

Enhancing Partnerships with Relatives in Care Settings for Older People

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Summary of project

This short report outlines a project that aimed to implement guidelines that seek to involve relatives of older people in decision-making processes. Getting research into practice is complex and needs to take account of many variables. Creative strategies need to be designed and used to enhance this process.

If involvement of relatives in care processes is to become a reality, then attention needs to be given to helping staff to explore the meaning of involvement and to develop meaningful relationships with relatives which seek to value them as experts.

Background

Involvement of service users is a priority on the political agenda if we are to move towards meeting the needs of older people for the provision of high quality services. However, the significant contribution that relatives make to care processes is often overlooked when considering involvement in decision-making (Hertzberg and Ekman 2000). This problem is compounded by the fact that it is difficult to discern from policy documents

exactly what 'involvement' means and therefore how it should be realised by health care professionals.

In 1999, Walker, Dewar and Riddell published a qualitative research study that sought to identify more clearly what involvement meant to relatives and found four markers of satisfactory involvement:

- Feeling that information is shared
- Feeling included in the decision-making process
- Feeling that there is a contact person available, and
- Feeling that the service is responsive to their needs (Walker et al. 1999, 2001)

Their work resulted in the production of guidelines that aimed to facilitate better involvement of relatives in the care planning processes. These guidelines were further developed in a recent project that involved relatives of people with dementia reviewing the guidelines for their applicability (Goulbourne et al. 2001) (See also Dissemination Series 2002, Vol.1. No.4). The guidelines were modified and disseminated to a small group of health and social care professionals. Carers all felt that the guidelines were important, but raised questions about the reality of implementing them in practice. Professionals echoed this concern.

The lack of any clear definition of the concept of involvement has made the process of implementation difficult. Walker et al's study (1999) identified factors that inhibit relative involvement in care planning. These support the findings of other studies (Collier and Schirm 1992, Duncan and Morgan 1994) and include lack of communication, lack of agreed agendas and lack of recognition of the relative's expertise.

At the heart of these barriers is effective communication. An important way of facilitating relative involvement, therefore, is through open discussion between key workers and relatives in order to develop

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and enable open and collaborative involvement in decisions about care. This endorses principles of good practice (Callery and Smith 1991, Kenny 1990), but operationalising such an approach requires support from the employing organisations in which key workers practice (Kirk 1998).

Project aim

This project set out to implement guidelines that seek to involve relatives of older people in decision-making processes. A framework of work-based learning was used to facilitate the processes of developing practice (See Dissemination Series 2003 Vol.2 No.3).

Participants in the project

Two Clinical Development Nurses (CDN), who work with older people in the hospital setting, were nominated by the Trust on the basis of their eligibility and willingness to participate. Each CDN worked with a team of practitioners in the hospital setting to develop practice in relation to the guidelines.

The project leader, an academic supervisor and an appointed workplace supervisor supported the CDNs. In addition, the project leader supported and collected data from the nurses in the workplace setting and evaluated the effect of work-based learning on the implementation of the guidelines.

Assessment of current practice relating to involvement

At the beginning of the project, a variety of data were collected to identify what was currently happening in practice with regard to the involvement of relatives.

This was analysed and fed back to staff at a series of meetings to enable a discussion about which areas of involvement were a priority to develop in each of the different care settings.

Data collection and analysis was an ongoing process throughout the project. Themes emerged that related both to the process of implementing the guidelines and to the process of involvement.

Enhancing relative involvement

A number of different ideas came out of the discussions that the project team had with the staff in each ward about:

- What was currently happening to involve relatives

- What the relatives thought would make involvement better

However, what seemed to be simple strategies often turned out to be far more complex, and the influence of organisational and cultural factors could not be ignored. Flexibility was one of the key factors that enabled change to progress in this project. This meant being able to adapt constantly to the needs of the practitioners and the relatives, and judging the appropriateness of these adaptations against the project aim of enhancing relative involvement.

Newsletter

A number of initiatives were introduced to try to enhance the sharing of information between relatives, staff and patients. From observations on the wards, communication tended to be one-way, from staff to relatives, and there were few formal systems in operation to encourage two-way communication and to ensure that it was open to all relatives.

Throughout the project, staff were keen to implement practical solutions to share information, e.g. a newsletter. Relatives felt that they would like more information on the general aspects relating to ward life and staff felt that this would be an efficient method of communicating this sort of information. Whilst advantages of adopting this approach could be seen, there are issues relating to the sustainability of such an activity, and also to ensuring that the newsletter shares information rather than just gives information from professionals.

