End of Life Care: An Evaluation of the Implementation of the Gold Standards Framework and The Liverpool Care Pathway for people with dementia in five care settings across Greater Manchester

Evaluation Report 2008

EXECUTIVE SUMMARY

<table>
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<th>Project Title:</th>
<th>An evaluation to determine the impacts of introducing the Gold Standards Framework (GSF) and Liverpool Care Pathway (LCP) to staff, patients/residents, family caregivers and practitioners involved in the care of older people with dementia in Greater Manchester care settings.</th>
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3. EXECUTIVE SUMMARY

3.0 Introduction
There has been a growing awareness of how important the perspective of the person is with dementia (Cheston et al 2003). Dementia is an irreversible degenerative syndrome characterised by deficits in memory, language and personality change resulting in difficulties with self care management, self neglect and psychiatric syndromes (Harris 2006). Alzheimer’s disease is the most common form of dementia which develops gradually and occurs most commonly after the age of sixty years of age. Kitwood (1997) acknowledges that often as a result of admission to a care home or hospitalisation dementia can sometimes advance extremely fast. One area in the care of older people which has received little attention is ‘end of life’ care of people with dementia, many of who are more likely to die in care homes. There is currently limited research evidence about the quality of dying for people with dementia in long term care settings. Whilst there are numerous moral and ethical difficulties to surmount when undertaking research into sensitive areas such as older people with dementia, Hughes and Robinson (2006) also identify three main areas of difficulties to providing good palliative care with advanced dementia in nursing and residential homes; communication, organisation (systems) and education (specialist knowledge and skills).

3.1 Background
The Greater Manchester End of Life Care Initiative aims to deliver education, training and improvement in the quality of care received by older adults with dementia in a care setting when coming to the end of their lives. The NHS North West Strategic Health Authority - Greater Manchester (formerly GMSHA), in conjunction with key stakeholders, identified mental health services as a “key strategic priority, initially focusing on older people with mental illness in care homes, in particular patients/residents diagnosed with Dementia”. This has been influenced by: the DoH Investment plan (2003) to improve the care of people coming to the end of life, the demographic changes of an ageing population including the prevalence of dementia in older people and the changing nature of care home provision.

A review of the literature suggested that long term care settings/care homes are faced with several barriers to providing good quality palliative care to patients/residents with dementia. The complex needs of patients/residents with dementia and the recognition of the dying trajectory is not always identified and met. A relevant knowledge base and skills are needed amongst care staff to sustain training, promote consultation and a team effort in the promotion of a palliative care philosophy in long term care settings including care homes.

Four Care Homes and one NHS (Mental Health) ward were identified for inclusion in the evaluation by the NHS North West GM End of Life Care Project. The End of Life Care tools include the Gold Standards Framework (GSF) and The Liverpool Care Pathway (LCP). Use of these tools formed part of the criteria for inclusion in the evaluation. Members of the Primary Care Team, Palliative Care Team and the Relatives/ carers of persons with dementia were also involved in the local implementation of the tools of care within each care setting. End of Life Care ‘Champions’ were appointed in each of the settings and provide leadership to facilitate the successful implementation of the end of life care tools.
3.2 Aim of the evaluation
To evaluate the Greater Manchester End of Life Care Initiative by assessing perceptions of staff on the role and appropriateness of the Gold Standards Framework (GSF) and Liverpool Care Pathway (LCP) in the individual care of patients/residents with dementia, the experience and role of carers/family members with the care service within identified care settings and the job satisfaction of the Multidisciplinary Team (MDT) in a range of long term care settings in the Greater Manchester area. MDT members included GP’s, District nurses, physiotherapists, speech and language therapists, dieticians, Macmillan Nurses and palliative care team.

