

A GUIDE TO BEST PRACTICE DEMENTIA CARE: LESSONS LEARNT FROM A SERIOUS CASE REVIEW

Mrs Michelle Loos, Community Practitioner. Southwark & Lambeth Memory Service South London and Maudsley NHS Trust.

Mrs Jo Delrée, Senior Lecturer, Department of Mental Health and Learning Disabilities. School of Health and Social Care. London South Bank University

Professor Sally Hardy, Head of Mental Health and Learning Disabilities London South Bank University. Professor of Mental Health and Practice Innovation LSBU Adjunct Professor Monash University Faculty of Health Melbourne Victoria Australia. Visiting Professor England Centre of Practice Development Canterbury Christchurch University Kent.

For more information please contact **Corresponding Author**, Mrs Michelle Loos. E Mail: Michelle.Loos@slam.nhs.uk

ABSTRACT

This reflective paper discusses a clinical scenario and compares best practice guidelines with published literature against a backdrop of evidence taken from a Serious Case Review (SCR). Mrs B (*pseudonym*) was a 94 year-old lady with dementia and blindness plus several other co-morbidities, including a previous stroke. She lived in a care-home and had a history of falling. The last fall was fatal, due to aspiration pneumonia and fractured vertebrae of the neck. A Serious Case Review process highlighted a number of failures in interdisciplinary working practices which contributed ultimately to Mrs B's avoidable death. The article discusses how applying evidence based best practice could have led to better care outcomes. A series of seven recommendations and lessons learned are presented for a multi-agency approach to best practice in dementia care.

BACKGROUND

Adult Serious Case Reviews (SCRs) are commissioned by local safeguarding boards to investigate how agencies involved in the care of an individual who has suffered a serious incident have worked together to safeguard that vulnerable adult. The aim of a SCR is to identify where and how care can be improved, and to identify lessons learned to inform practice and policy changes. Manthorpe & Martineau, (2016) suggest that SCRs provide opportunity to gain insight into practices in care homes and monitor activity during the transfer of care between hospitals and care home environments. The process an SCR takes can vary depending on the health care providers policies and level of record keeping, with documentary accuracy often coming into question. When considering dementia care more specifically, Manthorpe and Martineau (2016) conclude that SCRs also offer opportunity to undertake an in-depth analysis of personal, public and professional failings, which may help to identify and improve the quality of care being delivered.

The Case of Mrs B

Mrs B is a 94 year-old lady with dementia and blindness plus several other co-morbidities, including a previous stroke. She lived in a care-home and had a history of falling. The last fall was fatal, due to aspiration pneumonia and a fractured vertebrae of the neck. Following a previous fall, advice had been given to care staff to contact the local 'Falls Matron' and to ensure Mrs B attend Accident and Emergency due to extensive bruising sustained. However, this was not acted upon.

Mrs B was experiencing recurrent falls and subsequently sustained a range of serious injuries. The World Health Organisation (2016) have reported that falls and

falls related injuries are the second leading cause of accidental or unintentional injury deaths worldwide. The injuries sustained and the overall impact as a result of such falls will always present problems for all aspects of health and social care delivery. It is highly likely that Mrs B would have been experiencing significant pain and also a fear of falling (Lisk and Yeong, 2014), but due to her cognitive decline related to her dementia, her ability to fully express this may often be limited, and this of course presents many challenges to providing compassionate person centred care. In addition, one of Mrs B's family members had previously raised concerns regarding the poor level of care that Mrs B was receiving and had noted a lack of suitably trained staff.

Mrs B had a number of co-morbidities, which alongside the diagnosis of dementia, could have impacted upon her quality of life. It is well recognised that the assessment of symptoms and subsequent treatment in the context of cognitive impairment can be complex, especially when there are additional co-morbid conditions as well as difficulty with communication (Mitchell et al. 2009) Looking further at physical symptoms, another factor recognised as adversely affecting quality of life for those with dementia is pain (Beer et al., 2010; Hodgson et al., 2014) and in people who have dementia this can often go unrecognised and be under reported and poorly managed (McAuliffe et al. 2009).

