Findings from HSR&D's Evaluation of Parkinson's Disease Research, Education and Clinical Centers: Patient and Caregiver Surveys (2006) VA Administrative Data

National VA Parkinson's Disease Consortium Conference
Pittsburgh, PA
September 3-5, 2008

Presentation by
PI: Martin P. Charns, DBA
Co-PI: Irene E. Cramer, PhD, MSSA

From material prepared by the presenters and HSR&D's
Center for Organization, Leadership and Management Research:
John Gardner, PhD; Ann Hendricks, PhD; Robert Holloway, MD, MPH;
Richard Lin, MD, MPH; Mark Meterko, PhD; Marjorie Nealon Seibert, MBA;
Terri K. Pogoda, PhD; Kelly Stolzmann, MS

Overview: VA Administrative Data

Ann Hendricks, PhD
John Gardner, PhD
Health Care Financing & Economics

HSR&D's Evaluation of Parkinson's Disease Research, Education and Clinical Centers

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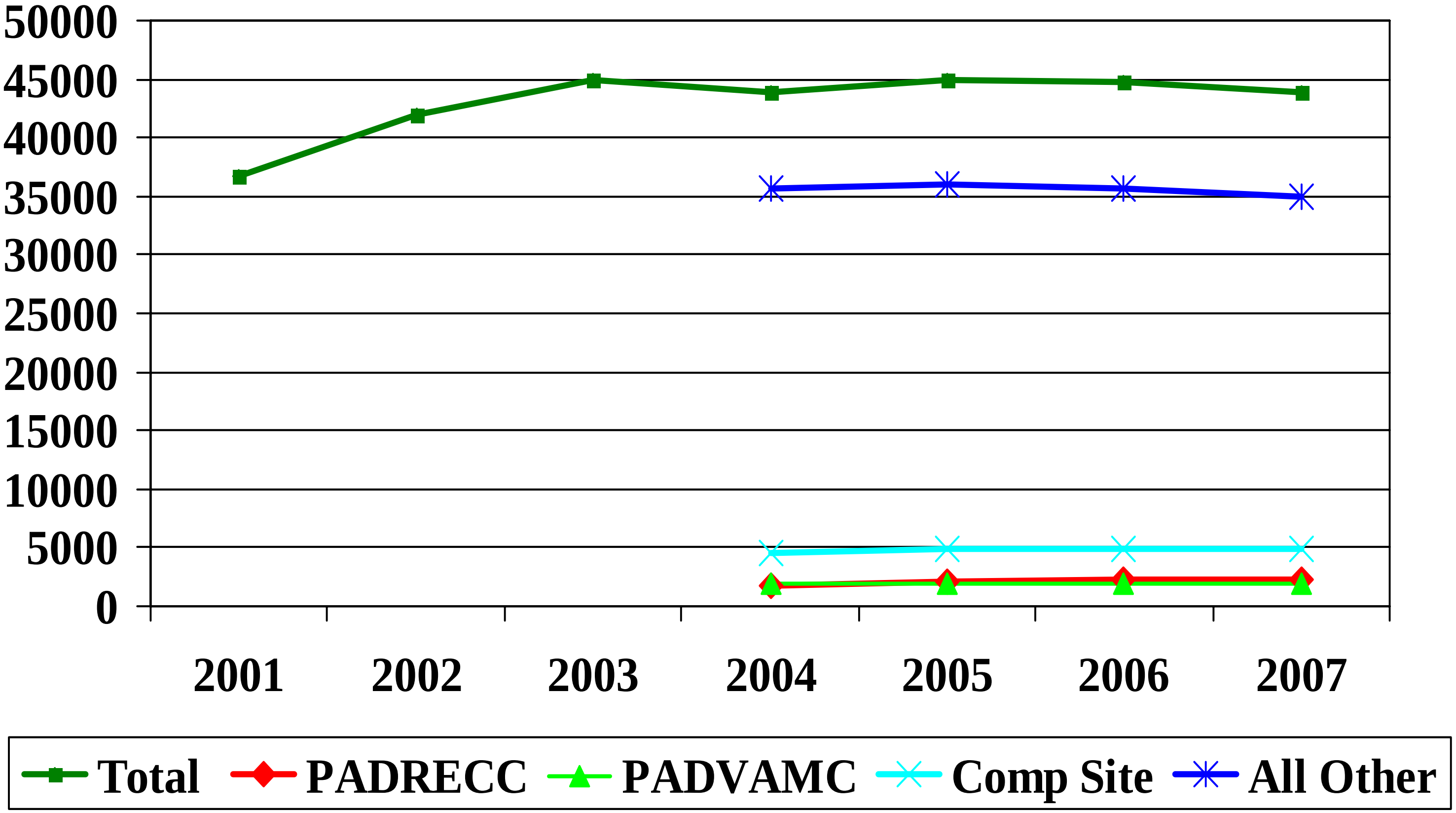
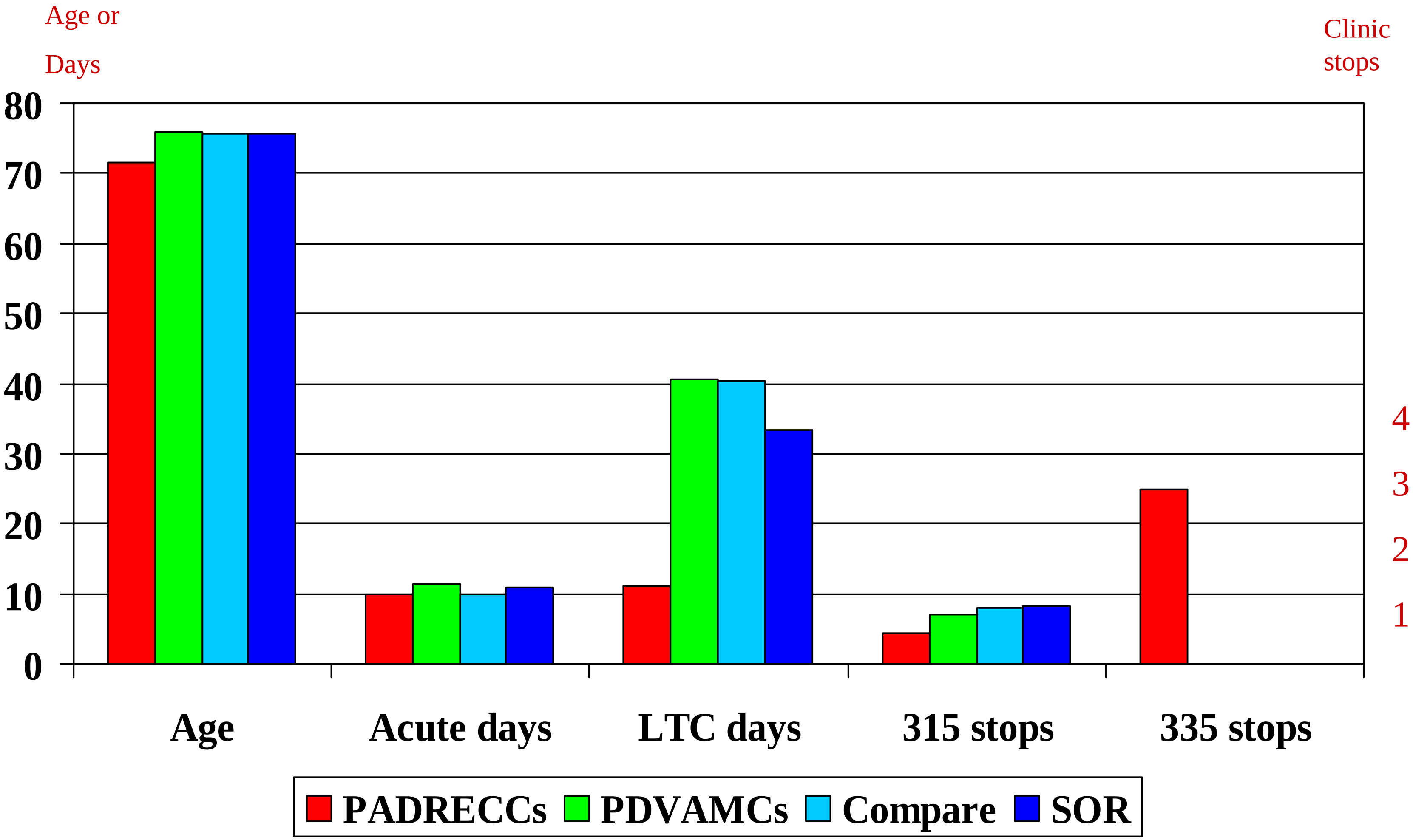
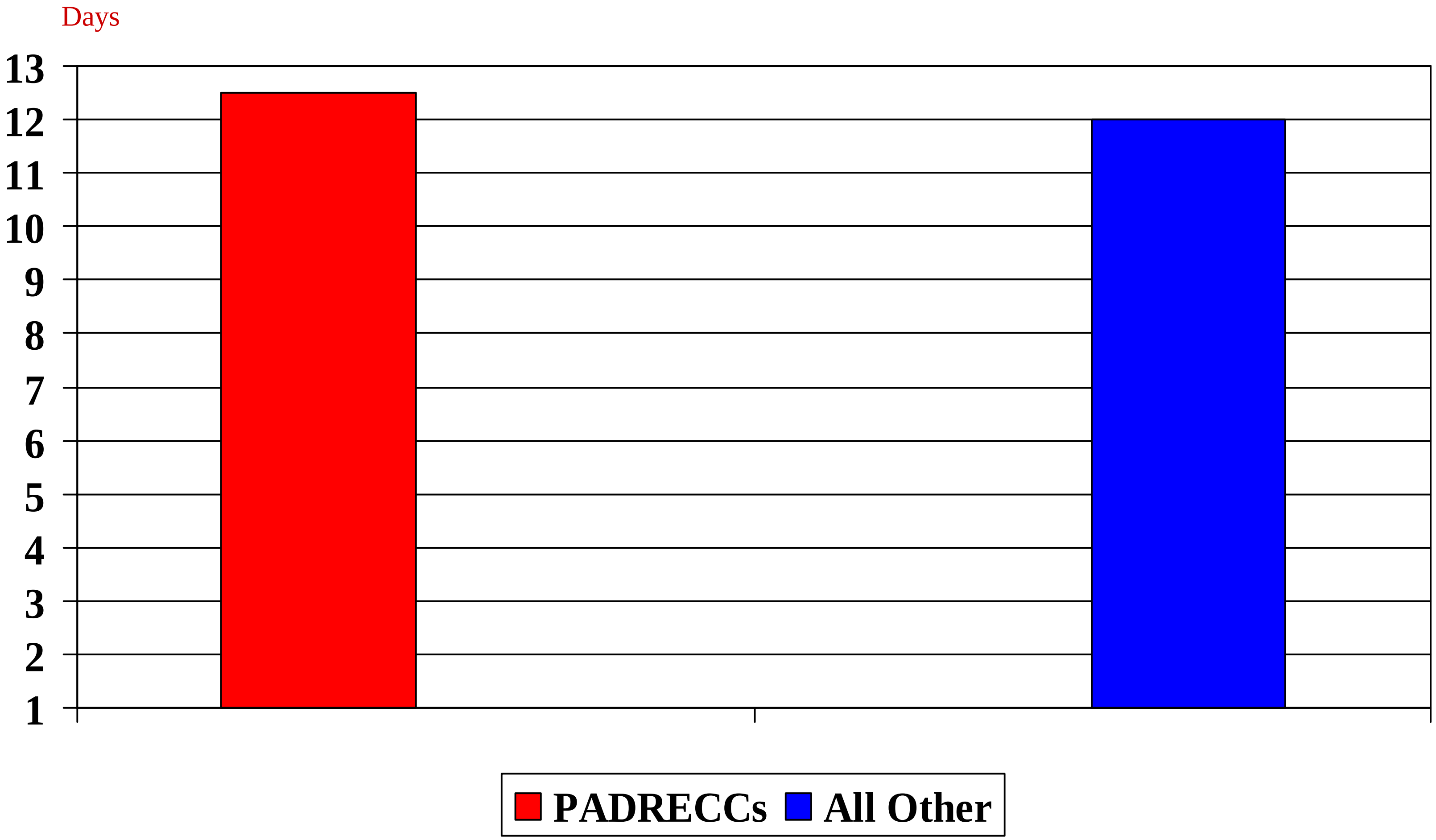
VA Patients with PD Diagnosis 2001-2007