3.3 Research questions
• What are the current end of life care needs of older persons with dementia who reside in care settings?
• How do end of life care tools enhance or hinder the ability of providers to respond to residents/patients end of life care needs?
• Do end of life care tools improve the quality of care received by persons with dementia and their carers/relatives within care homes?
• Do end of life care tools assist professionals to meet the end of life care needs of residents/patients and support the needs of carers and staff?

3.4 Methods
A case study approach was adopted so that existing tools and interventions could be explored and compared across cases (care settings). All documentary evidence was collated and a variety of approaches to data collection was used; qualitative, quantitative and economic analysis. This included surveys, interviews, focus groups and documents and records for the purpose of economic evaluation. Adopting a multi-method approach to this research allowed information to be drawn together from the various care settings to ensure a ‘whole system analyses’. Listening to the views and contributions of the participants of a range of stakeholders gave them a voice, which the research team has represented. Stakeholders included; Care home staff (all grades), Representatives of the Primary Health Care Team / Palliative Care team, The Mental Health Team, the GSF/LCP Facilitators for end of life care project and the carers/relatives of patients/residents with dementia.

3.5 Results
3.5.1 Care setting staff and stakeholder views and experiences.
There is an emerging picture of overall staff confidence in the planning and implementation of end of life care for persons with advanced dementia. There is general agreement that the support of the GP and communication with the MDT is essential to the quality of end of life care within the care settings. Meeting the needs of the family carers could sometimes be challenging for care staff and the importance of a trusting relationship cannot be underestimated. Conflict between staff, colleagues and families was more apparent prior to or in the early implementation of the end of life care tools. Staff reported that this was often as a result of misunderstandings, communication difficulties with their colleagues or the family carer’s attitude and personal experiences of death and dying.
3.5.1.1 Care Staff Survey
All Staff reported their satisfaction with the education and training sessions and their willingness to continue with additional professional development in palliative care specific to the person with dementia. There was general agreement with staff that the GSF/LCP tools enable staff to assess, monitor and implement appropriate care to meet the needs of the dying residents. This includes communication and utilisation of the expertise of multi disciplinary team. When asked if staff had confidence in their ability to care for a resident who is at the end of life without the need for hospitalisation 80% (n=65) in the baseline questionnaire and 98% (n=62) in the follow up questionnaire agreed / strongly agreed with this statement.

3.5.1.2 Care Staff Interviews
Nineteen Semi structured interviews were undertaken with care setting managers, end of life care champions and facilitators. Staff expressed satisfaction in the use of the GSF/LCP tools in facilitating communication and promoting a structured approach to meeting the needs of residents/patients. Staff placed a high value on the education and training and the role of the lead facilitators in the success of the implementation of the tools and express a desire for this to continue. Conflict was more apparent in the early implementation of the care tools or prior to implementation and was often as a result of misunderstandings, communication difficulties and also the attitude of colleagues or family carers towards death and dying.

3.5.1.3 General Practitioner Survey
There is an emerging theme that the majority of GP’s, including ‘out of hours’, had a positive experience of ‘end of life care’ delivered within each care setting during the implementation of the project. GP’s reported good levels of communication within the care settings, the adoption of the GSF and LCP tools, the involvement of carers and an emerging confidence in the care setting staff to manage the palliative care needs of residents with advanced dementia. GP’s also reported the usefulness of the ‘out of hours’ handover reporting form to facilitate communication with service providers. Some concerns were highlighted over the continuity of care and stability of the workforce within the care settings which may impact upon the sustainability of end of life care initiatives and the GP’s confidence in the care setting staff.

3.5.1.4 Multi Disciplinary Team (MDT)Survey
MDT Members, who participated in the questionnaire during the implementation of the project, were satisfied that the care setting staff can recognise the need for and deliver end of life care to people with advanced dementia but thought that education and training should be ongoing. MDT members suggested that further follow up research may be required so that the professionals involved can give an experienced view of the care settings management of end of life care for people with dementia.

