

CAREGIVER NURSING PROTOCOL:



INTEGRATING NURSING INTERVENTION WITH SOCIAL WORK SERVICES

Family Caregiver Support Program 2005



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CAREGIVER NURSING PROTOCOL: INTEGRATING NURSING INTERVENTION WITH SOCIAL WORK SERVICES

Philadelphia Corporation for Aging

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TABLE OF CONTENTS

Introduction.....	3
What are the characteristics of caregivers in FCSP who could use a nursing intervention?.....	4
What should the nurse provide?	4
For how long?	5
What is the process?.....	5
Nurse Qualifications	5
Description of Intervention and Characteristics that made the intervention effective	6
Comments and Observations	8
Conclusions	8
Nursing/Social Work Intervention for Caregivers Case Example.....	9
Types of Nursing Interventions	10
Appendix	11
Appendix 1 – Family Caregiver Support Program Nursing Referral Form	12
Appendix 2 – Family Caregiver Support Program Nursing Assessment Form	13
Appendix 3 – Family Caregiver Support Program Nursing Care Plan Form	15

INTRODUCTION

This protocol grows out of a study conducted by Philadelphia Corporation for Aging's Family Caregiver Support Program (FCSP) and funded by the Administration on Aging (grant #90CG 2530). The purpose of the study was to determine if providing caregivers with the services of a nurse, as part of a larger caregiver program, would improve the health of the caregiver. Also needed was a determination of "what" nursing interventions would be appropriate. Research had previously shown that caregivers were likely to ignore their own health, and that this had serious consequences for the caregiver and for the carerecipient alike. We were further concerned with the health of African American caregivers in particular. In addition to the problems facing all caregivers, African Americans often have more difficulty in accessing the health care system, which suggested that African American caregivers might have even greater health problems than their Caucasian counterparts.

Our study compared the experience of a group of caregivers, evenly split between Caucasian and African American daughters and daughters-in-law who received a nursing intervention with a control group, matched for race, who did not receive the intervention over a three month period. Both groups received a comprehensive evaluation by the nurse, which complemented the assessment they received from the social work staff at the time they become clients of the FCSP. These caregivers had been assessed in domains of physical health, functioning, strengths, stress, and history of caregiving by trained social workers. The physical environment was also assessed to evaluate barriers to caregiving and carerecipient independence. Caregivers in FCSP received financial reimbursement for services such as; homemaker, personal care or day care services as well as supplies and overnight care, to help ease the stress and burden of caregiving. Financial assistance was also available to improve the physical environment to enable the carerecipient to be as independent as possible and relieve caregiver stress and strain in performing caregiving tasks.

The overall findings showed that in areas of depressive symptoms and feelings of mastery over the caregiving situation, the presence of a nurse did make a difference. Benefits were shown for both the Caucasian and African American caregivers. Because of the success we had with our intervention we have developed this protocol so other agencies can develop similar programs.

WHAT ARE THE CHARACTERISTICS OF CAREGIVERS IN FCSP WHO COULD USE A NURSING INTERVENTION?

Physical Health Care

- > Caregivers who don't have health insurance and/or who have not had any recent medical care.
- > Caregivers who have chronic illness such as diabetes, hypertension, unstable health conditions, etc. and need additional follow-up.

Education

- > Carerecipients who are frequently hospitalized within a short period of time or frequent ER visits.
- > Caregivers and carereceivers who need health education re: body mechanics, diet for diabetes, weight loss, skin care, smoking cessation, stress management/high Zarit score, relaxation techniques.
- > Caregivers who have difficulty/frustration managing carerecipient's symptoms or behavior.
- > Caregivers who require medical information concerning end of life issues re: peg tube, ventilator, etc.
- > Caregivers who are non-compliant with self medications and need medication education.
- > Caregivers who have difficulty navigating the medical system.

Mental Health: Emotional/Social well-being

- > Caregivers who are feeling depressed, hopeless, anxious, angry, etc.
- > Caregivers who are isolated.

WHAT SHOULD THE NURSE PROVIDE?

- > Nursing assessment based on the Home Health Model with a focus on the caregiver.
- > Health education re; diet, disease management, etc.
- > Information concerning prevention re; complications of aging, skin integrity, constipation, mobility, turning, transfers, medications.
- > Help to link caregiver to medical treatment.
- > Future planning for caregiver.
- > Mental health support.

FOR HOW LONG?

- > 1-6 visits.
- > Length and pattern of visits to be determined; based on issues identified in collaboration with the caregiver and social worker.

