What is the impact of volunteers providing care and support for people with dementia in acute hospitals? A systematic review.

Claire L HALL,

Nurse Researcher, Oxford Institute for Nursing, Midwifery and Allied Health Research (OxINMAHR), Oxford Brookes University, Oxford University Hospitals NHS Foundation Trust MSc BA RMN
@NurseClaireHall

Joanne BROOKE,

Reader in Complex Older Persons Care, Oxford Institute for Nursing, Midwifery and Allied Health Research (OxINMAHR), Oxford Brookes University CPsychol MSc BSc RN

jbrooke@brookes.ac.uk

@DrJoBrooke

Sarah T PENDLEBURY, Consultant Physician and Associate Professor Stroke Prevention Research Unit, Nuffield Department of Clinical Neurosciences, University of Oxford and the Oxford NIHR Biomedical Research Centre and the Departments of General Medicine and Geratology, Oxford University Hospitals NHS Foundation Trust MRCP DPhil

Debra JACKSON,

Director for OxINMAHR, Professor of Nursing

Oxford Institute for Nursing, Midwifery and Allied Health Research (OxINMAHR), Oxford Brookes University, Oxford University Hospitals NHS Foundation Trust PhD FACN

djackson@brookes.ac.uk

@debraejackson

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ABSTRACT

A quarter of acute hospital beds are occupied by people with dementia, and a hospital stay may impact negatively on their health and wellbeing. The development and implementation of volunteers to provide social, activity-based, one-to-one support for people with dementia in acute hospitals has become routine practice. However the evidence to support this practice has not been identified or evaluated. This systematic review considers the effect of volunteers on the care and experience of people with co-morbid cognitive impairment/dementia in acute hospitals. The systematic search identified 444 papers, although only three papers included specific analysis relating to the impact of volunteers. The evidence suggests volunteers may have potential to enhance the experiences of people with dementia in acute hospitals, however there is currently a marked lack of evidence to support the widespread implementation of volunteers. There is therefore an urgent need for multi-site robust research to provide evidence of the impact of volunteers supporting people with cognitive impairment/dementia during an acute hospital stay.

Keywords: Nursing, Dementia, Volunteer, Person-Centred Care, Systematic Review, Evidence-Based Practice

Introduction

There are 850,000 people living with dementia in the UK (Alzheimer's Society, 2014), and this figure is predicted to rise to over one million by 2025, and to exceed two million by 2050 (Lewis et al., 2014). The high prevalence of dementia has a major impact on health services, and current estimates suggest that one quarter of all hospital beds are occupied by people with dementia (Alzheimer's Society, 2009) with particularly high rates of co-morbid cognitive impairment in acute medicine and elderly care beds (Sampson et al., 2009; Pendlebury et al., 2015a, Pendlebury et al, 2015b). People with dementia stay in hospital longer and have more unplanned readmissions than other patients with the same conditions (Care Quality Commission, 2013). Nearly 50% of carers reported that a hospital stay had a significant negative impact on the person with dementia, including a deterioration in their physical and mental health, dependence and confusion (Alzheimer's Society, 2009; Pendlebury at al., 2015). The increased length of hospital stay for people with cognitive impairment/dementia is associated with negative outcomes, such as weight loss, incontinence, pressure ulcers, functional decline, reduced communication skills and depression (Pendlebury et al., 2015).

In the UK, the Prime Minister's Challenge on Dementia 2012 and 2020 (Department of Health 2012, 2015) identified dementia as a national priority, which included a focus on acute care for people with co-morbid dementia. In addition, the UK National Institute for Health and Clinical Excellence (NICE, 2006) guidelines endorsed the principles of person-centred care in all settings for people with dementia citing Kitwood's (1997) seminal work on the importance of ensuring each person with dementia is enabled to maintain their personhood despite declining cognitive and social function. The challenge of implementing this approach in acute hospital settings alongside organisational pressures of financial and productivity targets remains problematic (Francis, 2013).

