Targeting Stigma and Hesitancy to Participate in Research Among Patients with Neurological Disorders

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Stigma

Definition: *“Mark of disgrace associated with a particular circumstance, quality, or person.”*

Synonyms:

Shame,

Dishonor,

Humiliation,

(bad) Reputation: *“ the stigma of bankruptcy”*

Stigma separates individuals from society

- Stigma discredits and separates an individual from society.
- The stigmatized person is seen as “other” or “less than” other members of society.

Goffman, 1963; Green, et al. Sociological Inquiry, 2005.

External vs. Internal Stigma

- External stigma: How society perceives/treats a stigmatized person.
  - Structural stigma (stems from government or institutions, such as legal restrictions)
  - Public stigma (from the general population).
- Internal stigma: How a person regards themselves with respect to stigma. *"If you tell*

a person something often enough,

They will start to believe it"

Goffman, 1963. Green, et al. Sociological Inquiry, 2005.

Breaking Down STIGMA

The Social Cognitive Stigma Model has 4 key parts :

1. A *"signal" marks someone as a potential target* of negative reactions. This could be a diagnosis like mental illness or the person's appearance. For example, an obvious physical abnormality or a person's body size/shape.
2. The *"signal" prompts others to apply negative stereotypes* or cognitive framework that gives a meaning to the signal. For example, *"Overweight people are all sloppy and lazy".*

Corrigan PW (2000) Clinical Psycol Sci Pract 7(1) 48-67.

Breaking Down STIGMA

3. These negative cognitive frameworks or *stereotypes* contribute to an *emotional response* such as pity or fear. For example, belief that a person with epilepsy is dangerous and will hurt innocent bystanders may generate fear.

4. *The emotional response can lead to negative behaviors.* For example:

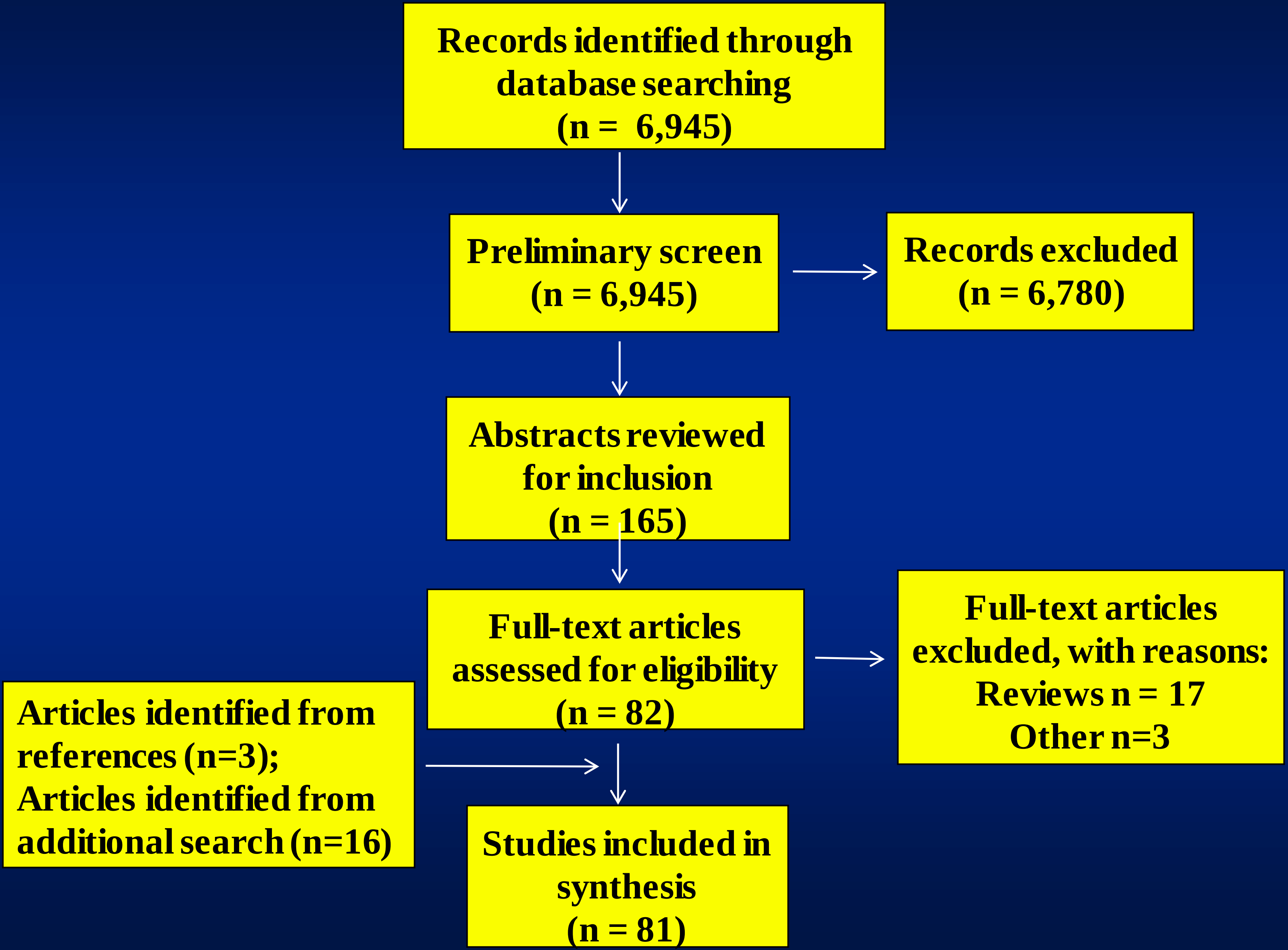
-avoiding being in the same room as a person with HIV.

