Abstract

There are an increasing number of people living with dementia in care home settings. Recent reports suggest that people who deliver care to residents living with dementia in care homes require specialist support to provide optimum care. To address this need Four Seasons Health Care, the largest provider of care homes within the UK today, sought to design a dementia care framework that enhanced the quality of life for people living with dementia in their care homes. The framework was designed using a robust evidence base, engagement with people living with dementia, their care partners, policy-writers, multi-disciplinary professionals and people within the organization. This paper describes the methodology behind the dementia care framework and outcomes data from the first phase (of 20 care homes that included the care of 451 people living with dementia). The main outcome of was a significant improvement in the quality of the lives of residents across biological, psychological, social and spiritual needs.

Key Words

Dementia, Care Homes, Residential Care, Person-Centred Care & Health Informatics

Introduction

There are around 500,000 people who live across 20,000 care homes in the UK today (Laing, 2013; Cousins et al, 2016; Mitchell et al, 2016). In a recent report by the Alzheimer’s Society (2013) it was estimated that approximately four out of five residents living in care homes live with some form of dementia. With an increasing proportion of people living with dementia residing in care homes it is paramount that health care workers (including nurses, care assistants, kitchen and domestic support workers) have specialist knowledge about dementia. This assertion is supported by the National Institute of Clinical Excellence, an organisation which provides national guidance and advice on how to improve health and social care in the UK. NICE (2015) highlights the importance of developing care home nurses to possess specialist knowledge in older people’s nursing, such as dementia care. Furthermore, a recent report on the challenges facing care homes in the UK (Spilsbury et al. 2015) specifically identified dementia as an important area which required practice development within care home settings.

Service Development
Four Seasons Health Care operate approximately 300 care homes across the UK with upwards of 290 specialist dementia units. In order to support the specialist needs of people living with dementia, Four Seasons Health Care revisited their dementia strategy and in 2016 co-designed a dementia care framework with people living with dementia, care partners, senior leadership team members and specialist clinicians throughout their organisation. The dementia care framework is comprised of four main elements:

1. Resident and Relative Charters
2. Roll out of Specialist Dementia Education Support
3. Thematic Resident and Care Audit for Dementia
4. Accreditation

**Resident and Relative Charters**

The first component of this dementia care framework was the co-design of a resident and relative charter (Four Seasons Health Care, 2017a; 2017b). These charters articulate the promises that Four Seasons Health Care care homes make to their residents and their relatives. Each care home which commences on the dementia care framework will have their individual charters. The rationale for these charters was to embed a person-centred culture by placing an emphasis on care which focuses on the individual experience of each resident (McCormack, 2017). Some examples from one of the charters can be found in table one.

**Table One: Example from Resident’s Charter**

<table>
<thead>
<tr>
<th>I can trust you to:</th>
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<tbody>
<tr>
<td>- Continuously monitor my health and wellbeing and deliver the right care for me.</td>
</tr>
<tr>
<td>- Understand how I want to be cared for and if you have to make decisions for me, you do your best to include me and support me in doing what is best for me.</td>
</tr>
<tr>
<td>- Help me to remain as active as possible for as long as possible.</td>
</tr>
<tr>
<td>- Care for me with team members who have the right skills to care for me and understand me as a person.</td>
</tr>
<tr>
<td>- Support me to continue the hobbies and social activities I enjoy.</td>
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<tr>
<td>- Support me to keep my links with my friends and community networks.</td>
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**Educational Support**

The Dementia Care Framework’s education programme provides support and training to the whole team at the care home (i.e. domestic, maintenance and cooking services) with additional modules for those working directly within dementia services (i.e. nurses and care
assistant). This programme consists of 80% face-to-face training and support sessions and 20% via e-learning modules. Aspects of education relate to meaningful activity, how to involve people living with dementia in their local communities, how to help people living with dementia to overcome episodes of distress and sustain wellbeing and how to effectively communicate with people living with dementia as per best practice recommendations (Sheeran, 20017; Russell 2017; Mitchell and Agnelli, 2015a; 2015b; DH 2009).

**Thematic Resident and Care Audit for dementia (TRaCAD)**

Perhaps the most important clinical element of the dementia care framework is the thematic resident and care audit for dementia (TRaCAD). This audit tool is underpinned by over 320 externally recognised standards from credible sources such as NICE, Alzheimer’s Society and the Department of Health. This evidence was translated into a comprehensive audit which includes a number of questions which colleagues must answer about people with dementia for whom they care. The key differentiator is that the audit process considers the experience of care of a single individual.

This novel audit tool was designed by Four Seasons Health Care and is available on internal IPads which nurses (or senior care assistants in residential units) complete. The system then produces a report of actions that the member of staff (and care home unit) must complete to optimise the care that resident living with dementia receives. This live system also enables a team of dementia specialists to monitor the progress of care homes undertaking the dementia care framework and identify areas for support.