An acute hospital setting is not an optimal environment for a person with dementia. Therefore, it is essential to identify strategies and interventions to improve patient experience and to promote overall health and wellbeing (Houghton et al., 2016). while facilitating optimal acute care. However, the limited fiscal and human resources available to acute hospitals internationally, has led to the need to explore alternative and innovative strategies to enhance the quality of care for people with dementia including the use of resources external to the existing health care team. One such strategy is the implementation of volunteers in both acute health and social care (Naylor et al., 2013; Roberts et al., 2015; Baczynska et al., 2016).

It is estimated that there are more than 78,000 volunteers in acute hospitals in England providing over 13 million hours of care and support per year in a variety of settings (Galea et al., 2013). Individual NHS Trusts adopt varying approaches to the use of volunteers.. The number of volunteers per Trust ranges from 35 to over 1,300 (Galea et al., 2013) and volunteer roles include befriending and visiting, meet-and-greet, activities, entertainment and administrative support (Galea et al., 2013). In acute elderly care wards, volunteers may act as 'sitters' of patients at risk of falls, engaging patients in conversations, playing cards, and supporting hydration and nutrition, as well as alerting staff if the patient attempts to mobilise. A number of these initiatives have been found to significantly reduce falls (Boswell et al., 2001; Donoghue et al., 2005: Giles et al., 2006) but no study

has specifically reported the impact of volunteers on patients with dementia in the acute care environment.

Volunteers have also been embedded in acute hospitals to work with patients with co-morbid cognitive impairment dementia providing one-to-one interaction, social and cognitive stimulation, and company with the aim of enhancing care and patient experience and this strategy has been promoted as good practice (Thompson & Heath, 2013; Alzheimer's UK 2016). However, there has been no formal review or evaluation of the evidence base for this approach. We therefore undertook a systematic review to determine the patient, carer and staff impact of the use of volunteers in the care of patients with co-morbid dementia/cognitive impairment in the acute hospital setting.

Methods

A comprehensive review of the literature exploring the impact of volunteers to support patients with dementia in the acute hospital setting was completed with adherence to systematic review guidelines and frameworks (Bettany-Saltikov, 2012; Wright et al., 2007).

Aim and objectives

The aim of this systematic review was to establish an evidence-base regarding the implementation of volunteers to support the care and experience of people with dementia during an acute hospital stay. The specific objectives were to identify and review:

- empirical evidence of the implementation of volunteers to support people with dementia;
- empirical evidence to gain an understanding of the impact of volunteers on the care and experience of people with dementia, carers and staff; and
- variables connected with the successful implementation of volunteer programmes, including recruitment, training and support

Inclusion and exclusion criteria

The inclusion and exclusion criteria were developed from the aim of the review, all empirical studies that reported data specifically related to the impact of volunteers on the care and experiences of people with dementia during an acute hospital stay were included. No study was excluded based on methodological approaches. Volunteers were operationalised as unpaid, non-hospital staff, not a patient, and not related to or already associated with the patient.

Literature search strategy

The following databases were searched: EMBASE, CINAHL, MedLine, PsychInfo, BNI and Global Health from their inception to July 2016. The exploded search terms used covered [Dementia or Cognitive Impairment] AND [Volunteer] AND [Hospital] and are shown in Table 1. Search terms were used to generate index terms specific to each database and these were added into the search. Duplicates were excluded and inclusion and exclusion criteria were applied, as detailed and presented in Figure 1 by a PRISMA flow chart (Moher et al. 2009). The database search produced 585 papers, after duplicates were removed, 444 papers remained, title/abstract screening excluded 427 papers, full text papers were accessed for the remaining 17 papers, of which three papers were identified for inclusion in the review (Figure 1).