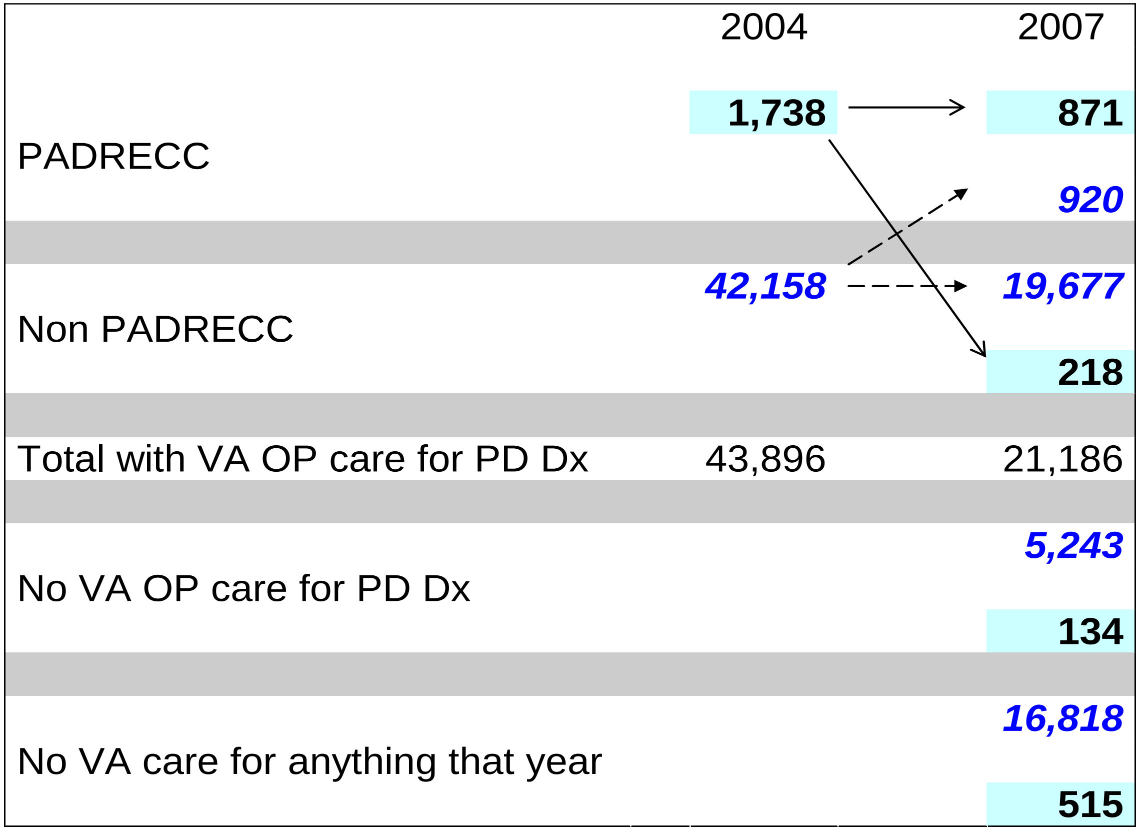
PADRECC patients are younger, have more neurology care total and much fewer LTC days of care



