

Research and Issues Regarding the Stigma Associated with Dementia

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Why is Stigma Associated with Dementia?

- ✓ Dementia occurs primarily in older adults: Associated stigma of aging.
- ✓ Genetic mutations contribute to a predisposition for development of dementia.
- ✓ Cognitive losses are associated with dementia.

Responses to Perceived Stigma

- ✓ Awareness of responses of others (Clare and others, 2005, 2006)
- ✓ Negative self-attributes of persons in early stage dementia (Burgener and colleagues, 1999)
- ✓ Anecdotal accounts of perceived and experienced stigma in persons with dementia (Benbow and colleagues, 2000)



Outcomes of Perceived Stigma in Persons with Dementia (PwD)

- 'Malignant social psychology' resulting in lower self-worth (Kitwood, 1997)
- Social interactions characterized by feelings of disempowerment and banishment (Harris & Sterin, 1999)
- Negative self-attributes: 'stupid', 'worthless', 'in the way'; self-described steps to protect self socially (Burgener, 1999)

Stigma: A Global Concern

British Broadcasting Company report, March 1, 2010:

Ruth Sutherland, acting chief executive of the Alzheimer's Society, agreed there was a problem (stigma).

- "People with dementia tell us that, once diagnosed, others begin to act differently or avoid them altogether."
- "This has a huge impact on their lives, but we know that with the right support people can continue to enjoy a good quality of life."



Limitations of Studies

- ✓ Lack of normative data for measures of perceived stigma in PwD
- ✓ Lack of data regarding racial/ethnic and population (rural/urban) differences in perceived stigma
- ✓ Need to identify effects of stigma on long-term outcomes such as health and psychological well being
- ✓ Need to understand the interactions among caregiver and PwD perceived stigma and effects on long-term outcomes of each group

Research Program of Stigma in PwD

- Adaptation and initial testing of an instrument to measure perceived stigma in PwD
- Initial findings from two pilot studies (one longitudinal):
 - Strength of perceived stigma in PwD and family caregivers
 - Relationship of perceived stigma to outcomes of PwD and family caregivers
 - Comparison of magnitude of perceived stigma in PwD to other disease-specific populations (cancer and HIV/AIDS)
 - Differences in perceived stigma among PwD and family caregivers



Perceived Stigma Measure

Stigma Impact Scale:

- ✓ 24-Item scale developed and tested with HIV/AIDS and cancer populations (Fife & Wright, 2000)
- ✓ Items rated on a 4-point scale: 'Strongly agree' to 'Strongly disagree'
- ✓ Items represent 4 aspects of the stigma experience:
 - ✓ Social rejection (9 items)
 - ✓ Financial insecurity (3 items)
 - ✓ Internalized shame (5 items)
 - ✓ Social isolation (7 items)

Pilot Study One: Stigma Impact Scale: Reliability

	Person with AD/ PD	Caregiver
	Alpha	Alpha
Stigma Impact Scale (24)	0.89	0.92
Financial Insecurity (3)	0.66	0.61
Social Rejection (9)	0.82	0.85
Internalized Shame (5)	0.76	0.86
Social Isolation (7)	0.71	0.79

Subscale to Total Scale Correlations

	r-value	r-value
Financial Insecurity	0.55	0.53
Social Rejection	0.89	0.92
Internalized Shame	0.74	0.82
Social Isolation	0.82	0.90

Relationships Among Perceived Stigma of PwD and Outcomes

	Social Isolation	Social Rejection	Internalized Shame	SIS Total Scale Score
Mental Status (MMSE)		-0.43*		-0.47*
Self-Esteem (RSS)			-0.47*	
Depression (GDS)		0.59*		
Personal Control (MS)		-0.50*		

*p<.05

Relationships Among Caregiver Perceived Stigma and PwD Outcomes

PwD Outcomes	Social Isolation	Social Rejection	Internalized Shame
Number of Medical Diagnoses	0.42*	0.48*	0.50*
Self-Esteem (RSS)			-0.53*

Perceived Stigma of PwD and Other Populations (Parkinson's and Cancer)

