



Implementing & Validating Guidelines to Facilitate the Involvement of Carers

Phase 1

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Summary of project

This project was carried out by members of staff in the Department of Health and Nursing at Queen Margaret University College (QMUC) and completes the first phase of a comprehensive piece of work which plans to facilitate involvement of carers in the processes of care planning for people with dementia. In 1999, Walker, Dewar and Riddell published a qualitative research study identifying factors that inhibit carer involvement in care planning for people with dementia admitted to hospital. The work resulted in the production of guidelines that aimed to facilitate better involvement of carers in care planning processes for people with dementia when in hospital. This project has taken these guidelines and involved carers in a validation exercise to ensure they are relevant and appropriate for use in both hospital and community settings.

Background to the project

Since the early eighties, researchers, carers' organisations and other interested groups have argued that change is

needed within the NHS and community care services to value and provide adequate support for carers. By investigating the concept of carer involvement in one hospital setting, the study by Walker et al. (2001) enabled a deep exploration of some of the main issues highlighted repeatedly in the literature, in particular, the lack of information given to carers and their exclusion from the decision-making process. Involvement in decision making is a complex process. Walker et al.'s study (2001) unravelled some of these complexities in hospital settings and produced a set of guidelines to enhance lay carer involvement in decision making for the person with dementia. This project extends Walker et al.'s (2001) work by focusing on validating the accuracy, relevance and feasibility of 'carer guidelines' for those caring for family members with dementia, and subsequently disseminating these guidelines to a variety of health/social work professionals and voluntary organisations. These processes of validation and dissemination have been established through collaborative approaches to inquiry with a group of lay carers.

Aims of the project

- To emphasise the importance of collaboration in care planning between lay carers and health professionals.
- To inform policy at local and potentially national level to directly influence principles of good practice.
- To generate further knowledge and expand the debate surrounding qualitative processes of inquiry.

The specific objectives

- To evaluate the relevance of the guidelines to carers of people with dementia.
- To differentiate between the degrees of relevance of guidelines for carers at different stages on the caring continuum.
- To explore the guidelines' fitness for purpose in various community and hospital settings.
- To disseminate with core groups of carers revised guidelines to carer organisations, local education institutions and local Trusts.

Methods

Thirty-four carers of people with dementia were invited to participate in the project. Potential participants were identified through local day centres, carer support groups and individual professionals. Contact was either direct or through professionals acting as gate keepers. A letter outlined the purpose of the project, and those willing to participate returned to the project team an acknowledgement slip attached to their letter.

Securing a group of carers for this project was not a straightforward process. Difficulties arose in relation to the following aspects:

- indirect approaches via gatekeepers
- timing of sampling process
- difficulty in commitment due to constantly changing circumstances
- possibility of coercion with more direct sampling approaches
- tight time limits which reduced flexibility in sampling.

Nineteen carers were able to work in the project, making up a small but special group of individuals. Whilst it is acknowledged that the concerns they brought to the project may be different from those of other carers, there were common concerns. These included their overriding concerns regarding the importance of knowing the person with dementia; their expertise in caring going unrecognised; and their difficulty in having a voice in the health and social care arena. All these issues have been echoed in other work, specifically Motenko (1989), Jones and Mieson (1992), Keady (1996), McCarty (1996), Almborg, Grafstrom and Winbald (1997), Jansson, Almborg, Grafstrom and Winbald (1998), Walker et al. (1999).

Fifteen participants shared their experiences as carers with project team members at four concurrent focus group discussions held at two separate workshops. The other four participants provided written feedback. Information collected from the discussion and debate engendered by the focus groups, together with the written feedback, helped the project team make appropriate amendments to the guidelines. These amended guidelines were analysed further by the carers, and changes had to be made to ensure the purpose and content of the guidelines were clear to all and transferable to a variety of settings, such as respite and day care services, home and hospital.

All carers who attended the workshops were sent the newly constructed guidelines and associated questions, together with corresponding rationale and recommendations for each guideline.

Box 1: Summary of the recommendations for guidelines:

Guideline 1: Initiating contact

This guideline addresses the importance of professionals making an insightful assessment of the carer's situation when they first make contact. The professional is usually the GP, and their role as gate keeper to other services and accessing key people was endorsed by carers.

Guideline 2: Maintaining contact

This guideline addresses the importance of maintaining flexible, open and negotiated approaches to ensure that contact with the key person/people is effective. Notably, carers identified the need for accessibility, commitment and availability of the key person/people.

Guidelines 3 & 4: Involvement in care

Guideline 3 reflects the ways in which the different professionals who the carers encounter will value the carers' expertise about the people needing care. Carers will know their expertise is valued because their involvement in care planning activities will be sought by professionals in different ways, depending on the care setting. How carers are involved, and the level to which they want to be involved, will be decided by the carers themselves.

