CULTURAL CONSIDERATIONS IN CAREGIVING
Caring for Minorities

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Objectives:
• List barriers minorities face when receiving ALZ care & treatment.
• Describe adaptive mechanisms of minority caregivers and patients with ALZ.
• Identify ways for improved care for minority patients.

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Caring for Minorities
The African-American Experience
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African American Experience
- Understand the specific experiences and adaptive mechanisms of this particular cohort who are embedded in a unique historical, socio-political-economic-cultural context
- A model for understanding human adaptation in general
- Addressing the need for adequate support

Significance
- Highest users of health services and long-term care
- Multiple social structural paradox:
  - Low income, low home ownership, high unmet housing needs, greater exposure to risk factors for mental illness (violet crimes, homelessness, incarceration)
- High rates of disability and health problems that are disabling
Significance

- Alzheimer’s disease is the single largest, looming, unaddressed public health threat facing the nation, but we now know the threat is even more substantial in the African-American and Hispanic communities.

Significance

- Minority groups are more likely to have Alzheimer’s, less likely to know it and, as a result, less likely to receive available treatments and supportive services that can help them cope with the disease.

The Demographics
Black/African American Elders

- Ethnic minority elders projected to be 40% of older US population by 2040
- By 2050, African Americans will represent 12% of older adult population
- Increasing heterogeneity
  - Caribbean, African, Migratory patterns (South to North)

African American Population by Region

Experiences of Older African Americans
Statistics

- African-Americans are about two times more likely and Hispanics are about one and one-half times more likely than their white counterparts to have Alzheimer’s and other dementias. Although whites make up the great majority of the more than five million people with Alzheimer’s and other dementias, African-Americans and Hispanics are at higher risk for developing the disease.

The Mental Health Paradox

Risk for Depression

- African Americans elders have higher prevalence than Whites of chronic conditions that are risk factors for distress/depression
  - Stroke, Diabetes, Heart disease, Cancer
- African Americans have greater functional disability, also a risk factor for depression
- Yet, African Americans have lower rates of depression symptoms than Whites even when compared to other groups with the same level or even greater impairment
Rates of Distress/Depression

- Subsyndromal forms of depressive illness more common than major depression
  - Prevalence rates from 15% to 17% (Blazer, 2002; Beekman, et al., 1995).

- Rates higher among older adults with physical health problems and functional disabilities or who receive home care
  - Prevalence rates from 25% to 33% plus (Bruce et al., 2002).

Rates of Distress/Depression

- Early studies show rates for African American elders from 7% (Eaton & Kessler,) to 18.3% (Stallones et al.)

- Recent research – rates vary across settings
  - Primary care 17%
  - Home care 30%
  - Community 21%
  - Rehabilitation 30%

Rates of Distress/Depression

- Philadelphia survey of African American (N=98,870) and White (N=156,935) elders 60 years of age or older found:
  - 48% of African Americans versus 33% Whites reported fair to poor health.
  - 34% of older African Americans reported no depressive symptoms (Geriatric Depression Scale) compared to 43% of Whites.
  - 50% of older African Americans reported 1-3 depressive symptoms compared to 42% Whites.
  - 17% African Americans reported 4+ symptoms compared to 15% Whites (p=0.01).
Mental Health Paradox Continues

- Black patients more likely than white patients obtain mental health care from primary care providers.
  - Less likely to be diagnosed
  - Less likely to be given anti-depressant medications
  - African Americans derive same benefits as Whites from depression treatments
  - Preference for “talk” versus pharma therapies
- Use of anti-depressant use increased among White but not Black patients

The Picture is Confusing

- African Americans (particularly elders with impairment, chronic health conditions) have lower rates of depressive symptoms yet a significant number are distressed
- Wide variation in prevalence rates based on region, neighborhood, gender, urban-rural, setting (e.g., primary care, home care, community)
- Unclear if differential rates due to differential symptom presentation (somatic versus dysphoric mood), differential and/or missed diagnoses, view of reporting as complaining
- African Americans who are depressed/distressed are under treated
- Unclear as to preferred coping strategies, preferred treatment approaches, definition of depression, factors contributing to depression