PADRECC patients averaged 1/2 more days of outpatient care than other PD patients in VA, 2005



How many PD patients (with Dx in 2004) received any VA PD outpatient care in 2007, by PADRECC/non-PADRECC location?



	2004	2007
PADRECC	**1,738**	**871** ***920***
Non PADRECC	***42,158***	***19,677*** **218**
Total with VA OP care for PD Dx	43,896	21,186
No VA OP care for PD Dx		***5,243*** **134**
No VA care for anything that year		***16,818*** **515**

PADRECC patients in 2004 shown with blue shading in both years.
Non-PADRECC patients in 2004 shown in blue italics in both years.

Overview: Patient and Caregiver Surveys

Irene E. Cramer, PhD, MSSA

Center for Organization, Leadership, and Management Research

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Key Evaluation Questions (addressed by the survey)

- Does the organizational model affect outcomes?
  - PADRECC vs. non-PADRECC
  - Single hub vs. mini-network
  - Chronic care model
- Outcomes
  - Health status
  - Quality of life
  - Experience of care
  - Unmet needs

Methodology: Sampling

- Used VA’s Outpatient Care Dataset (National Patient Care Database)
- Selected if in previous six months in 2004
  - ICD-9 code 332 and/or
  - Visit to PADRECC
- Stratified sample by site location
  - PADRECC
  - Comparison Site (PD population size, neurologists on site, academic affiliation, distance from hub)
  - All Other VAMCs in a PADRECC SoR
  - Adapted to address mini-network structure

Methodology: Sampling

- Identified 40,480 VA patients
  - Deleted patients who had died and with incomplete contact information
- Mailed pre-screeners to 6,507 patients to obtain
  - Self report of PD diagnosis
  - Informed consent
- 3,811 responded: 2,796 met eligibility
- 2,375 patients completed and returned surveys (85%)
  - Requested contact information for informal caregiver
- 818 caregivers completed and returned surveys

Methodology: Measures

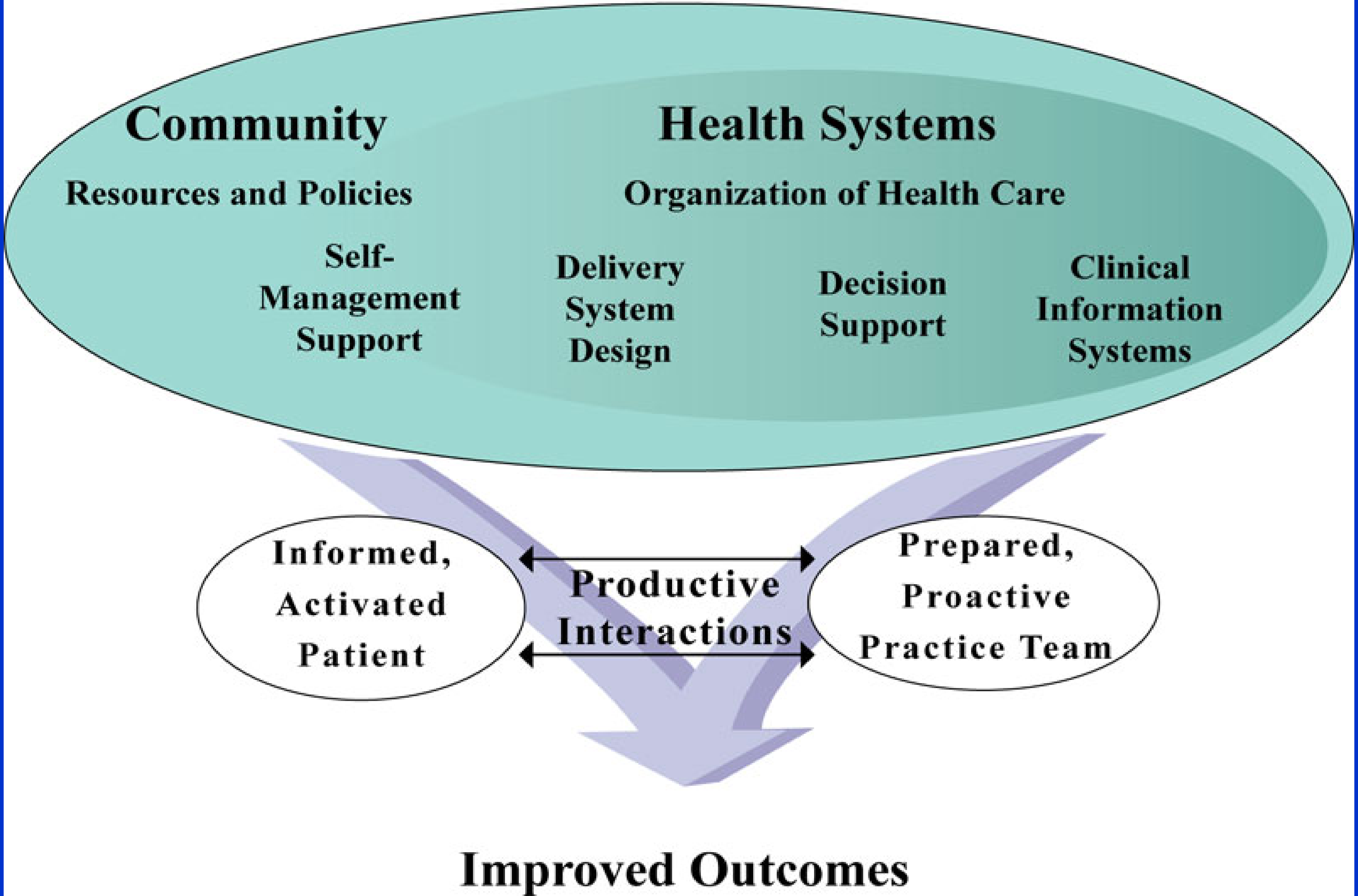
- General health status, HRQOL and health-related behaviors (SF-12, VA's Survey of Healthcare Experiences of Patients (SHEP))
- PD-related health status and HRQOL (PDQ-8, UPDRS-ADL)
- Service utilization (outpatient, education and support, research)
- Experience of care and satisfaction (SHEP, Patient Assessment of Chronic Illness Care (PACIC))
- For Caregivers: Montgomery Caregiver Burden
- Demographics

