Using Knowledge about Prevalence of Psychiatric Disorders to Design Collaborative HIV Care Judith A. Cook Pamela Steigman **Dennis D Grey**

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Collaborators

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Women's Interagency HIV Study Consortium

Agenda

- Introduce the concepts of collaborative care in medicine & disease prevalence in psychiatric epidemiology
- Discuss use of a laptop-administered diagnostic battery to assess prevalence of psychiatric disorders
- Describe prevalence research conducted at the University of Illinois at Chicago & present results from a pilot study
- Learn about models of collaborative care & their application in your own work

Prevalence

> The total number of cases of a disease in a given population at a specific time > Allows us to understand the relative frequency of different kinds of mental illness



HIV+ and Mental Health

 There is a high prevalence of MH disorders in cohorts of HIV+ individuals, especially women

 MH disorders are associated with lower likelihood of HIV treatment, poorer treatment adherence, & poorer HIV outcomes.

 The treatment of MH disorders not only can improve quality of life for people living with HIV, but also influences HIV disease progression.

Prevalence of Depression in Different U.S. Study Populations

General Population	HIV+ Men	HIV+ Women
20% ^a	21% ^b	51% ^e
	20% ^c	
	15% ^d	

- ^a Kessler et al., 1994, Arch Gen Psych
- ^b Lyketsos et al., 1993, *JAMA*
- ^c Hays et al., 1992, *J Consult Clin Psych*
- ^d Samboorthi et al., 2000, *J Gen Int Med*
- ^e Cook et al., 2003, *JAIDS*

Association Between Depressive Symptoms & Adherence



Adherent Not Adherent

(Cook et al., 2004, American Journal of Public Health)

Survival Curves of Aids-Related Death Stratified by Level of Depressive Symptoms (controlling for HAART use & adherence)



(Cook et al., 2004, American Journal of Public Health)

>The high prevalence of mental illness among HIV+ individuals leads to the need for care coordination

Care Coordination

- In today's presentation, we're referring to integrating mental health treatment with HIV care
- In general medicine, the CC movement grew out of recognition of the high prevalence of psychiatric disorders in primary care populations
 - People with chronic physical illnesses have high rates of MH disorders
 - Many people receive treatment for their MH disorders in primary care settings

Care Coordination Challenges in Serving HIV+ Women



Trauma, Mental Health, Distrust, and Stigma Among HIV-Positive Persons: Implications for Effective Care, Whetten et al., *Psychosomatic Medicine*, 2008, 70:531–538.

World Mental Health (WMH) Composite International Diagnostic Interview (CIDI)

- Allows researchers to assess & study the impact of mental disorders
- Valid & reliable way for non-clinicians to generate diagnoses using the DSM-IV framework.
 - Measures prevalence
 - Measures severity
 - Determines risk factors
 - Assesses service use
 - Assesses use of medications
 - Assesses who is treated, who isn't, & barriers to treatment

Why Use the CIDI in Research?

Allows non-clinicians to generate reliable & valid psychiatric diagnoses

- Uses non-stigmatizing language (e.g., "ongoing sadness or discouragement" versus "depression")
- Identifies lifetime, 12-month, and 30-day mental health disorders
- Diagnoses allow better estimation of treatment needs than do symptom measures

The computerized format is easy to use, reduces errors, & eliminates post-interview data entry

Structure of the CIDI

Comprised of 1 Screening Section 41 Modules Researchers choose modules of interest Makes it possible to select the percentage of respondents to be screened per module, if desired Interviewer Observation Module

WMH CIDI Modules

- Household Screening
- Depression
- > Mania
- Panic Disorder
- Specific Phobia
- Social Phobia
- Agoraphobia
- Generalized Anxiety Disorder
- Suicidality
- Intermittent Explosive Dis
- Conduct Disorder
- > Oppositional Defiant Dis
- > ADHD
- Gambling
- > Personality Disorders

- Services
- > Alcohol Use
- > Illegal Substance Use
- Post-Traumatic Stress Disorder
- > 30-day Functioning
- > Premenstrual Syndrome
- Obsessive Compulsive Disorder
- > Psychosis
- Separation Anxiety
- Eating Disorders
- > Tobacco Use
- Neurasthenia
- > Pharmacoepidemiology
 - Interviewer Observation