WHAT IS THE PROCESS

- > As each new caregiver enters the program, based on the results of the baseline assessment, a referral will be made after consultation with the FCSP supervisor. Criteria listed previously, as well as basic demographics, special instructions, best time to call, insurance information including numbers is included on the form with check off boxes. (appendix 1)
- > Nurse completes the nursing assessment (appendix 2) and develops a care plan (appendix 3) which includes the prescribed visiting pattern and desired outcomes.
- > The nurse and social worker will collaborate, working together to address caregiver issues and needed referrals.
- > The nursing records, at the end of the intervention, will be incorporated into the caregiver's file.

NURSE QUALIFICATIONS

- > Experience in aging and an understanding of geriatrics (physical, mental health and family issues).
- > Minimum 2 years experience in gerontology and adult health.
- > Bachelor's degree in nursing or related field.
- > Community/Home Health experience.

DESCRIPTION OF INTERVENTION AND CHARACTERISTICS THAT MADE THE INTERVENTION EFFECTIVE

The nurse introduced the concept of the intervention by offering the services of a nurse for the caregiver, rather than directly for the carereceiver. The nurse would work with the participant to identify health needs important to the caregiver. Together, the caregiver and the nurse designed a care plan to address issues that would fall into the following categories:

1. Disease Management. Many of the participants had been previously diagnosed with hypertension, diabetes, arthritis, elevated cholesterol levels or other common medical problems. In particular, many participants were aware that they were diagnosed with diabetes but they had little understanding of the disease process, signs and symptoms, glucose management, use of medications or glucose monitoring. Interventions to translate medical information into a language that could be used by the participants were provided with the goal being an improved understanding of the disease process, signs and symptoms to report to the physician and knowledge of medications to treat the problem. All participants received written medication information. Caregivers who spoke Spanish or who were bilingual were given medication information in Spanish.

2. Symptom Management. A number of the participants in the program had needs for smoking cessation, bladder control improvement, constipation prevention, pain management and other related problems which are able to be discussed within the confines of the caregiver's home rather than in a physician's office. Obesity, excessive sodium use and other dietary issues can also be addressed in the caregiver's own kitchen by observing meal planning and offering suggestions for alternatives. HIV prevention was discussed with many participants. In particular, weight management was a specific need identified by many participants.

3. Emotional issues of the caregivers. Many participants reported symptoms consistent with depression. This appeared to be particularly prominent in caregivers who were reluctant to take over the caregiving role but felt that there was no other alternative and those who had limited opportunity for activities outside the home. Although participants who worked outside the home had additional sources of stress, those who remained home with the carereceiver on a daily basis experienced stress as well.

4. Behavior Management issues of the carereceivers. Repetitive questions, impairment of memory, loss of personal care abilities, confusion, wandering, combativeness or insomnia were addressed in terms of what common approaches may be implemented, what had been attempted by the caregiver and understanding why confused individuals may act in ways that are perceived as negative.

DESCRIPTION OF INTERVENTION AND CHARACTERISTICS THAT MADE THE INTERVENTION EFFECTIVE (CONT.)

5. **Health concerns of the carereceivers.** A number of the participants cared for family members who were bed bound. Specific interventions to address the prevention of complications from bed rest were provided including constipation, pressure ulcers and depression. Fall prevention interventions were provided for many of the carereceivers.

6. **Access issues.** A number of participants had lost their medical insurance when they left the work force to care for family members. Others had no coverage or very limited coverage. A small number of caregivers were provided with health services through public health centers; however, these centers may offer limited benefits to this population who cannot leave the home and the carereceiver for prolonged periods of time to seek their own medical care. On one occasion, a participant who was severely depressed but who lacked health insurance or resources was referred to a university study focusing on depression. Program information for mammograms and PAP tests were provided. Telemedicine, a system using two-way audio and video communication as well as electronic vital signs was used to provide data of participant's blood pressure readings. In general, the system allowed caregivers to collect information about their blood pressure and pulse and share this information with their health care provider. Participants, who lacked insurance, lacked the ability to leave the carereceivers for prolonged periods of time or who had to pay out of pocket for their care, used the system to obtain multiple blood pressure readings which decreased the number of visits to the health care provider.

7. **End of Life issues.** Caregivers voiced the need for information on advance directives, CPR, feeding tubes and other issues that arise with elderly clients. A discussion of the pros and cons of medical interventions and establishing a dialogue with carereceivers and other family members was provided.

8. **Future Planning.** Participants were asked to consider what other activities they would do if being a caregiver was no longer necessary due to death, placement or other issues. This began the dialogue of future planning and transitioning from the role of caregiver to another role. For some, viewing the caregiving role as a marketable skill was quite helpful.