-not wanting to live in a neighborhood with people from a specific country or region

Investigating & targeting epilepsy stigma

- Part 1: Systematic literature review of epilepsy-stigma research in Western countries over the past 10 years
- Part 2: Prospective randomized controlled trial (RCT) to develop and test novel health communication approaches to reduce public epilepsy stigma
- Grant from the Centers for Disease Control and Prevention (1U48DP005030 SIP008).

Literature Review Flow Diagram:



Records identified through database searching (n = 6,945)

Preliminary screen (n = 6,945)

Records excluded (n = 6,780)

Abstracts reviewed for inclusion (n = 165)

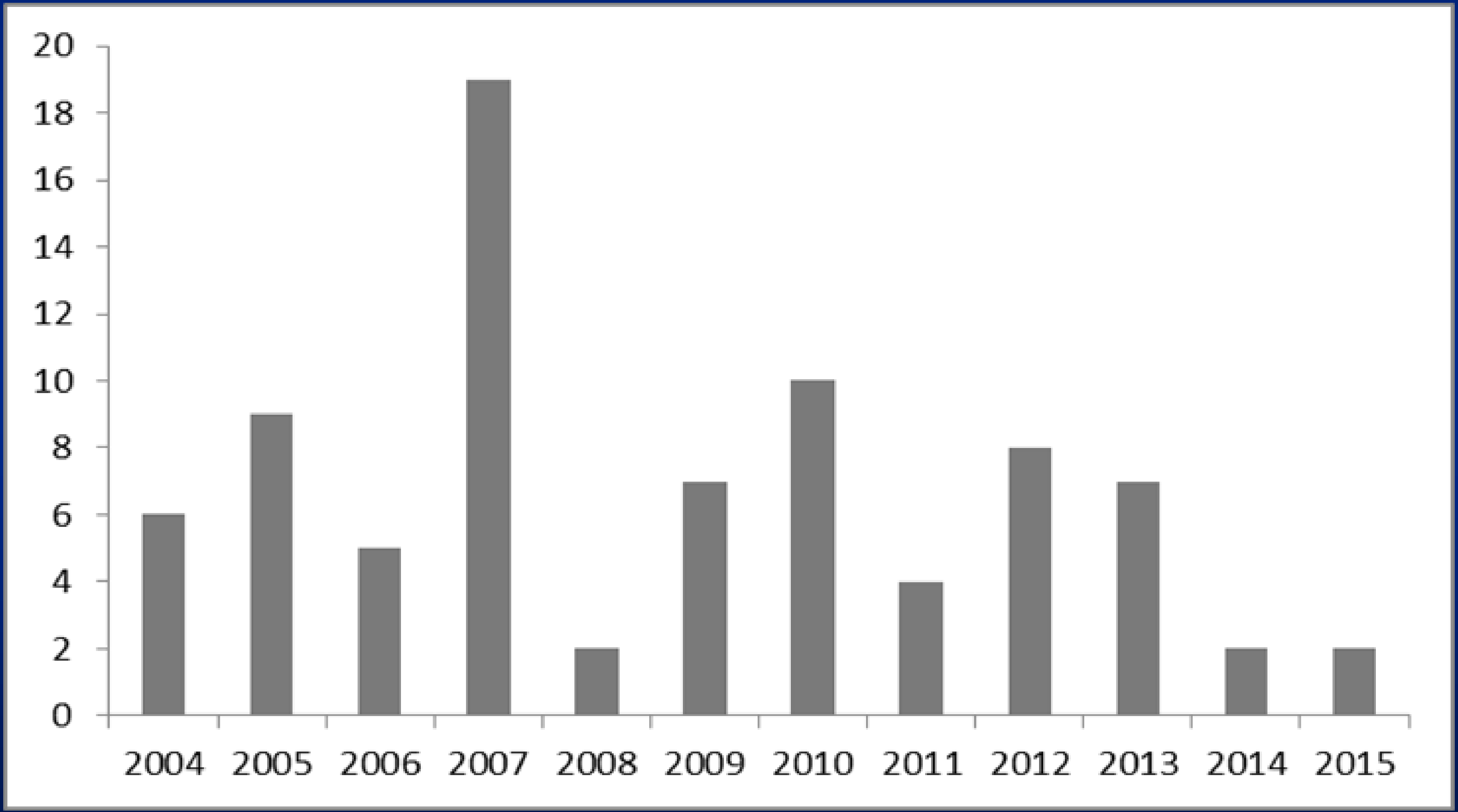
Full-text articles assessed for eligibility (n = 82)

Full-text articles excluded, with reasons:
Reviews n = 17
Other n=3

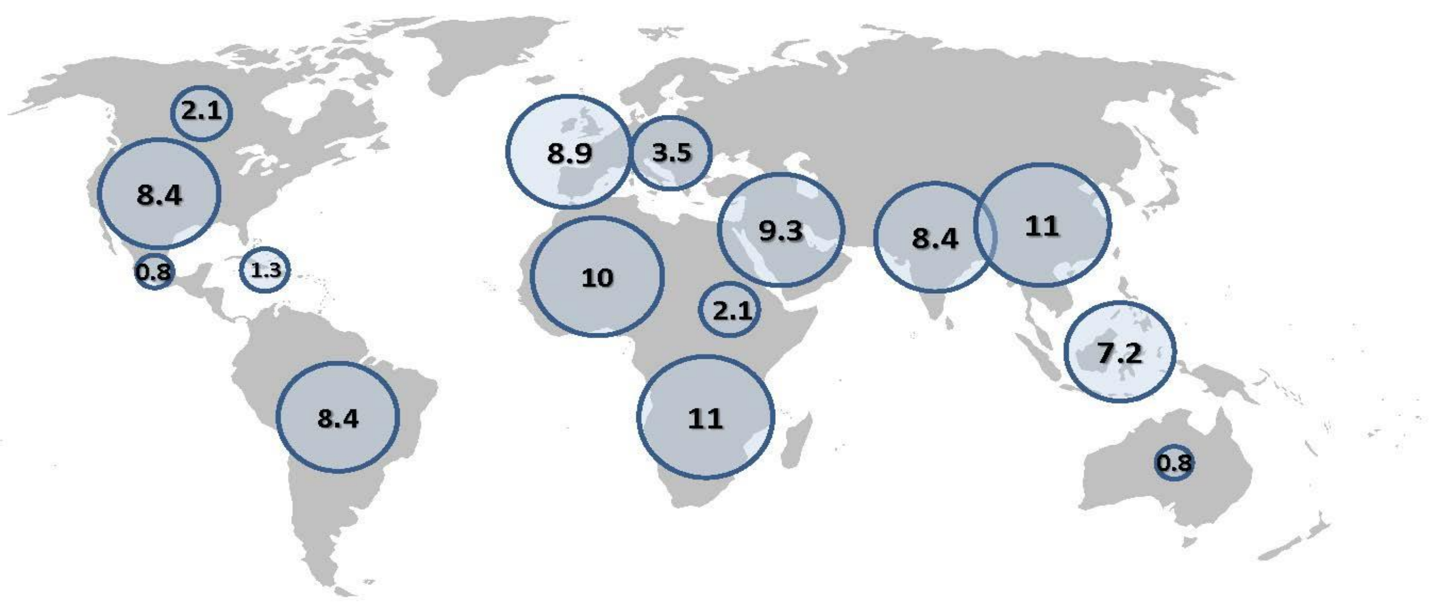
Articles identified from references (n=3);
Articles identified from additional search (n=16)