CIDI Module Standard Format

Establish frequency & severity of symptoms Identify worst episode to characterize symptoms Physical cause questions Onset & recency questions \geq Discuss worst 3 episodes in lifetime (difficult recall) >Number & length of lifetime episodes (difficult recall) Episodes during past 12 months Symptoms during past 12 months Interference during past 12 months Treatment series Disorders in close relatives

Life Events Timeline

A recall aid to help the participant recall important events and ages at each event



10-Point Interference Scale

- Allows for assessment of how much the reported symptoms have interfered with the respondent's daily life in the past 12 months.
- This is important because number/frequency of symptoms do not always correspond to level of interference
- Some people with low levels of symptoms will have high interference and vice versa

None		Mild		Mo			Se	ever	0	Very Severe
0	1	2	3	4	5	6	7	8	9	10

e.g., What number describes how much your sadness or lack of interest interfered with each of the following activities during that period?

Physical Cause Questions

Also known as "organic exclusion questions" or those that might preclude psychiatric diagnosis

- R indicates that symptoms were the result of physical causes, injury, medication, drugs/alcohol EXAMPLE:
 - Episodes of this sort sometimes occur as a result of physical causes such as physical illness or injury or the use of medication, drugs, or alcohol. Do you think <u>your</u> episodes of (sadness/or/discouragement /or lack of interest) <u>ever</u> occurred as the result of such physical causes?
 - Do you think your episodes were <u>always</u> the result of physical causes?
 - Briefly, what were the physical causes?
- Following consultation with the project's psychiatrist, a detailed list of probes was created to elicit accurate information regarding physical cause.

Modules with Special Format

Several sections deviate from standard format:

- Specific Phobias
 - Assesses severity of 6 types of phobias first
 - Assesses symptoms, interference, & treatment as a whole
- Suicidality
 - Use of response card to protect privacy & reduce embarrassment
 - Does not assess physical cause, interference, treatment
- Psychosis
 - Not used to generate a diagnosis, but as a screen for symptoms
 - Interviewer asks six questions about common symptoms of psychosis

Special Format (cont.)

PTSD

- List of events
- For each endorsed situation, assess onset & duration
- Use of Random Event, generated by the computer
- Use of Worst Event, generated by R
- Determination that Random Event & Worst Event are not linked
- Assessment of symptoms related to Worst Event
- Assessment of symptoms related to Random Event
- Assessment of worst 12-month Event

Services Module

- Asks about the use of different professional services, including hospitalizations, support groups, & different health professionals, for treatment of emotional problems.
- Includes non-traditional services such as self-help & pastoral counseling.

Items also ask about access & barriers to services, and how helpful the services were/are to R.

Interviewer Observation Module

Allows IWer to assess the interview situation, R's state-of-mind, & quality of the information received

Specifically, questions address:

- Whether others were present during the interview
- How well the R understood the questions and cooperated
- How much effort the R put into answering the questions
- Whether the R was hallucinating or under the influence
- Living conditions
- Presence of physical conditions
- IWer's overall rating of R's functioning
 - 0-10 being persistent danger to self or others
 - 100 being superior functioning
- Space for notes or comments

Parts of CIDI Interview Reviewed by Psychiatrist

After the interview, the project psychiatrist reviews interview transcripts & listens to the audio recording to assess whether:

physical cause is indicated for episodes of depression, mania, anxiety, OCD, etc.
 psychotic symptoms are present, such as seeing visions, hearing voices, mind being controlled, etc.

WMH CIDI Demonstration

Using the Computerized CIDI

CAPI Modularization Program					
Sample ID 13947821232	ĺ	Interviewer ID 01	196	Lock all section percentages	
🔽 Household Listing	100	▼ Post-Traumatic Stress Disorder	100	🔽 Marriage	100
🔽 Screening	100	Chronic Conditions	100	🔽 Children	100
🔽 Depression	100	🔽 Neurasthenia	100	🔽 Social Networks	100
🔽 Mania	100	🔽 30-Day Functioning	100	Adult Demographics (DA)	100
🔽 Panic Disorder	100	🔽 30-Day Symptoms	100	✓ Child Demographics (DE)	100
🔽 Specific Phobia	100	🔽 Tobacco	100	🔽 Childhood	100
🔽 Social Phobia	100	Eating Disorders	100	Attention-Deficit/Hyperactivity	100
🔽 Agoraphobia	100	Premenstrual Syndrome	100	Oppositional-Defiant Disorder	100
🔽 Generalized Anxiety Disorder	100	Obsessive-Compulsive Disorder	100	Conduct Disorder	100
🔽 Intermittent Explosive Disorder	100	Psychosis	100	🔽 Separation Anxiety Disorder	100
🔽 Suicidality	100	🔽 Gambling	100	🔽 Family Burden	100
🔽 Services	100	Employment	100	Respondent Contacts	100
🔽 Pharmacoepidemiology	100	🔽 Finances	100	✓ Interviewer Observation	100
🔽 Substance Use	100	(<u>Start the interview</u>)	iange lo	ck password E <u>x</u> it	