Chronic Care Model (CCM)

(Wagner et al., 1996; Wagner 1998)

- Chronic Care Model (CCM) is a framework:
  - Systematic planned approach to care
  - Through productive, planned interactions
  - Between informed, activated patients and families and prepared proactive practice teams
  - With consistent delivery of evidence based care
  - With support for patient self management
- Leads to improved patient outcomes

The Chronic Care Model



Developed by The MacColl Institute
® ACP-ASIM Journals and Books

PACIC Scale (CCM model)

(Glascow, Wagner et al., 2005a)

- **Patient Activation:** Solicit patient input and involvement in decision- making
- **Delivery System Design / Decision Support:** Organize care and provide information to patients to enhance their understanding of care
- **Goal Setting/Tailoring:** Acquire information for setting specific collaborative goals
- **Problem Solving/Contextual:** Consider potential barriers and patient's social and cultural environment in treatment planning
- **Follow-up/Coordination:** Arrange care that extends and reinforces office-based treatment, and make proactive contact with patients to assess progress and coordinate care

PACIC Scale (5As model)

(Glascow, et al., 2005b)

- ASSESS patient behaviors, attitudes and goals
- ADVISE patients based on science (EBP)
- AGREE on the problem, goal and plan of action
- ASSIST patients in developing realistic goals and identify barriers to and strategies for reaching goals
- ARRANGE for additional resources, support, etc

Demographics

ITEM	All Patients N=2375 Percent	Matched Patients N=818 Percent	Caregivers N=818 Percent
Age: 60 or less	8.2	7.5	35.9
61 – 70	17.9	20.1	26.9
71 – 80	44.5	45.6	28.1
Over 80	29.5	26.8	9.1
Female			87.5
Caucasian	92.9	96.8	96.4
Education:			
High school or less	42.0	34.8	31.0
Some college or more	58.0	65.2	69.0
Medicare	91.9	91.5	54.4

Social Support

ITEM	All Patients N=2375 Percent	Matched Patients N=818 Percent	Caregivers N=818 Percent
Married	77.6	82.5	85.5
Lives alone	12.2	8.6	
Lives with patient			68.7
Someone helps with care	80.7	84.6	
Help not needed	15.7	13.3	
Need help but have none	3.6	2.0	
Spouse provides care	81.6	85.1	62.4
Other relative/friend provides care	16.6	15.0	22.1
Had help with survey	43.1	39.9	

Health Status: General

ITEM/SCALE 0 – 100 with higher score indicating better health	All Patients N=2375 Mean	Matched Patients N=818 Mean	Caregivers N=818 Mean
V-SF-12 Physical Health*	32.8	33.6	45.7
V-SF-12 Mental Health*	43.3	44.9	49.4
Self rated health	34.7	37.6	57.4
Physical health compared to 1 year ago	35.5	36.2	47.4
Mental health compared to 1 year ago	43.2	44.5	48.5