Studies included in synthesis (n = 81)

Number of studies focused on epilepsy stigma by publication year



Where has epilepsy stigma research been conducted?



Epilepsy Stigma Interventions

- Only 12 studies included an intervention
- Only 1 U.S. study
- Only 3 randomized, controlled trials
- Most targeted students or professionals
- Most interventions were lengthy/didactic
- Outcomes suggested improved epilepsy knowledge and attitudes

Implications from a systematized literature review on epilepsy stigma

-Few investigators

--Current stigma instruments do not lead to new insights

-Limited intervention research

-Most interventions not practical

-Few interventions with young adults

-Effects on behaviors towards PWE is unknown

-Use qualitative methods (Ask new questions to get new answers)

-Use standardized tools that avoid “leading” questions

-Develop and test new interventions addressing epilepsy stigma

- Use web/social media to push communication

Key Gaps in Stigma Research

– Can we use technology-based health communication approaches ?

– Can interventions be brief & practical ?

– Can we target young adults and impact stigma for decades to come?

– Can stigma reductions messages really change public behavior?

Herrmann, L. K. et al. (2016). Epilepsy misconceptions and stigma reduction: Current status in Western countries. *Epilepsy & Behavior*, 60, 165-173.

Study Design

- Prospective randomized controlled trial (RCT)
- Compared 2 novel communication approaches to reduce epilepsy stigma vs. educational control
- Sample: N=300, 100 in each intervention
- Enroll sample on-line
- Assess epilepsy attitudes and knowledge after exposure

Developing new stigma reduction approaches

Community advisory board (CAB)

- 8 young adults, 2 with epilepsy
- 1 community leader
- 1 parent of a child with epilepsy
- 1 older adult with epilepsy
- 2 epileptologists

Key messages :

- Focus 1: personal fear/social avoidance of people with epilepsy
- Focus 2: perceived deficits in occupational and social roles