A clinical case review approach

Undertaking a critical analysis of Mrs B's care experiences commenced with reviewing her case materials in detail and highlighting pertinent issues. This was then followed by a literature search, relating elements of Mrs B's history and the

recorded clinical activity to the evidence base around best practice for dementia care. A critical appraisal of the literature reviewed was also taken into consideration, whilst acknowledging the potential for conflicting evidence arising when seeking international published materials around a single clinical issue, for example in Mrs B's case, preventing falls in the older population.

The importance of interdisciplinary working with people with dementia is recognised within a number of documents including the Dementia Strategy (2009) and NICE Guidelines (2006). It is argued that an integrated approach to dementia is required in all instances, as a single discipline is unable to manage the complexity of issues (physical, psychological, psychiatric and social) which can occur with this condition (Lloyd-Williams *et al.* 2014; Banerjee, 2014). Evidence suggests that often residents in care homes have unmet needs, may be admitted to hospital unnecessarily and their dignity be compromised by poor access to healthcare (British Geriatrics Society, 2012; Care Quality Commission (CQC), 2012; NHS Confederation 2012).

Popham and Orrell (2012) identified that care homes can be organised around staffing priorities, rather than delivering person centred practice. Although they recognise that this might well be unintentional, undertaking a Serious Case Review can help to identify, articulate and tackle the culture of care which causes fault lines and leads to poor practice, abuse, neglect and poorly managed care delivery. A study carried out by Robbins *et al.* (2013) identified a number of factors as barriers to delivering effective healthcare in UK care homes and concluded that a big challenge to providing effective care home residents arises as a result of the complexity of the medical problems presented. They also recommend better training for social and

healthcare staff to assist them with anticipating and managing (rather than simply reacting to) fluctuations in someone's health; better communication of information at the point of arrival and departure, provision of adequate time to assess and manage health problems; and being clear about where responsibility lies for various aspects of healthcare management. A common care philosophy, clear roles, good communication and shared decision-making and goal setting (Jayadevappa and Chhatre 2011) have also been identified as factors which increase the effectiveness of interdisciplinary care.

What were the key issues arising from Mrs B's case review?

The case study review process identified that when high quality person-centred care is provided, and residents are treated with respect and dignity, overall satisfaction and quality of life is increased. The concept of person centred care was discussed at length by a number of scholars, and can be described as an approach which promotes "a social, humanistic, and holistic perspective on how to understand and promote the best possible life and care for people with dementia" (Edvardsson et al. 2014 page number). Previous Serious Case Reviews (SCR's) highlight the need for improved communication and engagement between care homes and primary care (Davies et al. 2011).

A study by Kupeli et al. (2016) suggested that a low-skilled workforce affects the ability of staff to deliver high quality care, which in turn leads to poor recognition of changes in a person's presentation and lack of knowledge regarding the best response to such changes. This latter point does appear to be rather pertinent in the case of Mrs B.

There were many study findings identified that made recommendations that resonate with the Mrs B's case. For example, many SCR's highlight inadequate and ineffective communication, as well as complicated organisational and disciplinary boundaries as factors which can lead to ineffective coordination and sub-optimal provision of care to those with complex care needs, like Mrs B (Cohen- Mansfield *et al.* 2012; Bunn *et al.* 2014).

Looking more closely at the issue of physical health, research indicates that quality of life is higher amongst people with dementia whose general health status is better (Black *et al.* 2012; Marvenato *et al.*, 2015; Nikmat *et al.* 2015) and that the more chronic health problems a person with dementia has, the lower their quality of life (Beerens *et al.*, 2014; Leon-Salas *et al.* 2015). Dementia is often associated with a range of chronic diseases (Lee *et al.* 2009). Mrs B had a number of co-morbidities, which alongside the diagnosis of dementia, would potentially have impacted upon her quality of life. It is well recognised that the assessment of symptoms and their subsequent treatment is complex in the context of cognitive impairment, especially when there are co-morbidities as well as difficulty with communication (Mitchell *et al.* 2009). This perhaps contributed to the paucity of assessment in Mrs B's case.