Persistent STICKING POINTS

- Continued comparison with Whites:
  - Unable to explain differences
  - Comparisons based on domains derived from and relevant to dominant group
  - Ignores extreme heterogeneity within cultural groups, vast regional differences
  - Differences reflect measured and unmeasured differences and processes not yet well understood
- Lack of understanding of historically and culturally grounded practices that inform self-care/health practices
Persistent STICKING POINTS

- Historical (and current) unethical research as collective cultural framework of older African Americans
  - Mistrust of pharmacological and preference for “talk” research
  - Use of mental health statistics as a tool to promote segregation and racism
  - Tuskegee, Holmes Prison experiments
  - Historical mistreatment of African Americans in medical texts
- Under recruitment of African American elders, particularly men

Why Participate in Research? Emerging Topics

- Legacy
  - Leaving behind lessons learned
  - Desire for voices to be heard, have a meaning, make a difference
  - Chasm between young and old and responsibility of elder
- Get it Straight
  - Aging plus gender plus misunderstanding/lack of knowledge of African American experience
- Tension of Mistrust but Understanding Importance:
  - Distrusts of medicine/pills, experimentation as solution
  - Historical events and experiences profoundly influence continued mistrust.

Critical Findings

- Health disparities
- Functional limitations associated with depressive symptoms for both African American and White elders but different predictors
- Depressive symptoms untreated among African American and White elders with functional difficulties
- African American elders use wider range of adaptive strategies than Whites
  - Social Support
  - Spirituality
  - Control-oriented strategies

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How do Control Strategies Buffer Depressive Symptoms?

- Maintain participation in meaningful activities
- Behavioral activation — active/effective ingredient in CBT
- Activity engagement may maintain reserve capacity to overcome health set backs

Why Do African Americans Use Control-oriented Strategies More than Whites?

- Control strategy use may be grounded in an historically-based cultural tradition of resiliency and pushing through adversity
  - Why do some African Americans not use these strategies?

Emerging Adaptive Mechanisms

COGNITIVE:

- Self-talk (e.g., saying to self “snap out of it,” or “got to move on”)
- Cognitive reframing, (e.g., could be worse; I’m still living; they didn’t kill me yet)
- Holding on to religious beliefs
- Cognitive comparisons (e.g., not as bad as it could be; not as bad as it was for parents)
- Minimization of problems
- Readjustment of expectations
- Don’t “claim” it as a problem
Emerging Adaptive Mechanisms

BEHAVIORAL:
- Prayer
- Purposive business (keep on keeping on)
- “Talk to someone in your groove”
- Purposeful involvement with friends, activities
- Do versus “complain”
  - “This is how it is but I’m not complaining.”

An Emerging Dynamic

- Sources of strength and modes of coping in response to and reinforced by historical, health, societal and community forces
- Modes of coping are immediately adaptive but do they contribute to minimization of symptoms and misdiagnoses?

LOOKING BACK TO MOVE FORWARD

- Health disparities are complex reflecting deeply rooted historical, socio-political and economic forces that play out in specific behavioral choices and preferred coping responses of individuals
- Race and ethnic origins are broad indicators of complex social and behavioral patterns that have historical basis
- Must understand the historical and current context of peoples lives and embrace the complexity
NEW CULTURE OF RESEARCH

- Understanding stance of targeted group
- Establishing trust
  - Bridge cultural divides between clinic and community; between researchers and target community
- Mixed methodologies – emic perspective and comparative large scale studies
- Different ways of involving target group
  - Identifying/refining the questions we should be asking
  - Member checks – did we get it right?
  - Naming and framing programs/approaches
- Give back
  - Overcoming the research timeline
  - Closing the gap
  - Sharing what we learn through the preferred ways of the target group

Features of Successful Support

- Learn the Cultural Map for Living
- Dispel long held perceptions about support groups
- Recruit prominent members of the minority community to serve as liaisons or coaches.
- Obtain support from churches and houses of faith.

Features of Successful Support

- Identify an appropriate community based meeting place.
- Identify and train Black and Latino group facilitators.
- Recruit Black and Latino professionals for speakers bureau activities
Features of Successful Support

- Use the media
- Offer tangible hope
- Maintain personal contact with support group members

In Conclusion

Pressing needs

- Intention
- Inclusion
- Follow-through