Cui et al. Epilepsy & Behavior. 52.108-18, 2015

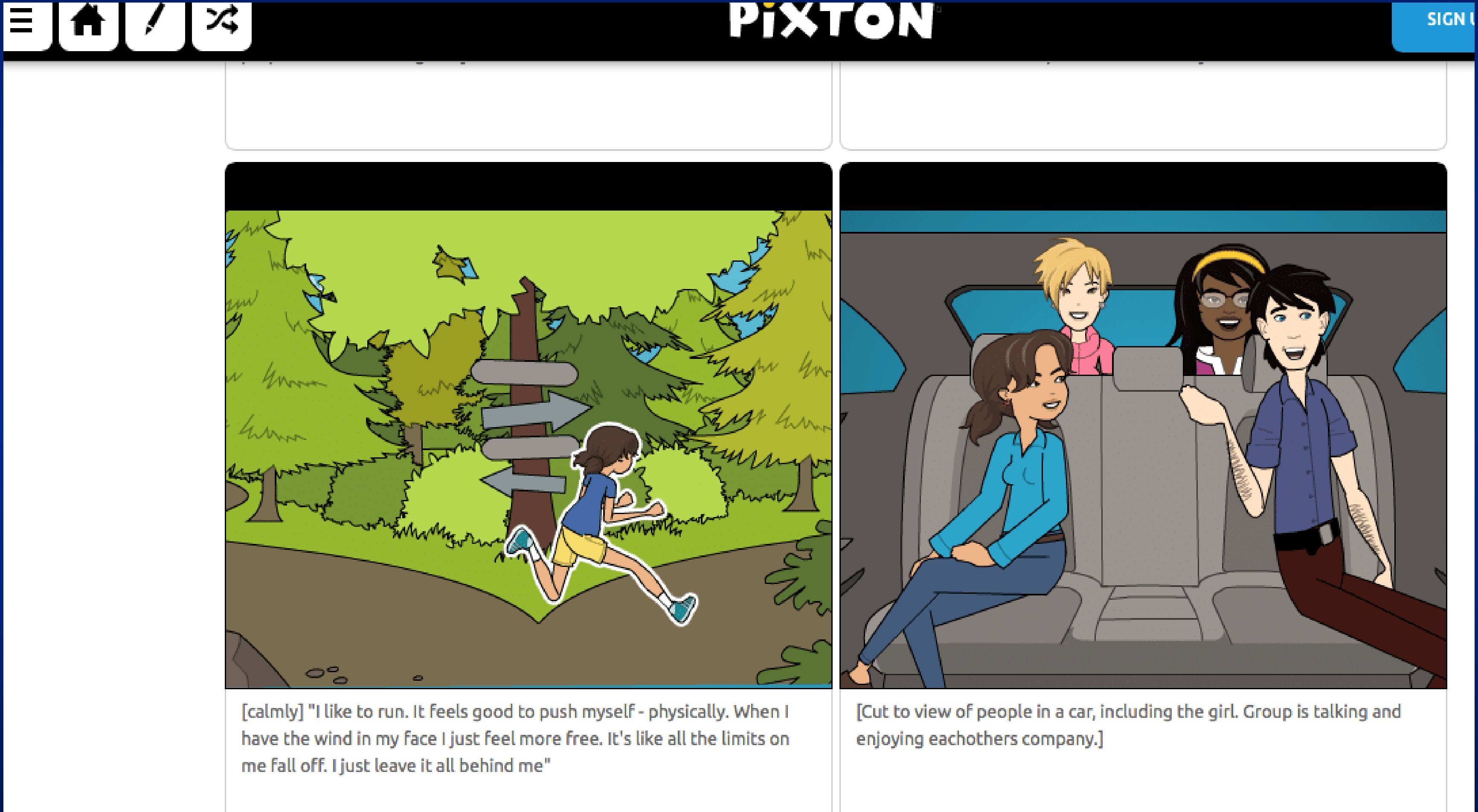
Additional CAB recommendations

- Be brief, credible, relatable
- Use formats widely used by young people
- Emphasize: Normal people just like their peers without epilepsy
- Recognize abilities of successful, happy, and independent people with epilepsy

Key Messages to Storyboards

- Each researcher provided 2-3 story ideas that incorporated the key messages for about 15 story ideas.
- Research team refined stories to 6, scripts were developed, narrowed to 4, which were made into comic strips using Pixton, free software
  - Elimination of stories
    - CAB input
    - Fit to key messages
    - Style: in-depth narratives versus multiple perspectives
- Refinement of scripts, casting, production
- REMEMBER: Avoid stigma and controversy without diluting key message

From key messages to Stories



[calmly] "I like to run. It feels good to push myself - physically. When I have the wind in my face I just feel more free. It's like all the limits on me fall off. I just leave it all behind me"

[Cut to view of people in a car, including the girl. Group is talking and enjoying eachothers company.]

Stigma-reduction Products

- Storyboards developed into 2 experimental videos
  - Suitable for web-based viewing & highlighting epilepsy stigma
  - Local actors with and without epilepsy in videos
  - Same actors in both videos

Control video: Powerpoint presentation with attractive graphics that features same key message

Key message logos

DIFFERENT

Just Like You

Outcomes

- Post-video acceptability and perceived impact on epilepsy attitudes and people with epilepsy (Likert Scales)
- Epilepsy Knowledge Questionnaire (EKQ)
- The Attitudes and Beliefs about Living with Epilepsy (ABLE) Scale

Enrollment

- 18-29 years olds from local college campuses and community locations (coffee houses, CD/game exchanges, libraries)
- Email to African-American students through CWRU office of Multi-Cultural Affairs.
- Local recruitment for 40% of sample
- Online recruitment on social media and news aggregation sites (e.g Reddit, Buzzfeed). Remainder of the sample obtained in approx. 30 hours

Variable	All respondents N= 295	Role Competency n= 92	Social Inclusion n = 94	Control n= 109
Age in years – Mean (SD)	23.10 (3.27)	23.10 (3.32)	23.13 (3.37)	23.08 (3.17)
Gender – n (%)				
-Male	174 (59.0)	60 (65.2)	60 (63.8)	54 (49.5)
-Female	121 (41.0)	32 (34.8)	34 (36.2)	55 (50.5)
Race – n (%)				
-White	208 (70.7)	60 (65.3)	70 (67.4)	78 (71.8)
- African- American	40 (13.3)	15 (15.8	13 (13.7)	12 (10.9)
Ethnicity – n (%)				
-Hispanic	41 (13.9)	9 (9.8)	18 (19.1)	14 (12.8)
Education – n (%)				
-Some College / Technical School	92 (31.2)	31 (33.7)	32 (34.0)	29 (26.6)
- College Graduate	160 (54.2)	50 (54.3)	48 (51.1)	62 (56.9)
Epilepsy Experience n (%)				
- Does not know anyone with epilepsy	145 (49.2)	47 (51.1)	45 (47.9)	53 (48.6)

Viewing Time

Mean times watched (seconds):

-306 (SD 77.7) social inclusion (74% total)

-218 (67.4) role competency (78 % total)

-81 (14.2) control (87% total)

Viewed at least 75% of the video

32.9% social inclusion

73.2 % role competency

75.7% control

Summary Findings

- >90% rated all videos as understandable.
- Majority felt videos were memorable and impacted attitudes
- Half would share videos on social networking sites.
- Likert scale attitude change slightly higher in the role competency and control videos compared to the social inclusion video (p=.021).
- Trend for the 2 experimental videos to be associated with higher knowledge compared to control (p = 0.058).

Standardized Scale Change

Variable	Role Competency Video n= 95	Social Inclusion Video n = 95	Control n= 110	Statistic
ABLE – Mean (SD)				
-Negative Stereotypes	2.51 (1.29)	2.55 (1.35)	2.64 (1.31)	ANOVA p=.72
-Risk and Safety Concerns	2.89 (0.69)	2.70 (0.73)	2.74 (0.63)	ANOVA p=.13
-Work and Social Role Expectations	2.22 (0.56)	2.14 (0.73)	2.29 (0.50)	ANOVA p=.11
-Fear and Social Avoidance	2.66 (1.15)	2.67 (1.27)	2.83 (1.19)	ANOVA p=.47
Composite Score*	2.57 (0.73)	2.51 (0.82)	2.63 (0.73)	ANOVA p=.74
Epilepsy Knowledge Questionnaire – Mean (SD)	6.42 (1.61)	6.25 (1.79)	5.95 (1.84)	ANOVA p=.12

Post-hoc analyses

- More stigmatizing attitudes: Men, younger individuals, whites, those who knew someone with epilepsy
- Men and women had similar levels of knowledge in the 2 experimental videos, but men had less knowledge in the control video group.

