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GETTING TO KNOW THE LIFE STORIES OF PEOPLE WITH DEMENTIA IN RESIDENTIAL CARE SETTINGS

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Objective:
This project focused upon increasing awareness of the personal life stories of residents with dementia providing a means for families to connect with residential care staff as collaborators in care.

Methods & Materials:
Through a Family Biography Workshop (FBW), families shared with staff the telling of stories that illuminated the events of the person’s life, the meaning attributed to such events and the character of the person. Stories were embedded within the context of family and intergenerational history. The FBW process, a series of six weekly two-hour sessions, involved families and staff working collaboratively to complete a set of exercises designed to help them build a narrative of their demented family member’s story.

Results:
Focus groups were used to assess how successful the FBW had been in promoting participatory approaches to dementia care informed by the life story. For family carers, reviving memories of their relatives as ‘whole’ persons enabled some to ‘step out’ of their everyday experience and see beyond the disease-saturated context. For others, a personal benefit was realised as they recognised the gaining of insight into their experience of the grieving process. For staff, the more insight gained in identifying aspects of family life and seeing the resident within the family context, the more empowered they felt to provide person-centred rather than task-oriented care. Residents benefited from being more socially stimulated as staffs confidence to initiate and engage with residents using their knowledge of their life story developed. Residents were perceived to respond to staff as if they were known to them as friends, family and not strangers ignorant of them as people. Overall, the benefit of co-creating a family biography for each resident with dementia was recognised in terms fostering a sense of community and feelings of belonging for the family and staff alike.

Conclusions:
This qualitative project has provided direction for a larger project measuring the effect of a participatory biography approach to residential dementia care in terms of: family, resident and staff roles and involvement in care; family, resident and staff relationships; staff attitudes, knowledge and care practices; staff job satisfaction and morale; and the planning, implementation and evaluation of collaborative dementia care.

This project has enabled the research team to practically substantiate the application of such an approach and has informed the larger project design. The following strategies will be employed: (1) A longitudinal design, commencing the process of developing the life story in the community, at-home, so that information is available upon admission to a residential setting; (2) Using life stories as an education strategy for orienting existing and new staff to participatory care and its benefits; (3) Linking new families with a staff member upon admission who is responsible for facilitating the incremental collection of family biography information; (4) Linking existing families with new families using established support networks within the residential setting; and (5) Modifying case review or case conference approaches that involve family members and provide a platform for ongoing sharing of life story information.