	Dementia	Parkinson's	Cancer
Stigma Impact Scale: Total Score	42.7 (9.0)	40.2 (12.4)	(not available)
Financial Insecurity	2.8 (2.1)	2.5 (2.6)	5.7 (2.3)
Social Rejection	15.4 (4.3)	14.2 (5.0)	14.8 (4.1)
Internalized Shame	9.6 (2.4)	7.7 (3.1)*	8.4 (2.7)
Social Isolation	15.0 (2.8)	15.7 (4.8)	14.6 (4.4)
*p<.05 (t-test)			

Pilot Study Two: Study Design

- Study Purpose: To explore the impact of perceived stigma on PwD and their family caregivers
- Study Design: Descriptive, comparative, multi-site (USA: Illinois/Iowa/North Carolina), longitudinal design (baseline, 6, 12 and 18 months)
- Sample: PwD within one year of initial diagnosis (early to early-middle stages of dementia)
- PwD had a confirmed diagnosis of:
 - Alzheimer's disease or
 - Mixed dementia or
 - Vascular dementia

Sample Characteristics

Variable	Sample n	Mean/ S.D.	Range
PwD Age (Years)	32	80.1 (9.8)	62.8-105
Caregiver Age	33	66.8 (14.6)	26.6-85
PwD Education (Years)	33	13.3 (4.0)	5.0-22.0
Caregiver Education	31	14.8 (2.2)	11.0-20.5
Length of Dx. (months)	33	14.0 (14.9)	2.0-60.0

Sample Characteristics (Continued)

Variable	Frequency	% of Sample
Gender: Female	16	48.5%
Male	17	51.5%
Marital Status:		
Married	16	50%
Single (Div., Never Married)	5	15%
Widowed	11	35%
Living Arrangement:		
Lives alone	10	30.3%
Assisted Living	2	6%
With spouse/family member	21	63.7%

Background & Predictor Variables

- Subject Characteristics: Demographic Data form (gender, living situation, ethnic background)
- Disease Stage: Clinical Dementia Rating Scale
- Mental Ability: Mini-Mental State Exam (MMSE)
- Caregiver Knowledge of Dementia: Knowledge of Alzheimer's Test
- Perceived Stigma: Stigma Impact Scale (SIS) (PwD and Family Caregiver)

PwD Outcome Variables

- Psychological Well-Being: Geriatric Depression Scale
- Behavioral Competence:
 - Behavioral Symptoms: Revised Memory and Behavior Problems
 - Personal Control: Mastery Scale
 - Physical Health: Health Subscale from MOS-36 Scale
 - Self-Esteem: Rosenberg's Self-Esteem Scale
 - Anxiety: Rating Anxiety in Dementia
- Environment/Interactions:
 - Social Support and Activity:
 - Duke Social Support Index
 - Recreational and Social Activities
- Personal Responses to Stigma: Qualitative Interview

Study Procedures

- ☑ All study instruments were administered in face-to-face interviews in the home.
- ☑ Large-print scales for item ratings were used to help guide responses from PwD.
- ☑ Family caregivers completed the study instruments in a separate location from the PwD.
- ☑ Approximately 90 minutes were required to obtain informed, written consent and administer study instruments.
- ☑ Little or no tiring was noted or reported.
- ☑ Overall, interview was well-tolerated.

Predictor Variables

Variable	Mean/S.D.	Range
MMSE (0-30)	21.9 (4.0)	16 - 30
Caregiver Knowledge of Dementia (0-22)	15.8 (2.3)	12-20
Stigma Impact Scale: PwD (0-96)	36.5 (9.9)	20-58
Stigma Impact Scale: Caregiver (0-96)	32.3 (7.9)	20-46


PwD Outcomes

Variable	Mean/S.D.	Range
Recreational & Social Activities (PwD) (26-104)	64.9 (12.3)	40-85
Duke Social Support (19-76)	58.9 (11.9)	31-75
MOS Physical Health (5-25)	13.7 (4.0)	7-20
Personal Control (7-35)	26.8 (3.8)	21-34
Self Esteem (10-50)	39.7 (5.9)	22-49
Memory & Behavior Sym. (24-96)	19.1 (12.3)	6-56
Anxiety in Dementia (0-60)	13.3 (10.7)	0-39

Relationships Among Perceived Stigma & PwD Outcomes

Variable	PwD SIS	Caregiver SIS
Recreational & Social Activities (PwD/Caregiver)	-0.03	-0.43*
Duke Social Support	-0.42*	-0.21
MOS Physical Health	-0.47*	0.02
Personal Control	-0.30	-0.06
Self Esteem	-0.37*	-0.27
Memory & Behavior Symptoms	-0.04	0.17
Anxiety in Dementia	0.64*	-0.39