CAPI Screen Layout



Women's Interagency HIV Study



Women's Interagency HIV Study (WIHS) Cohort study of HIV-positive women recruited in 6 cities: Chicago, Los Angeles, San Francisco/Bay Area, Bronx, Brooklyn, Washington, DC Data collection bi-annually beginning in 1994 (1st cohort) until present Bi-annual in-person interviews, physical exam, blood work, gynecological exam Chart abstraction of medical records

WIHS CIDI Pilot

> 240 randomly selected WIHS study participants were administered the CIDI >40 women interviewed at each of the 6 WIHS study sites for a total of 240 Sampling frame: randomly selected ID #s at each site; women were invited to participate sequentially from that list Research honorarium varied by site 5% refusal rate; >1% non-completion rate > Average completion time of 123 minutes



Pilot Study Participant Characteristics

- Serostatus: 100% HIV+
- > Average Age: 45 years
- Race/Ethnicity: 74% African American, 13% Hispanic/Latina; 8% Caucasian; 5% Other
- Marital Status: 25% married or living as married
- Education: 40% < high school graduate; 32% high school graduate; 28% some college</p>
- Employment Status: 37% employed at the time of interview

Prevalence of Mood Disorders (N=239)

	12-month		Lifetim	e
	<u>%</u>	<u>N</u>	<u>%</u>	<u>N</u>
Major Depression	16	39	28	66
(very low mood that lasts for at least 2 weeks; affects a person's relationships, work/school life, sleeping/eating habits, and overall general health.)				
Dysthymia	8	18	8	18
(a long-lasting type of depression with symptoms less severe than major depression)				
Bipolar Disorder	5	13	7	17
(characterized by abnormally elevated and abnormally depressed states lasting a period of time in a way that interferes with functioning.)				
One or More Mood Disorders	19	45	30	71

Prevalence of Anxiety Disorders					
(N=239)	12-Month		Lifetime		
	<u>%</u>	N	<u>%</u>	<u>N</u>	
Specific Phobia	22	53	30	71	
Social Phobia	15	36	20	47	
Panic Disorder	15	35	37	89	
Post Traumatic Stress Disorder	12	29	29	70	
Agoraphobia without Panic	7	17	9	22	
Obsessive/Compulsive Disorder	8	20	15	36	
Generalized Anxiety Disorder	6	15	15	36	
One or More Anxiety Disorders	47	112	66	157	

Prevalence of Substance Use Disorders (N=239)

	12-Month	Lifetime		
	<u>%</u> <u>N</u>	<u>%</u> <u>N</u>		
Alcohol Abuse	5 13	41 99		
Drug Abuse	5 12	48 116		
Alcohol & Drug Abuse	8 18	60 143		

DSM-IV Disorder Prevalence in WIHS Pilot vs. Representative Sample of U.S. Women

U.S. Women^{a,b}

23% any anxiety disorder
5% with PTSD
8% with social phobia
12% with specific phobia
4% with panic disorder
12% any mood disorder
2% with alcohol abuse
>1% with drug abuse
35% with any disorder

Pilot Study Population^b 47% any anxiety disorder 12% with PTSD 15% with social phobia 22% with specific phobia 15% with panic disorder 19% any mood disorder 5% with SA disorder 5% with drug abuse 54% with any disorder

 ^a Source: National Comorbidity Survey-Replication, Kessler et al., 2005
 ^b 12-month prevalence

WIHS CIDI R01 Study Now in Progress

- Involves assessment of the entire cohort
- >777 participants have completed the CIDI interview (66% of the targeted sample)
- > Average length of the CIDI = 131minutes (2 hours, 11 minutes)
- Interviews expected to be completed in Spring 2012