The use of multiple medications is common in this population, with studies showing that people with dementia might take between 7-8 medicines per day (Morley, 2009). This raises several concerns. Firstly, difficulties with communication could mean a decreased ability to articulate any adverse side-effects (Onder *et al.* 2011). Secondly, people with advanced dementia can have a limited life-expectancy which may lower benefits from drug treatment, and finally some medications are known to have a detrimental effect on cognitive functioning (Holmes, 2009).

It is highly likely that Mrs B was taking several medications, as she had a number of health conditions. An example of good inter-disciplinary working should have included regular reviews of Mrs B's medications to ensure that she was not taking medication unnecessarily, or taking medication that was causing more harm than benefit e.g. increasing risk of falls (Lisk and Yeong, 2014). There was however no evidence of this in the scenario.

Risk assessment and risk management: falls

It is recognised that falls are common and problematic in care facilities and hospitals and that consequences of falling can lead to high rates of injury, reduced quality of life and in some cases, as with Mrs B, death (Cameron *et al.* 2012). It would appear that chances for Mrs B's injuries to be further explored on at least one occasion were missed and care-home staff were not proactive in following up with community services. If this had been pursued further, it is likely that Mrs B may have been given the opportunity for further assessment of her recurrent falls e.g. at a Falls Clinic, or had input from a community Occupational Therapist/Physiotherapist, who could have suggested an exercise programme and recommended aids and adaptations which may have ensured Mrs B was able to mobilise more safely.

Another key risk, when looking into Mrs B's case is her reduced vision. Sensory impairments, including visual impairment are common in the older population (Grue *et al.* 2009; Dillon *et al.* 2010). Older people with age related eye disease and visual impairment are likely to report their health as being affected and tend to experience more co morbidities (Finger *et al.* 2011). It is reasonable to assume that Mrs B's reduced vision may well have led to her experiencing a lack of confidence when

navigating her way around her environment and possibly leading to increased risk of falls. This is something which should have been taken into account when planning care for Mrs B and, where possible, adjustments made to her care plan to help meet her needs in this area. This could have involved the use of better signage within the home, assistance from staff when mobilising from one room to another and the use of other sensory stimulation/ Assistive Technology etc. (Behrman et al. 2014; NICE 2012)

Lessons learned & recommendations for best practice

Having examined the issues arising from this case study with reference to available literature, it is clear that a multitude of factors affected the quality of care provided to Mrs B including: poor communication between professionals, poor coordination of services across different settings, lack of training and knowledge of person-centred dementia care, a lack of leadership in the care- home, inadequate reviews and lack of joint working with relatives. Particularly alarming is the fact that advice to transfer Mrs B to Accident and Emergency (A&E) was ignored, despite her history of recurrent falls and subsequent serious injuries. This was a missed opportunity to identify Mrs B's injuries sooner, and possibly averting her death at this time.

From reviewing the available literature as well as examining the case study, the following seven recommendations are made:

- 1: Regular reviews from the person's own GP, would enable greater overall understanding of the individuals physical health and medication regime. This would lead to increased responsiveness to any concerns raised by staff whether in hospital,

at home, or when resident in a care-home (Gill, 2012; Morley, 2011; Jedenius *et al.* 2011). In terms of accommodation for people with dementia, it has been found that people in facilities with specialised workers or GP's will usually have a higher quality of life (Marventano *et al.*,2015). Improving quality of life for people who have dementia is a key priority identified by the National Dementia Strategy (Department of Health, 2011). The National Dementia Strategy Living Well with Dementia (Department of Health 2009) also promotes the importance of person-centred and therapeutic approaches that focus on enabling an individual to live well, even in the context of an incurable and progressive disorder.