*p<.05



Relevance of Perceived Stigma in PwD

- Across studies, perceived stigma is related to important outcomes in PwD: self-esteem, depression, physical health, social support, anxiety, and personal control
- All relationships were in the expected direction and moderate in strength
- Relationships support the susceptibility of PwD to stigma in the early to early-middle disease stages

Relevance of Perceived Stigma in PwD (Continued)

- Social rejection most highly correlated with total perceived stigma, $r=.89$, followed by social isolation, $r=.81$
- Impact of perceived stigma on emotional, self-esteem, and social functioning supported by these findings
- Highly-rated items (social rejection):
 - ☑ I feel set apart from others who are well
 - ☑ I feel more lonely than usual
 - ☑ I have a sense of being unequal to others

Observations

- PwD tended to be more 'positive' in item ratings than actual descriptions of experiences of stigma: ie., rated items such as 'I do not feel I can be open with others about my illness' with 'strongly disagree', but later reported fear of telling others about their disease.
- Stigma of dementia may influence subject recruitment: < 5% of contacts agreed to participate as a subject = large recruitment burden.
- Many respondents supported numerical ratings with personal accounts of stigma.



Observations

- ‘Perceived stigma’, although abstract in nature, was a concept PwD were able to relate to through the SIS items
- Rating items using the 4-point scale with large-print visual reminder was effective in eliciting responses
- Tiring during the interview was not evident



Conclusions

- ✓ Perceived stigma is a meaningful and measurable reality for persons with dementia
- ✓ The reliability and validity of the SIS, as adapted for PwD, has been supported by these findings.
- ✓ The magnitude of perceived stigma in PwD is comparable to or exceeds that experienced by other populations with chronic/terminal illnesses
- ✓ Item ratings should be supported by open-ended questions to verify ratings
- ✓ Support for larger studies is evident in the findings from pilot studies

References

- Benbow, S.M., & Reynolds, D. (2000). Challenging the stigma of Alzheimer's disease. *Hospital Medicine*, 61, 174-177.
- Burgener, S., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and Parkinson disease. *Dementia: The International Journal of Social Research and Practice*, 7(1), 31-53.
- Burgener, S.C. (1999a). Care decisions in irreversible dementia: Who speaks for the patient? *Journal of Gerontological Nursing*, 25(8), 53-55.
- Burgener, S.C., & Dickerson-Putman, J. (1999). Assessing the patient in the early stages of irreversible dementia: the relevance of patient perspectives. *Journal of Gerontological Nursing*, 25(2), 33-41.
- Falk, G. (2001). *Stigma: How we treat outsiders*. Amherst, NY: Prometheus Books
- Fife, B.L., & Wright, E.R. (2000). The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior*, 41, 50-67.
- Harris, P.B., & Sterin, G.J. (1999). Insider's perspective: defining and preserving the self in dementia. *Journal of Mental Health and Aging*, 5, 241-256.

References (Continued)

- Jolley, D.J., & Benbow, S.M. (2000). Stigma and Alzheimer's disease: causes, consequences and a constructive approach. *International Journal of Clinical Practice*, 54(2), 117-119.
- Kitwood, T. (1997a). *Dementia reconsidered*. Bristol, PA: Open University Press.
- Kitwood, T. (1997b). The experience of dementia. *Aging and Mental Health*, 1, 13-22.
- Link, B.G., Struening, E., Cullen, F.T., Shrout, P.E., & Donrhenwend, B.P. (1989). A modified labeling theory approach to mental disorders: an empirical assessment. *American Sociological Review*, 54, 400-423.
- Link, B.G., Struening, E.L., Rahav, M., Phelan, J.C., & Nuttbrock, L. (1997). On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behavior*, 38, 177-190.
- Reingold, A.L., & Krishnan, S. (2001). The study of potentially stigmatizing conditions: An epidemiologic perspective. Paper presented at the National Institutes of Health International Stigma Conference, Bethesda, MD.
- Sabat, S.R. (2002). Selfhood and Alzheimer's disease. In P.B. Harris (Ed.), *The person with Alzheimer's Disease: Pathways to understanding the experience*. Baltimore, MD: John Hopkins Press.