CONFERANCE ABSTRACT

Responsive community care for people with dementia & their families: Evaluating a person centred and integrated care model

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Introduction: In 2013, Genio, a non-governmental agency, provided innovative two year funding to develop individualised supports for people with dementia (PwD) and their informal carers in the community. This paper aims to report on the evaluation of an integrated care model in two community settings in Ireland, with a focus on the innovative supports provided.

Methods: Data were collected pre- and post-implementation of individual supports. A mixed methods approach was employed and included the following: service providers’ awareness and knowledge of dementia; survey and interviews with PwD and informal carers about their experiences of community dementia care, interviews with service providers about their experience of community dementia care, and an economic analysis. Ethical approval was secured from the Faculty of Health Sciences Research Ethics Committees in Trinity College Dublin and relevant Ethics Committees in the services.

Results: Results are based on data collected at two time points from service providers and PwD and informal carers. Service providers demonstrated reasonably high levels of dementia awareness and knowledge. For PwD and informal carers, the most valuable source of support was the provision of flexible, individualised home support hours. These benefits outweighed the provision of assistive technology and carer respite (weekend away for the informal carer). There was a range of positive outcomes reported by/on behalf of PwD and informal carers e.g. provision of additional home support hours when ‘mainstream’ supports were unavailable (overnight, at weekends etc), relief of carer burden, and satisfaction with facilitation of input into the selection of hours.

Discussion: Tensions arose in the mainstreaming of additional hours provided by the project due to budgetary constraints within the health service and the limitations of existing community care services. The sustainability of project gains must be considered in the context of broader national developments.
Conclusions (comprising key findings): Responsive care is best provided within a person-centred, relational care approach in order to acknowledge and respond to the needs of the PwD and informal carer dyad in the provision of dementia care services. Provision of additional, flexible home support hours was of the greatest benefit to informal carers in terms of support, and relief of carer burden. A re-conceptualisation of the provision of community care services would be required in order for project outcomes to be maintained and for the project ethos to continue.

Suggestions for future research: This research focused on those with advanced dementia. It would be valuable in future research to further explore the implementation of responsive care for PwD and their informal carers in the community across all stages of the dementia journey. It would also be useful to examine how assistive technology might better support PwD and their informal carers in advanced dementia.

Keywords: person-centred care; community care; integrated care; dementia