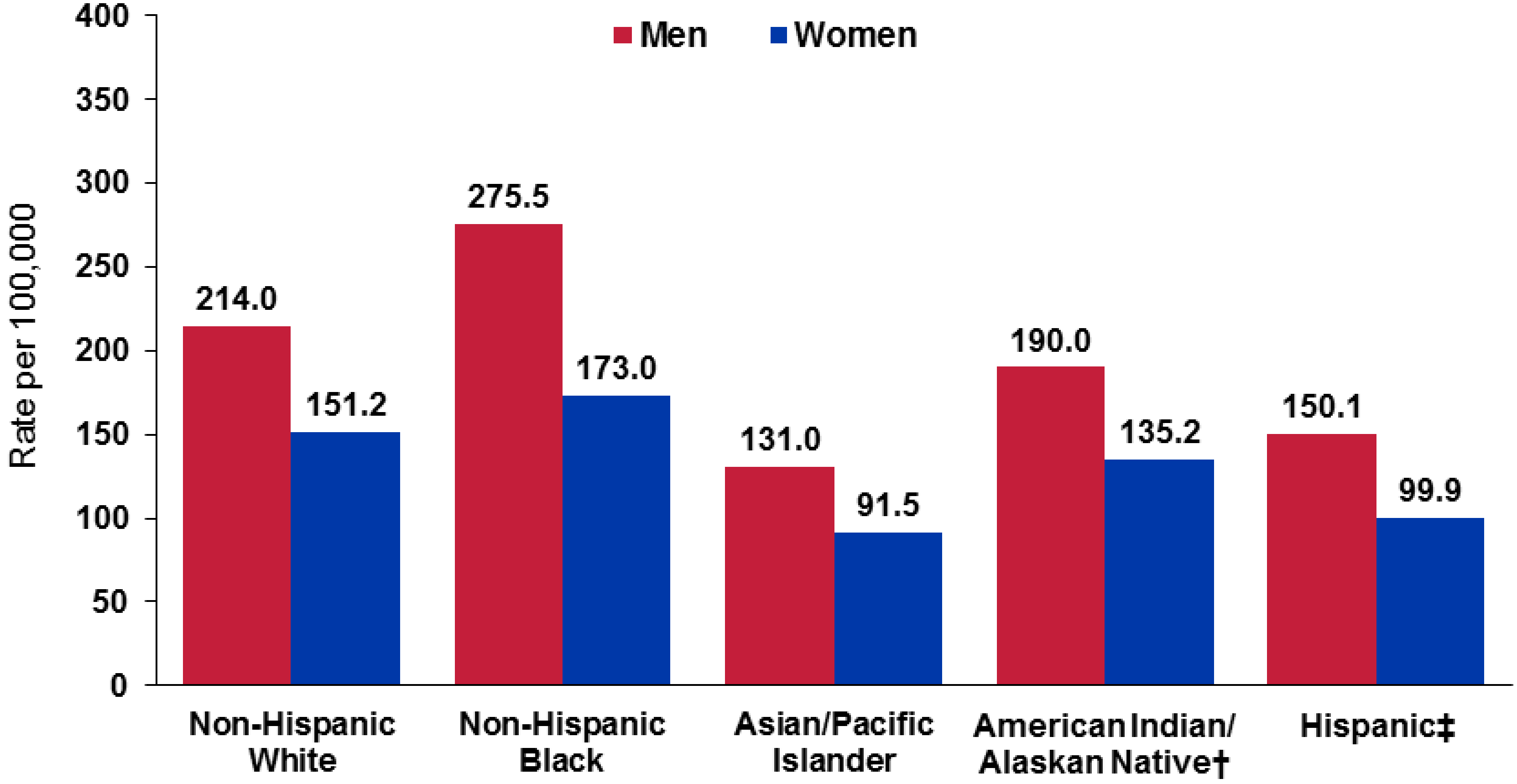
*Age-adjusted to the 2000 US standard population.

†Data based on Indian Health Service Contract Health Service Delivery Areas. Rates exclude data from Kansas.

‡Persons of Hispanic origin may be of any race.

Source: National American Association of Central Caner Registries, 2014.

Cancer Death Rates* by Race and Ethnicity, US, 2007-2011



*Per 100,000, age-adjusted to the 2000 US standard population.

†Data based on Indian Health Service Contract Health Service Delivery Areas.

‡Persons of Hispanic origin may be of any race.

Sources: National Center for Health Statistics, Centers for Disease Control and Prevention, 2014.

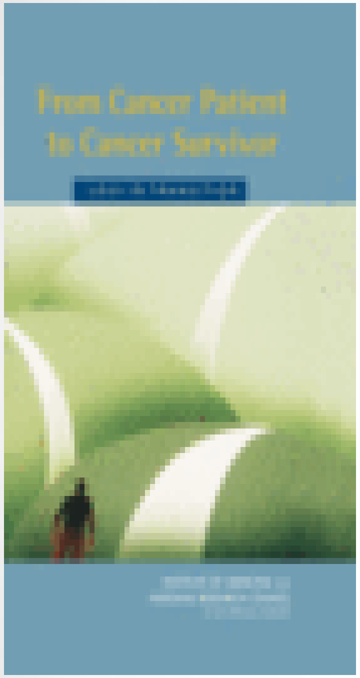
Natural History of Prostate Cancer

- Prostate cancer is biologically heterogeneous.
- Some prostate cancers grow slowly and never cause symptoms.
- Other prostate cancers are fast growing an metastasize quickly.
- Other types grow at a modest pace.

Side Effects of Treatment

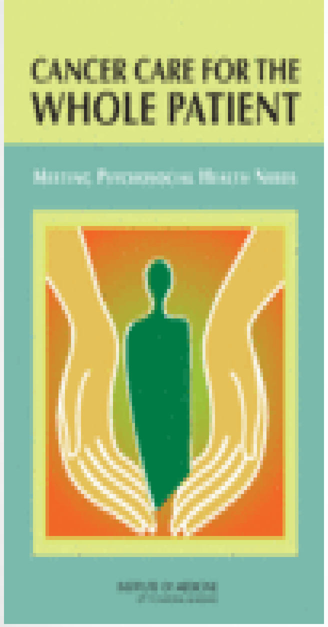
Treatment	Side Effect	Frequency
Radical prostatectomy	• Erectile dysfunction • Urinary incontinence	20–70% 15–50%
External beam radiation therapy	• Erectile dysfunction • Urinary incontinence	20–45% 2–16%
Androgen deprivation therapy	• Sexual dysfunction • Hot flashes	20–70% 50–60%
Watchful waiting	• Erectile dysfunction	30%

Psychosocial Needs & Services



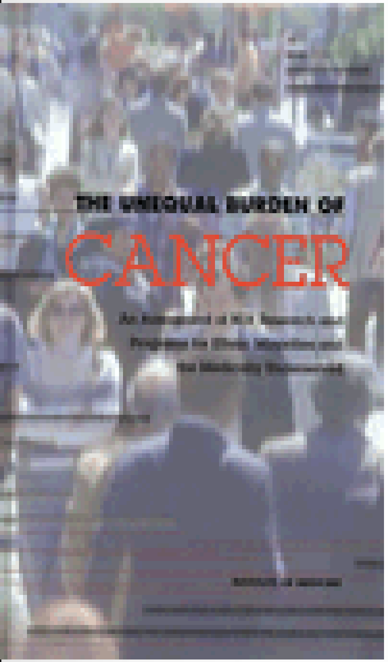
Information about illness, treatments, health, and services	Provision of information, e.g. on illness, treatments, effects on health, and psychosocial services, and help to patients/families in understanding and using the information
Help in coping with emotions accompanying illness and treatment	Peer support programs; Counseling/psychotherapy to individuals or groups; Pharmacological management of mental symptoms
Help in managing illness	Comprehensive illness self-management/self-care programs
Assistance in changing behaviors to minimize impact of disease	Behavioral/health promotion interventions, such as: -provider assessment/monitoring of health behaviors (i.e., smoking, exercise); -brief physician counseling -patient education

Other Needs and Services



Material and logistical resources, such as transportation	Provision of resources
Help in managing disruptions in work, school, and family life	Family and caregiver education; Assistance with activities of daily living; Legal protections and services; Cognitive testing and educational assistance;
Financial advice and/or assistance	Financial planning/counseling; Insurance counseling Eligibility assessment/counseling for other benefits Supplemental financial grants

Prostate Cancer Disparities in Survivorship



THE UNEQUAL BURDEN OF

CANCER

- African American men are more likely to:
  - Experience poorer treatment outcomes
  - Less satisfaction with treatment outcomes
  - Greater symptom distress
  - More persistent urinary, bowel, sexual symptoms
  - Family disruption

  Lubeck et al., J Urology 2001; Sandra et al., NEJM 2008; Campbell et al., J Pain Symp Mgmt)
- Low access to educational and psychosocial interventions

Broad Categories of Factors that may influence receipt of optimal cancer care

- Although differences have been noted in patterns of cancer prevention, detection, and treatment, many of these differences are **not the result of clinical profiles *only***.

- More recently, recommendations to address these differences have focused on **addressing the influence of nonclinical factors** on the receipt of cancer care as a means of reducing/eliminating disparities in health.