2: Increased input from the multi-professional clinical team, for example Occupational Therapist, Physiotherapist, and a full holistic health and wellbeing assessment would be able to promptly ascertain potential and risk factors leading to Mrs B's risk and causality of her falls (NICE, 2013; Ambrose *et al.* 2013). Jayadevappa and Chhatre (2011) also assert that a common care philosophy, clear roles, good communication and shared decision-making and goal setting are essential for successful interdisciplinary care.

3: Improved care planning is essential element of best practice care delivery. Working to a clear and person centred care package enables all involved in the care delivery to take into account individual needs, for example in this case of Mrs B's visual impairment (Berhman *et al.* 2014; NICE 2012).

4: Increased liaison with family members from the care team, to address and rectify concerns at an earlier stage/ more credence given to family's concerns and input (Feill *et al.*2011)

5: Prompt response when receiving information and acting on advice given from other agencies involved in the persons care. IN this example, care staff failed to respond and ensure Mrs B was to attend A and E. This act might have been what led to Mrs B's injuries being identified earlier and her death avoided (Goodman, 2011; Ellins *et al.*2012).

6: Improved, clear and consistent communication between health and social care providers may have ensured that Mrs B's care was more integrated and therefore more effective (Wolfs *et al.* 2011; Dementia Strategy, 2009; Lloyd-Williams *et al.* 2014; Bunn *et al.* 2014; Robbins *et al.* 2013).

7: Improved consideration of the culture of care in care homes. This can be achieved by taking into consideration the overall management of the care-home, including better staff training, good leadership, use of person-centred dementia care (Kitwood, 1997; Edvardsson *et al.*, 2014; Bone *et al.*, 2010; Robbins *et al.*, 2013)

Conclusion

Older people who have complex health needs require a respectful delivery of services from healthcare professionals who are able to recognise and respond to their needs, ensuring they are able to access a variety of services (Goodman, 2011, Ellins et al., 2012), but there is evidence that some people with dementia have less access to treatment and monitoring of their health than those without dementia (Bunn et al. 2014). Poor communication amongst professionals, a lack of joint working and a lack of knowledge and awareness of dementia are all recognised as barriers to good care (Bunn et al. 2014).

With an estimated 70 per cent of UK care home residents having dementia (Alzheimer's Society, 2012), it is crucial that care is properly integrated and coordinated to provide holistic, person-centred care for each individual in order to prevent incidents such as that of Mrs B's being repeated in future. This reflective paper has outlined a critical appraisal of the literature, compared with information from a serious case review. It has identified a series of seven recommendations for preventing avoidable deaths, of an individual with dementia, living in a care home.

The critical reflective review process has identified a number of key lessons around how an inter-professional/inter-agency approach to caring for a woman who was the focus of a serious case-review led can be used to learn lessons in promoting best practice dementia care delivery. This paper also examined and makes recommendations for the roles of the various professionals involved in one person's care, and how if they were communicating effectively, sharing their clinical assessments around risk, would provide valuable information to evaluate their effectiveness as a clinical team, working across service boundaries (i.e. care homes and hospital settings).

REFERENCES

Alzheimer's Society (2012) *Dementia 2012: A National Challenge*. Alzheimer's Society, London.

Ambrose, A.F., Paul, G. and Hausdorff, J.M., 2013. Risk factors for falls among older adults: a review of the literature. *Maturitas*, 75(1), pp.51-61.

Banerjee, S., 2015. Multimorbidity—older adults need health care that can count past one. *The Lancet*, 385(9968), pp.587-589.

Beerens, H.C., Sutcliffe, C., Renom-Guiteras, A., Soto, M.E., Suhonen, R., Zabalegui, A., Bökberg, C., Saks, K., Hamers, J.P. and RightTimePlaceCare Consortium, 2014. Quality of life and quality of care for people with dementia receiving long term institutional care or professional home care: the European RightTimePlaceCare study. *Journal of the American Medical Directors Association*, 15(1), pp.54-61.

Behrman, S., Chouliaras, L. and Ebmeier, K.P., 2014. Considering the senses in the diagnosis and management of dementia. *Maturitas*, 77(4), pp.305-310.