So How Do We Change Epilepsy Stigma?

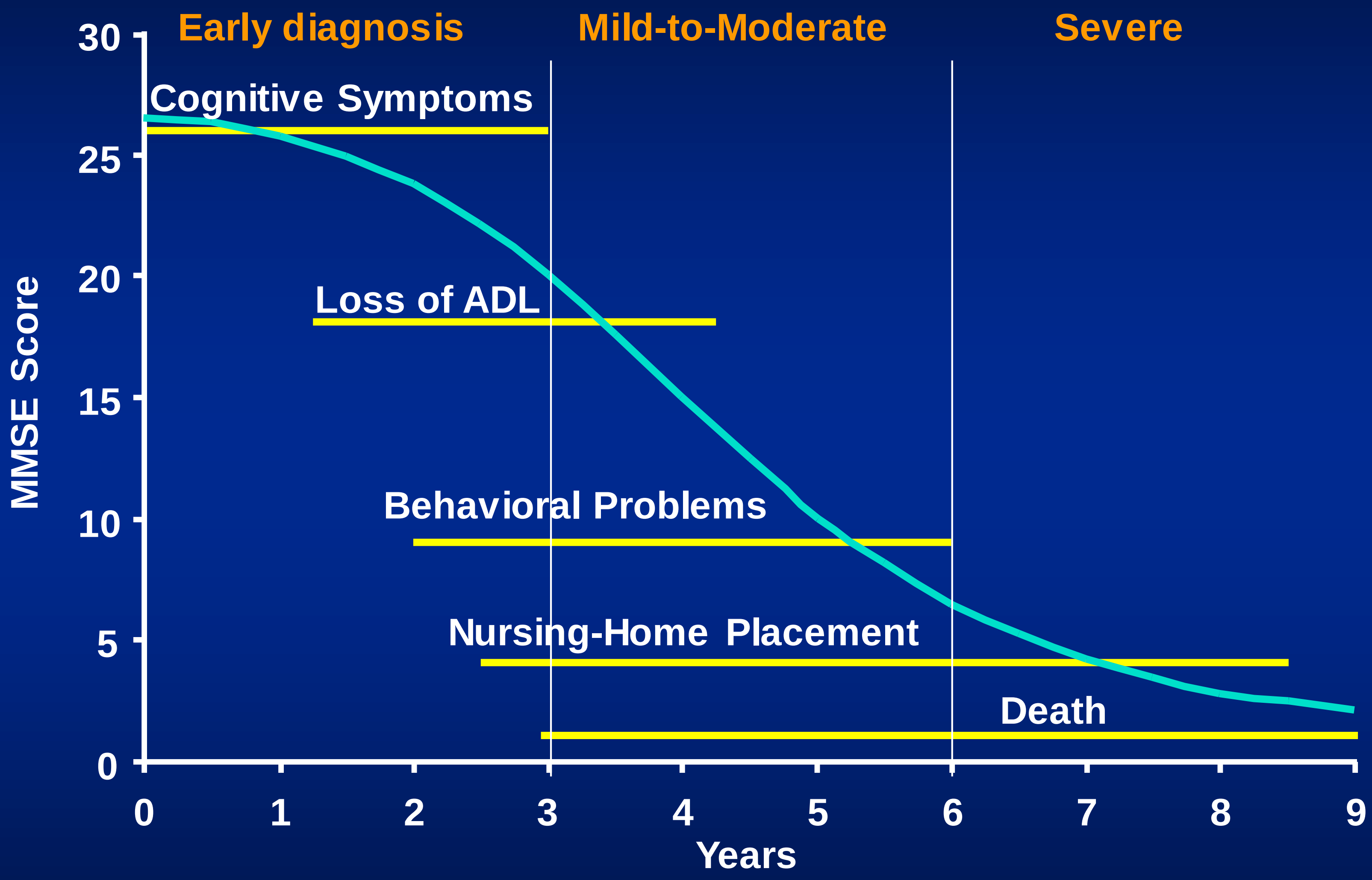
- Brief education (no more than 5 minutes!)
- Delivered by credible & relatable messengers
- Web-delivered approaches can be massively scaled-up
- Target “high-risk” sub-groups and young people
- Further research to refine messages and delivery approach

Alzheimer’s Disease in the U.S.: A rapidly growing concern

- In 2016, an estimated 5.4 million Americans have Alzheimer's disease (AD)
- One in nine people age 65 and older has AD.
- By mid-century, the number of people age 65 and older with AD will nearly triple, from 5.4 million to a projected 13.8 million

http://www.alz.org/facts/

“Textbook” Progression of AD



MMSE = Mini-Mental State Examination; ADL = activities of daily living.

Feldman H, Gracon S. In: Gauthier S, ed. *Clinical Diagnosis and Management of Alzheimer’s Disease*. Boston, Mass: Butterworth-Heinemann; 1996:239-252.

AFRICAN AMERICANS

African Americans make up 13.6% of the U.S. population but bear over 33% of the costs of Alzheimer's and other dementias.

African Americans are 2 to 3 times more likely to develop Alzheimer's as non-Hispanic whites.

UsAgainstAlzheimer's

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GLOBAL CEOINITIATIVE ON ALZHEIMER'S DISEASE

LATINOS

Latinos are about 1.5 times more likely to develop Alzheimer’s and are less likely to receive a diagnosis from a physician.

Latinos make up 17% of the US population but only 1% of clinical trial research participants.

