

The Guided Care Program For Families and Friends

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Today's Talk

Supporting Caregivers: Description of

The Guided Care Program for Family and Friends

- Rationale
- Considerations and Decisions
- Overview of the Program
- Early Experiences

Challenges and Opportunities Moving Forward

The Care Model

Community
Resources and
Policies

Health System

Health Care Organization

Self-
Management
Support

Delivery
System
Design

Decision
Support

Clinical
Information
Systems

Informed,
Empowered Patient
and Family

Productive Interactions

Patient-Centered
Coordinated
Timely & Efficient
Evidence-Based & Safe

Prepared,
Proactive
Practice Team

Improved Outcomes

Source: Improving Chronic Illness Care (www.improvingchroniccare.org)

Considerations to Approach: Who is a Caregiver?

Issue: Guided Care is a lifetime model of care
(patients are not “discharged”)

- Broad definition of caregiver - relative or unpaid non-relatives providing any health-related help

Issue: Not all caregivers identify with the term
“caregiver”

- Reliance on terminology of “families and friends” as much as possible

Considerations to Approach: Emphasis on Diffusion, Sustainability

Issue: Need to demonstrate a business case

- Support of family caregivers must be balanced with responsibilities to other stakeholders
- Constraints on Guided Care Nurse time; create flexibility in model and opportunities for group interactions

Issue: Reliance on an available labor pool

- Guided Care Nurse support of family caregivers officially business hours Monday - Friday; flexibility for off-hours communication at nurse discretion

Considerations to Approach: What Type of Support?

Issue: Heterogeneity of patients and their caregivers
potential challenge to meaningful group interactions

- Emphasis on broad life skills rather than content or knowledge

Issue: Nurse support rather than social workers,
counselors, or psychologists

- Reliance on structured program
- Emphasis on process and facilitating group discussion rather than teaching

The Guided Care Program for Family and Friends

- Education & referral to community resources
- Ongoing “Coaching” related to patient care
- Caregiver “Assessment” (Summer-Fall 2006)
- Workshop (Spring 2007)
 - 6 weekly Guided Care Nurse facilitated sessions
- Support Group (Summer 2007-End of Study)
 - Monthly group meetings

Program for Family and Friends “Assessment”

Purposes:

- To establish working relationships with patients' primary “caregiver”
- To allow patient caregivers to state their own needs/concerns
- To provide education and community service referral as necessary

Family and Friend Intake Form

mailed and ideally completed in advance

30-minute meeting, ideally in-person

Family and Friend Intake Form

- Personalized cover letter
- Demographics and health
- Characteristics of care arrangement
- Tasks for which help is provided (personal care, household, medically-oriented tasks)
- General stress level related to care
- Caregiver supportive services used/barriers to use
- Requests for information
- Rewards, strengths, challenges

Program for Family and Friends Workshop

- Six 90-minute sessions facilitated by Guided Care Nurse
- Structured, interactive sessions using problem solving techniques (modeled on chronic disease self management)
- Open to any involved families or friends
- Pilot-tested spring 2006

Topics :

1: Introduction to Self Management

2: Taking Care of You

3: Social Support and Relationships

4: Communication With the Medical Community

5: Planning for the Future

6: Staying on Track

Program for Family and Friends Support Groups

Objectives:

- To reinforce Workshop skills and techniques
- To cultivate communication and ongoing relationship between nurse and families of patients
- To provide families with the opportunity to share experiences

Logistics:

Monthly group facilitated by Guided Care Nurse

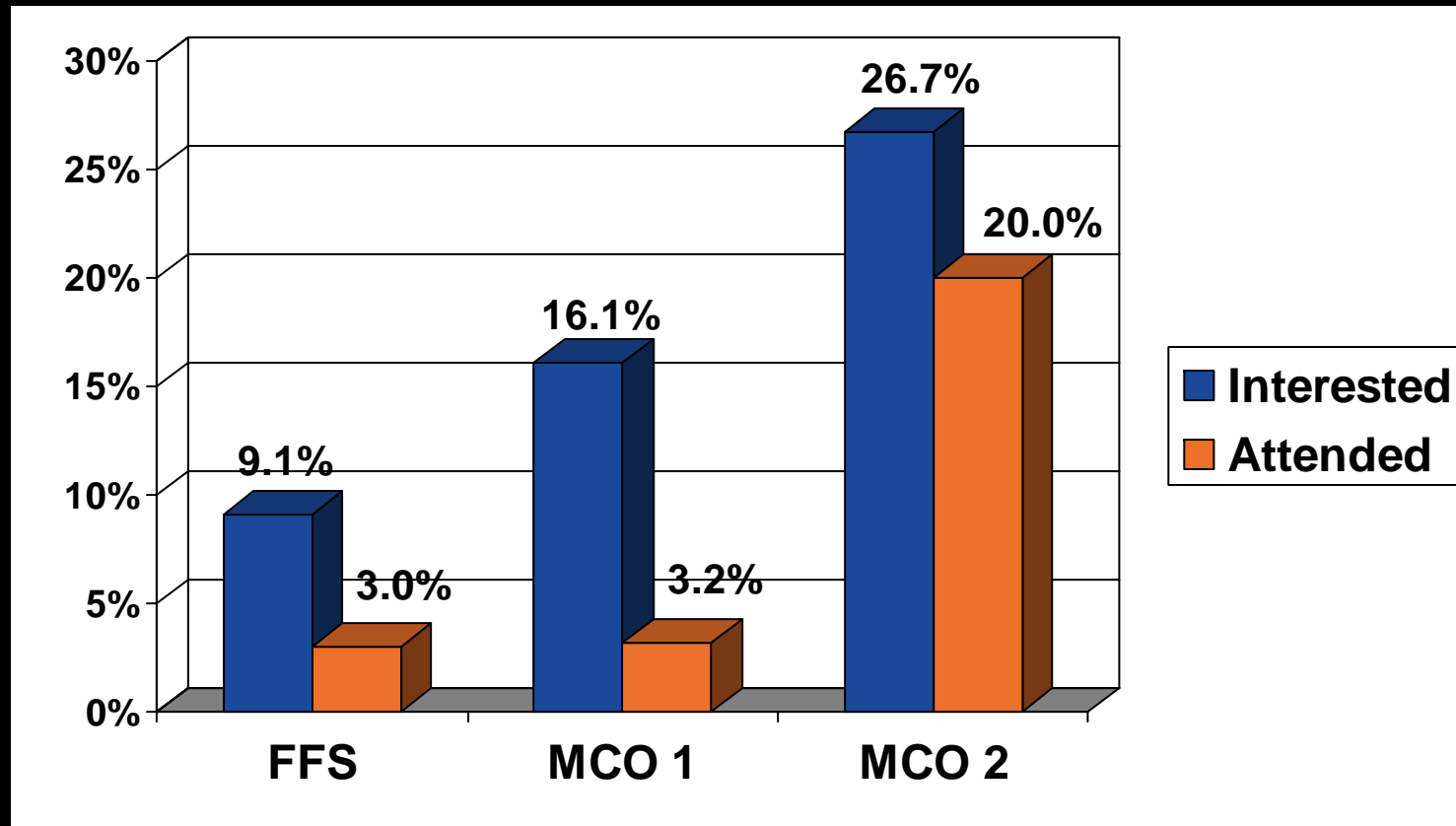
60 minutes in duration

Group self-directs regarding topics to be covered

Experience To Date

- Half of Guided Care participants receiving help from family or friends
- 308 formally consented caregivers (predominantly female, spouses or children, 24 hours of care/week)
- Among formally enrolled primary caregivers:
 - Completion rates of initial assessments and Workshop and Support Group participation rates lower than anticipated
 - Guided Care Nurses in frequent contact with caregivers throughout course of patients' coaching & monitoring calls, physician office visits, and transitions across settings of care

Guided Care Program for Families and Friends, Workshop Participation



Lessons Learned

- Ambiguity in Defining Family Caregivers
 - “Patients” serving as “Caregiver”
 - “Caregivers who are also “Patients”
 - “Caregivers” who do not identify as such
- Challenges of Program Logistics
 - Heterogeneity of study sample impediment to attendance of Support Group and Workshops, completion of In-Person Assessments
 - Multi-component intervention and competing demands, stakeholders
- Opportunities
 - Integration of families in chronic care processes, potential synergies with patient education and resources

The Guided Care Program for Family And Friends

Advisory Committee:

- Cynthia Epstein-Smith, New York University
- Dolores Gallagher Thompson, Stanford University
- Rick Greene, Administration on Aging
- Beth Logan, Consultant in Aging and Dementia Care
- Mary Mittelman, New York University
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