The TRaCAD is made up of almost 300 questions and provides Four Seasons Health Care senior managers with visibility of the details of every audit along with the status of action which has been generated. It focuses on a variety of areas relating to the person’s holistic care including: washing and dressing, elimination, end-of-life care, activities, nutrition, cognition, capacity and mobility. Importantly, a unit cannot become dementia care framework accredited until every resident living with dementia scores 100% in their individual audit. In other words, all 300 questions in the dementia care framework must be compliant for each individual resident. This provides a robust and detailed quality assurance to dementia care within Four Seasons Health Care care homes. The time to complete an audit varies depending on the individual needs of each resident, however on average it takes around one hour.

The TRaCAD includes technical questions about a person’s care, for example relating to deprivation of liberty, restraint and cognitive enhancing medications, as well as experiential-based questions that ascertain if a person feels at home in their unit, if staff are friendly and if their meal-time experience is pleasurable. Example questions include: “Staff are aware of the life history of a resident and are able to tell you when asked”, “The care plan identifies individual signs or behaviours to look for that may indicate the resident is in pain” and “There is a clear record of the residents likes and dislikes including favourite foods and drinks”.
The TRaCAd also includes questions about the resident which are to be answered by the resident themselves or by their family member. In addition, the TRaCAd also requires care staff to observe the resident living with dementia to ensure that they are in a state of wellbeing. Examples of these questions include: “You have observed staff giving the resident choices about their care”, “the resident looks comfortable – look at posture, facial expression and vocalisation”, and “do staff knock on your door and wait for you to give permission for you to enter”. In addition, the TRaCAd also directs staff to complete validated risk assessments and if required the system will direct the user to take appropriate action (for example an Abbey Pain Scale of 5 has not always been understood as something that requires investigation or onward referral) (Abbey et al. 2004).

**Continuous Feedback**

An innovative feature of the dementia care framework relates to the live feedback system. All our dementia care units have an anonymous live feedback system, utilising the IPads, so that residents, friends and families, visiting professionals and colleagues can provide feedback about a range of areas. These comments and suggestions can be made quickly and easily, via a static or mobile iPad which is prominently displayed at the entrance of every Four Seasons Health Care care home. Feedback is also gathered from colleagues as we know happy and supported teams are vital to positive resident experiences. The system records these comments and makes them available immediately to the home and support teams so as any feedback, whether positive or negative, can be appropriately resolved or responded to. It is important to assert that our residents who live with dementia are continually supported to use the technology by Four Seasons Health Care colleagues. As an organisation we recognise that people living with dementia are the experts in their care and this feedback system harnesses their voice.

**Accreditation and Beyond**

Each dementia unit within Four Seasons Health Care will be required to complete multiple actions for every resident so as to ensure they are receiving optimum levels of care. To become ‘dementia care accredited’ all residents must have a number of criteria fulfilled. These include: review of medications (so as to reduce antipsychotic, anxiolytic & sedative medications where appropriate and increase analgesia or cognitive enhancers), develop strategies for care based on the use of life-history information, tailor communication to meet the needs of individuals, advocate a number of evidence-based non-pharmacological interventions or raising awareness about timely end-of-life care discussions. Once all residents who live in the dementia units have displayed their charters, had all care staff complete all components of their dementia training, had all residents assessed using the TRaCAd tool and had all outstanding actions from the TRaCAd tool addressed, the care home will receive dementia care framework accreditation. To maintain accreditation, the care home must review all their residents, using TRaCAd, when clinically significant changes
occur or within a minimum period of six months. The care home must also ensure that all their employees keep their continuing professional development in dementia care up-to-date.

**Sample**

The first phase of the dementia care framework was commenced in 20 care homes throughout the UK. 13 care homes were recruited from England, 4 from Scotland and 3 from Northern Ireland. 451 residents living with dementia lived across these 20 care homes. In total, 538 colleagues directly cared for people with dementia care (for example nurses and care assistants) took part in the modular educational programme.

**Results**

The dementia care framework helped care teams identify 8,176 specific individual elements of care based on the individual care reviews, completed using the TRaCAd audit described above, which could be improved. Table two describes the most common areas that required improvement throughout the first phase. Of these 8,176 areas that required action, 2,118 of these were fixed and resolved immediately once identified (25.91%). The remaining 6,084 actions were resolved in a timely manner, most within a few days or weeks.