Data extraction, analysis and synthesis

Each paper described the implementation of volunteers, information on each schemes was extracted from the introduction and methods section of the papers (refer to Table 2). Qualitative and quantitative data for thematic synthesis was extracted from the results section of the papers. Data from the included papers were analysed in a thematic synthesis, guided by the methods of Thomas and Harden (2008), which included coding, developing descriptive themes and generating analytical themes. The thematic analysis was completed by CH and discussed and developed with JB.

Findings

Overview of studies included

Three studies were included in the review, one was completed in the UK (Wong Shee et al. (2014), and the remaining two were completed in Australia (McDonnell et al. 2014; Bateman et al. 2016). All explored the impact of volunteer programmes over a short period of time, ranging from six to twelve months. Two studies completed qualitative exploration of a volunteers programme, including observations, interviews and focus groups (Wong Shee et al. 2014; McDonnell et al. 2014), whilst the remaining study applied a pre-post quasi-experimental design collecting both qualitative and quantitative data.

Quality appraisal

Due to the different methodological approaches of each paper, Wong Shee et al. (2014) and McDonnell et al. (2014) were assessed against the Critical Appraisal Skills Programme (CASP) for qualitative studies, which considers the appropriateness of methodology, design, recruitment strategy, data collection, data analysis, findings, and the value of the research (CASP 2014). Bateman et al. (2016) was assessed against the Joanna Briggs Institute Critical Appraisal Checklist for Quasi-Experimental Studies, which also considers pre and post measurements, lost to follow-up, reliability of outcome measures and statistical analysis. Wong Shee et al. (2014) and Bateman et al. (2016) received acceptable levels of quality appraisal. McDonnell et al. (2014) could be critiqued due to an unclear recruitment strategy, and a number of assumptions in the discussion from qualitative data that could not be substantiated.

Wong Shee et al. (2014) evaluated the feasibility and acceptability of a volunteer diversional therapy program for patients with cognitive impairment undergoing inpatient rehabilitation. Thematic analysis identified five themes (values, attitudes, knowledge, purpose, support) in two dimensions (personal, team culture).

McDonnell et al. (2014) evaluated the effect of an on-ward volunteer service in an acute orthopaedic ward with patients with dementia. The paper overall identified that the service had a positive effect on patient experience; patients were engaged through a variety of activities and enjoyed the volunteers' presence. Staff valued the initiative because they could see the difference that it made to patients and their own work load.

Bateman et al. (2016) report a quasi-experimental pre—post design pilot study, in a rural acute hospital. The paper identified a significant reduction in length of stay for patients, and an increase in the use of analgesic medications and reduction, although not significant in the use of antipsychotic

medication. There were no effects on the stress of nursing staff or their attitudes to dementia. Volunteers gained significantly in confidence and attitudes to dementia. The program was highly acceptable, with almost all staff and volunteers perceiving the program as beneficial.

Emergent themes from the thematic analysis of the three studies included: perceived benefit for patients with dementia, providing a unique service, volunteer's role within the team, and support and training of volunteers.

Overarching theme: Perceived benefit for patients with dementia

An emergent theme across all studies was the perceived benefit of the implementation of volunteers to support patients with dementia (Bateman et al., 2013; McDonnell et al., 2014; Wong Shee et al., 2014). This emergent theme was based on the perceptions of patients, family members and a range of healthcare professionals. None of the studies formally measured or reported outcomes of patient experience, quality of life, and quality of care, agitation, restlessness, depression or length of hospital stay.

Both patients and carers reported that they valued volunteer-led activities (Wong Shee et al., 2014). The majority of staff also agreed that the volunteer programme was worthwhile and should continue (Bateman et al. 2013). Staff, including managers reported from their own observations that patients' wellbeing appeared enhanced by having someone to talk to and who had the time to listen (McDonnell et al. 2014). Staff were also able to recognise the potential of the intervention to improve patient experience (McDonnell et al. 2014).