Socio-Ecological Model

Public Policy national, state, local laws and regulations

Community relationships between organizations

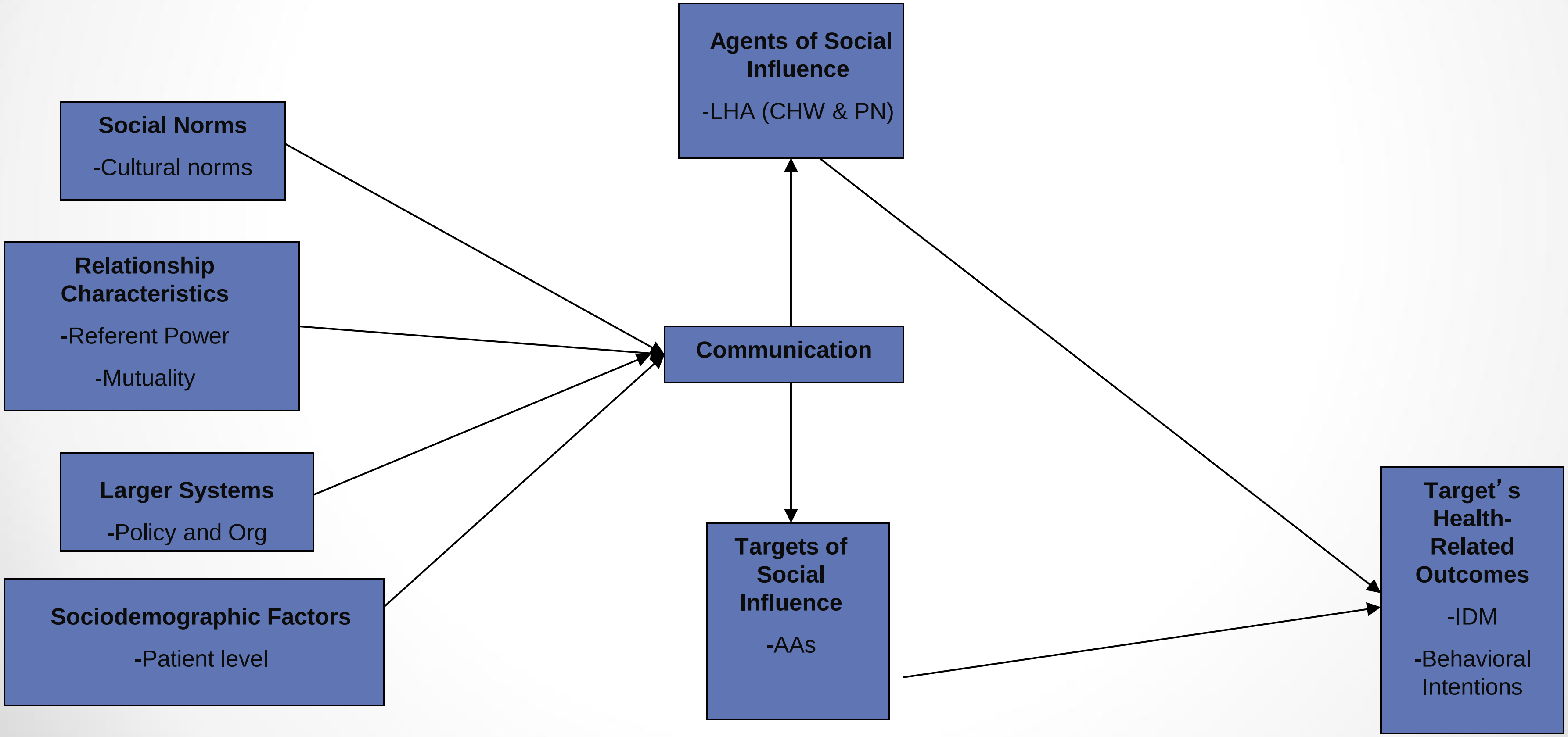
Organizational organizations, social institutions

Interpersonal families, friends ,social networks

Individual knowledge, attitudes, skills

Multilevel Intervention Framework

- Interdependence Model of Social Influence and Interpersonal Communication



Agents of Social Influence

-LHA (CHW & PN)

Social Norms

-Cultural norms

Relationship Characteristics

-Referent Power

-Mutuality

Communication

Larger Systems

-Policy and Org

Sociodemographic Factors

-Patient level

Targets of Social Influence

-AAs

Target's Health-Related Outcomes

-IDM

-Behavioral Intentions

Guiding Research Principles

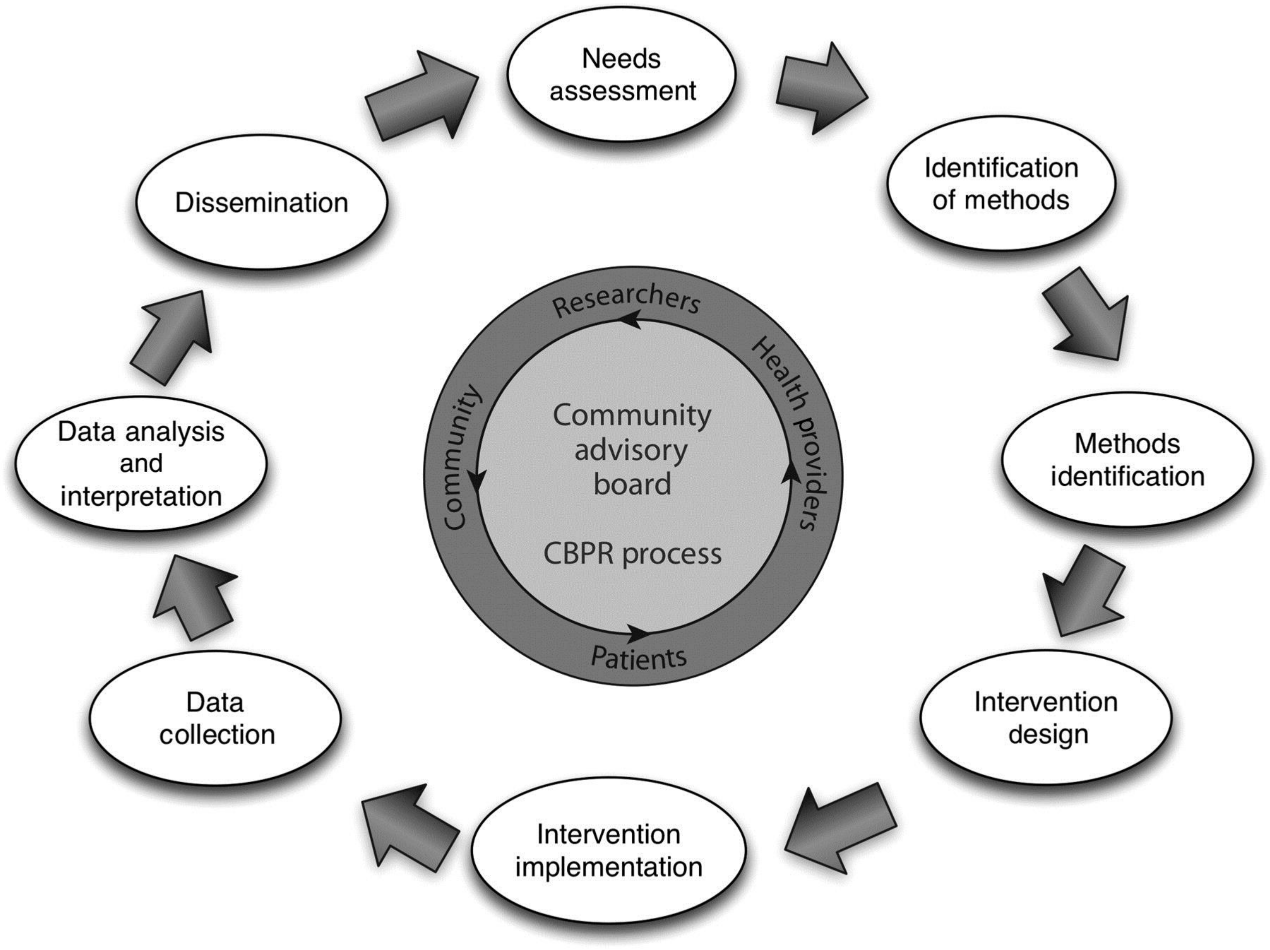
- "If the issue is in the *community*, then the solution is in the *community*."
- "Ensure research approaches are community *based* and NOT community *placed*."
- "Individuals desire to be healthy, but are often adversely impacted by *factors beyond their control*."

What is community-based participatory research (CBPR)?

- “a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings”

  W.K. Kellogg Foundation (2001)

Community Based Participatory Framework



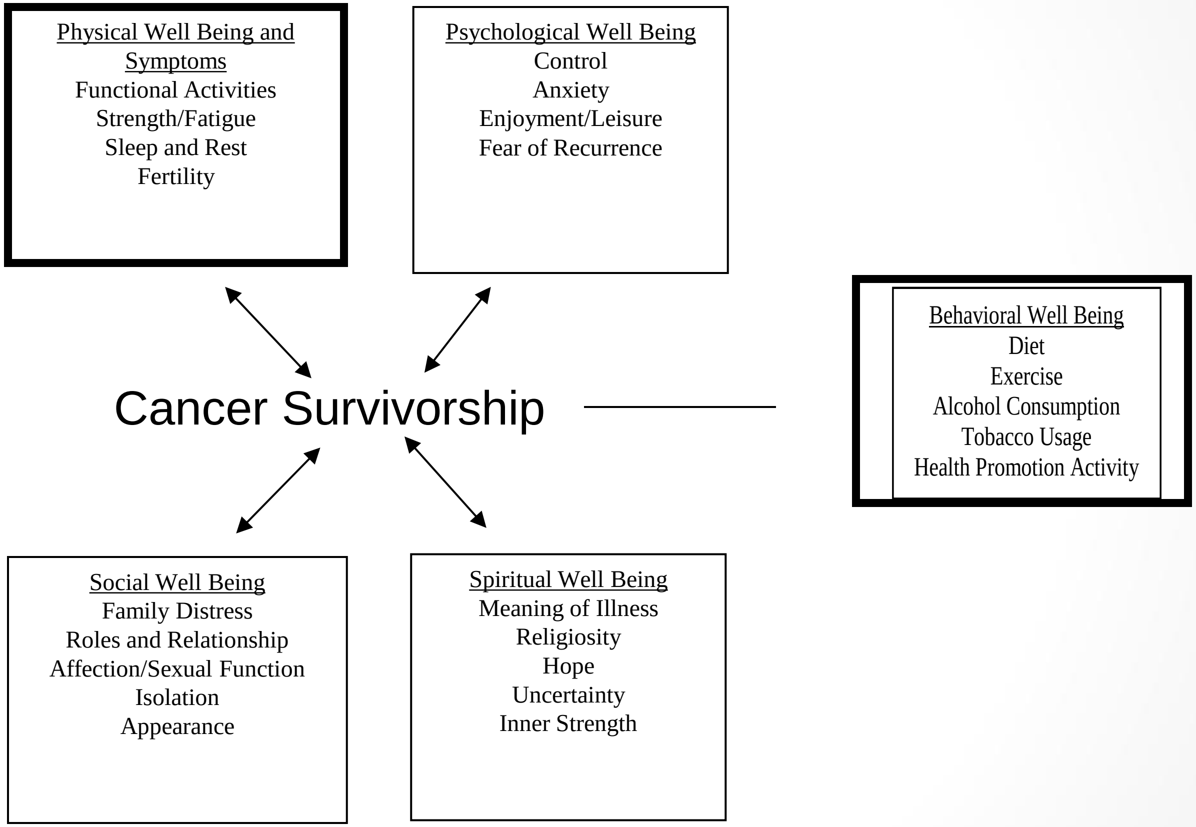
Formative Research

Pilot Studies

- To identify salient psychosocial issues among African American prostate cancer survivors and their spouses.