**Table Two: Impact of Dementia Care Framework**

<table>
<thead>
<tr>
<th>Impact on person living with dementia following implementation of dementia care framework programme</th>
<th>Percentage Increase</th>
<th>Resident (n=451)</th>
</tr>
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<tbody>
<tr>
<td>The care plan identifies any spiritual preferences and practices that the resident may have and details of how these needs are met</td>
<td>47.89%</td>
<td>216</td>
</tr>
<tr>
<td>The care plan includes details of what items/people the resident has formed attachments to and how they feel when separated from them</td>
<td>47.01%</td>
<td>212</td>
</tr>
<tr>
<td>The care plan includes details of what is psychologically comforting for the resident (e.g. appropriate use of touch, doll therapy etc.)</td>
<td>43.68%</td>
<td>197</td>
</tr>
<tr>
<td>The care plan includes details of how the resident's occupational needs (e.g. vocational activities) are met</td>
<td>43.02%</td>
<td>194</td>
</tr>
<tr>
<td>The care plan details those community links that are important to the resident and shows how staff facilitate these</td>
<td>42.79%</td>
<td>193</td>
</tr>
<tr>
<td>The care plan includes details of how to maintain and support the resident's unique identity (e.g. using preferred name, style of dress etc.)</td>
<td>41.91%</td>
<td>189</td>
</tr>
<tr>
<td>The activities care plan has been updated and evaluated a minimum of monthly</td>
<td>41.69%</td>
<td>188</td>
</tr>
<tr>
<td>The care plan details how the resident wishes to be included in communal activities and evidence that their choices are respected</td>
<td>41.24%</td>
<td>186</td>
</tr>
<tr>
<td>The activities lifestyle plan (in my choices) has been completed</td>
<td>37.47%</td>
<td>169</td>
</tr>
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</table>
Discussion

This article focuses on the most common improvements that were noted across twenty care homes in the UK once they implemented their dementia care framework programme. As noted in the results section, many of the aspects of which improved related to a resident’s psychological, social and spiritual needs. Such an outcome is unsurprising given the plethora of evidence that suggests that care providers often deliver good physical care and support of a person’s medical needs but can overlook other broader holistic needs (McCormack and McCance, 2010).

These broader holistic needs are important to consider as they contribute to enhancing a person’s overall wellbeing. The term personhood has long been used within dementia care literature and is defined as the ‘attributes that make up being a person’ (Kitwood, 1997; Dewing, 2008). Personhood is ‘a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust’ (Kitwood, 1997). Implementation of the dementia care framework helped enhance the personhood of people living with dementia within care homes as it sought to illuminate aspects of life which may had diminished like; engagement with one’s local community, or fulfilment of one’s spiritual need or indeed provision and engagement in meaningful modes of life and activity.

While it is of course unrealistic to expect that all people living with dementia should be in a constant state of wellbeing, it is important to identify practises that support those residents to live well for as much of their lives as possible. It has long been acknowledged that many people living with dementia, who exhibit frequent distress, are likely to expressing feelings of personhood which is undermined (Kitwood, 1997; Brooker, 2007; McCormack and McCance, 2010; Mitchell and Agnelli, 2015a). In other words, they are living a life in which they are not supported to meet their psychological, social and spiritual needs.

The dementia care framework (incorporating resident and relative charters, specialist blended dementia education programmes, the TRaCAD and accreditation) helped nurses, care assistants, kitchen and domestic colleagues working with residents living with dementia to understand the importance of personhood and how they could use strategies (such as life-history information, non-pharmacological interventions, communication toolkits or validated assessment tools) to improve quality of life for their individual residents. While his theory is twenty years old, Kitwood’s (1997) seminal theory still has relevance to dementia care today. In particular his model which outlined the essential psychological needs of people with dementia should also be considered along with the key results of this study. A summary of this model can be viewed in table three.
Table Three: Psychological Needs of People Living With Dementia (Adapted from Kitwood, 1997; Mitchell and Agnelli, 2015a)

<table>
<thead>
<tr>
<th>Need</th>
<th>Description</th>
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<tbody>
<tr>
<td>Comfort</td>
<td>the feeling of trust that comes from others.</td>
</tr>
<tr>
<td>Attachment</td>
<td>security and finding familiarity in unusual places.</td>
</tr>
<tr>
<td>Inclusion</td>
<td>being involved in the lives of others.</td>
</tr>
<tr>
<td>Occupation</td>
<td>being involved in the processes of normal life.</td>
</tr>
<tr>
<td>Identity</td>
<td>what distinguishes a person from others and makes them unique.</td>
</tr>
</tbody>
</table>

These five needs, which are indeed present in all human beings, are important when considering the clinical manifestations of the dementia diseases. Through fulfilment of these needs, people living with dementia are more likely to sustain long periods of wellbeing because their personhood has been retained or enhanced. In this study, the dementia care framework placed the resident, and their family, at the centre of their care. While this ideology is not innovative, the methodology employed used standardised digital technology across a number of care homes within the UK; this is unique within the care home sector.

We believe that the dementia care framework provides a practical approach to ensuring that all colleagues caring for individuals living with dementia in our care homes are supported and encouraged to meet these critical care needs alongside providing good clinical care.

Conclusion

This paper has described Four Seasons Health Care’s Dementia Care Framework. It has reported some of the most pertinent findings from its first phase across 20 care homes. Interestingly, these findings demonstrate that a structured dementia care programme can facilitate care homes to deliver optimum services to people living with dementia. Perhaps most importantly, facilitating people to live well with dementia in care homes requires an appreciation of the importance of holistic care. Furthermore, good care homes should seek to not only provide optimum care, but provide optimum modes of life for their residents.
References