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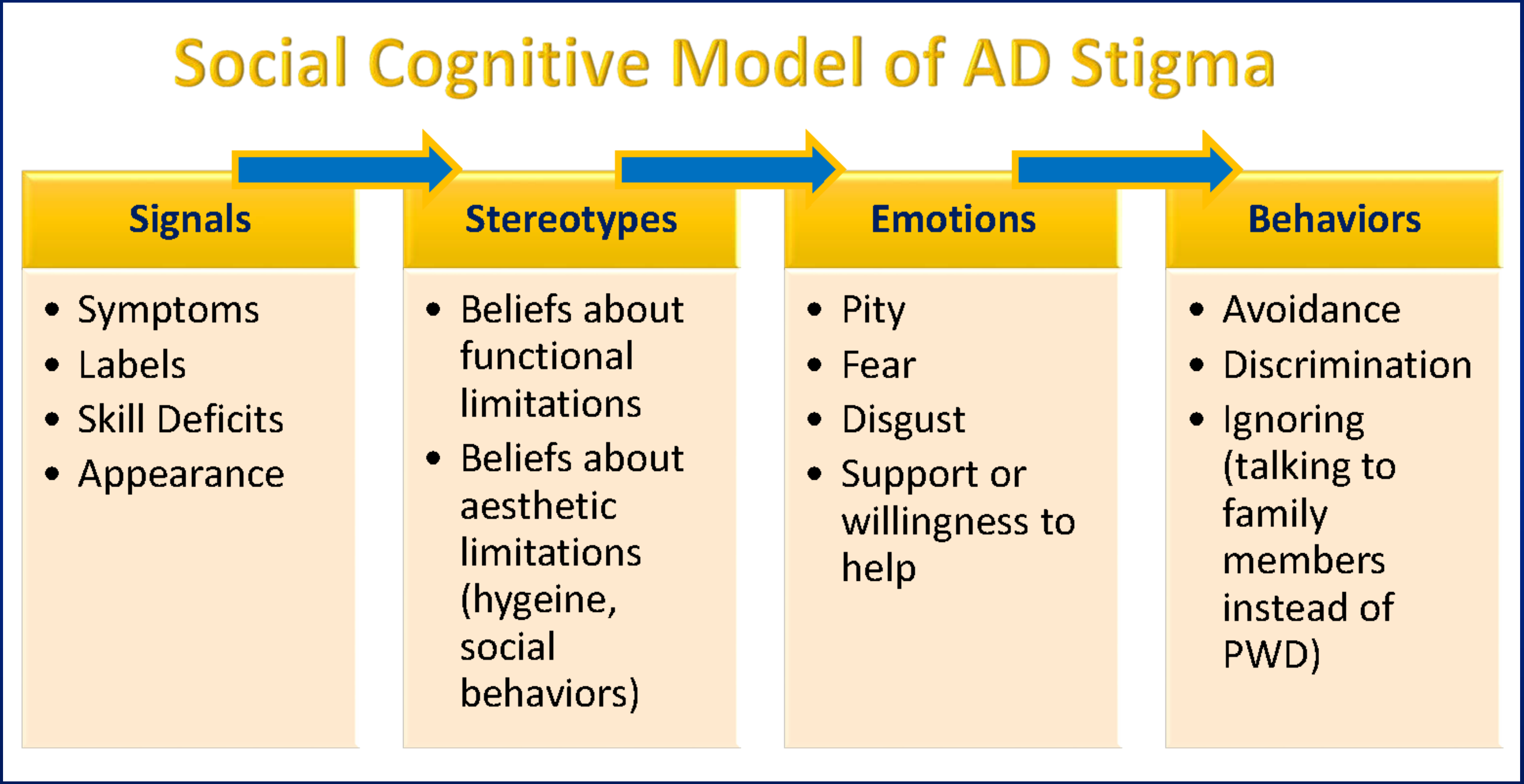
Social-Cognitive Model of AD Stigma



Social Cognitive Model of AD Stigma

Signals

- Symptoms
- Labels
- Skill Deficits
- Appearance

Stereotypes

- Beliefs about functional limitations
- Beliefs about aesthetic limitations (hygeine, social behaviors)

Emotions

- Pity
- Fear
- Disgust
- Support or willingness to help

Behaviors

- Avoidance
- Discrimination
- Ignoring (talking to family members instead of PWD)

How common is AD stigma?

- A 2003 Alzheimer’s Society of Canada survey found that 81% felt that they would be “looked upon differently” if they had AD
- Not all emotional response to people with AD is negative—many individuals feel a desire to help
- However, a 2014 European study found 25-50% of public had fearful attitudes towards people with AD. Fear level was mid-way between that attributed to people with depression (AD worse) and people with schizophrenia (AD better)
- Some AD stigma overlaps with aging stigma

Knesebeck, International Psychogeriatrics 2014, 26, 435-441

www.Alzheimer.ca/english/media/stigma03-poll.htm

What factors seem to drive AD stigma?

Stigmatizing attitudes are greater in those with:

- Less knowledge of AD
- No/minimal experience with AD
- Lower levels of education
- Some studies find gender differences (men> women)
- Some studies find age differences (younger>older)

Werner Int Journal of Geriatric Psych 2004: 19, 391-97, Philipson Austalasian J on Aging, 33 (3) 2014, 158-163

What are the effects of stigma on people with cognitive loss/AD?

- Anxiety, depression and worry about how others may respond
- Loss of social status, embarrassment & shame
- Denial of diagnosis, treatment avoidance

Riley R, Nurs Clin North America 2014: 49(2) 213-231

What are the effects of stigma on people with cognitive loss/AD?

- Keeping diagnosis a secret
- Social withdrawal/isolation
- Overdependence on family
- Decreased quality of life

Riley R, Nurs Clin North America 2014: 49(2) 213-231

What are the effects of stigma on family or care partners with AD?

