Dementia Research - 
a Care home perspective

This case study summarises a Care home Manager’s experience of taking part in a research study. The manager shares both personal and professional perspectives of the challenges faced during the study and provides advice to other Care home staff considering taking part in research in the residential care setting.

Background

Research evidence shows the effectiveness of psychosocial treatments for people with dementia and there is a range of manuals and training materials available to support their use. However, there is no indicator of the effectiveness or quality of specific components and no intervention is widely used or systematically applied in clinical practice. The WHELD (Improving Well-being and Health for People with Dementia) study sought to determine the most effective combination of psychosocial treatments for people with dementia living in Care homes. This was achieved by training Care home staff to provide person-centred care, and by using exercise and social interaction to improve residents’ mental health, reduce the use of sedative drugs and improve quality of life.

The Care home manager was invited to talk about taking part in this study by a member of the ENRICH team. She said that a person-centred approach was already central to the Care home, and she and her staff worked with residents, so taking part in the WHELD study both tested and validated existing practice. The manager described her personal philosophy as, “dignity, independence and fulfilment for people residing in Care homes”.

She said this meant working with them on their own terms. Her experience was that person-centred care is challenging, motivating, rewarding and therapeutic for carers, family members and residents alike.

Why take part in research?

The manager explained that nurses and other staff at this Care home are encouraged to be proactive in updating and sharing their knowledge of current research through reading academic journals, attending presentations with research investigators and participating in or observing novel clinical practice. She identified several reasons why she felt research benefits staff, residents and relatives in the Care home:

- Informing and improving caring practice.
- Integrating novel and up to date interventions with existing practice optimises the care ‘package’
• Speaking with authority. Research empowers residents, relatives and staff to speak and work more confidently. Residents and carers have a better knowledge of the care available and staff deepen their understanding of their work.

• Motivating the workforce, residents and relatives. Research is not ‘business as usual’; it changes routines and brings different people together in an enjoyable, supportive environment.

• “Getting results.” Therapeutic interventions improve the residents’ quality of life.

• Developing personally and professionally. Taking part in research expands knowledge horizons and encourages the development of staff.

• Offering an alternative perspective. Nurses on a clinical placement in a Care home can see the effectiveness of psychosocial interventions in residential care and how over-medication can be avoided.

Lessons learned

Residents’ perceptions of research

Care and research staff initially held a wine and cheese evening at the home to present the study to residents, relatives and carers and to invite them to participate. Residents and family members were generally supportive with only one family carer asking that their relative opt out.

Residents reported that this meeting was an important way of demystifying the research. They felt relieved that they knew what was going to happen and when. The meeting was scheduled as part of the residents’ activity programme and had a therapeutic aspect, helping support some of their cognitive and emotional needs.

Potential for disruption to daily routine

Research activities had to be squeezed into an already busy schedule of meals, social time and rest periods. This could be distressing to residents and some staff because it took them out of their usual routine. Care and research staff met regularly from an early stage to foster good working relations at all levels. It was important that all times and dates the research team attended were scheduled a long time in advance. Nonetheless, some last minute changes were necessary and the care and research teams needed to work flexibly around these changes. A collaborative and willing attitude helped alleviate some of the frustration that arose from working with rigid and routinized systems.

The message to Care home staff

The manager offered the following advice to other Care homes considering participating in research:

• Taking part in research can generate high levels of motivation. Staff were happy to change their usual working patterns, work more flexibly and give up their free time to support the study.

• It was helpful to have a passionate and patient attitude to the study.

• It was important to schedule a series of meetings throughout the study to build optimal working relations between care staff and the research team. This provided the opportunity to air concerns, plan and diarise research activities and discuss potential pitfalls.

• Being part of a study is an opportunity to enrich the lives of people living with dementia, as well as the family members and staff that care for them.

For more information

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