- Identify the preferred communication channels (including, medium, tone, and appeal) for African American men and their spouses to receive education related to ways to address psychosocial issues associated with prostate cancer survivorship.

Theoretical Model



Physical Well Being and Symptoms
Functional Activities
Strength/Fatigue
Sleep and Rest
Fertility

Psychological Well Being
Control
Anxiety
Enjoyment/Leisure
Fear of Recurrence

Cancer Survivorship

Behavioral Well Being
Diet
Exercise
Alcohol Consumption
Tobacco Usage
Health Promotion Activity

Social Well Being
Family Distress
Roles and Relationship
Affection/Sexual Function
Isolation
Appearance

Spiritual Well Being
Meaning of Illness
Religiosity
Hope
Uncertainty
Inner Strength

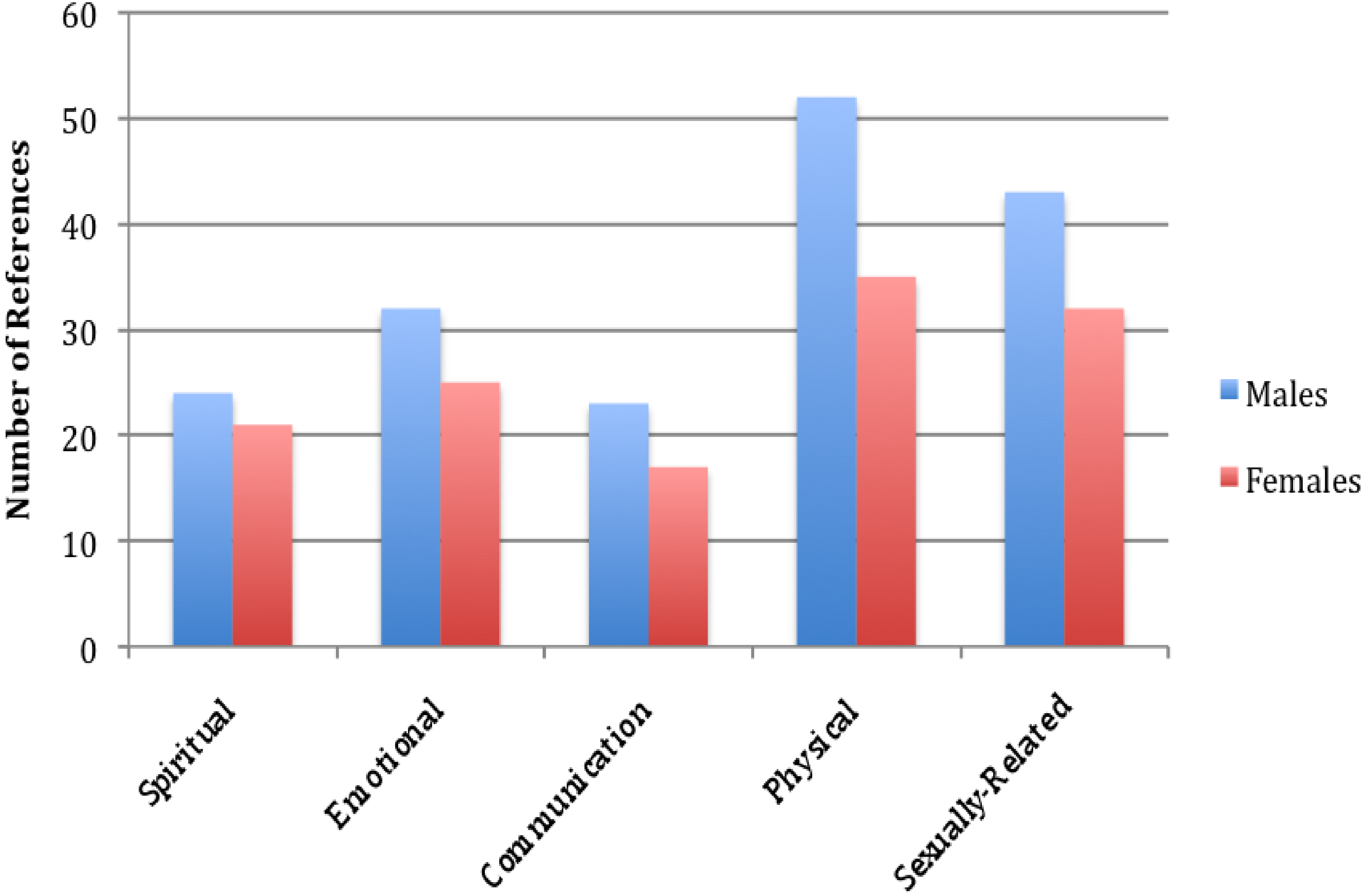
Figure 1. Quality of life: conceptual model

Methods

- Purposive Sampling Strategy
  - 24 participants or 12 couples
- In-depth Interviews
  - Conducted in libraries, homes, and Moffitt
- Inclusion criteria for the male participants included:
  - a) diagnosed and treated for prostate cancer within the last five years and at least one year post-diagnosis;
  - b) age 40 to 70 years;
  - c) AA heterosexual, married male; and
  - d) no diagnosis of recurrent prostate cancer or any other type of cancer.
  - Couples were enrolled based on inclusion criteria for the male and the willingness of his spouse to participate.

Results

- Male participants - between 51 to 70 years of age, (mean of 59.75 years).
- Couples - married throughout prostate cancer diagnosis and treatment
  - lengths of marriage among ranged from 5 years to 46 years.
- Surgery and radiation were the most common forms of treatment,
  - 33.3% (4) reporting surgery,
  - 42% (5) reporting radiation therapy,
  - 25% (3) reporting a combination of surgery and radiation therapy.

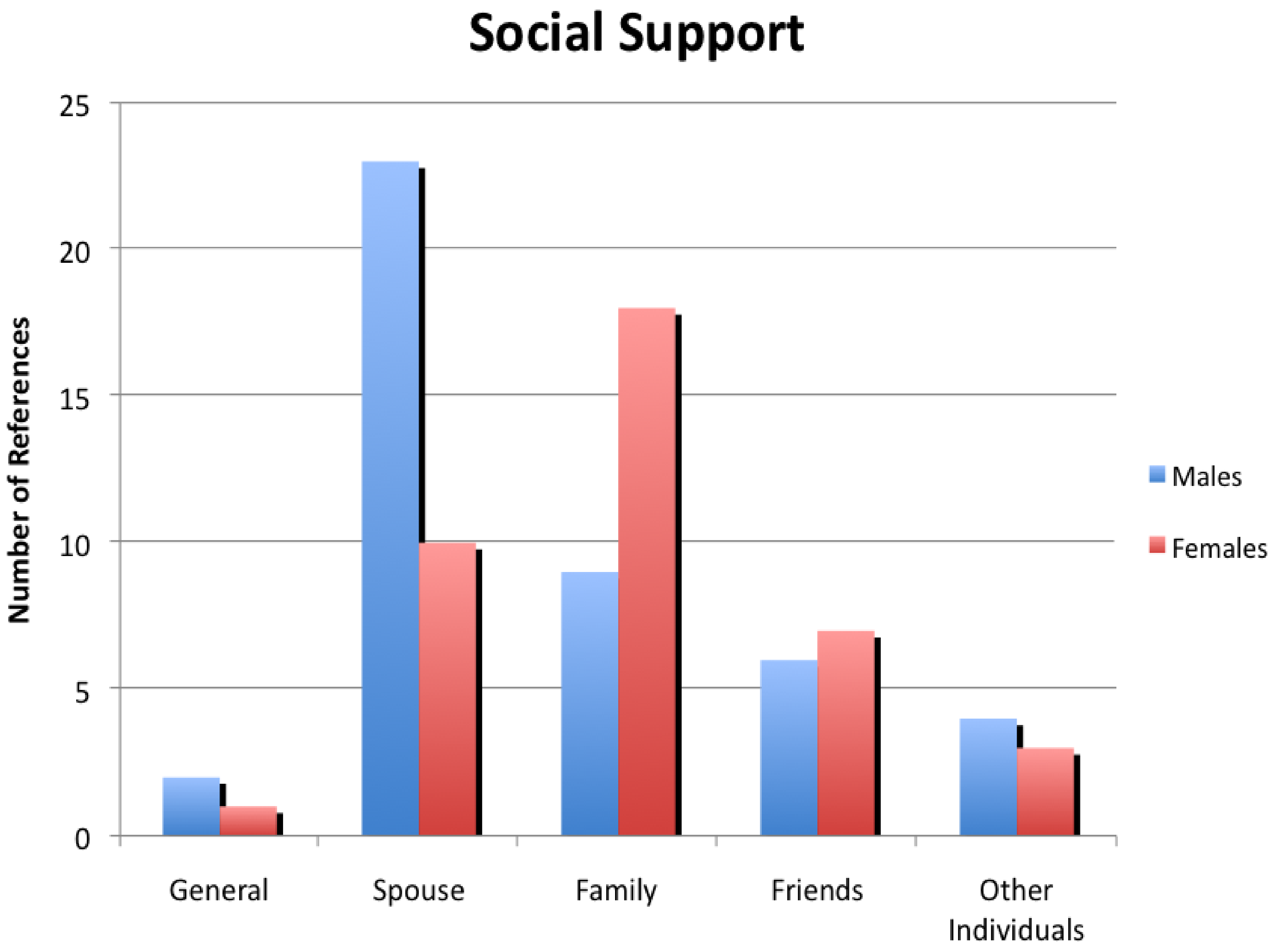


Effects of Prostate Cancer

Physical Functioning

Themes	Survivor	Spouse
Sexual Functioning	Loss of sexual desire & performance	Husband's wellness
Communication	Difficulties with patient-provider communication	Difficulties with partner communication
Social support	Support regarding sexual functioning	Change in sexual relationship with spouse
Management Techniques	Lack of effective treatments for erectile dysfunction	Minimal information about prostate cancer treatment
Temporal Orientation	Self-Evaluation of Purpose and Meaning of Life	Impact of Length of Time Married
Marital Role Delineation	Affect on masculinity & manhood	Impact of marriage commitment & affection

Rivers B, August E, Gwede C, Hart A, Donovan K, Powsang J, Quinn G. (2011) Psychosocial Issues Related to Sexual Functioning Among African American men treated for Prostate Cancer and their Spouses. *Psycho-Oncology.* Jan;20(1):106-10.


