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
Informed, Empowered Patient and Family

Productive Interactions

Improved Outcomes

Prepared, Proactive Practice Team

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

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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:
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- Dolores Gallagher Thompson, Stanford University
- Rick Greene, Administration on Aging
- Beth Logan, Consultant in Aging and Dementia Care
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