Bone, C., Cheung, G. and Wade, B., 2010. Evaluating person centred care and dementia care mapping in a psychogeriatric hospital in New Zealand: a pilot study. *New Zealand Journal of Occupational Therapy*, 57(1), p.35.

British Geriatrics Society, 2011. *A Quest for Quality. An Inquiry into the Quality of Healthcare Support for Older People in Care Homes: A Call for Leadership, Partnership and Improvement: British Geriatrics Joint Working Party Inquiry*

Bunn, F., Burn, A.M., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J. and Brayne, C., 2014. Comorbidity and dementia: a scoping review of the literature. *BMC Medicine*, 12(1), p.1.

Cameron, I.D., Gillespie, L.D., Robertson, M.C., Murray, G.R., Hill, K.D., Cumming, R.G. and Kerse, N., 2012. Interventions for preventing falls in older people in care facilities and hospitals. *Cochrane Database Syst Rev*, 12.

Care Quality Commission, 2012. *Health care in care homes: A special review of the provision of health care to those in care homes*. London: Care Quality Commission. Care Quality Commission Meeting the Health care needs of people in Care Homes March 2012. <http://www.cqc.or.uk?public/reports-surveys-and-reviews/reviews-and-studies/meeting-health-care-needs-people-care-homes> (accessed June 2016)

Care Quality Commission 2014. *Cracks in the Pathway: People's experiences of dementia care as they move between care homes and hospitals*. London: Care Quality Commission.

Chenoweth, L., King, M.T., Jeon, Y.H., Brodaty, H., Stein-Parbury, J., Norman, R., Haas, M. and Luscombe, G., 2009. *Caring for Aged Dementia Care Resident Study*

(CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *The Lancet Neurology*, 8(4), pp.317-325.

Cohen-Mansfield, J., Jensen, B., Resnick, B. and Norris, M., 2012. Assessment and treatment of behaviour problems in dementia in nursing home residents: a comparison of the approaches of physicians, psychologists, and nurse practitioners. *International Journal of Geriatric Psychiatry*, 27(2), pp.135-145.

Davies, S.L., Goodman, C., Bunn, F., Victor, C., Dickinson, A., Iliffe, S., Gage, H., Martin, W. and Froggatt, K., 2011. A systematic review of integrated working between care homes and health care services. *BMC health services research*, 11(1), p.1.

Department of Health, (2009). Living well with dementia: A National Dementia Strategy. London: Department of Health Publications

Edvardsson, D., Sandman, P.O. and Borell, L., 2014. Implementing national guidelines for person-centered care of people with dementia in residential aged care: effects on perceived person-centeredness, staff strain, and stress of conscience. *International Psychogeriatrics*, 26(07), pp.1171-1179.

Ellins, J., Glasby, J., Tanner, D., McIver, S., Davidson, D., Littlechild, R., Snelling, I., Miller, R., Hall, K. and Spence, K., 2012. Understanding and improving transitions of older people: a user and carer centred approach. Final report.

Feil, D.G., Lukman, R., Simon, B., Walston, A. and Vickrey, B., 2011. Impact of dementia on caring for patients' diabetes. *Aging & mental health*, 15(7), pp.894-903.

Goodman, C., 2011. The organisational culture of nursing staff providing long-term dementia care is related to quality of care. Evidence Based Nursing, p.ebnurs1158.
Goodwin, N., Smith, J., Davies, A., Perry, C., Rosen, R., Dixon, J., and Ham, C., (2012) Integrated care for patients and populations: Improving outcomes by working together. <http://www.kingsfund.org.uk/sites/files/kf/integrated-care-patients-populations-paper-nuffield-trust-kings-fund-january-2012.pdf>

Jayadevappa, R. and Chhatre, S., 2011. Patient centred care-a conceptual model and review of the state of the art. *The Open Health Services and Policy Journal*, 4(1).

