Literacy in the Lives of People with Serious Mental Illness

What we know

- People living with serious mental illness experience significant pre-mature mortality not explained by suicide rates or smoking

- Experience high levels of stigma

- Are more likely than people without mental health symptoms/illness to have limited literacy

- Limited literacy is also highly stigmatized

Mental and Substance Use Conditions

- Limit people's access to

  - Health and Life
  - Personal Security in public, institutional and personal spaces
  - Stable and sustainable housing
  - Participation in civic life, valued relationships and roles

Literacy in a Busy, Urban Behavioral Health Clinic

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Background

- Study purpose: to examine whether literacy varies by psychiatric diagnosis.

- "If I could just help him to learn to read...."

Background

- High prevalence in the US of both Limited literacy and mental illness:
  - 1in 5 US adults suffer from Mental Illness annually
  - 90 Million adults experience limited health literacy

- Limited literacy and mental illness commonly co-occur:
  - In one study, 54% of patients in urban psychiatric clinic had limited literacy skills
  - Another nationally representative sample showed that 75% of people with a self-reported mental health problem had limited literacy skills

Background

- Limited literacy presents unique challenges in mental health care.
    - Standard psych evaluation does not include literacy assessment
    - Several treatment modalities assume adequate literacy (such as journaling in CBT)
    - Double stigma

Methods

- Interviews and chart reviews (N=100) conducted in behavioral health outpatient clinic

- Relationships between SES, REALM, measures of verbal and visual intellectual abilities, and psychiatric diagnoses were examined.

- Data collected over a period of 8 months, 2004-2005 in behavioral health outpatient clinic of a busy public urban safety-net hospital

Data

- Data collection: structured interview followed by structured medical record review.

  - demographic and socioeconomic information (age, gender, race, ethnicity, primary language, education and work status)

- Literacy assessed using REALM

- Medical records reviewed to gather additional data on Mental Illness (Axis I and II) and medical disease (Axis III)

TABLE 1. Demographics (N = 100)

	N
Sex	
Male	61
Female	39
Race	
Caucasian	29
African American	48
Hispanic	11
Other	12
Age	
18–29 yrs	13
30–39 yrs	28
40–49 yrs	36
50–59 yrs	18
60+ yrs	5
Education	
<High school	36
High school of GED	39
>High school	25
Primary language	
English	92
Other language	7
Any axis I diagnosis of chart review	
Depression	12
Psychotic disorder	23
Bipolar	55
Anxiety/panic disorder	14
Substance abuse	38
ADHD	5
PTSD	19
No diagnosis	3
Mean REALM score (*SD*)	55.88 (13.89); range: 3–66
Mean WAIS score (*SD*)	16.6 (6.25); range: 0–30
Mean Ravens score (*SD*)	15.6 (4.82); range: 3–24

Results

Variable	Limited Literacy		χ^2	Sig. Level
	N	%		
Education			15.4	<0.01
Less than high school	36	61		
High school or GED	39	51		
More than high school	25	12		
Psychotic disorder	23	65	4.9	0.03
No psychotic disorder	77	39		
Substance abuse	38	26	8.65	<0.01
No substance abuse	62	56		
PTSD	19	26	3.31	0.07
No PTSD	81	49		
Anxiety disorder	14	29 (4)	1.78	0.18
No anxiety disorder	86	48 (41)		
Depression	12	50 (6)	0.14	0.71
No depression	88	44 (39)		
Bipolar	55	40 (22)	1.23	0.27
No bipolar	45	51 (23)		

TABLE 2. Bivariate Analysis With REALM Scores (N = 100)

Results

TABLE 3. Logistic Regression Analysis of Diagnoses, Race/Ethnicity, and Age on Limited Literacy (N = 100)[a]