Social Support
Number of References
25
20
15
10
5
0
General
Spouse
Family
Friends
Other Individuals
Males
Females

Communication

Themes	Survivor	Spouse
Dyad Interaction	Lack of information sharing with spouse	Concern of the lack of communication
Patient-Provider	Difficulties of the communication “triangle” between the provider, patient, and spouse	Concern with the lack of information and knowledge from the provider
Strategies to overcome communication barriers	Transparency in communication	Express greater involvement with the healthcare provider and the need for support groups for caretakers
Marriage Enhancement	Improved Relationship	Increased role as emotional and physical caretakers

Rivers B, August E, Quinn GP, Gwede CK, Powsang JM, Green BL, Jacobsen PB. (2012) Understanding the Psychosocial Issues of African American Couples Surviving Prostate Cancer. April 29. [Epub ahead of print]

Resources for Support

- Majority of respondents talked about people as a source of support;
- Men were asked if they recalled receiving educational resources (videotapes or brochures) the majority did not recall;
- Respondents did not express barriers or reluctance to the use of educational resources for prostate cancer patients, however majority mentioned the need for materials specific to African American men and testing.

Format for Educational Resources

- Men were asked in what format they would prefer to receive information about prostate cancer/ treatment options
    - Half the men saying they would prefer to receive educational information in the mail and read it alone
    - Other half thought electronically based materials such as DVD or website would be more helpful.

- Several women noted that a DVD or website would allow them to view the information, at the same time, with their spouses.

- Men were asked from whom they would like to receive the information - majority of men said health care provider.

- About 1/3 of the men said they would like to have this information in community based settings.

Socio-Cultural Factors Affecting the African American Dyad

- Spirituality/Religiosity
- Acculturation
- Knowledge, attitudes & beliefs
- Family context - health, quality of relationship
- Social & emotional support
- Functional support
- Partnership, intimacy and sexuality

Summary

- Cancer is a disease that affects the entire family, and often a community
- Role of knowledge across continuum of Prostate Cancer
- Identification of Culturally Appropriate Communication Channels
- Culturally and literacy appropriate community-based educational resources
- Need for target educational approaches at diagnosis through survivorship

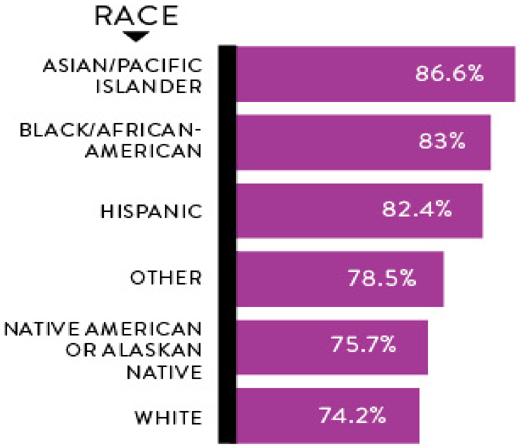
m-Health Interventions

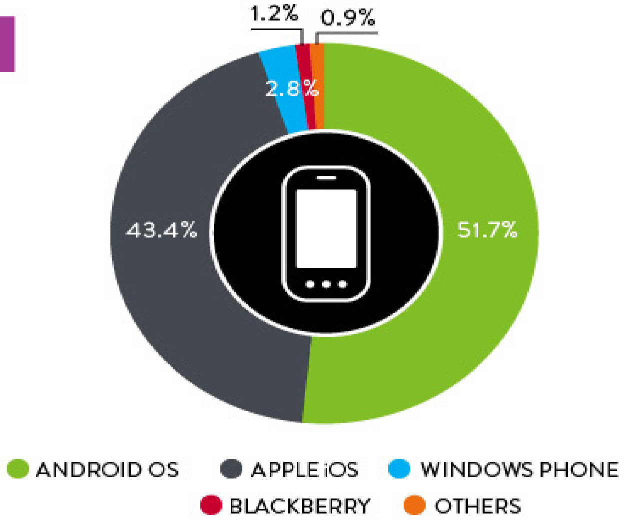
Innovative Approaches

US SMARTPHONE MARKET SHARE BY RACE, OPERATING SYSTEM AND GENDER

Q4 2014

SMARTPHONE OWNERSHIP





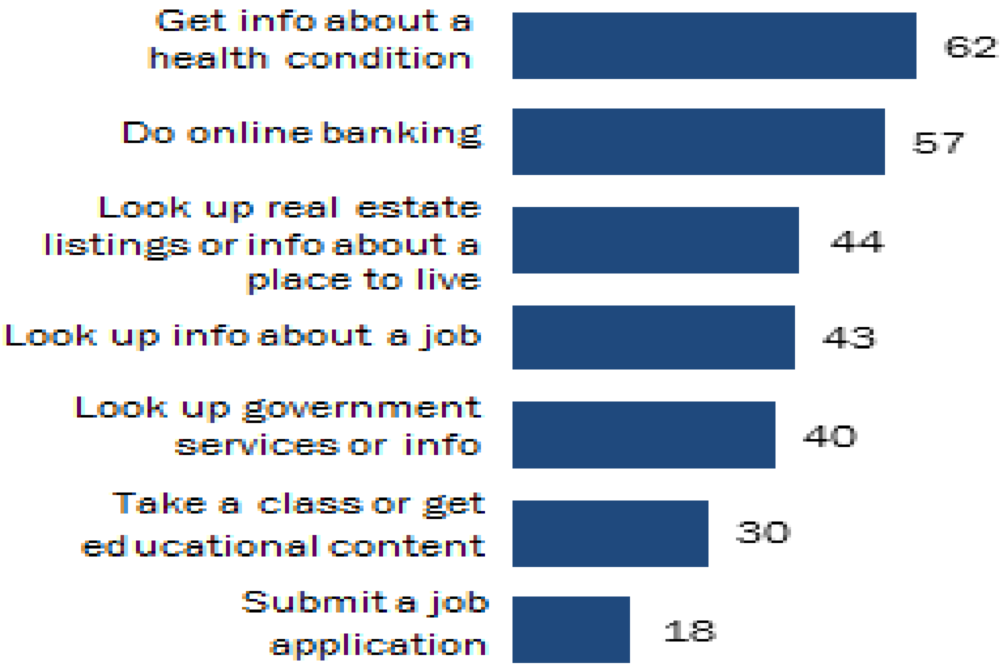
Read As: During Q4 2014, 51.7% of U.S. smartphone owners used a handset that runs on the Android operating system.

Source: Nielsen

nielsen AN UNCOMMON SENSE OF THE CONSUMER™

More than Half of Smartphone Owners Have Used Their Phone to get Health Information, do Online Banking

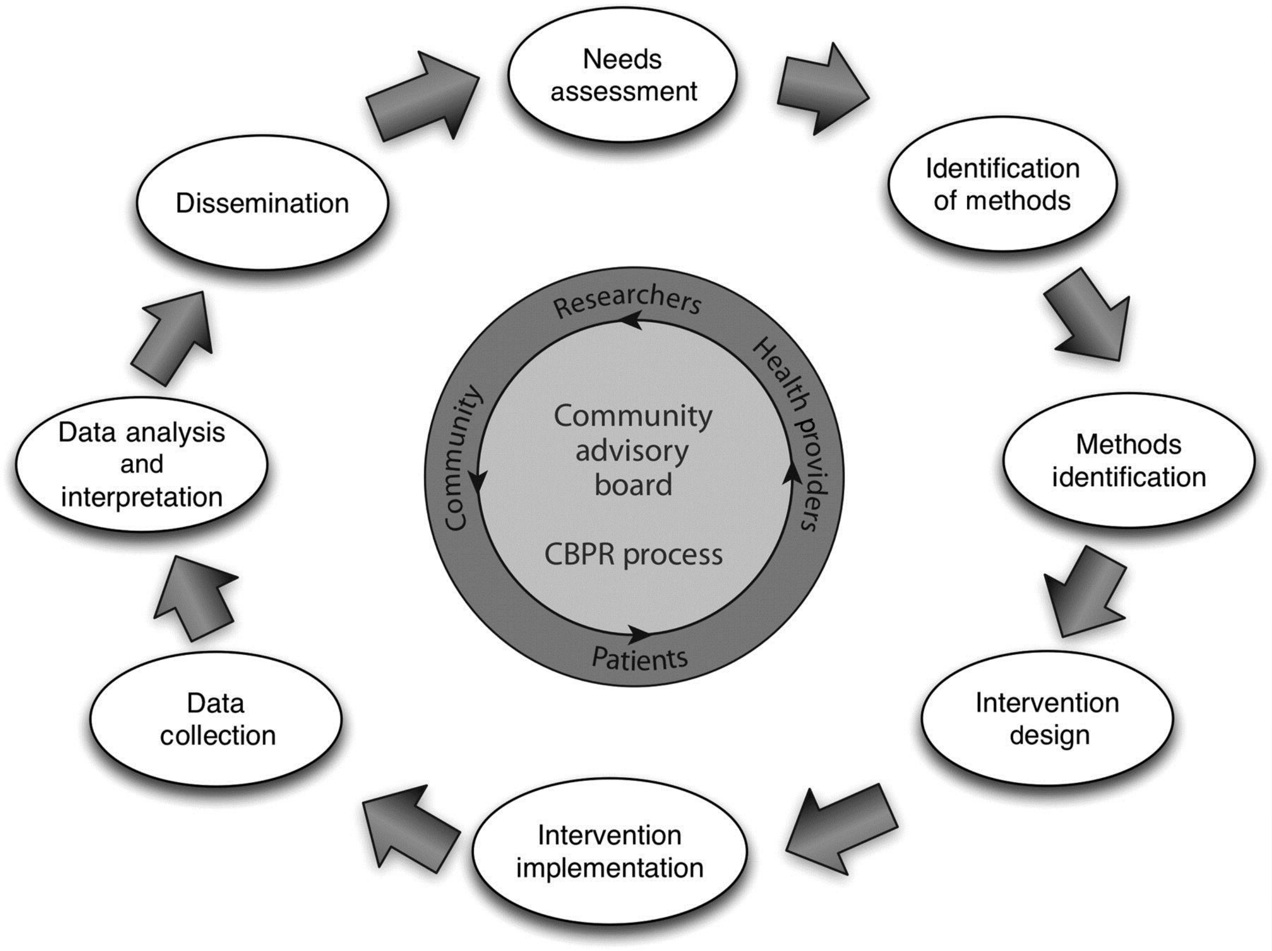
% of smartphone owners who have used their phone to do the following in the last year