3.5.1.5 Focus Groups
The focus group members included a range of care staff including qualified and unqualified nursing / care staff. Whereas staff interviews highlighted the issue of implementation, staff who participated in the focus groups were asked for their experience of using the end of life care tools for people with dementia who were at the end of life. Staff were able as a consequence of the project, to identify key factors which might indicate that a resident with
advanced dementia has entered the ‘dying phase’. These included increasing physical and mental frailty, very withdrawn and apathetic, poor appetite and eventually the refusal of food and fluids. Staff acknowledged the need for a trusting relationship between the GP and the potential difficulties for GP’s when anticipatory prescribing was requested. These difficulties as suggested by care staff reinforced the need for GP’s to have confidence in care staff to make informed decisions as to when medications could and should be used appropriately to meet the needs of the patient/resident. There was also acknowledgment by staff of the emotional context in which relatives/carers were involved in decision making at the end of life for the people with dementia. Changes of mind on available treatment and care options, requesting hospitalisation of their relative were issues, although infrequently, they did occasionally need to be discussed at length with relatives/carers. Some reservations were also expressed by staff concerning the discussion of advance care planning (ACP) prior to the resident demonstrating any sign of physical and mental decline.

3.5.1.6 Carers/Relatives Perspectives
The evidence was presented in the form of three case studies reflecting as far as possible the experience of family representatives of the resident/patient with advanced dementia who died within the care setting. The four family carers/relatives interviewed expressed satisfaction with the end of life care received by their relative and identified several important issues:

- The relationship that the care staff has with the residents is very important to ensure that needs are met at the end of life.
- Advance care planning is beneficial to identify the disease trajectory, to prepare for the death of a relative and identify personal choices and preferences that the resident/patient may have.
- The importance of good communication between care staff and the resident’s family and how this can be facilitated through the use of the GSF and LCP.
- The opportunity to discuss issues with the medical staff was not essential but should be an option if required.

Open and honest discussions on sensitive issues did improve the experience of end of life care for the person, the carer/family and the staff. Although often an uncomfortable process it staff did accept that it assisted carers/family members to prepare for the death of their relative and prompted a discussion on the treatment and care options.

3.6 Economic Assessment and Appraisal
As a result of the End of Life Project and the care interventions, the aggregate percentage for dementia patients dying in a care setting increased from 48% (23 out of 48 deaths) to 63% (20 out of 32 deaths) for the two periods i.e. before and after, in the five project settings. This data represented the full financial year before the project started (viz. 2005/06) and the most recent full year of the project, when the initial training phase was completed, i.e. October 2006 – September 2007. The Control comparison group of homes all had high percentages for both periods. Ten residents/patients were transferred to hospital between October 2006 – September 2007. The average hospital length of stay before death for those transferred was 14 days. This could indicate a potential cost benefits to secondary care providers if acute hospital
admission was avoided for people with dementia who need end of life care.

However the key analysis of whether patients died in their preferred place for death showed that all of those who stated “Home” (18 (60%)) chose to stay and died in their home, with all those that stated “Hospital” (8 (27%)) dying in hospital. (The remaining 4 cases (13%) did not have an answer recorded and all of the remaining 4 cases died in hospital). The data indicates that patients who indicated a preferred place of care/death had their needs met indicating a successful application of the EoL care policy, and there is evidence to suggest that those patients who remained in the project homes after 30th September 2007 also died in their preferred place for death. The research team obtained some control data from three care settings (known as the control group) to see if the activity in the project settings for dementia was any different to elsewhere. Results from the control groups all had high percentages for both periods.

3.7 Conclusions and Recommendations

1. This evaluation has identified the potential impact of the GSF and LCP in improving staff confidence in delivering end of life care to people with dementia in long term care settings and has resulted in the reduction in unscheduled hospital transfers for end of life care.

2. Stakeholders involved in the research agree that the GSF/LCP tools enable staff to assess, monitor and implement appropriate care to meet the needs of the dying residents. Staff appeared to experience high levels of satisfaction and confidence in the care of residents with dementia, who were cared for using the GSF/LCP tools at the end of life.