Such activities raised some issues around the desire to develop 'quick fix' solutions, perhaps at the expense of considering the 'real issues'. Evidence for the initial assessment of the current situation suggested that there were more complex issues relating to involvement than could be met by the newsletter alone. For example, staff held different values and beliefs about involvement, or staff found it challenging to involve certain relatives whom they saw as 'difficult'. The newsletter was not necessarily going to provide a solution to these complex issues in practice. It became apparent that there needed to be a balance in the type of strategies taken forward if the aims of the project were to be met.

Life story work

The staff and relatives saw life story work as a way of bringing the 'theory' of sharing to life. Staff were used to 'giving care' and 'giving information' and relatives

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were used to 'giving up care' and 'leaving it up to the professionals'. At the start of the project many staff believed that their practice relating to the involvement of relatives was good. This acted as a barrier, as if staff did not believe that practice needed to be developed, the energy and motivation that would be put in was limited. These beliefs and traditional expectations about care in hospital needed to be challenged before sharing could become a reality. Life story work was one way of doing this. An expert in life story work facilitated staff and relatives in a series of workshops which included the implementation of life story work in practice. Staff recognised the value of information about past life history and that relatives had unique expertise and a valuable contribution to make in this area. Some evaluatory comments from staff include:

"it gives greater opportunity to discuss with relatives the patient's life prior to admission."

"it gives a more rounded picture of the patient's life, gives talking points."

Action learning

During early discussions with staff about their experiences of involving relatives, many said that they found communicating with distressed relatives difficult. They often found that relatives could be angry about various issues, including unhappiness about the care given. Staff felt disempowered by this experience. They would sometimes avoid contact with the relatives or apologise repeatedly without negotiating a way forward. Staff wanted to find ways of dealing with these difficult situations.

The approach adopted here was to hold action learning sets with all grades of nurses, which were facilitated by members of the project team. Staff brought their own issues in relation to relative involvement, and action points were developed. Action learning is 'a process of learning and reflection that happens with the support of a group or 'set' of colleagues working with real problems with the intention of getting things done' (McGill and Beaty 2001).

Staff found this approach to exploring their experiences and developing new ways of practising beneficial. They felt they had learnt:

"a new understanding of the relatives I work with. I feel more confident in my relationship with them."

"to involve relatives in a more open relationship and discuss all aspects with them."

Action learning enabled staff of all grades to work through real issues related to involvement and to develop new ways of working. The feedback about what staff felt they had learnt during this process was positive, potentially very powerful and qualitatively different from feedback following implementation of other initiatives in this project. Action learning promotes deep learning, and in this case helped individuals to explore their values and beliefs underpinning the giving and receiving of feedback.

Implementing the guidelines

The staff involved in this project felt that the guidelines that were developed in the previous work (Dewar et al, 2002) referred more specifically to a community setting. Instead, staff chose to use the four key markers for satisfactory involvement that had underpinned the development of the guidelines (see Background section) to shape the way in which they worked, as they felt that these were less restrictive than the guidelines. This does raise questions about the usefulness of specific guidelines and the extent to which they stifle individual creativity within different settings. There is a real need to debate fully with staff their interpretation of the guidelines and to be flexible in the ways that staff chose to implement them.

Developing ownership within a project is one of the key factors identified in change theory literature. Indeed, as Stenhouse (1975) states in relation to practitioner research, 'control over research and any changes that result from it should be in the hands of those who have to live with the consequences'. At the start of the project there seemed to be a lack of ownership of the guidelines by the staff. The fact that staff in another project generated the guidelines could have contributed to this. There seemed to be a change in the staff's commitment when they had to work to develop their own action plans related to involving relatives, as these were strategies generated from real issues in their practice which they chose to develop.

Conclusion

When outlining the processes used in this project to implement guidelines that seek to involve relatives of older people in decision-making processes, this short report has attempted to acknowledge that bringing theory alive can be difficult.

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In this project, we needed to bring to life some of the more theoretical statements that encapsulate involvement, for example, 'feeling that information is shared'. The challenge was to find practical strategies that could be initiated by all grades of staff but that would also challenge their views about sharing information and the value of this. Through this process, it was recognised that there needed to be a balance in the types of strategies used to meet the aims of the project. This meant the inclusion of some 'quick fix' approaches, e.g. a newsletter, and some other approaches that enabled 'real issues' to be explored, e.g. action learning. Staff found that it was only when they began to implement the practical strategies that they began to understand the complexities of involvement.

The project has recognised that understanding the ideal and working with reality can be challenging, particularly in relation to the notion of negotiating care. Some staff in this study expressed concern about their ability to meet the needs of relatives. Through analysis of practice, the need for a systematic approach to identify relatives' expectations and work towards a mutually acceptable plan of care was highlighted. Frameworks of questions that can guide staff into a negotiating conversation have been developed to enable both parties to be open and honest in the face of unrealistic expectations.

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Further Reading

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

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