Variable	Model 1		Model 2		Model 3		Model 4	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Psychotic disorder	2.67*	(0.95, 7.44)					1.75	(0.58, 5.28)
Substance abuse disorder			0.29***	(0.11, 0.72)			0.43**	(0.13, .90)
PTSD					0.42	(0.13, 1.36)	0.53	(0.16, 1.80)
Race								
African American	1.55	(0.56, 4.30)	1.57	(0.56, 4.41)	1.77	(0.65, 4.82)	1.38	(0.48, 3.98)
Hispanic	3.39	(0.75, 15.24)	3.98*	(0.84, 18.84)	3.24	(0.72, 14.59)	3.58	(0.75, 16.98)
Other race	2.63	(0.60, 11.65)	2.82	(0.65, 12.31)	3.63*	(0.85, 15.47)	2.42	(0.53, 11.06)
Age	1.03	(0.98, 1.07)	1.03	(0.98, 1.07)	1.03	(0.98, 1.07)	1.02	(0.98, 1.07)

[a]Each model, except number 4, includes only 1 diagnosis. The reference group for race is white.
*$p < 0.10$.
**$p < 0.05$.
***$p < 0.01$.

Results

- Further analyses examined the models with additional factors included
  - WAIS, RAVENS
  - In the subsample of people under the age of 50

- Results consistent with the model presented

Conclusions

- REALM score highly associated with level of education and diagnosis of a psychiatric disorder

- Relationships between limited literacy and psychiatric diagnosis are complex

- Patients with psychotic disorders were more likely to have limited literacy

- Presence of PTSD or substance abuse disorder associated with lower likelihood of limited literacy in this sample.

- Clinicians and providers should increase attention to literacy levels and examine strategies for patient assessment and education.

- Successful rehabilitation approaches should include thorough assessments and consideration of literacy

Limited Literacy as a Barrier to Recovery

- Partnered with the NKI, Center for the Study of Recovery in Social Contexts
- MDMH
- Massachusetts Mental Health Center

Theoretical Perspectives: Fundamental Cause

- "fundamental cause" as a persistent association with disease despite changes in intervening mechanisms. (Link and Phelan)
- Fundamental causes involve access to flexible resources that can be used to avoid risks or to minimize the consequences of disease once it occurs.
  - money, knowledge, power, prestige, and beneficial social connections
  - influence a number of risk factors and disease outcomes.
- Limited literacy may influence mental health through multiple mechanisms and is known to influence numerous health outcomes.
- Problems with literacy curtail people's access to resources that would allow them to avoid risks or minimize consequences of mental health problems.

Theoretical Perspectives: Capabilities

- Sen's Capabilities Framework (1999) suggests that literacy is a central component of well-being.
- Nussbaum (2001) ranks literacy as a "central" capability enabling an individual to use the senses and to imagine, think, and reason in a "'truly human' way, a way informed and cultivated by an adequate education..." (Nussbaum 2001, p.87).
- Examining the lives of people with serious mental illness within this framework provides a stark look at the "disabling environments" within which they live.

