Complete Summary

GUIDELINE TITLE

Family involvement in care for persons with dementia (FIC).

BIBLIOGRAPHIC SOURCE(S)

Kelley LS, Specht JKP, Maas ML. Family involvement in care for persons with dementia (FIC). Iowa City (IA): University of Iowa Gerontological Nursing Interventions Research Center, Research Dissemination Core; 1999. 39 p. [41 references]

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SCOPE

DISEASE/CONDITION(S)

Dementia

GUIDELINE CATEGORY

Management

CLINICAL SPECIALTY

Geriatrics
Nursing

INTENDED USERS

Advanced Practice Nurses
Nurses

GUIDELINE OBJECTIVE(S)

- To provide guidelines for implementing a program to involve family members in the care of their relative with dementia through partnerships with other care providers.
- To provide quality care for persons with dementia and assist family members to enact meaningful and satisfactory caregiving roles regardless of setting.

TARGET POPULATION

- Persons with dementia and their family members
- Family members who have had the most intimate and continuing care responsibility for the person with dementia (often the spouse, daughter, or daughter-in-law)
- Family members of persons with dementia who are experiencing new and increasing caregiving demands
- Families who are new to the care setting (e.g. hospital, nursing home, etc.)
- Families who are new to the care provider

INTERVENTIONS AND PRACTICES CONSIDERED

Family involvement in care (FIC): An intervention involving negotiation, clarification, and establishment of mutually satisfactory role expectations between the family caregiver(s) and formal care providers who assist family members with role and environmental changes to accomplish the needed care for the person with dementia. FIC encompasses the following elements:

- Orientation to physical care environments
- Education of all caregivers
- Formation of partnership agreement
- Education of family members for FIC
- Follow-up evaluation and re-negotiation of the partnership agreement

MAJOR OUTCOMES CONSIDERED

Outcome 1: Family interview reveals that family member(s) report:

- satisfaction with level of involvement in person with dementia's care
- satisfaction in information shared by other caregivers regarding person with dementia's care
- satisfaction with care person with dementia is receiving
- satisfaction with other caregivers listening to their suggestions and carrying out requested care strategies
- satisfaction with other caregivers being approachable, knowing who I am and treating me with respect

Outcome 2: Family/Person with Dementia Record Documents:

- increased patient social interaction
- decreased patient catastrophic episodes
- individualized plan for how family and other caregivers will be involved in care
- evaluation statements for how the FIC plan is working
- specific behavioral changes in FIC plan as agreed upon in family conference

Outcome 3: Other caregivers' observed:

- commenting positively about family caregiver involvement
- making care decisions with family caregiver
- sharing information with family caregivers

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

The guideline developer performed searches of electronic databases, including Medline, HealthSTAR, PsychInfo, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL). The developer also reviewed bibliographies of journal articles.

NUMBER OF SOURCE DOCUMENTS

Over 500 source documents were identified, 41 of which were key to the protocol.

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

METHODS USED TO ANALYZE THE EVIDENCE

Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not applicable

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Not stated

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

Clinical Validation-Trial Implementation Period
Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Clinical validation from quasi-experimental longitudinal trial in 20 nursing homes.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

DESCRIPTION OF INTERVENTION

Family involvement in care (FIC) is an intervention to facilitate quality care for the person with dementia and assist family members to find meaningful and satisfactory caregiving roles regardless of setting. FIC is initiated by professional formal care providers on initial (or first appropriate) contact with the family.

I. Orientation to physical care environments to foster an awareness of the environmental assets, as well as potential deficits.
    - Introduction of primary family member contact (FM) and primary nurse care manager (NCM), if appropriate
    - Tour of the home, facility (e.g. caregiver's home nursing home, special care unit, hospital) care area
    - Review of philosophies and policies of the new care situation
    - Introduction of family members and care providers
    - Facilitate family members discussion of expectations and concerns
    - Review and signing of Partnership Intent Statement

II. Education of all caregivers
    - Caring for persons with dementia
        - General care principles
        - Information about the process of role adjustments that often occur for the person with dementia in new care situations and therapeutic approaches to facilitate satisfactory care relationships
    - Family caregiving roles
        - General family caregiving principles
        - General information about the process of role adjustments that often occur for family member caregivers in new care situations and therapeutic approaches to facilitate satisfactory care relationships
    - Negotiation skills
    - Partnership formation

- Rationale for partnering of families and other caregivers; benefits for staff, other providers, person with dementia, and family members
- Partnering to facilitate family members desired amount and kind of involvement (more involvement is not necessarily the goal here)
- Partnership maintenance
- Partnership termination

III. Negotiation and formation of the partnership agreement

- Goals and activities of new care situation for care of person with dementia
- Goals and activities of the family caregiver in the new care situation mutually agreed upon
- Goals and activities put in writing. Copies of the form are given to the family and other caregivers (copy retained in the formal record for persons in formal setting)
- The Partnership Agreement is negotiated, specifically documenting the family caregiver's involvement, the other care providers' involvement, and the anticipated length of time of the intervention

IV. Education of family members for FIC

- Education of the family member(s) by the professional care provider begins with the initial contact and continues throughout the partnership
- Information about Alzheimer's disease and related dementias and therapeutic care activities
- Information about the process of role adjustments that occur for the person with dementia in a new care situations and therapeutic approaches to facilitate satisfactory care relationships
- General information about the process of role adjustments that occur for family and other caregivers in new care situations and therapeutic approaches to facilitate satisfactory care relationships

V. Follow-up evaluation and renegotiation of the Partnership Agreement

- At least weekly communication will be maintained between the family caregiver and NCM
- Weekly contact in person or by phone of family and other caregiver
- The NCM will solicit feedback and suggestions from family and other caregivers at each visit
- The Partnership Agreements are discussed and renegotiated as needed, at least monthly
- At each quarterly visit the NCM will lead a discussion wherein the family caregiver shares with other caregiver reminiscences about the person with dementia's life prior to having dementia, and other caregivers share their observations/experiences that they have had with the person with dementia. Care strategies are reviewed and revisions made

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

Not stated

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Family Involvement in Care may improve family members' satisfaction with care relationships and quality of care for the person with dementia.

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

This research-based practice protocol is a general guideline. Patient care continues to require individualization based on patient needs and requests.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

The appendices in the guideline document include strategies for implementation as well as tools to evaluate outcome and process factors following implementation.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Living with Illness
Staying Healthy

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

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ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

1999

GUIDELINE DEVELOPER(S)

University of Iowa Gerontological Nursing Interventions Research Center, Research Dissemination Core - Academic Institution

SOURCE(S) OF FUNDING

This protocol was developed under funding provided by Grant No. P30NRO3979, National Institute of Nursing Research, National Institutes of Health (NIH).

GUIDELINE COMMITTEE

Research Development and Dissemination Core

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

GUIDELINE STATUS

This is the current release of the guideline.

An update is currently in progress.

GUIDELINE AVAILABILITY

Electronic copies: Not available at this time.

Print copies: Available from the University of Iowa Gerontological Nursing Interventions Research Center, Research Dissemination Core, 4118 Westlawn, Iowa City, IA 52242. For more information, please see the University of Iowa Gerontological Nursing Interventions Research Center Web site.

AVAILABILITY OF COMPANION DOCUMENTS

None available

NGC STATUS

This summary was completed by ECRI on July 26, 1999. The information was verified by the guideline developer as of November 12, 1999.

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Date Modified: 11/15/2004