* V-SF-12: version of SF-12 developed specifically for veterans

Health Status: Comorbidities and PD-related

ITEM/SCALE	All Patients N=2375 Percent	Matched Patients N=818 Percent	Caregivers N=818 Percent
Arthritis	55.3	54.4	49.6
Hypertension	54.5	50.5	45.1
Chronic low back pain	46.0	47.1	29.7
Enlarged prostate	44.8	46.6	8.7
Depression	40.3	37.2	26.4
Anxiety	37.0	32.4	26.7
Experienced hallucinations	21.9	19.3	
Never get exercise	45.8	42.0	21.8
PDQ-8 (mean score with range 0 - 100; 100=worse health)	X=39.9	X=37.8	
UPDRS-ADL (mean score with range 0 - 52; 52=worse health)	X=16.9	X=16.5	

Caregiver Perspectives

(Montgomery Caregiver Burden: Objective Burden)

Since survey respondent began caregiving, assisting or having contact with the patient has meant less	**A Little/Lot Less Percent**
Time to yourself	51.7
Privacy	34.8
Money to meet expenses	30.6
Personal freedom	52.4
Energy	43.5
Time for recreation and/or social activities	49.4
Vacation activities or trips	59.1
Relationships with other family members	22.6
Your health	23.6

Montgomery Caregiver Burden: Subjective Burden

The informal caregiver feels	Often/Most of the time Percent
It is painful to watch patient age	54.7
Useful in relationship with patient	66.5
Strained in relationship with patient	12.9
That contributing to well-being of patient	76.8
Patient tries to manipulate caregiver	7.7
Pleased with relationship with patient	79.1
Patient does not appreciate what caregiver does	10.7
Nervous and depressed about relationship w/patient	8.5
Patient makes requests over and above needs	6.8
I don't do as much as I could or should for him/her	9.0
Patient expects me to take care as if caregiver were the only one patient could depend on	20.7
Guilty over our relationship	4.9

Service Utilization

ITEM	All Patients N=2375 Percent	Matched Patients N=818 Percent	Caregivers N=818 Percent
During past year used:			
VA-only	37.7	34.6	4.3
Non-VA only	5.0	5.1	76.2
VA & Non-VA	56.6	59.6	9.6
None	0.7	0.8	10.0
VA PD-related education/support	15.8	17.4	
Would like to participate	73.6	79.6	
VA PD-related research	12.8	13.9	
Would like to participate	84.8	90.0	
Selected from PADRECC VAMC	37.7	38.6	

Experience of Care: Satisfaction

ITEM/SCALE (Range: 1 – 100 with 100=best)	All Patients N=2375 Mean	Matched Patients N=818 Mean	Caregivers N=818 Mean
Quality of last visit	72.1	75.1	
Access to care	81.1	84.0	
Continuity of care	76.6	79.3	
Coordination of care	79.8	83.8	
Attention to personal preferences	83.7	86.7	
Emotional support	80.4	83.7	
Patient education	69.0	74.9	

Experience of Care: Adherence to Chronic Care Model
Patient Assessment of Chronic Illness Care (PACIC)
Classic CCM Scales

PACIC Classic CCM Scales (Range 1 – 5 with 5 = best rating)	All Patients N=2375 Mean	Matched Patients N=818 Mean	Caregivers N=818 Mean
Patient activation	2.8	3.0	3.1
Delivery system design	2.7	2.9	3.0
Individualized goal setting and treatment planning	2.2	2.3	2.5
Problem solving that addresses contextual issues	2.5	2.7	2.8
Follow-up and coordination	1.8	2.0	2.2

Experience of Care: Adherence to Chronic Care Model Patient Assessment of Chronic Illness Care (PACIC)

5 A's Scales

PACIC 5A's Scales (Range 1 – 5 with 5 = best rating)	All Patients N=2375 Mean	Matched Patients N=818 Mean	Caregivers N=818 Mean
ADVISE	2.3	2.3	2.3
AGREE	2.8	2.8	3.0
ARRANGE	1.8	1.8	1.7
ASSESS	2.7	2.7	2.8
ASSIST	2.5	2.4	2.5
Care was well organized	3.7	3.8	3.7

References

1. Glascow, R.E., et al. (2005) *Use of the Patient Assessment of Chronic Illness Care (PACIC) with diabetic patients: relationship to patient characteristics, receipt of care, and self-management*. Diabetes Care, 28(11): 2655-2661
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4. Glascow, R.E., et al.. (2005) *Development and validation of the Patient Assessment of Chronic Illness Care (PACIC).* Medical Care, 43(5): 436-444

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Evaluation of Parkinson’s Disease Research, Education, and Clinical Centers

Patient and Organizational Factors Related to Education and Support Services Use

Terri K. Pogoda, PhD

Center for Organization, Leadership, and Management Research

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Ways of Receiving Education and Support Services (ESS), Stratified by Site (in percentages)

	PADRECC VAMC Sites N = 230	Other VAMC Sites N = 124
One-on-one discussions with providers	55.7	50.8
Classes	**19.1**	**8.9***
Support groups	**36.5**	**16.1*******
Written materials	**60.0**	**31.5*******
Videos or movies	**17.4**	**9.7** ‡
Conferences	**20.0**	**8.1****
Others ways of utilization	6.1	5.7

A higher proportion of PADRECC VAMC Site patients received a variety of ESS.