Pew Research Center American Trends Panel survey, October 3-27 2014.

PEW RESEARCH CENTER

Community Based Participatory Framework



Community Navigation

- Iteration of the Patient Navigation Model
- Historically applied in the context of eliminating barriers to timely cancer diagnosis and treatment;
- More recently, expanded to include timely movement of an individual across the entire cancer continuum;
- Other potential outcomes metrics:
    - Self-efficacy
    - Social Support
    - Anxiety and Distress

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Navigator Guided Education for Prostate Cancer Patients and their Caregivers

PI: Brian M. Rivers, PhD, MPH

Patient-Centered Outcomes Research Institute (PCORI)

- Created to help people make informed health care decisions and improve health care delivery.

- Research is guided by patients, caregivers, and the broader health care community.

Background

- More than 90% of prostate cancers are discovered in the local or regional stages, for which the 5-year relative survival rate is near 100%.

- Despite great potential for survival, *health related quality of life* is often compromised in men and their support network after prostate cancer treatment.

- Being *knowledgeable about cancer* improves coping and decision-making abilities during diagnosis, treatment, and post-treatment.

Background Cont’ d.

- Newly diagnosed patients commonly report unmet information needs.

- Information seeking has been demonstrated to mediate individuals disruption of QOL associated with cancer diagnosis and treatment.

- Benefits of information include:
    - Improved ability to cope during the diagnosis, treatment and post-treatment;
    - Reductions in anxiety and mood disturbances;
    - Improved communication with family members.

Psychoeducational Interventions

- Significant gap between ongoing information and emotional needs of prostate cancer patients and available interventions.

- Four mediating outcomes of providing psychosocial and supportive care information include:
    - Improved social support
    - Increased knowledge of treatment and disease
    - Improved self-efficacy
    - Service utilization

Elements	Focus Group Responses	Implications for Adaptation and study design
Overall Design and Content of PHIN	• Positive Tone and Style • Variety of Educational Tools • Portability • Delivery of Sessions • Saliency of topics • Environment/Access • Barriers/Relevancy • Focus more on Symptom Management	• Re-Develop Modules to include representative tone and style of communication. • Consider individual vs. family delivery of the module content • Model symptom management techniques and exercises
Cultural Appropriateness and Sensitivity of PHIN	• Core cultural values (communalism-value centered education, religion/spiritualism as a coping mechanism, expressiveness, respect for verbal communication skills, connect commitment to family and family history)	• Family and community imagery depicted in PHIN • Include testimonials of AA prostate cancer survivors and their spouses
Linguistic/Literacy Issues	• Easy to understand information • Explanatory approach • Integration of concepts	• Attention to plain language • Personal perspectives incorporated • Concrete vs Abstract Messages
Layout/Graphics	• Color patterns • Imaging • Use of fonts, pictures and arrangement of such	• Augment PHIN to reflect images, pictures, and color patterns commensurate with population core values
Learning Stimulation/Motivation	• Role Modeling • Testimonials	• Reflect role modeling techniques in educational resources

Additional Topics for Psychoeducational Intervention based on Previous Research and (Manne et al, 2004)

Modules	Topic & Description	Display
1	**Medical Information about prostate cancer and treatment** – Information will be provided about the late- and long-term effects of treatment for localized prostate cancer.	Text/Graphics/Experts
2	**Maintaining good behavioral during and after treatment** – A comprehensive review of the role of behavior will be presented. The focus will entail the benefits of eating a healthy diet and how to sustain such.	Text/Graphics/Demonstration
3	**Stress management and coping skills training** – Effective coping strategies will be explored through role play and didactic presentations.	Text Graphics/Modeling
4	**Maintaining good communication and how to better get support needs met** – An overview of the role of social support will be presented and practical exercises provided.	Modeling
5	**Maintaining intimacy and dealing with sexual concerns** – Topics will be addressed and effective strategies presented to enhance couples ability to cope with sexual concerns.	Text/Graphics
6	**Survivorship Issues** – Salient issues post-treatment will be reviewed.	Text/Journaling

Prostate Cancer Knowledge Model

Definition:

A knowledge model: a collection of **interconnected concept maps** and associated **digital resources** (videos, images, PDF’ s, etc) about a **particular domain** (Prostate Cancer).

Concept Maps

What are Concept Maps?

- A graphical **two-dimensional** display of knowledge
- Concept Maps are graphical tools for **organizing** and **representing** information about Prostate Cancer
- Represent **organized knowledge** in meaningful diagrams that express concepts and propositions
- Concept Maps can facilitate **learning** and **understanding**

Theories Underlying Concept Maps:

Concept Maps are based on:

- A Theory of **Knowledge**
- A Theory of **Learning**

Personalized Health Information Navigator (PHIN)

Components of the Prostate Cancer knowledge model:

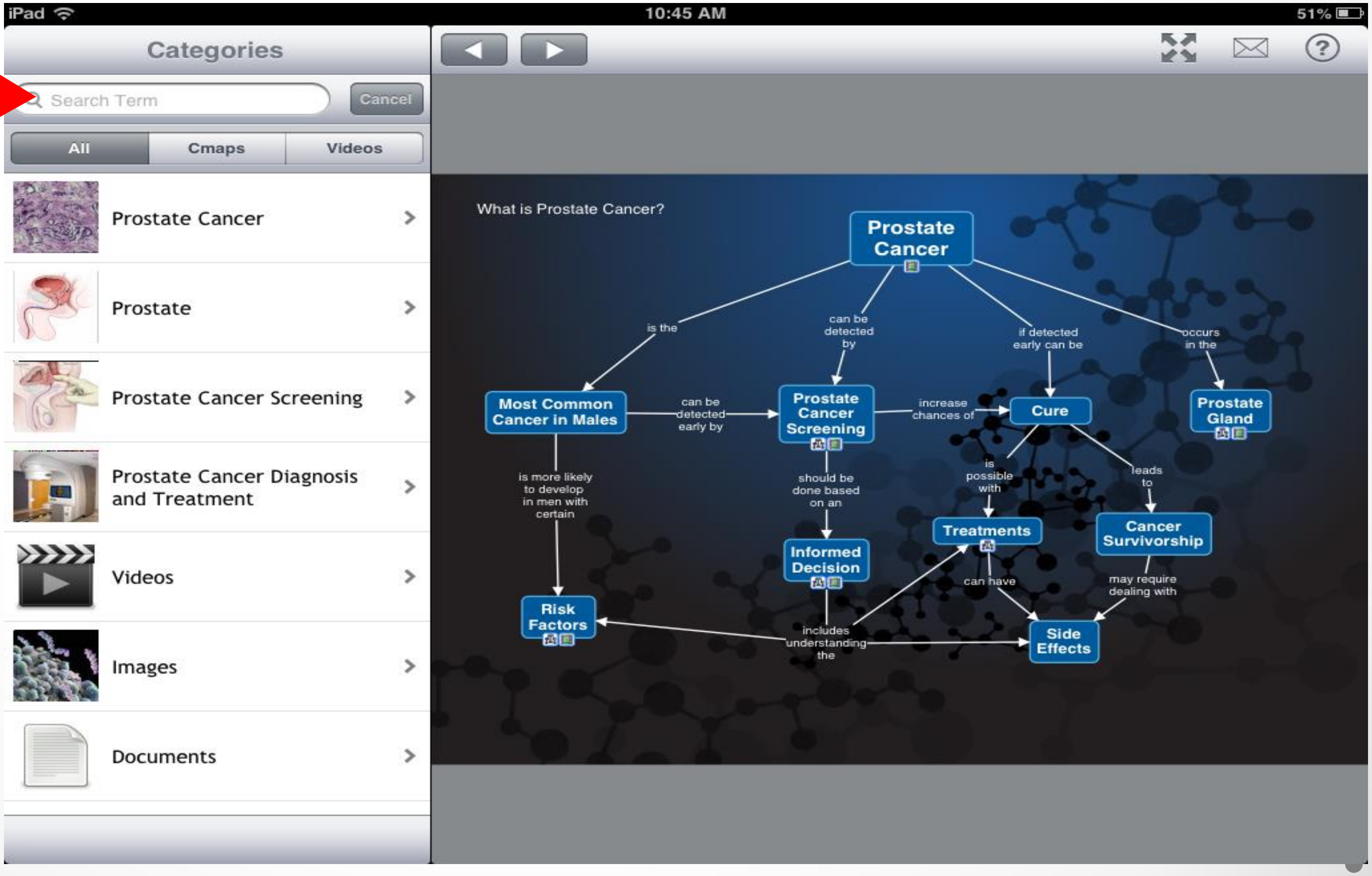
- ➢ 28 interconnected concept maps
- ➢ 133 video clips (no more than 3 minutes in length).
- ➢ 21 Images
- ➢ 2 Help videos (Explain the rationale behind concept maps and describes how to navigate the knowledge model and access and search for the multimedia resources)