3. All staff interviewed and those staff who participated in the focus group expressed a confidence that residents with advanced dementia who had entered the dying phase and who expressed a wish to stay in their home setting would not be transferred to hospital unless following the assessment by the GP or at the request of the patient / relatives.

4. Care staff in this study reported that they were able to relieve physiological symptoms and discomfort from using the end of life care tools. Pain assessment tools for use with the patient/resident with dementia were reported as being very useful to care staff in the identification of pain in the patient/resident, the management of pain in the administration of appropriate medication and care and also to inform the discussions with GP and MDT.

5. There is also evidence that psychosocial and spiritual domains were identified as being important by staff in the care settings and that this was demonstrated with the need to be family centred and provide an emotionally supportive environment of love and care for the dying person.

6. The end of life care tools promoted good communication with the wider MDT and this was evident in the examples that were cited. Use of the GSF tools as a framework of care including the GSF meetings were identified as being valuable in the predication and diagnosis of the spiral of decline in the resident/patient with advanced dementia.
7. The economic benefits were indicated that there was potential for reducing unnecessary, unscheduled hospital admissions to acute settings, if the end of life care tools were implemented.

8. The focus group participation highlighted the experience of Health Care Assistants in the end of life care for person with dementia in the care settings. The importance of the role of the Health Care Assistants (HCA) must not be underestimated in promoting effective end of life care for people with dementia in the care setting. HCA are often the staff who deliver 'hands on' care to residents/patients, they also implement the care plan and monitor the residents comfort and symptoms.

9. ACP when used within the care setting was implemented successfully. ACP should be acknowledged as requiring a high level communication skill. Care staff requested further education and training in the development of communication skills to facilitate the full adoption of this process.

10. Open and honest discussions on sensitive issues did improve the experience of end of life care for the person, the carer/family and the staff. Although often an uncomfortable process staff did accept that it assisted carers/family members to prepare for the death of their relative and prompted a discussion on the treatment and care options.

11. General Practitioners and other MDT members need to be encouraged to participate in joint educational and training sessions to promote confidence and trust in the competence of care setting staff.

12. A sustained educational programme is needed urgently for all staff, including HCA’s and stakeholders involved in the care and treatment of residents/patients with dementia and the creation of a ‘research awareness culture’ within the long term care settings. This would enhance care by underpinning care processes with the evidence-base for practice.

13. There is a need to review the educational outcomes in pre registration nurse education for both general and mental health nursing students to include the physiological and psychological markers for recognising and managing the dying trajectory, particularly for persons with cognitive loss.

14. Staff suggested that the sustainability of the change in practice is dependant on the continuation and provision of necessary resources. This focused on staffing issues and the role of the end of life care champions within each setting.

15. There is a need for continued data collection to confirm the economic benefits of using end of life care tools for persons with dementia who are at the end of life. Within this evaluation there were difficulties accessing data to corroborate this aspect of the evaluation, which, together with time constraints require that a more detailed understanding of this issue in future research.
16. The role of the facilitators and individual care setting champions was critical to providing the necessary support to the individual care settings. This role should be a substantive post and essential to the success of any future implementation and sustainability of EoL/GSF tools in care settings.

17. There is potential for increased uptake nationally of the EoL/GSF tools in a number of care setting using the model of implementation of the NHS NW GM Project team.

18. The researchers are concerned about the “halo effect” of improvements in the care settings and this raises questions regarding the sustainability of the change in practice once the research has completed. Staffing issues, staff numbers, skill mix and the role of the end of life care champions within each setting are the primary areas of concern regarding the sustainability of change in practice. Further research would be beneficial to monitor the sustainability of the application of the End of Life Care tools within each care setting. This would also require sustained funding of palliative care / end of life care clinicians.

REFERENCES