‡ ≤ .06 significance
* ≤.05 significance
** ≤.01 significance
*** ≤.001 significance
**** ≤.0001 significance

Types of ESS Received, Stratified by Site (in percentages)

	PADRECC VAMC Sites N = 233	Other VAMC Sites N = 125
General information about PD	**74.8**	**55.7*****
Treatment and side effects	**50.4**	**33.9****
Medication and side effects	**58.3**	**42.7****
Financial assistance	4.4	6.5
Emotional support for me or my family	21.7	14.5
Rehabilitation services	22.6	19.4
Other topics	12.6	9.7

A higher proportion of PADRECC VAMC Site patients received a variety of ESS.

* ≤.05 significance
** ≤.01 significance
*** ≤.001 significance
**** ≤.0001 significance

Reasons for Non-participation in PD-related ESS, Stratified by Site

(in percentages)

	PADRECC VAMC Sites N = 616	Other VAMC Sites N = 1278
Did not know about services	**37.7**	**59.9******
Was never asked to participate	**38.8**	**56.5******
No education available	**7.8**	**11.6****
Participated in education elsewhere	8.0	9.5
Not interested	**10.1**	**5.2******
Did not have the time	**5.4**	**2.0******
Family/friends did not want patient to participate	.7	.5
Did not seem like education would help	**8.6**	**4.9*****

Patients from Other VAMCs more frequently reported not being aware of the availability of ESS or were never asked to participate.

* ≤.05 significance
** ≤.01 significance
*** ≤.001 significance
**** ≤.0001 significance

Write-in Option Responses:
Reasons for Non-participation in PD-related ESS, Stratified by Site (in percentages)

	PADRECC VAMC Sites N=154	Other VAMC Sites N = 155
Distance	**42.9**	**22.6******
Transportation	15.6	10.3
Poor health/mobility	7.8	11.0
Use Non-VA provider	**3.9**	**12.3****
Other	**29.9**	**43.9****

More patients indicated that distance was a barrier to accessing ESS. Our results may underestimate the problem.

* ≤.05 significance
** ≤.01 significance
*** ≤.001 significance
**** ≤.0001 significance

Findings: Education and Support Services

- Compared to Other VAMC patients, proportionally more PADRECC VAMC patients:
  - Received a variety of ESS that included general information about PD, treatment, medication, and associated side effects
  - Received ESS through classes, written materials, videos, support groups and conferences
- Only 26% of PADRECC VAMC patients and 8% of Other VAMC patients reporting utilizing ESS
  - There are more patients to reach

Patient and PADRECC Effects on Patient Empowerment and Satisfaction in Care of Parkinson’s Disease

Martin P. Charns, DBA
Center for Organization, Leadership, and Management Research

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Dependent Variables

- Patient Assessment of Chronic Illness Care (PACIC)
- Survey of Health Experience of Patients (SHEP)

Patient Characteristics

- Demographics
- Health-Related Measures
- Whether patient had care at a PADRECC in past year prior to survey selection

Analyses

- Correlations
- Comparison of PADRECC VAMC vs. Non-PADRECC VAMC sites (t-tests)
- Hierarchical Linear Models (HLM)
  - Accounts for nesting of patients in VAMCs
  - Effects of patient characteristics
  - Effects of facility characteristics – VAMC complexity and PADRECC VAMC

Correlations Between Patient Demographics and PACIC

Demographics	Patient Activation	Delivery System	Goal Setting	Problem Solving	Follow-up	PACIC Summary
Age	🟩 -0.07	-0.02	-0.02	-0.02	-0.02	-0.03
Hispanic	0.00	0.00	0.02	0.02	🟩 0.05	0.02
Minority	-0.03	-0.04	-0.01	-0.01	-0.04	-0.01
Education	0.04	-0.03	-0.04	🟩 -0.07	-0.03	-0.03
Married	🟩 0.05	0.00	-0.01	0.00	-0.02	0.00
Have Help	0.01	0.01	0.02	0.03	0.02	0.02
Need Help	🟩 -0.08	🟩 -0.07	🟩 -0.05	🟩 -0.06	-0.04	🟩 -0.07
Live Alone	-0.03	-0.01	0.00	-0.01	0.00	-0.01
Employed	🟩 0.05	0.02	0.02	0.00	0.00	0.02

🟩 p<.05

Correlations Between Patient Health Status and PACIC

Health Status	Patient Activation	Delivery System	Goal Setting	Problem Solving	Follow-up	PACIC Summary
General Health	🟩 0.09	🟩 0.11	🟩 0.07	🟩 0.06	🟩 0.05	🟩 0.08
PCS	🟩 0.09	🟩 0.10	🟩 0.10	🟩 0.08	🟩 0.08	🟩 0.10
MCS	🟩 0.09	🟩 0.10	0.01	0.02	-0.01	0.04
HS Trend Physical	🟩 0.09	🟩 0.12	🟩 0.09	🟩 0.07	🟩 0.08	🟩 0.10
N Physical Conditions	🟩 -0.06	-0.03	🟩 -0.06	-0.04	-0.01	-0.04
N Mental Conditions	🟩 -0.06	🟩 -0.05	-0.02	-0.01	0.04	-0.02
PDQ8	🟩 -0.07	🟩 -0.10	-0.04	🟩 -0.05	0.00	🟩 -0.06
UPDRS-ADL	-0.04	🟩 -0.06	-0.03	-0.03	0.00	-0.04
HS Trend Mental	🟩 0.09	🟩 0.10	🟩 0.06	🟩 0.05	0.03	🟩 0.08
Have Hallucinations	-0.02	-0.04	0.00	0.00	0.04	-0.01