Components of the collection of concept maps:

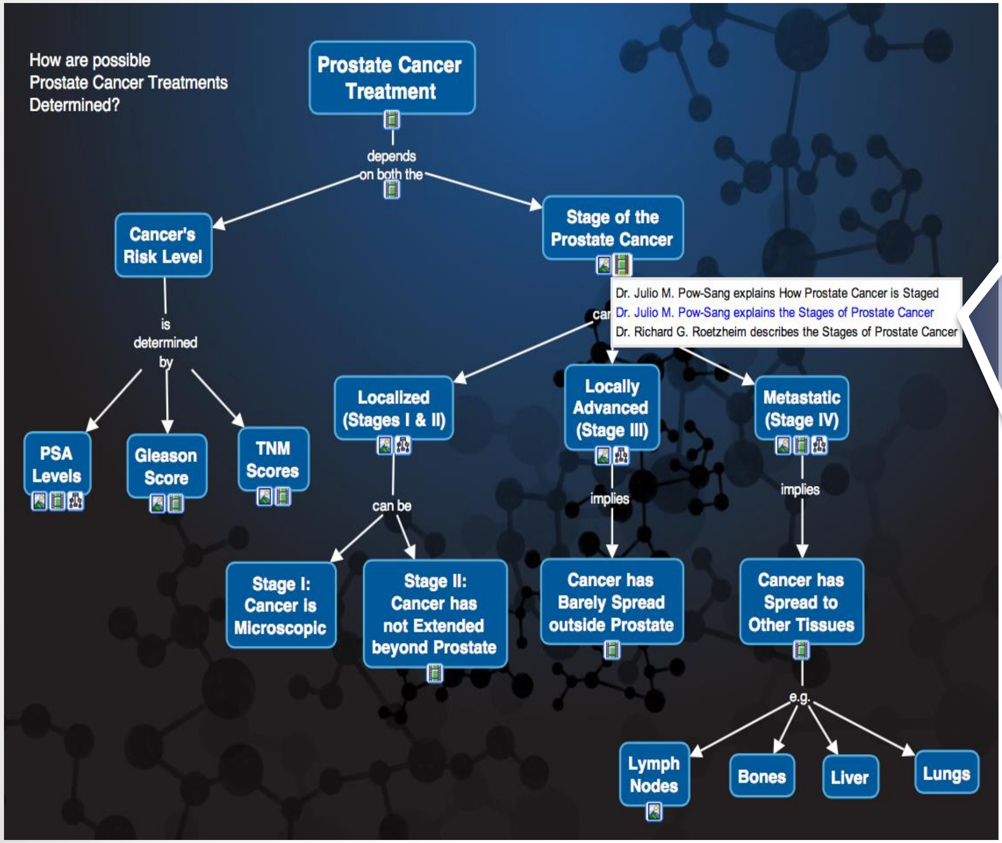
- ➢ **548** propositions
- ➢ 1022 concepts (**535** unique concepts)
- ➢ 499 linking phrases (**224** unique linking phrases)

PHIN
iPad Interface

The search capabilities provided by PHIN simplifies direct access to information.



PHIN Resources Cont'd.



How are possible Prostate Cancer Treatments Determined?

Prostate Cancer Treatment

depends on both the

Cancer's Risk Level

is determined by

PSA Levels

Gleason Score

TNM Scores

Stage of the Prostate Cancer

Dr. Julio M. Pow-Sang explains How Prostate Cancer is Staged
Dr. Julio M. Pow-Sang explains the Stages of Prostate Cancer
Dr. Richard G. Roetzheim describes the Stages of Prostate Cancer

Localized (Stages I & II)

can be

Stage I: Cancer is Microscopic

Stage II: Cancer has not Extended beyond Prostate

Locally Advanced (Stage III)

implies

Cancer has Barely Spread outside Prostate

Metastatic (Stage IV)

implies

Cancer has Spread to Other Tissues

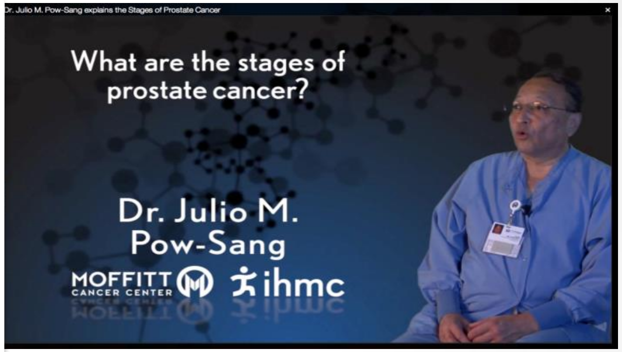
e.g.

Lymph Nodes

Bones

Liver

Lungs



Dr. Julio M. Pow-Sang explains the Stages of Prostate Cancer

What are the stages of prostate cancer?

Dr. Julio M. Pow-Sang

What is the experience like to have a DRE?

Dr. Richard G. Roetzheim

Specific Aims

1. To evaluate the impact of providing newly diagnosed patients and their caregivers with a prostate cancer treatment information mobile tablet technology-based interactive application on patient and caregiver outcomes (decisional satisfaction, decisional conflict) and shared decision-making practices (decision making involvement).

2. To investigate the mechanism by which the app improves shared decision making among patients and caregivers.

3. To identify men and caregivers who are most likely to benefit.

Target Audience: 600 dyads (patients and caregivers)

NIH National Institute
on Minority Health
and Health Disparities

A Health IT Based Psychoeducational Intervention for African American Prostate Cancer Patients

1 R01M00783-01

PI: Brian Rivers, PhD, MPH

Specific Aims

1. To evaluate the impact of MPHN on the quality of life outcomes among African American men newly diagnosed with prostate cancer.

2. To investigate the mechanism by which MPHN improves quality of life among African American men newly diagnosed with prostate cancer.

3. To examine whether clinical factors and information-seeking moderate the impact of MPHN on quality of life.

4. To explore the impact of MPHN on psychological reports of stress and biomarkers of stress (cortisol and telomere).

Target Audience: 500 African American Men

Background

- Being diagnosed with prostate cancer is a significant stressor accompanied by declines in QOL, specifically physical and mental well-being;
- Newly diagnosed patients commonly report unmet information needs;
- Lazarus Transactional Model of Stress and Coping provided a framework to explain how men and their caregivers cope with the stress and uncertainty of a prostate cancer diagnosis through information acquisition;
- Information seeking has been demonstrated to mediate individuals disruption of QOL associated with cancer diagnosis and treatment;
- Benefits of information include
    - Improved ability to cope during the diagnosis, treatment and post-treatment;
    - Reductions in anxiety and mood disturbances; and
    - Improved communication with family members;

- AA have limited access to recommended prostate cancer information and experience multiple barriers to receiving psychosocial information and services;

- Mistrust of the medical community and difficulty accessing credible and reliable information through trusted channels of communication;

- Associations between anxiety as a result of prostate cancer and prognostic features for prostate cancer among AA have not been well investigated;

- The relationship of prostate cancer anxiety to the common determinants of QOL remains poorly understood;

Approach

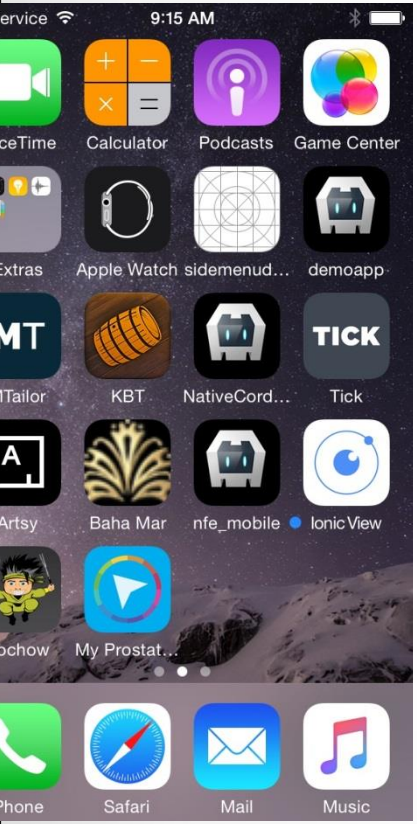
- Community-based randomized control trial;

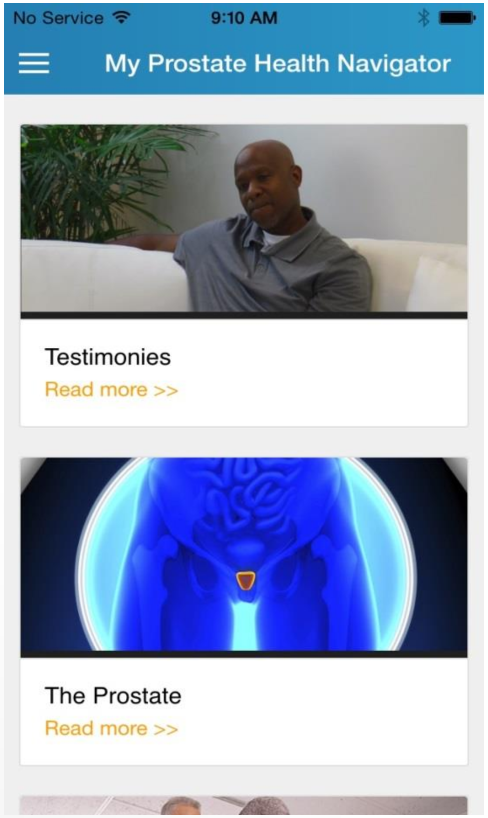
- Community navigator (CN) guided digital psychoeducational intervention vs usual care among men newly diagnosed with prostate cancer and their spouses;