COMMENTS AND OBSERVATIONS

Nursing interventions for this diverse group of women ranged from providing emotional support to alerting the participant to serious health problems. Once a caregiver agreed to participate in the program, it was necessary to carve out some time for nursing visits, time which was frequently scarce. It was noted that many women stated they could express their needs and problems with the nurse rather than with a physician. This may be an effect of gender, the care being rendered in the participants own house, or a perception about nurses. Caregivers appeared to respond more openly when a white lab coat was worn.

The major problem with the intervention mirrored the problems in the greater society: access to health care remains a problem for over 45 million Americans. Nursing assessments provided some identification of health problems, however securing a source of health care was not possible in all cases. Participants did appear to derive a benefit from nursing visits, particularly having attention for their own health needs instead of the usual focus on the carereceiver.

CONCLUSIONS

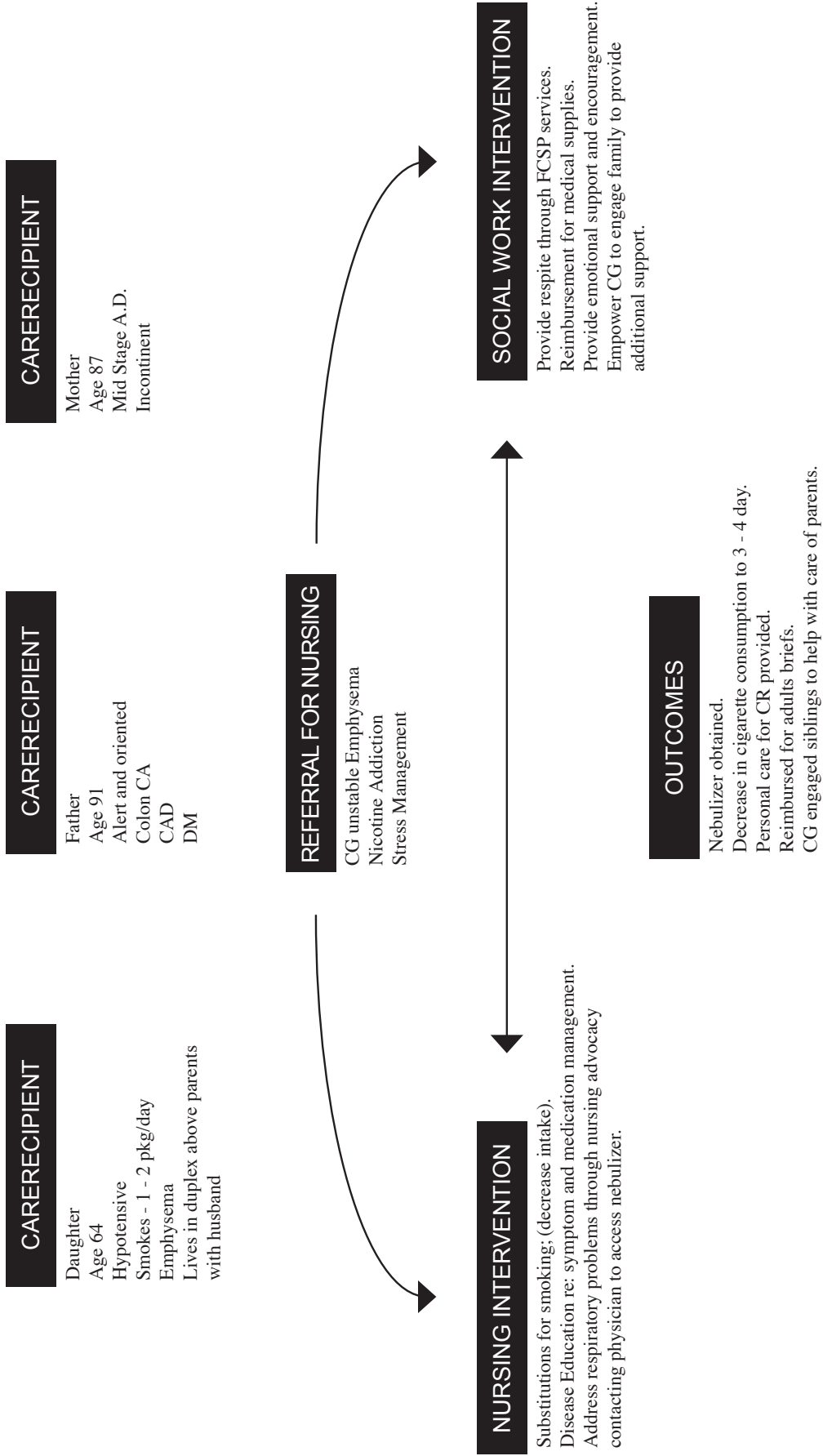
As said in the introduction, the overall findings showed that in areas of depressive symptoms and feelings of mastery over the caregiving situation the presence of a nurse did make a difference. There were two time constraints created by the research protocol which may have prevented seeing further benefits. First, the intervention was set at three months, rather than tailoring the time frame to the specific need of the caregiver. Second, we were not able to evaluate the effect of any follow up medical intervention based on recommendations of our nurse. These constraints will not exist in a clinical setting.