Staff perceived that agitation and restlessness of patients with dementia was reduced, and their wellbeing enhanced by spending time with the volunteers (Wong Shee et al., 2014; McDonnell et al. 2014). These positive outcomes were considered by staff to be due to social interactions and the volunteers supporting patients with dementia in meaningful activities (Wong Shee et al., 2014; McDonnell et al. 2014). Staff also reported that the volunteers supported an improvement in the quality of care, as they helped patients with physical care, as well as providing company, andbelieved this led to a smoother recovery from operations and enabled them to provide better care for the other patients on the ward as they had additional time (Bateman et al., 2016).

Overarching theme: Providing a unique service

Volunteer interventions were highly valued by ward staff, as their active presence with patients supported nurses to attend to tasks that only qualified staff could perform, such as administering medications (McDonnell et al., 2014). Staff also appreciated volunteers for being able to spend time with patients who were anxious or distressed, thereby supporting these patients in a unique and valued way. As a result of volunteer support, staff felt more able to concentrate on their tasks, knowing that volunteers were present with patients on the ward, recognising them as 'additional pair of eyes in the ward area' (McDonnell et al., 2014 p.31, Bateman et al., 2016).

Staff recognised that volunteers were able to offer the one-to-one support that people with cognitive impairment needed, thereby providing company and engaging with the patient in a way that they felt they were unable to do due to competing commitments (Wong Shee et al., 2014; Bateman et al., 2016). Volunteers were able to provide individualised input to meet the specific

needs and preferences of patients, rather than group activities such as; music, dancing, artwork, or games (McDonnell et al., 2014).

The relationship between the volunteer and the patient with dementia was also discussed and valued. McDonnell et al. (2014) reported the view of one carer, who was grateful that the volunteers on the ward had been able to spend time to listen and talk to her husband, making a 'meaningful connection' (p.302) with him.. Furthermore, McDonnell et al. (2014) noted that staff had particular motivations and needs behind their communication with patients; whereas the volunteers were communicating and engaging with patients purely for enjoyment and patient benefit. Thus, the staff felt that employing additional staff members to provide the service offered by the volunteers may not have achieved the same success.

Overarching theme: Volunteer's role within the team

Some difficulties between staff and volunteers in the initial and development stages of the projects were noted; volunteers were not always welcomed (McDonnell et al., 2014), volunteers felt frustrated by nurse's responses to their requests for help for patients (Wong Shee et al., 2014). Volunteers felt connected to each other and the research team, but to a lesser extent with the nursing team (Wong Shee et al., 2014).

One nurse reported feeling that the volunteers interfered in patient/nurse care (Bateman et al., 2016). However, difficulties in all the programmes seemed to alleviate over the course of the projects. In post-programme staff questionnaires, the majority of staff reported enjoyment in the program (Bateman et al., 2016). McDonnell et al. (2014) reported that structures such as a rota and a sign in sheet helped nurses to know when volunteers were coming, and these eased tensions about the uncertainty of the volunteer attendance.

Some of the tasks suggested for the volunteers by the nurses revealed that the nurses did not fully understand the role of volunteers on the ward (Wong Shee et al., 2014). Communication improved as volunteers and staff developed a clear understanding of each other's role (McDonnell et al., 2014). Staff also had concerns regarding patient confidentiality and the provision of personal information and medical history, whereas volunteers felt they would benefit from understanding a patient's functional level and ability to do activities and when changes occurred in their condition (Wong Shee et al., 2014).

Wong Shee et al. (2014) and McDonnell et al. (2014) both excluded assistance with feeding from the volunteer's activities; however, this was highlighted by both authors in the feedback from staff as something they felt the volunteers could help with and be of benefit to patients. Assistance with nutrition and hydration was included in the Bateman et al (2016) study, and was judged to be successful; nurses reported patient's had improved dietary intake when accompanied by a volunteer at mealtimes, however this was not formally measured.