- Eligible participants will be identified within 2-months of their initial diagnosis and select community-based clinical practices;

Development of the application:

My Prostate Health Navigator





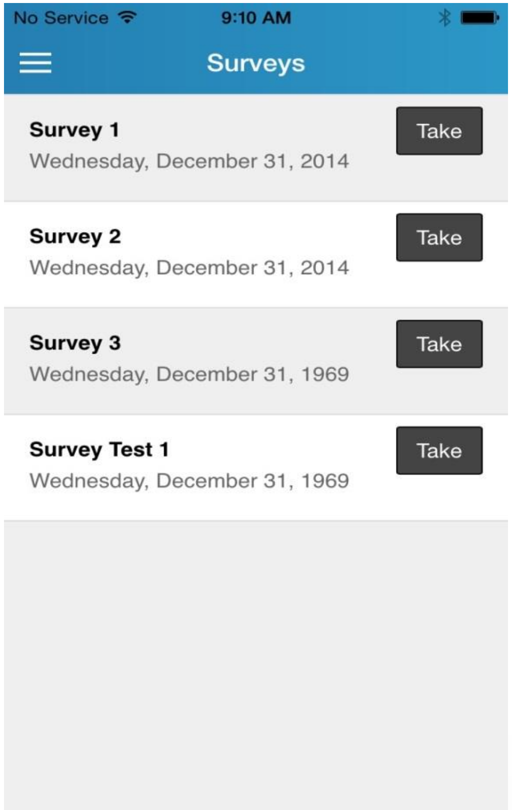
My Prostate Health Navigator

Testimonies

Read more >>

The Prostate

Read more >>



Surveys

Survey 1
Wednesday, December 31, 2014

Take

Survey 2
Wednesday, December 31, 2014

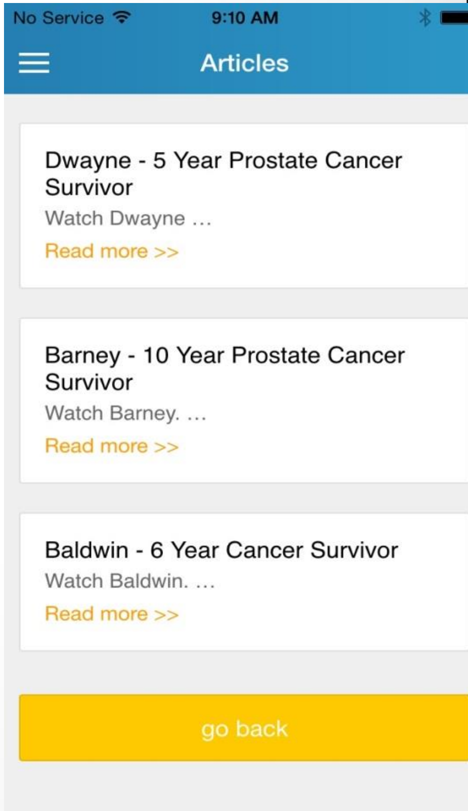
Take

Survey 3
Wednesday, December 31, 1969

Take

Survey Test 1
Wednesday, December 31, 1969

Take



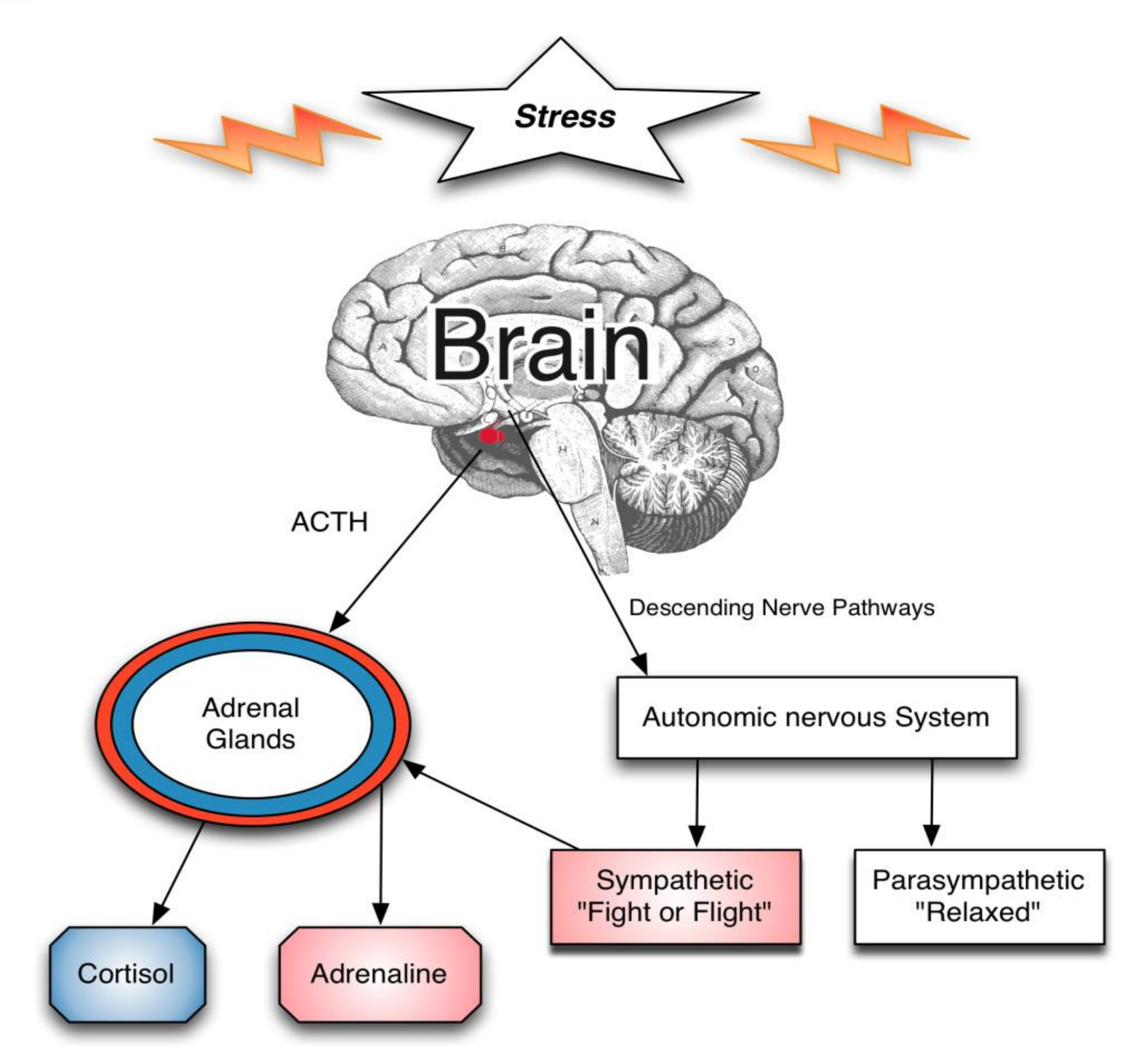
Articles

Dwayne - 5 Year Prostate Cancer Survivor
Watch Dwayne ...
Read more >>

Barney - 10 Year Prostate Cancer Survivor
Watch Barney. ...
Read more >>

Baldwin - 6 Year Cancer Survivor
Watch Baldwin. ...
Read more >>

go back



Stress

Brain

ACTH

Descending Nerve Pathways

Adrenal Glands

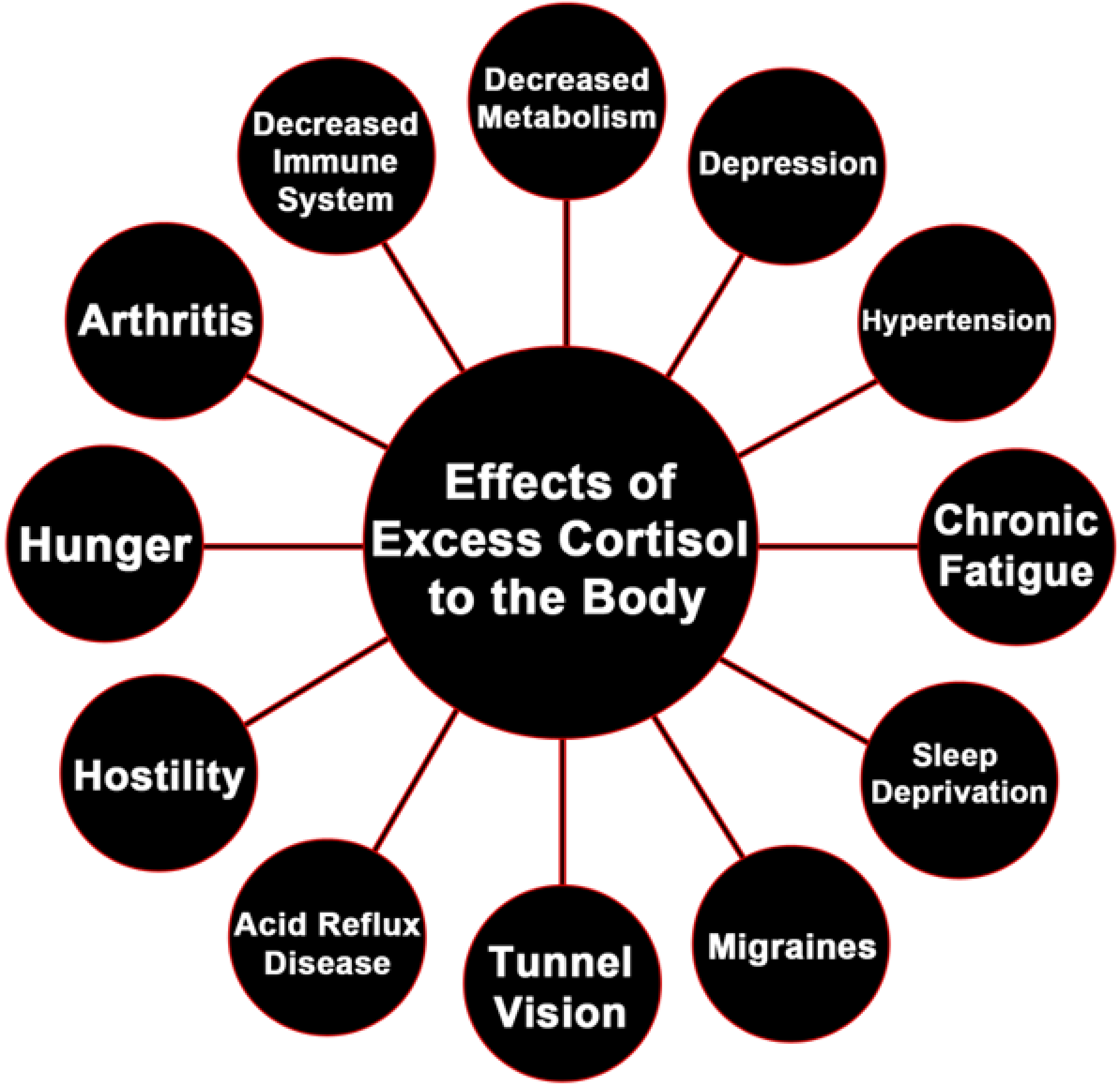
Autonomic nervous System

Sympathetic "Fight or Flight"