Because of the conditions created by the need to collect data for research purposes, we cannot be overly specific about outcomes that might occur from this program in a clinical setting. For example, we selected only daughter and daughter-in-law caregivers for this study in order to restrict the sample to one type of caregiver for research purposes. In a clinical setting this protocol would be appropriate for any type of caregiver; male, female, spouse and caregivers with other relations to the carereceiver, as well as daughters and daughters-in-law. Overall, we would expect to see a greater sense of mastery over problems, improved feelings of well-being and increased knowledge on the part of the caregiver. Further outcomes may depend on the exact way in which the nurse is used within the caregiving program. For instance, if caregivers are entered into this protocol when they first become clients of the program the nurse may uncover health conditions of which the caregiver is unaware, although this may occur even if the caregiver has been a client for some time. The presence of another set of “eyes and ears” may also assist the caregiver in heading off health problems for both the caregiver and the carereceiver. Although the carereceiver is not the target of the intervention, it is likely that the nurse, like the social worker who manages the case, will see the carerecipient and be able to observe significant changes or problems.

We feel that the intervention will benefit the emotional and physical health of the caregiver and by so doing have a positive effect on the carerecipient and perhaps even other family members as well.

Nursing/Social Work Intervention for Caregivers

Case Example



TYPES OF NURSING INTERVENTIONS

Diseases

- Rheumatoid Arthritis (RA)
- Degenerative Joint Disorder (DJD)
- Diabetes Mellitus (DM)
- Hypertension (HPT)
- Obesity
- Hypercholesterolemia
- Depression
- Incontinence

Interventions

- Monitoring: BP, blood glucose
- Teaching: diabetes, hypertension, CHF, COPD
- Medication teaching, scheduling
- Symptom management; constipation, pain management, UTI prevention
- Protocol related management: adverse drug reactions, pain, fall prevention, herbal remedies/drug interactions
- Continence management
- HIV disease prevention
- Pressure ulcer prevention/treatment
- Smoking cessation
- Weight loss management
- Back injury prevention/treatment
- Glaucoma treatment/instillation of eye drop
- Prevention care bedridden individuals
- Home management for individuals with asthma, COPD

Access Issues

- Medical and Dental Clinics
- Reduced/free private physician services
- Medication access
- Speech, Physical, and/or Occupational Therapy referrals
- Study referrals
- Mammogram/PAP test
- Community Mental Health
- Telehealth intervention

Psychosocial Support

- Viewing caregiver skills as marketable skill
- Future planning
- Language to dialogue between children and parents
- Understanding confusion
- “Compliance” issues
- Placement issues
- Suicide detection and prevention

End of Life Support

- Knowledge of Cardiopulmonary Resuscitation (CPR), artificial methods of feeding and ventilation

APPENDIX



APPENDIX 1

Family Caregiver Support Program Nursing Referral Form

Date: _____

Care Manager Name: _____ Telephone: _____

Caregiver Name: _____ Telephone: _____

Address: _____ Best time to call: _____

Reason for Referral (check all that apply)

Does CG live with CR Yes No

Carerecipient frequently hospitalized within a short period of time or frequent ER visits.

Caregivers who:

- have no health insurance
- have not had medical care
- have a chronic illness
 - diabetes
 - hypertension
 - other (please indicate)
- have an unstable health condition & need follow-up
- need health education re:
 - body mechanics
 - diet for diabetes, weight loss, or blood pressure
 - managing skin care (pressure ulcers)
 - smoking cessation
 - stress management / high Zarit score
 - relaxation techniques
- require medical information concerning end of life issues re: peg tube, ventilator, etc.
- have difficulty with medication management and need medication information for self and/or carerecipient.
- have difficulty navigating the medical system.
- are feeling depressed; hopeless, anxious.
- have difficulty, frustration managing carerecipient's symptoms or behavior.