The Human Development Index
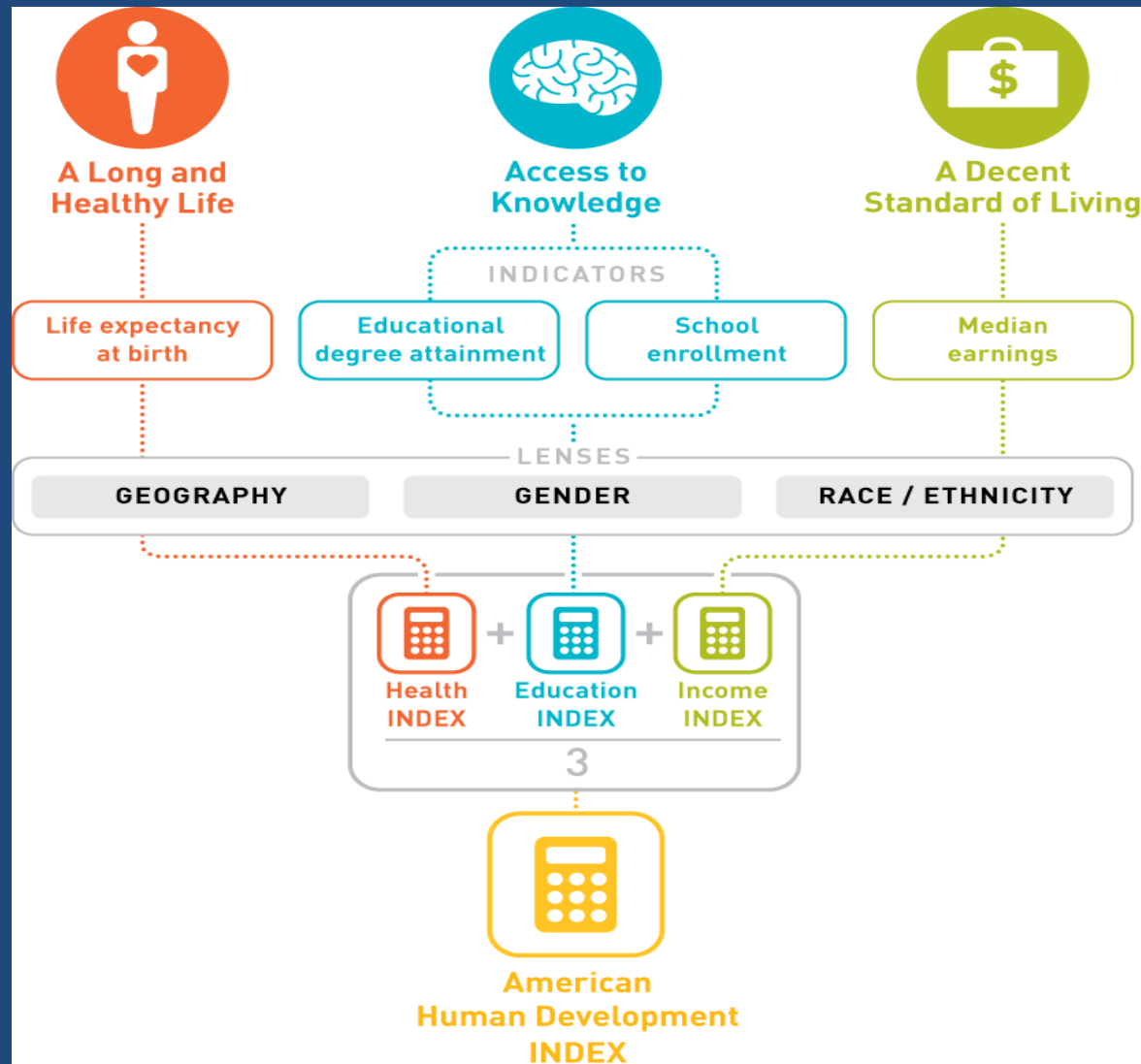
Three New York City's

Congressional District	Human Development Index	Life Expectancy	Education Index	School Enrollment	Income	Rank[1]
Upper East Side (CD 14)	8.79	82 years	9.44	100%	$60,099	1
Queens (CD 15)	5.87	82 years	5.64	91%	$29,608	102
E. Harlem South Bronx (CD 16)	3.20	79 years	2.57	84%	$17,995	432

[1] Out of 436 U.S. Congressional Districts

Another Lens on Human Development:
Mental Health

A Long and Healthy Life • Access to Knowledge • A Decent Standard of Living

Mental Health Labels

Life Expectancy*:*
25-32 years less than general population.

Marginal Literacy Rates:
1.5x higher than general population
[75% v. 50%]

2009 NYS SSI benefits:
16% < Federal Poverty Level

Sources: Colton and Manderscheid 2006; Sentell and Shumway 2003; NYS OTDA www.otda.state.ny.us

NYS SMI: HDI ~ Morocco

Pilot Study

- CBPR perspective

- Limited literacy and mental illness:
  - both cause considerable distress
  - Stigmatization
  - diminished quality of life
  - impaired functioning.