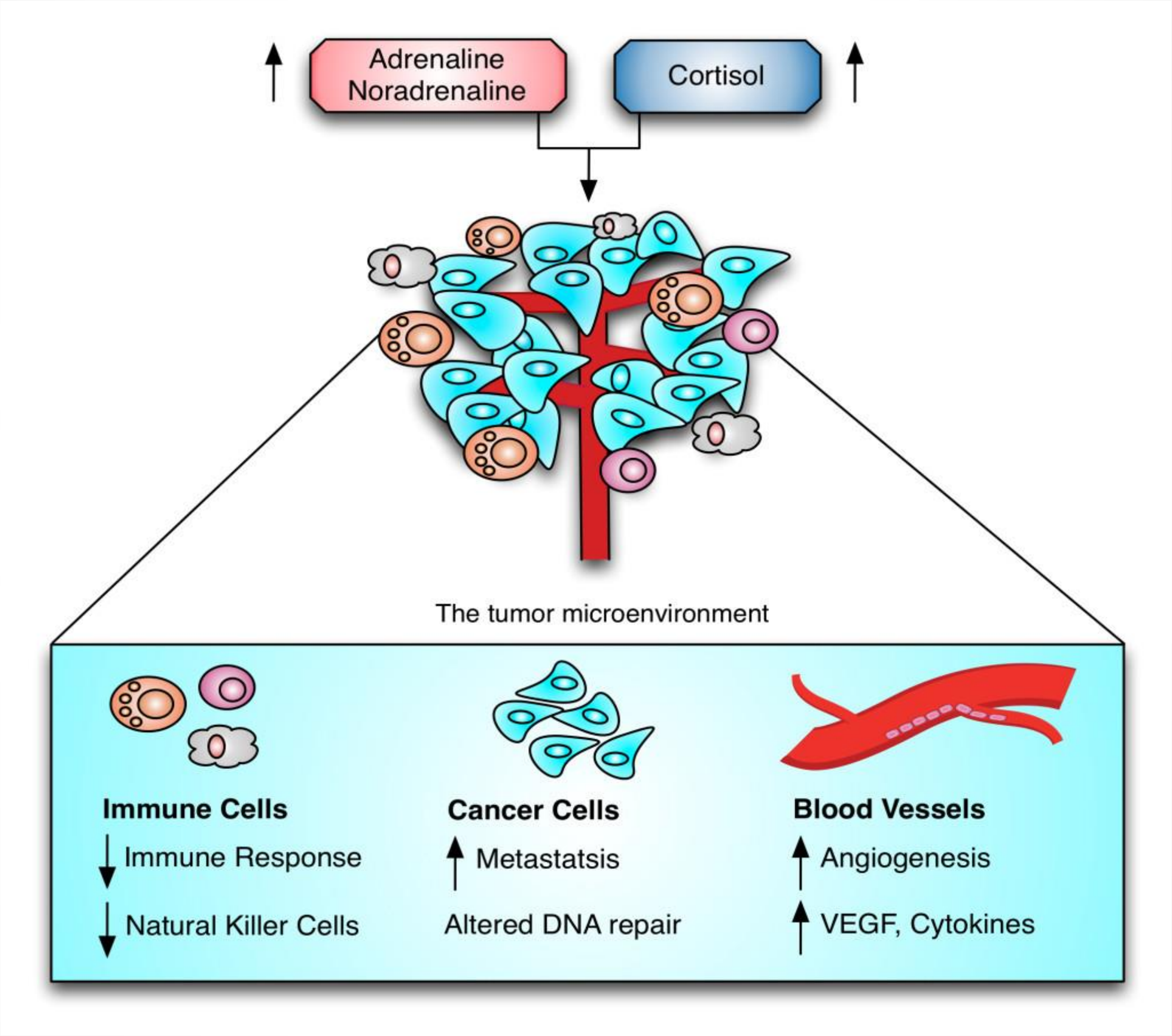
Parasympathetic "Relaxed"

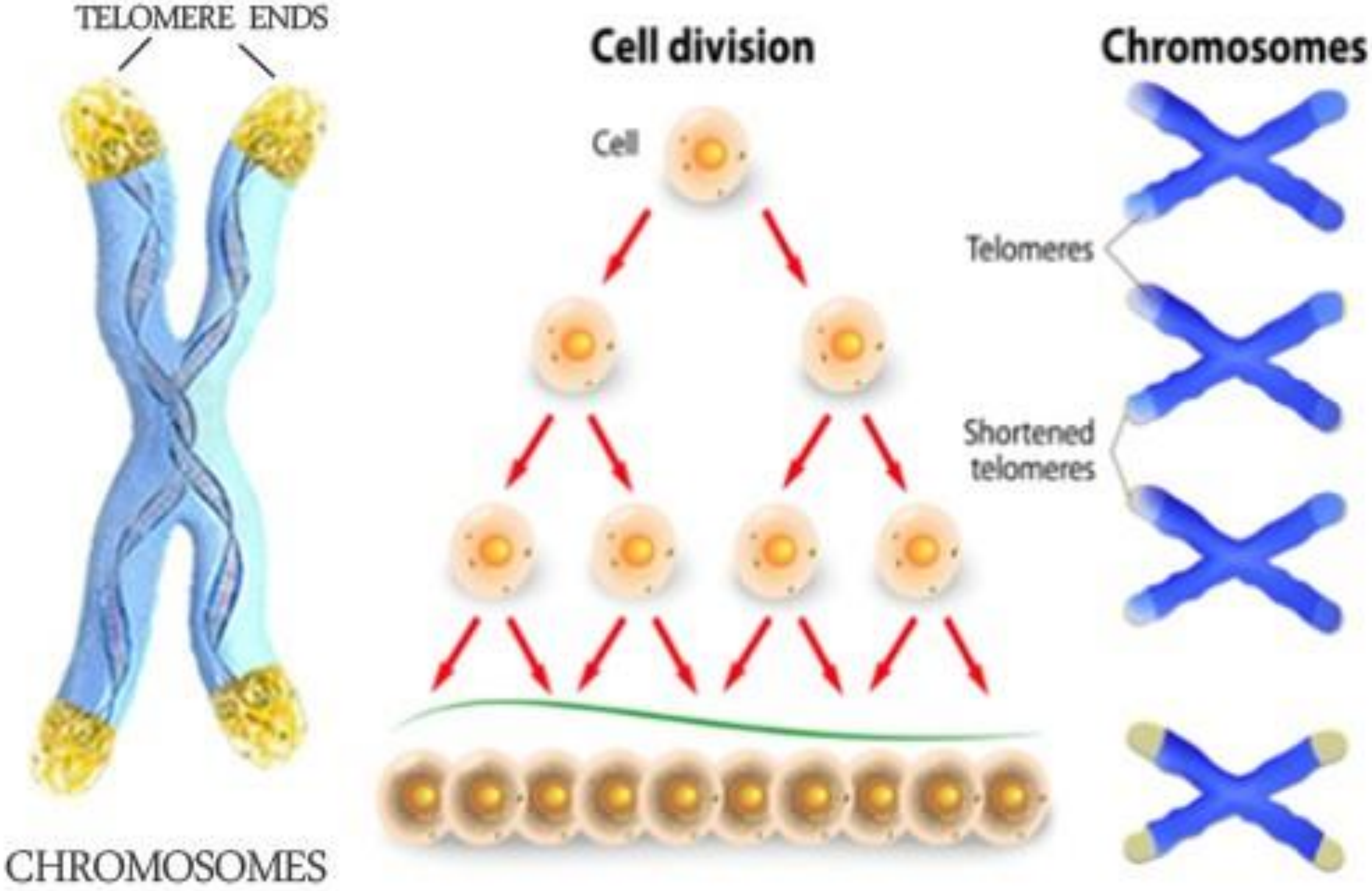
Cortisol

Adrenaline



Cortisol - The Stress Hormone


↑ Adrenaline Noradrenaline
Cortisol ↑
The tumor microenvironment
Immune Cells
↓ Immune Response
↓ Natural Killer Cells
Cancer Cells
↑ Metastatsis
Altered DNA repair
Blood Vessels
↑ Angiogenesis
↑ VEGF, Cytokines



Stress Speeds up Shortening of Telomeres

Study Population

- Patients must:
  - have been newly diagnosed (within 2 months) with biopsy-confirmed case of prostate cancer;
  - be 40-70 years, 3) able to speak and read English;
  - living within 120 miles of participating cancer center;
  - Men diagnosed with early stage, locally advanced or metastatic disease will be eligible to participate in this study.

- Caregivers must:
  - be aged 18 or older;
  - identified by patients as their primary caregiver (i.e., provider of emotional and/or physical care);

Patient Centered Care Coordination

Provide the *right information and navigaiton*, to the *right patient*, at the *right time*.

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Thank You