Guideline 4 addresses what involvement entails for carers in more formal settings (such as case conferences or family meetings), and the support and communication strategies carers require, depending on their level of involvement at that specific time.

Guideline 5: Making sure it's working

This guideline will give carers an opportunity to review how the progress of care and the level to which they are involved contributes to the quality of care the person is receiving. Continuing review of care between carers and professionals is crucial in ensuring the best possible care is given to the individual with dementia.

Disseminating the revised guidelines

Two dissemination workshops aimed at health care professionals were held. They were facilitated by available carers and the project team, and enabled various

professionals to agree the importance of these guidelines in ensuring that:

- carers' expertise is valued and they are more involved in decisions made about their relatives' care;
- the unique and constantly changing needs of an individual with dementia and their carer(s) are met by an integrated, accessible and streamlined service.

Evaluating the relevance of the guidelines for carers of people with dementia

Involvement in planning person-centred care for the person with dementia is not formally recognised or acknowledged by professionals (Walker et al., 1999). Carers' expertise (and so involvement in care planning processes) is often undermined rather than supported by professionals (Davies, Laker and Ellis, 1997).

The group of carers in this project found the guidelines relevant to their situation. In particular, they valued the emphasis placed on the knowledge they had of the person with dementia who they cared for; open communication between different professionals and carers; availability of contact; and awareness and accessibility of resources. The guidelines offered potential ways of working with professionals that fostered an equality of relationship. This would allow them to feel comfortable and better able to assert their needs.

Differentiating between the degrees of relevance of guidelines for carers at different stages of the caring continuum

Carers of people with dementia in this project had experience of a wide variety of care settings including day centres, respite, hospital and community care. Some carers were relatively new to this role, whilst others had been caring for many years. Overall, the five guidelines were relevant to carers' individual situations. Carers welcomed the notion of a key person to support their emotional and resource needs. It was acknowledged that in the community setting carers might need several key people to assist with the multitude of needs associated with caring for someone with dementia. It was clear that the General Practitioner (GP) had a prime role in initiating and facilitating stability for carers.

Exploring the guidelines' fitness for purpose in various community and hospital settings

From the carers' point of view, the guidelines met their needs. However, the carers were realistic about

the practical difficulties in implementing these guidelines. These included: attitudes of professionals; access to professionals; lack of co-ordination between services; and lack of specialist knowledge of both caring and dementia. The professionals who attended dissemination workshops echoed these concerns. Our recommendations attempt to address some of the potential barriers to putting the guidelines in place.

Wider dissemination of revised guidelines with core groups of carers, carer organisations, local education institutions and local Trusts

Dissemination of this work to date has been minimal. Despite targeting a wide professional audience, attendance at workshops was low. Further dissemination is required together with additional research (see recommendations) in order to assess feasibility of the guidelines from a professional viewpoint. The professionals who were able to comment on the guidelines were generally positive, but noted similar practical difficulties in implementation as did the carers.

RECOMMENDATIONS

For policy makers

- Develop standards from these guidelines that relate specifically to this process of lay carer involvement. This will allow auditing and further development. Current standards documents generally refer to involvement as a philosophy underpinning good practice, but do not specifically unpick the complexities of the process of involvement.
- Develop a comprehensive database of carers and professionals involved in dementia care, at local and national level, that is readily accessible by professional and non-professional people alike for use in developing, and subsequently increasing, potential networking.
- Develop a database of professionals and non-professionals interested in information and networking in relation to dementia care. Work in establishing such databases is crucial and demands urgent attention.
- Develop a dissemination strategy for project findings. This should include a wide range of organisations.

For professionals

- Enable the professional to engage in successful involvement with lay carers through professional coaching.

F O U N D A T I O N

- Recognise opportunities for coaching carers.
- Work in close partnership with, for example, voluntary organisations that have some personal contact with carers.

For managers

- Contribute to, resource and be supportive of carer involvement.

For educationalists

- Make more explicit the concept of carer involvement in nursing education curricula.
- Involve users in both the planning and delivery of educational programmes to ensure their perspectives are represented and a culture of partnership is engendered.
- Employ educational methods for facilitation and accreditation (of knowledge and skills) of professional workers in order to promote, implement and evaluate clinically effective working practices through initiatives such as Work Based Learning.

For future research and development work

- Extend this work to validate the guidelines with other client groups e.g. stroke, palliative care.
- Extend this work to validate the guidelines with other health care professionals e.g. occupational therapists, social workers.
- Evaluate the implementation of the guidelines in practice.

Phase two of the project is currently underway and involves the implementation of the guidelines in practice.

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Further reading

A copy of the original full report can be obtained from the website: <http://www.fons.org/projects/>

A project report has also been published: Dewar, B., Goulbourne, A., Irvine, L. and Riddell. (2002) The carer's role in planning care for people with dementia. *Professional Nurse*. Vol. 17. No. 5. pp318-321.

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