🟩 p<.05

Correlations Between Patient Demographics and SHEP

Demographics	Access	Continuity	Emotional Support	Patient Education	Visit Coordination	Patient Preferences	Overall Quality	Problem Fixed	Overall Satisfaction
Age	-.01	-.03	🟩 .05	-.01	🟩 -.04	.04	-.02	🟩 .05	.03
Hispanic	-.04	.00	-.03	🟩 .05	-.01	.01	-.01	-.02	.03
Minority	🟩 -.06	-.02	🟩 -.05	-.02	-.04	🟩 -.04	🟩 -.07	🟩 -.05	🟩 -.07
Education	-.02	🟩 -.05	-.03	-.03	-.01	-.02	.02	🟩 -.04	🟩 -.09
Married	🟩 .11	.01	🟩 .08	🟩 .10	🟩 .06	.03	🟩 .07	🟩 -.07	🟩 .07
Have Help	.00	🟩 .04	.03	.03	🟩 .06	.03	.01	.03	-.00
Need Help	🟩 -.11	-.03	🟩 -.09	🟩 -.11	🟩 -.09	🟩 -.08	🟩 -.13	🟩 -.11	🟩 -.13
Live Alone	🟩 -.06	-.03	🟩 -.05	🟩 -.07	-.04	-.03	-.04	🟩 -.07	🟩 -.06
Employed	.02	-.02	-.01	.01	.02	-.02	.02	.01	-.01

🟩 p<.05

Correlations Between Patient Health Status and SHEP

Health Status	Access	Continuity	Emotional Support	Patient Education	Visit Coordination	Patient Preferences	Overall Quality	Problem Fixed	Overall Satisfaction
General Health	🟩 .12	🟩 .05	🟩 .13	🟩 .14	🟩 .05	🟩 .09	🟩 .17	🟩 .13	🟩 .15
PCS	🟩 .10	.00	🟩 .08	🟩 .10	.04	🟩 .07	🟩 .09	🟩 .05	🟩 .13
MCS	🟩 .11	.04	🟩 .19	🟩 .17	🟩 .09	🟩 .13	🟩 .16	🟩 .16	🟩 .15
HS Trend Physical	🟩 .09	🟩 .05	🟩 .08	🟩 .10	🟩 .05	🟩 .05	🟩 .08	🟩 .07	🟩 .13
N Physical Conditions	🟩 -.07	-.02	-.03	-.04	.00	-.02	🟩 -.06	-.02	-.02
N Mental Conditions	🟩 -.10	-.01	🟩 -.11	🟩 -.10	-.03	🟩 -.08	🟩 -.08	🟩 -.11	🟩 -.09
PDQ8	🟩 -.18	-.02	🟩 -.18	🟩 -.20	🟩 -.10	🟩 -.13	🟩 -.18	🟩 -.17	🟩 -.20
UPDRS-ADL	🟩 -.12	-.02	🟩 -.12	🟩 -.13	🟩 -.06	🟩 -.11	🟩 -.10	🟩 -.11	🟩 -.16
HS Trend Mental	🟩 .10	🟩 .05	🟩 .13	🟩 .14	🟩 .05	🟩 .08	🟩 .12	🟩 .09	🟩 .12
Hallucinations	🟩 -12	-.01	🟩 -,12	🟩 -.12	-.03	🟩 -.10	🟩 -.11	🟩 -.10	🟩 -.10

🟩 p<.05

Differences Between PADRECC and Other Sites on PACIC and SHEP

Site	Patient Activation	Delivery System	Goal Setting	Problem Solving	Follow-up	PACIC Summary			
PADRECC	🟩 3.28	🟩 3.24	🟩 2.67	🟩 3.01	🟩 2.17	🟩 2.80			
Other	🟩 2.88	🟩 2.80	🟩 2.16	🟩 2.56	🟩 1.82	🟩 2.36			
Site	Access	Continuity	Emotional Support	Patient Education	Visit Coordination	Patient Preferences	Overall Quality	Problem Fixed	Overall Satisfaction
PADRECC	85.2	81.1	84.7	🟩 76.3	🟩 87.2	87.1	🟩 76.4	2.74	🟩 5.98
Other	83.3	77.4	81.7	🟩 70.9	🟩 81.4	85.3	🟩 71.9	2.73	🟩 5.86

🟩 p<.05

Findings: PADRECC VAMC

- No relationship between VAMC complexity and processes of care or satisfaction
- Strong relationship between PADRECC VAMC and processes of care (all 5 PACIC scales and summary score) and satisfaction (4 of 9 scales)
  - Even after accounting for relationships between individual patient characteristics and dependent variables