- Qualitative, Exploratory Project

Potential Pathways

- Directly Related to Reading and Writing:
  - Reading Health Information
  - Reading Prescriptions
  - Treatments involving reading/writing e.g. Journaling

- "Hidden" Processes
  - Low self-efficacy
  - "Non-adherence" to medications
  - Hesitance to ask questions
  - Lack of trust for provider
  - Inability to confirm/corroborate info from provider
  - External factors – schooling, jobs etc.

The role of stigma

- "a mark that (1) sets a person apart from others and (2) links the person to undesirable characteristics," through which a person is then socially isolated from others (Link et al. 1997: 179).

- A Double Stigma – both within and outside of the Mental Health System

- Studies have demonstrated that patients are embarrassed or ashamed to reveal reading ability

Specific Aims:

- to develop an interview guide, using CBPR methods, to explore the role and meaning of literacy in the lives of people with serious mental illness;
- to pilot test the interview guide by conducting 20 interviews with DMH clients with various levels of literacy;
- to develop a grant proposal to NIMH (Literacy Mechanism) to conduct a larger mixed-methods study of literacy and mental health.

Methods

- Screening Through REALM

- Team approach to development of interview guide

- 20 semi-structured interviews with DMH case managed clients (10 limited literacy/10 higher literacy)

Interview Guide: domains

- Demographics
- Barriers within the mental health care system
- Barriers outside of the mental health care system
  - Education
  - Work
  - Social support
  - Stigma
- Direct literacy questions
- Recovery questions
- Self-efficacy

Preliminary Analyses: Demographics

- 5 Females/ 6 Males
- 8 identify as African American
- Age Range: 20 – 52
- All Mass Health Recipients
- 3 limited-literacy/ 8 higher literacy

Preliminary Analyses: Emerging Themes

- Use of the Internet
- Reading and Journaling to manage symptoms/illness
- Stigma

Internet

- "When I feel like the doctor's treatment plan is not something I want to do and I'm looking for an alternative type of treatment plan, I could look up alternative types of treatment plans myself… And all I have to do is read about it"
- Going on-line at programs

In Support of Wellness

- " You know, I sometimes write just to vent and, you know, I find myself up at 3 oclock in the morning writing everything S.U.V could stand for, or just the journal rants."

- "I do have note cards that I write information on, and I'm supposed to read those, those are my instructions."

- "It relaxes me…well it makes me feel that I'm still mentally challenging myself."
- "The only writing I ever do is writing in a journal or diary to get it out. And reading. I read because it keeps me from getting angry, quick."

Challenges

- "Sometimes seeing, sometimes comprehending, because it impacts concentration, so I have a hard time concentrating."

Stigma

- "I'm sure there is [a stigma]. I know people who can't read will often sit in front of the newspaper, just anything to look like...I know that people do this, and I think that it's a horrible stigma."

- "Definitely there is a stigma, for example, about this resident who can't read. He hides this entirely, and most people don't know except me. He's come to me to talk about it. I was trying to help him read..."

Stigma

- "Because people think that everyone can read. Like, on time, I'm on the bus..and I couldn't read what it said in front of the thing..And then she says, "don't you read?!" And it is frustrating. You get yelled at for things that you can't read. You look at signs, you don't know what the sign is. Everybody is somehow expected to know how to read everything."

Lessons Learned

We don't know a lot about the relationship between literacy and mental health!

- Defining literacy – what matters to our folks
- How best to assess literacy?
- Challenges of a front-line work force
- How to talk about "literacy" with people with mental health problems given the double-stigma
- The need for multi-disciplinary teams

Exploring Literacy in Mental Health and Illness

Literacy work

- Different types of literacy
- Multiple ways to assess literacy
- The relationships among literacy and mental health status
  - Children
  - adults
- Literacy as a predictor of mental health status
- Literacy as an outcome of mental health status – the relationships among educational attainment and mental illness

- The impact of limited-literacy on depressive symptoms and depression
- The growing field of mental health literacy
- The meaning and impact of limited-literacy in the lives of people with serious mental illness
- Limited-literacy as a barrier to recovery and participation