Overarching theme: Support and training of volunteers

All papers indicated that specific training was given to the volunteers (Bateman et al., 2013; McDonnell et al., 2014; Wong Shee et al., 2014), developed new skills in communication and felt pleased to be making a meaningful contribution which was appreciated, and helpful to others

(Wong Shee et al., 2014). All volunteers enjoyed being part of the program, enjoyed their interactions with patients, gained personal satisfaction from their role and agreed that the program was worthwhile and should continue (Bateman et al., 2016).

Adequate training and support for the volunteers was important for retention (McDonnell et al., 2014); in particular, the volunteers recognised the importance of training in communication strategies for interacting effectively with people experiencing cognitive impairment (Wong Shee et al., 2014). Bateman et al. (2016) found there was no change in volunteer's knowledge of dementia and delirium, but there was a change in attitude, as volunteers' hope of living well with dementia increased. In addition, there was an improvement in the volunteers' understanding of the individual needs of patients. Volunteers also became more confident in their understanding and care of patients with dementia.

A Dementia Nurse Specialist led the initiative in one study and was seen as crucial to the success of this programme, as she provided on-going support to the volunteers (McDonnell et al., 2014). Volunteers wanted more staff involvement in their training programme in order to foster better working relationships and multi-disciplinary teamwork (Wong Shee et al., 2014). The support at strategic and senior levels of the hospital was necessary in order to sustain the intervention, as well as ward-level commitment and leadership.

Discussion

The small number of papers identified in our systematic review demonstrates the paucity of evidence related to the use of volunteers in the care of patients with co-morbid cognitive impairment and dementia in the acute hospital setting. Although the findings suggest that volunteers could be a valuable and feasible intervention to enhance the care of people with dementia, available data are limited to single site studies that were focussed more on staff impact than the experience and outcomes for patients and carers.

Benefits for patients with cognitive impairment/dementia

Benefits of the involvement of volunteers in hospitals generally has been acknowledged to improve patient satisfaction (Candy et al., 2015, Rogers et al. 2016). The benefits specifically for patients with cognitive impairment/dementia identified in our review included a significant increase of the use of analgesia, decreased length of hospital stay and a non-significant decrease in the use of antipsychotic medication (Bateman et al. 2016). This is supported by the work of Husebo et al. (2011), who found the increased use of analgesia for people with dementia living in nursing homes reduced their agitation, and the unnecessary prescription of antipsychotic medication. The importance of decreasing the length of a hospital stay for a person with cognitive impairment/dementia is essential due to the negative impact of a prolonged stay on both physical and cognitive function (Dewing and Dijk 2014).

Nurses reported a perceived benefit for their patients with dementia who were engaged with volunteers, alongside an increase in their work satisfaction (Wong Shee et al., 2013, McDonnell et al., 2013, Bateman et al., 2016). However patient benefit, quality of life, health outcomes or staff work satisfaction were not formally measured. The impact of work satisfaction is important as directly correlates with both nursing turnover and shortage (Lu et al., 2012). Improvement in nurses'

work environments has also been found to support the retention of nurses and improve hospital care (Aiken et al., 2012). A better understanding of the impact of volunteer initiatives on nurses could provide evidence that these initiatives support staff retention, which would in turn positively impact on the quality of care for patients with cognitive impairment.

Volunteer's role within the team

The review highlighted that the implementation of volunteers initially caused apprehension, tension and uncertainty within teams. However, once roles, boundaries and teamwork were established, these anxieties were resolved. A remaining issue is how integral volunteers should become in healthcare teams, as they could risk losing their unique strengths of flexibility and independence. One main benefit of volunteers is their ability to be creative because they operate independently from the hospital team (Naylor et al., 2013). Growing regulation and formalisation of roles and boundaries of volunteers could place restriction on their creativity and limit the positive impact of their presence on the ward.

Providing a unique service

Volunteers provide a different kind of patient support from that provided by nurses as their interactions are not focussed on professional care-associated tasks. The role of the volunteer in palliative care has been identified as distinctive, where volunteers became mediators between staff and patients (Burbeck et al., 2014). Volunteers adopt an approach that has been described as including both a family-type relationship while maintaining some characteristics of healthcare professionals (Burbeck et al., 2014). More studies are required on the relationship between volunteers and patients with dementia to understand the dynamics, motivations, interactions and which aspects provide additional benefits.