- Exclusion from social interactions (especially if part of a couple)— "Living on the fringes"
- Stigma can increase caregiver burden 18%

Garan et al. GeroNurseResearch.com, Daly et al. J Clin Nursing 22, 501-512, 2012
Werner et al. Gerontologist, 2011

What are the effects of stigma on family or care partners with AD?

- Loved one's symptoms (poor self-care, incontinence) may be looked upon as evidence of neglect
- Lack of support from other family/society

Garan et al. GeroNurseResearch.com, Daly et al. J Clin Nursing 22, 501-512, 2012

How do we combat AD stigma?

How do we combat AD stigma?

- There is a limited evidence-base for approaches specific to AD stigma-reduction
- We can learn from stigma-reduction research in other brain conditions that have heavy stigma load such as mental disorders, epilepsy and intellectual disability
- It is important to identify that a given approach <u>actually can reduce stigma</u>

Evidence-based stigma-reduction approaches

- Targeted education: Health literacy campaigns, formal course-work in traditional educational settings (esp. high school, college, healthcare workers).
- Advocacy & Protest: Twitter campaigns, other mass and social media that is flexible/fast/capable of being disseminated widely.

Seewoortum, Research in Dev Disabilities 35(2014) 3482-3495, www.nap.edu/23442

Evidence-based stigma-reduction approaches

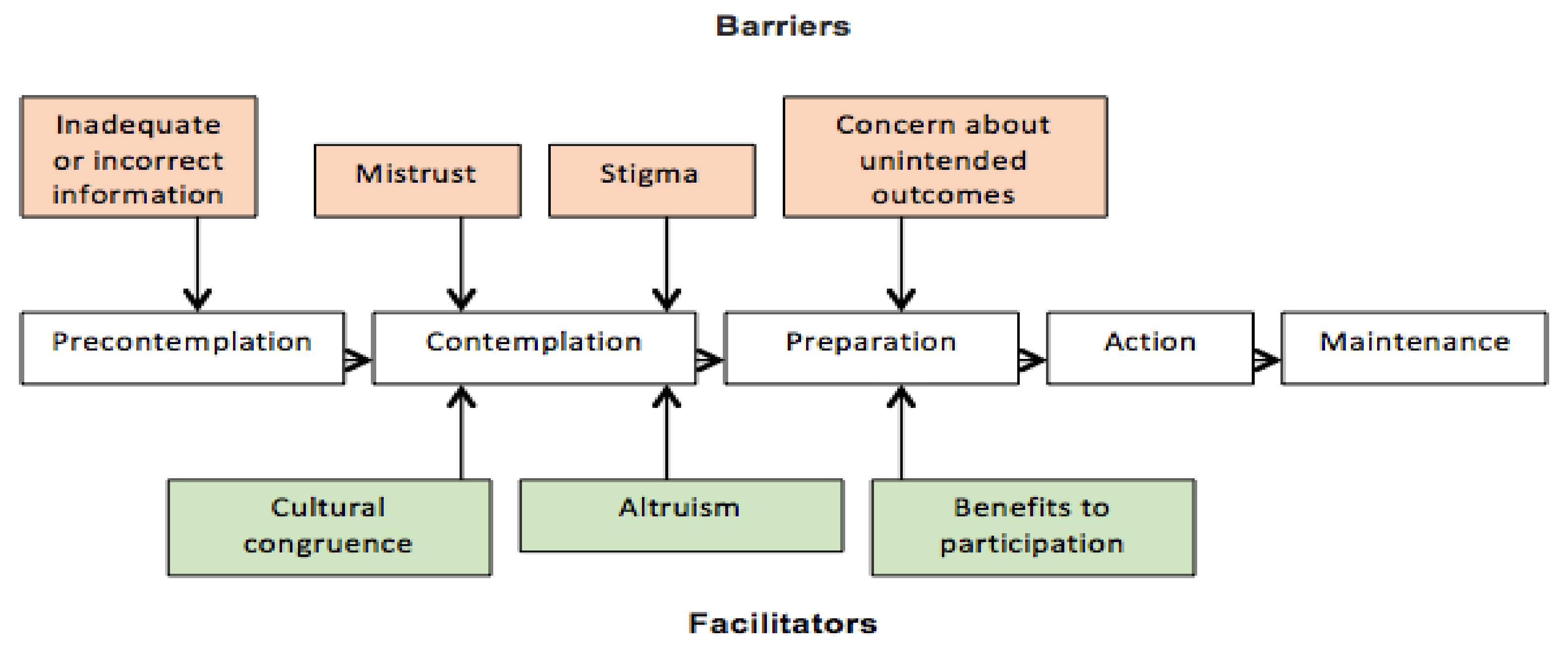
- Contact-based Education Programs: These combine contact between people with the brain disorder and content/information that is designed to raise knowledge and awareness.
- Peer Programs: People/families who have/deal with the brain disorder offer their experience and expertise to other individuals who have less experience. Programs range from informal self-help to specialized services in healthcare systems.

Targeting stigma, mistrust, personal concerns, altruism and cultural congruence to boost awareness and participation in dementia research (The POWER project)

3-phase project :

1) built upon an existing, successful MAB to develop 4 dementia-focused health communication videos (African-American, Hispanic focus)
2) test effects of videos on change in readiness to participate in dementia research (as measured by the trans-theoretical conceptual model)
3) examine effects of videos on barrier and facilitator engagement targets posited to lead to participation in dementia research, and
4) use findings to augment community outreach and engagement among under-represented groups

Trans-theoretical model of change applied to recruitment in dementia research: POWER project



Minority Advisory Board Members (MAB)