Funded by



R01 Participants (N=777)

- Average Age: 48 years (min-max = 27-77)
- Race/Ethnicity: 69% African American; 16% Hispanic/Latina; 12% White; 3% Other
- Education: 33% < HS education; 33% HS/GED; 26% some college; 8% college education/advanced degree
- Marital Status: 30% never married; 25% married/ cohabiting; 12% divorced; 10% widowed; 5% separated
- Employment: 34% employed at time of interview
- Income: 42% < \$12,000 annually</p>
- Insurance Coverage: 94% insured

Care Coordination: Two Examples

Whole Life Project - Florida

Core Center Model - Illinois

Whole Life Project - Florida

University of Miami School of Medicine – Collaboration between Departments of Psychiatry & Obstetrics/Gynecology Uses a Developmental Model of phased

- collaboration building
- Problem setting
- Direction setting
- Structuring

Services include: 1) on-site MH team in OB/GYN clinics, 2) cross-training OB/GYN staff in MH & MH staff in HIV primary care, 3) routine MH patient screening, 4) multi-disciplinary tx planning & case staffing, & 5) incorporating MH information into patient records

(Dodds et al., 2004, Public Health Reports)

Core Center Model - Illinois

- Multi-disciplinary clinic structure with co-located services
- Peers navigators educate & build relationships from initial patient orientation to ongoing support and follow-up at every clinic visit
- Immediate referral to clinician (MH or SA) who is on-site (very important)
- Clinicians on-call at all times & can be paged throughout the day
- Atmosphere of informality (no titles, equality of peers & professionals)
- Health benefits coordinator works closely with pt. to ensure access to MH tx

Care Coordination: Key Ingredients

- Formal mission statement describing philosophy of care integration making MH integral to health
- Structural integration enabling coordination of staff roles & responsibilities
- > Assessment/remediation of missing services & needed enhancements
- Cross-training of professionals
- > Training & use of HIV+ peers
- > Identification of (in)formal opinion leaders

Common Issues that Arise in Care Coordination

- > Turf Battles & Professional Silos
- Lack of Trained Peers & Resistance of Professionals to Working with Peers
- > Pt. Privacy & Confidentiality Issues
- Lack of Culturally Sensitive Treatments for Mental Illness
- Stigma Regarding Help-Seeking for MH Problems
- Lack of \$, Time & Resources

Applying Prevalence Results from our Pilot Study to Collaborative Care Design

- High prevalence of <u>PTSD</u> indicates importance of including <u>trauma-informed care</u>
- High prevalence of <u>depression</u> suggests that <u>culturally competent depression tx</u> & <u>motivational</u> <u>interviewing</u> should be part of care management
- High prevalence of <u>anxiety disorders</u> suggests need for <u>home-based services</u> since some women may have difficulty traveling to treatment centers
- High prevalence of <u>alcohol & substance use</u> <u>disorders</u> clearly indicates the need to integrate <u>addiction services</u>

Mental Health & HIV Care Coordination Planning Worksheet

A. Structural Analysis – What program divisions will be integrated? How would their current functioning need to change to promote integration? **B. Mission Statement** – Write a <u>brief</u> mission statement describing the new philosophy of care integration, explicitly stating how the importance of MH to physical health will be valued & rewarded in the new program. **C. Service Comprehensiveness and Enhancement** – List existing services that will be coordinated. Put a star next to those that need to be enhanced & briefly state how. Create a 2nd list of missing services that need to be added. D. Structural Integration - Based on your list above, briefly describe how existing staff roles and responsibilities will be restructured to enable coordination of mental health & HIV care. **E. Cross-Training** – Identify training needed by each of the service providers listed in C.

F. Use of Peers – Describe the nature of peers your program will use to integrate care (e.g., HIV+, people in recovery from MH or substance use disorders), & how they will be identified, trained & supervised.

G. Identification of (In)Formal Opinion Leaders – List names of staff who exert formal & informal control over important program features needed for success.

Free Center Resources You Can Use to Prepare for Care Coordination

> Women's Needs Assessment Protocol http://www.cmhsrp.uic.edu/nrtc/wnassessement.asp > HIV+ Mental Health Consumer Support Group Leadership Training Manual http://www.psych.uic.edu/mhsrp/hiv_support_group.htm Visit our New Center's Website http://www.cmhsrp.uic.edu/health/index.asp