Jedenius, E., Johnell, K., Fastbom, J., Strömquist, J., Winblad, B. and Andreasen, N., 2011. Dementia management programme in a community setting and the use of psychotropic drugs in the elderly population. *Scandinavian Journal of Primary Health Care*, 29(3), pp.181-186.

Kitwood, T., 1997. The concept of personhood and its relevance for a new culture of dementia care.

Kupeli, N., Leavey, G., Harrington, J., Lord, K., King, M., Nazareth, I., Moore, K., Sampson, E.L. and Jones, L., 2016. What are the barriers to care integration for

those at the advanced stages of dementia living in care homes in the UK? Health care professional perspective. *Dementia*, p.1471301216636302.

Lloyd-Williams, M., Abba, K. and Crowther, J., 2014. Supportive and palliative care for patients with chronic mental illness including dementia. *Current Opinion in Supportive and Palliative care*, 8(3), pp.303-307.

Lee, P.G., Cigolle, C. and Blaum, C., 2009. The Co-Occurrence of Chronic Diseases and Geriatric Syndromes: The Health and Retirement Study. *Journal of the American Geriatrics Society*, 57(3), pp.511-516.

Lisk. R., Yeong, K. (2014) Reducing mortality from hip fractures: a systematic quality improvement programme British Medical Journal Quality Improvement Report. 2014: 3: doi:10.1136/bmjquality.u205006.w2103

Marventano, S., Prieto-Flores, M.E., Sanz-Barbero, B., Martín-García, S., Fernandez-Mayoralas, G., Rojo-Perez, F., Martinez-Martin, P. and Forjaz, M.J., 2015. Quality of life in older people with dementia: A multilevel study of individual attributes and residential care centre characteristics. *Geriatrics & Gerontology International*, 15(1), pp.104-110.

Mitchell, S.L., Teno, J.M., Kiely, D.K., Shaffer, M.L., Jones, R.N., Prigerson, H.G., Volicer, L., Givens, J.L. and Hamel, M.B., 2009. The clinical course of advanced dementia. *New England Journal of Medicine*, 361(16), pp.1529-1538.

National Institute for Health and Clinical Excellence (NICE). Dementia: Supporting people with dementia and their carers in health and social care. NICE clinical guideline 42. National Institute for Health and Clinical Excellence: 2012.

Nikmat, A.W., Al-Mashoor, S.H. and Hashim, N.A., 2015. Quality of life in people with cognitive impairment: nursing homes versus home care. *International Psychogeriatrics*, 27(05), pp.815-824.

Onder, G., Lattanzio, F., Battaglia, M., Cerullo, F., Sportiello, R., Bernabei, R. and Landi, F., 2011. The risk of adverse drug reactions in older patients: beyond drug metabolism. *Current Drug Metabolism*, 12(7), pp.647-651.

Popham, C., & Orrell, M. (2012) What matters for people with dementia in care homes? *Aging and Mental Health* 16 (2) 181-188

Nikolaus, T., Topinkova, E., Tosato, M., Liperoti, R. and Landi, F., 2012. Assessment of nursing home residents in Europe: the Services and Health for Elderly in Long TERM care (SHELTER) study. *BMC health services research*, 12(1), p.1.

Robbins, I., Gordon, A., Dyas, J., Logan, P. and Gladman, J., 2013. Explaining the barriers to and tensions in delivering effective healthcare in UK care homes: a qualitative study. *BMJ open*, 3(7), p.e003178.

Shah, S.M., Carey, I.M., Harris, T., DeWilde, S. and Cook, D.G., 2011. Quality of chronic disease care for older people in care homes and the community in a primary care pay for performance system: retrospective study. *BMJ*, 342, p.d912.

Silva, R.B., Eslick, G.D. and Duque, G., 2013. Exercise for falls and fracture prevention in long term care facilities: a systematic review and meta-analysis. *Journal of the American Medical Directors Association*, 14(9), pp.685-689.

World Health Organisation Falls Fact sheet September (2016) Online
<http://www.who.int/mediacentre/factsheets/fs344/en/> Last Accessed January 2017.