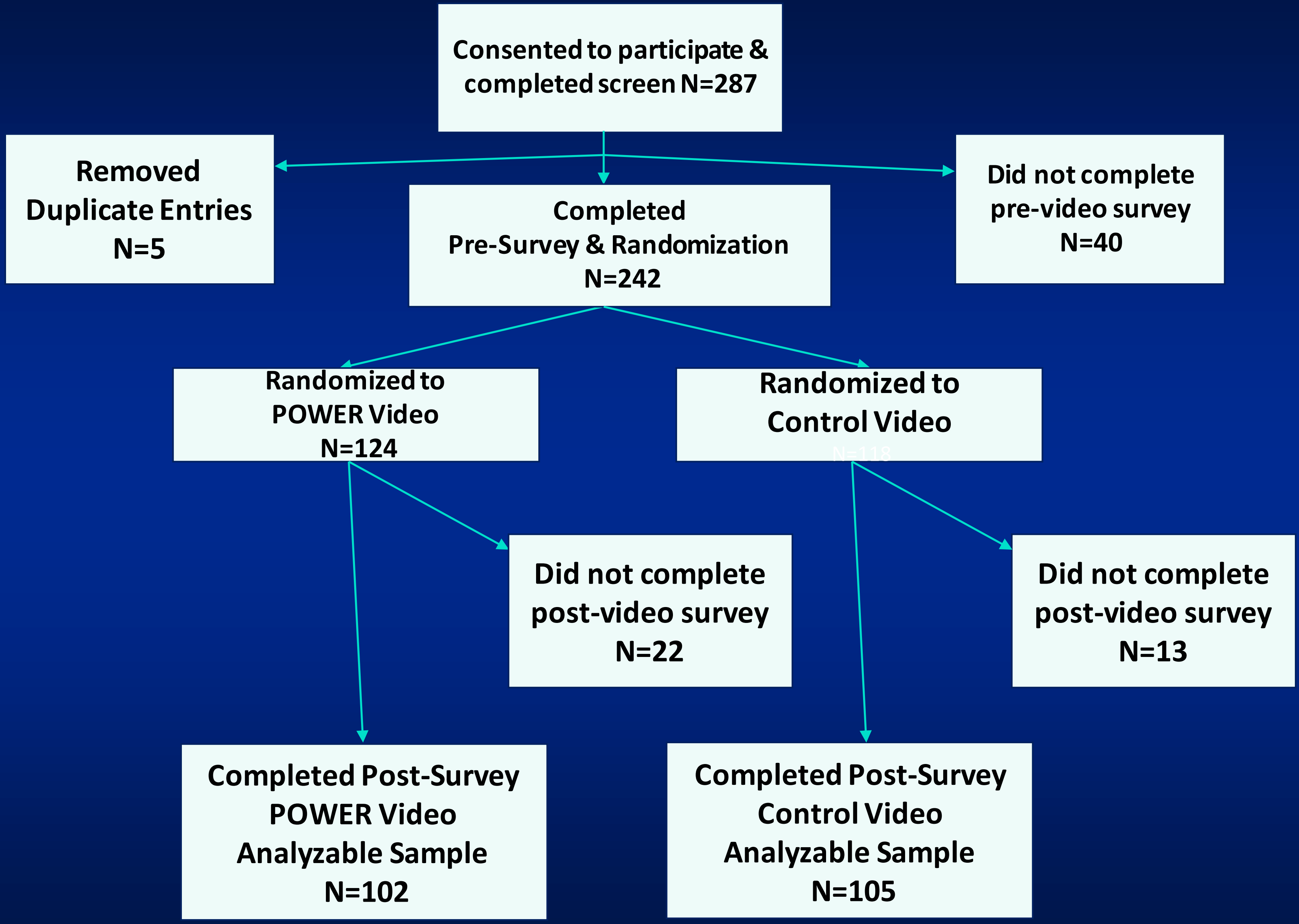
POWER Study Randomized Controlled Trial (RCT)

RCT tested the effects of the POWER vs. control video on dementia knowledge, barriers and facilitators to dementia research and change in research readiness using a randomized prospective pre/post on-line survey design.

H1: Individuals randomized to POWER would have reduced barriers, increased facilitators and improved readiness to change compared to control.

H2: individuals randomized to control would have greater improvement in dementia knowledge vs. individuals randomized to POWER.

POWER VIDEO PLACEHOLDER



Consented to participate & completed screen N=287

Removed Duplicate Entries N=5

Completed Pre-Survey & Randomization N=242

Did not complete pre-video survey N=40

Randomized to POWER Video N=124

Randomized to Control Video N=118

Did not complete post-video survey N=22

Did not complete post-video survey N=13

Completed Post-Survey POWER Video Analyzable Sample N=102

Completed Post-Survey Control Video Analyzable Sample N=105

POWER results

- Pre-video sample (n=242) mean age 57.6 (SD17.2), n=181 (74.8%) female, n=103 (42.6%) non-white.
- Analyzable sample (n=207) n=51 (41.1%) POWER and n=52 (44.1% (n= 52) control non-white
- Adjusted for age, gender, race and education, controls had a greater increase in dementia knowledge (p=0.004).
- POWER had significant reduction in barriers (p=.044) vs. control.
- No differences in facilitators to participation and research readiness between POWER versus controls.
- Among African Americans (n=59, 28.5% analyzable sample) trend for improvement in dementia knowledge (p=.059) and research readiness (p=.051), both favoring POWER vs. control.

General recommendations to overcome AD Stigma

- Educate the public (all ages !!)
- More support for early stage individuals/stress variability in progression
- Reduce isolation of the person with dementia (memory groups, maintain social contact)

General Recommendations (cont.)

- Be open and direct about both AD and AD stigma, realize that stigma can be unintentional
- Call attention to and criticize media stigma

DAILY NEWS

GET THE VIOLENT CRAZIES OFF OUR STREETS

NEWS' SPECIAL EDITORIAL

SEE PAGES 2 & 3

TEXAS CAMPUS TRAGEDY KILLS 11

GREAT NEW YORK EATS THAT FIT THE BILL

★★★ FOR JAMES BOND'S 'WORLD'

EXCLUSIVE INVESTIGATION

1,200 KILLED BY MENTAL PATIENTS

Shock 10-year toll exposes care crisis

QUESTIONS