There are also potentially beneficial effects for the volunteers themselves in personal development and education as well as in self-worth, confidence and contribution for the benefit of others (Naylor et al. 2013). More widely volunteering by older persons has been found to increase their social, physical and cognitive activities, impacting on a reduction in symptoms of depression, improved self-reported health, life satisfaction and well-being as well as lower mortality (Anderson et al., 2014, Jenkinson et al., 2013). The evidence of the benefits of volunteering evolves from observational studies and a lack of robustly designed research (Jenkinson et al. 2013). More in-depth research on the effect of volunteering on volunteers, including objective measures of psychosocial, physical and cognitive functioning as well as an exploration of individual differences is required (Anderson et al., 2014). A greater understanding of the benefits for volunteers would enable schemes to be designed that are rewarding and enjoyable and therefore more likely to be feasible and sustainable.

Support and training of volunteers

Support and careful implementation of volunteer initiatives is necessary to ensure their success (Naylor et al. 2013). Initial problems around the role identification, working patterns, and responsibilities could be resolved by training and information for ward staff and the use of volunteer coordinators or specialist nurses (McDonnell et al., 2014, Bateman et al., 2016). Rotas and sign in sheets (McDonnell et al., 2014), noticeboards and social media may also help provide a sense of connectedness, support and inclusion (Charalambous 2014). Studies on volunteers for people with dementia in nursing homes noted that a structured model was needed to ensure that volunteers

were distributed equally amongst residents (Damianakis et al., 2007, Van der Ploeg et al. 2014). Residents with advanced dementia and associated behavioural symptoms were often overlooked for volunteer support, despite potentially benefitting the most from the interventions provided by the volunteers (Van de Ploeg et al. 2014).

Our findings indicate that volunteers could have a role in assisting with nutrition and hydration of patients with dementia (Wong Shee et al., 2014, McDonnell et al., 2014,). Bateman et al. (2016) included assisting with nutrition and hydration in the role of their volunteers, but the effect of this specific assistance was not formally measured. Other studies on nutritional support, not specific to dementia, have shown positive effects (Wong et al., 2008, McMahon et al., 2013, Robison et al., 2015; Roberts et al., 2015) including positive effects on staff morale (Robison et al., 2015). Therefore, our findings demonstrate a lack of robust evidence on the quality of care delivered by volunteers or whether volunteers are the most suitable people to provide individualised care for patients with dementia given the specific physical and mental health needs of this group.

Limitations

All papers focused on small, single-site studies, and the impact of volunteer interventions were not quantified or formally measured with the exception of a small number of scales used in Bateman et al. (2016) which were focused on the impact on staff and volunteers rather than on patients or carers. Selection bias occurred in that patients were only included in all three studies if staff thought they might benefit from the support of a volunteer (Wong Shee et al., 2014; McDonnell et al., 2014; Bateman et al., 2016).

Future research

Future studies should attempt to address the following gaps in the evidence base identified in the review of the impact of volunteers including on: patient care, outcomes; including falls, pressure injury, hydration and nutrition; the concerns, views and experiences of persons with dementia and their carers; the dynamics of the relationship between volunteers and patients in different severities or sub-types of dementia or delirium and on specific aspects of dementia such as cognition, mental state, or behaviour and specific activities provided by volunteersthat are most beneficial to patients, carers and staff.

Conclusion

Available data suggest that volunteers to support the care of patients with co-morbid cognitive impairment in the acute hospital setting may provide benefit to patients, carers and staff but evidence is limited and further studies are required. Additional quantitative and qualitative data are required on the impact of volunteers particularly on patient outcomes, patient and carer experience, costs, and sustainability in order to understand whether the current widespread use of volunteers in this setting is justified.

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