Other reasons not listed _____

APPENDIX 2

Family Caregiver Support Program Nursing Assessment Form

CG Name: _____ DOB: _____

Reason for referral: _____ Date: _____

Number of years caregiving: _____ Works outside home Yes No

CR Name: _____ DOB: _____

Diagnoses of CR: _____

Medications: _____

CR:

Bedbound	<input type="checkbox"/> Yes <input type="checkbox"/> No	Cognitively impaired	<input type="checkbox"/> Yes <input type="checkbox"/> No
At risk for pressure ulcers	<input type="checkbox"/> Yes <input type="checkbox"/> No	Actual pressure ulcers	<input type="checkbox"/> Yes <input type="checkbox"/> No
Incontinent urine	<input type="checkbox"/> Yes <input type="checkbox"/> No	Incontinent bowel	<input type="checkbox"/> Yes <input type="checkbox"/> No
Foley	<input type="checkbox"/> Yes <input type="checkbox"/> No	Colostomy	<input type="checkbox"/> Yes <input type="checkbox"/> No
Up during night	<input type="checkbox"/> Yes <input type="checkbox"/> No	Number of times up/night	_____
Number of hours alone/day	_____	Other assistance	_____
Peg Tube	<input type="checkbox"/> Yes <input type="checkbox"/> No	Wandering	<input type="checkbox"/> Yes <input type="checkbox"/> No

Caregiver Support:

Family physician: _____ Telephone: _____

Type of insurance: _____ Prescription plan: _____

Access to health care/medication issues: _____

Date of last physician visit: _____ Reason: _____

Gyn Services: _____ Mammogram: _____ PAP: _____

Recent Hospitalizations/ER visits: _____

Counseling or Mental Health Services: _____

Alternatives Medicine Services: _____

Prescriptions: _____

_____ Allergies: _____

OTC/Herbs/Vitamins: _____

Method used for taking medications: _____

Height/Weight: _____ Do you want to gain or lose weight Yes No

Recent falls Yes No Ambulatory device Yes No PT/OT/ST Yes No

Appetite: _____ Weight change in 3 months: _____ Sleep habits: _____

Bladder function: _____ Bowel habits: _____

Time spent with CR: _____ Time for self: _____

APPENDIX 2 (CONT.)

Degree of stress in caregiving: small moderate significant

Impact of caregiving on health: small moderate significant

Financial stress: small moderate significant

Responsible for the caregiving of: children grandchildren other family

Rate pain 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 (circle) Site (s) _____

Rate energy level 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 (circle) Smoking _____

Recent back injury: _____

What kinds of care do you feel most comfortable performing? _____

What kinds of care do you feel you need help in performing? _____

What aspect of being a CG gives you the most stress? _____

How do you exhibit stress? (physical symptoms, emotional outbursts, etc.) _____

How do you relieve your stress? _____

Review of Systems

 Skin _____

 Eyes/Ears/Nose/Throat _____

 Cardiac _____

 Pulmonary _____

 Urinary _____

 GI _____

 Muscular-Skeletal _____

 Neurological _____

Vital Signs:

 Temp _____ Pulse _____ Resp _____ BP _____

 Pulse Ox _____

Assessment _____

APPENDIX 3

Family Caregiver Support Program Nursing Care Plan Form

DATE	ISSUE IDENTIFIED	INTERVENTION
	Disease Education: <input type="checkbox"/> Hypertension <input type="checkbox"/> CHF <input type="checkbox"/> Diabetes <input type="checkbox"/> OA; RA <input type="checkbox"/> Obesity <input type="checkbox"/> Hypercholesterolemia <input type="checkbox"/> Depression <input type="checkbox"/> Incontinence <input type="checkbox"/> Other: _____	
	Disease Management: <input type="checkbox"/> BP monitoring <input type="checkbox"/> Glucose monitoring <input type="checkbox"/> Medication desired/untoward effects, dose <input type="checkbox"/> Symptoms: constipation, pain <input type="checkbox"/> HIV disease and prevention <input type="checkbox"/> Pressure ulcer prevention and treatment <input type="checkbox"/> Smoking cessation <input type="checkbox"/> Weight loss management <input type="checkbox"/> Back injury prevention/treatment <input type="checkbox"/> Preventative care for bed bound individuals <input type="checkbox"/> Home management of COPD/asthma <input type="checkbox"/> Other: _____	
	Protocols: <input type="checkbox"/> Incontinence <input type="checkbox"/> Impaired mobility/falls <input type="checkbox"/> Adverse Drugs/Symptom Self Care <input type="checkbox"/> Pain	

Anticipated Visit Pattern _____

Notes _____

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